

**The experience of non-epileptic attack disorder (NEAD): A repertory grid study  
examining NEAD patients' construal of their disorder.**

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## **Abstract**

Non-epileptic attack disorder (NEAD) is a disorder resembling epilepsy, but is caused by psychological processes rather than neurological disturbance. Approximately 15-30% of patients referred to specialist epilepsy centres have NEAD as opposed to epilepsy. Research into NEAD has largely focused on the differential diagnosis of NEAD and identifying risk factors, such as abuse and psychopathology. Whilst this is important, there remains a paucity of research exploring the processes involved in the development and maintenance of NEAD, which contributes to the lack of research investigating treatment effectiveness and prognosis. Furthermore, there remains a paucity of research investigating patient perceptions and experiences, despite such factors influencing prognosis. Subsequently, the current study used repertory grid methodology to explore the largely overlooked domain of how individuals with NEAD construe their world (i.e., how they perceive themselves, others and their disorder).

Twelve individuals with a diagnosis of NEAD were recruited from a clinical neuropsychology department within North-West England. This study was an exploratory, cross-sectional study using the repertory grid technique to explore the participants' construals of themselves and others, including construals of their ideal self and self before NEAD. Based on personal construct theory, this method aimed at overcoming some of the methodological limitations inherent within NEAD research, by minimising researcher bias, exploring implicit and explicit perceptions and exploring both individual and group perceptions.

A case series of grids was presented. Individual and multiple analyses were used to explore participants' construct systems. A data driven approach enabled propositions to be developed from the individual grids, which were explored via a composite grid and SocioNet analysis. Despite some themes being identified, the findings revealed the uniqueness of the participants' ways of construing, including a lack of shared understanding amongst the participants. The participants were unhappy with their current self and no longer construed themselves to be the person they were before the onset of NEAD. They also construed themselves as being distinct and/or alienated from others, although some participants construed positive consequences as a result of their NEAD. Whilst most participants agreed with their NEAD diagnosis 'label', they were less accepting of the psychological factors that characterise the diagnosis. Finally, physical health difficulties were construed as being preferable to experiencing mental health difficulties.

The findings were discussed in relation to previous research and theoretical implications were highlighted. Clinical implications were highlighted, particularly how the current diagnostic and treatment system for individuals with NEAD may threaten their self-identity. Methodological considerations and recommendations for future research were also suggested. The repertory grid technique was found to be a useful and effective method to investigate the subjective perceptions of individuals with NEAD.

### **Declaration**

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification of this or any other university or institute of learning.

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## **CHAPTER ONE: INTRODUCTION**

### **1.1 Overview of Introduction**

This introduction will begin with an outline of the general aims of the study. Non-epileptic Attack Disorder (NEAD) is the focus of this investigation, and thus will be discussed in detail. Key areas that have been investigated within the research literature to date will be reviewed. The chapter will then progress to a detailed account of the personal construct framework and repertory grid methodology utilised within the current study. It concludes with the presentation of the current study.

### **1.2 General Aims of the Study**

Approximately 15-30% of patients referred to specialist epilepsy centres have NEAD as opposed to epilepsy (Abubakr, Kablinger & Caldito, 2003; Alper, 1994; Bodde et al., 2009a; Gates, 2002). NEAD is a disorder resembling epilepsy but is thought to be caused by psychological processes rather than by a disruption in electrical brain activity. Despite NEAD posing a clinical problem for patients and services, the processes involved in the development and maintenance of NEAD are not fully understood. It is necessary for further research to be carried out in this area to gain a better understanding of these processes, and lead to more effective treatments for NEAD. Increased identification and understanding of patients' subjective perceptions and interpretations is necessary to allow for the effective understanding of NEAD, to develop treatments and ensure better outcomes (Carton, Thompson & Duncan, 2003). This study aimed at investigating the largely overlooked domain of how individuals with NEAD construe their world (i.e., perceptions about themselves and others). It was designed to be exploratory in nature due to the paucity of research into the perceptions and experiences of individuals with NEAD.

A methodology capable of exploring perceptions of individuals with NEAD without imposing interviewer bias is the repertory grid technique (RGT), developed from Personal Construct Theory (PCT) (Fransella, Bell & Bannister, 2004; Kelly, 1955). This technique is able to uncover implicit attitudes that are not likely to be revealed via traditional interviews or self-report questionnaires predominantly used with this patient population (Winter, 1992). Furthermore, rather than simply exploring '*what*' individuals with NEAD think about their worlds, this technique allows for the exploration of '*how*' individuals with NEAD think about their worlds. For example, it is possible to explore whether individuals with NEAD have 'cognitively complex' construct systems (i.e., whether there is flexibility in their construing) (Bieri et al., 1966).

### **1.3 Definitions**

It has long been recognised there are different types of seizures: epileptic and non-epileptic (Betts, 1990). Epilepsy is a chronic neurological disorder characterised by recurrent unprovoked epileptic seizures, which are caused by transient disturbances of brain function due to neuronal discharges (Binder & Salinsky, 2007; Shneker & Fountain, 2003). Epileptic seizures are experienced by approximately 10% of the general population at some point in their lives, whereas 1% will

experience epilepsy (i.e., recurrent seizures) (Hauser, Annegers & Rocca, 1996). They are usually of short duration, lasting from seconds to a few minutes. However, status epilepticus can also occur, which is when the seizure continues, requiring urgent medical attention to prevent the seizure from becoming life-threatening. Epilepsy can be caused by a number of processes including metabolic disturbances, tumours, genetic defects and trauma (Shneker & Fountain, 2003). They can be classified into 'generalised' seizures and 'partial' seizures, based on the localisation of the neuronal disturbance and the possible cause of the seizure. See Shneker and Fountain (2003) for a more detailed description of epileptic seizure classifications. Over 70% of individuals with epilepsy will experience seizure cessation following treatment with antiepileptic medication and possible surgical procedures for intractable epilepsy (Cockerell, Johnson, Sander & Shorvon, 1997).

Alternatively, seizure-like events can have a non-epileptic aetiology. They can be caused organically, for example, through faints produced by neurological or cardiovascular events (Benbadis, 2009; Betts, 1990). The signs and symptoms of psychological disorders such as panic attacks, hyperventilation attacks and anxiety with derealisation/depersonalisation can also be mistaken for epilepsy. Non-epileptic seizures can also have a psychological cause (Benbadis, 2009; Betts, 1990). 'Non-epileptic seizures' is a generic term used for all these different conditions. This current study was concerned with the investigation of non-epileptic seizures that have a psychological cause, which does not include those conditions mistaken for seizures (e.g., panic attacks). Subsequently, when referring to non-epileptic seizures/attacks, this study will only be referring to this subgroup of non-epileptic conditions.

Different terminology has been used within the research literature to describe such phenomena, including '*non-epileptic seizures*', '*pseudoseizures*', '*pseudoepilepsy*', '*psychogenic non-epileptic seizures*', '*hystero-epilepsy*' and '*hysterical seizures*' (Binder & Salinsky, 2007; Francis & Baker, 1999). The current preferred terms are '*non-epileptic seizures*' and '*psychogenic non-epileptic seizures*' as they are less likely to imply faking of the seizures (Betts, 1990; Binder & Salinsky, 2007; Stone et al., 2003). There is also some debate as to whether to use the term '*seizures*', '*fits*' or '*attacks*' (LaFrance, 2010). The present study will use the term '*non-epileptic attack disorder*' (NEAD) to describe this disorder and describe the paroxysmal episodes as '*non-epileptic attacks*' (NEAs). Non-epileptic attacks (NEAs) are "*episodes of altered movement, sensation or experience similar to epilepsy, but caused by a psychological process and not associated with abnormal electrical discharges in the brain*" (Reuber & Elger, 2003, p.205). NEAD is diagnosed in patients who have recurring NEAs. The majority of NEAs are "*involuntary expressions of psychological distress, and not wilfully simulated events*" (Reuber & Elger, 2003, p.208). However, a small minority may wilfully simulate such events, as occurs in malingering or factitious disorders (Reuber & Elger, 2003).

NEAD poses a problem for both patients and services. Misdiagnosis of NEAD as epilepsy often results in patients taking potentially toxic anti-epileptic medication, with three-quarters of

individuals with NEAD taking anti-epileptic medication prior to correct diagnosis (Benbadis, 1999). Misdiagnosis may also result in hazardous emergency procedures (Binder & Salinsky, 2007; Dworetzky, Bubrick & Szaflarski, 2010; Reuber & Elger, 2003), with increased risk of morbidity and mortality (Reuber, Baker, Gill, Smith & Chadwick, 2004). Misdiagnosis also puts pressure on the health and social services, as extensive and often inappropriate resources are utilised (Francis & Baker, 1999).

#### **1.4 History of NEAD**

The distinction between epileptic and non-epileptic seizures has been identified from as early as Babylonian times. The Ancient Greek physician Aretaeus described varieties of epilepsy as '*ordinary*' and '*hysterical*' (Francis & Baker, 1999; Trimble, 1983). In the late 19<sup>th</sup> Century, Freud (1888/1966) provided detailed symptomatic descriptions of '*hystero-epilepsy*' or '*major hysteria*' as involving convulsive attacks, disturbances of sensory events and paralysis. Freud initially theorised that such hysterical seizures were caused by childhood sexual trauma, although he later suggested such seizures were related to "childhood sexual Oedipal fantasies" (Rosenbaum, 2000). This psychodynamic conceptualisation implicated unconscious conflicts associated with unbearable feelings of guilt and shame (Myers & Zaroff, 2004). The psychodynamic school of thought was followed by the behavioural conceptualisation of NEAD (Ramani, Quesney, Olson & Gumnit, 1980), in turn followed by the biopsychosocial model, which recognises different psychological, social, cognitive and behavioural factors in the development and maintenance of NEAD. The development of modern technology has allowed for more accurate diagnosis of NEAD, spurring more research into this area (Betts, 1990).

#### **1.6 Prevalence of NEAD**

The prevalence of NEAD within the general population and within clinical populations is difficult to establish, with the limited research yielding varying estimates. This variation is likely due to methodological difficulties within this research area, including small sample sizes, inconsistent definitions of NEAD, the inherent difficulties diagnosing NEAD and the sample bias from largely recruiting patients from highly specialist epilepsy centres (LaFrance, Blum, Miller, Ryan & Keitner, 2007). Benbadis and Hauser (2000) estimated the prevalence of NEAD within the general population as ranging from 2 to 33 per 100,000. Within patients referred to specialist epilepsy clinics, approximately 15-30% of patients receive a diagnosis of NEAD (Abubakr et al., 2003; Alper, 1994). Betts and Boden (1992) found 24% of individuals with NEAD had been misdiagnosed as having epilepsy. These figures suggest NEAD may be as common as multiple sclerosis (Benbadis, 2005).

The typical age of onset of NEAD is between 20-30 years old (Alper, 1994; Reuber & Elger, 2003; Reuber, 2008). This is in contrast to the typical onset of epilepsy, whereby half of all individuals with epilepsy will have developed the condition before five years old (Kim, 1991). There is also a significant gender difference, as approximately three-quarters of NEAD patients are female (Moore & Baker, 1997). This female majority has been demonstrated in other studies (Alper, 1994;

Kristensen & Alving, 1992; Lesser, 1996; Oto, Conway, McGonigal, Russell & Duncan, 2005). Potential explanations for this are considered later in this chapter.

### **1.7 Co-morbidity with epilepsy**

Approximately 10-60% of individuals with NEAD also have comorbid epilepsy (Abubakr et al., 2003; Benbadis, Agrawal & Tatum, 2001; Betts, 1990; Bodde et al., 2009a; Devinsky et al, 1996). As with the difficulties in establishing the prevalence of NEAD *per se*, this wide variation is likely to be due to methodological difficulties.

### **1.8 Semiology/Symptomatology of NEAD**

The clinical presentation of NEAD is extremely varied, although various semiologic features to help distinguish between NEAs and epileptic seizures have been suggested, including differences in onset, seizure course, motor manifestations, consciousness and duration (Reuber & Elger, 2003). Onset of an epileptic seizure is usually very sudden, without warning and over within a matter of seconds, as compared to a NEA, which can often be of gradual onset, precipitated by a traumatic event and can be sustained over a longer period (Binder & Salinsky, 2007; Brown, Syed, Benbadis, LaFrance & Reuber, 2011; Reuber & Elger, 2003). Individuals with NEAD often have convulsive movements that are easily confused with generalised epileptic seizures. Unlike epileptic seizures, however, the movements are often out of phase and pelvic thrusting movements are common, which are not displayed during epileptic seizures (Binder & Salinsky, 2007; Meierkord, Will, Fish & Shorvon, 1991). Excessive movement of limbs, trunk and head are the most common presentation within NEAs, with stiffening, tremors and atonia being less common (Reuber & Elger, 2003). Other distinctions may be within the level of responsiveness during the NEA and ictal eye closure. Individuals with epilepsy will remain unresponsive during generalised tonic-clonic seizures, whereas some individuals with NEAD can retain some level of conscious awareness, and eye closure associated with complete unresponsiveness is specific to NEAD (Chung, Gerber & Kirilin, 2006). Epileptic seizures are also more likely than NEAs to be followed by drowsiness, confusion and injury (Appleton, Baker, Chadwick & Smith, 1991). Groppe, Kapitany and Baumgartner (2000) identified different clusters of NEAs (Table 1). This, however, highlights potential differences in semiologic presentation rather than differences in the underlying processes of NEAD.

**Table 1. Clinical semiology of NEA by cluster analysis (Groppe et al., 2000)**

	<b>Cluster Name</b>	<b>Symptoms</b>
1	Psychogenic motor seizures	Clonic and hypermotor movements of the extremities, pelvic thrusting, head movement and tonic posturing of the head
2	Psychogenic minor motor or trembling seizures	Trembling of the upper and lower extremities
3	Psychogenic atonic seizures	Falling to the floor (only symptom)

### **1.8 Differential Diagnosis**

NEAD can be extremely difficult to distinguish from epilepsy due to both disorders being characterised by alterations in behaviour, sensation, consciousness and perception (Kuyk, Leijten, Meinardi, Spinhoven & VanDyck, 1997; LaFrance, 2008). NEAD is diagnosed by ruling out epilepsy

and other disorders, such as movement disorders, sleep disorders, syncope and psychological disorders that produce 'attacks' resembling seizures (e.g., panic disorder) (Binder & Salinsky, 2007; Reuber & Elger, 2003). The gold standard is to use video-electroencephalogram (EEG) monitoring (Binder & Salinsky, 2007; Cragar, Berry, Fakhoury, Cibula & Schmitt, 2002; Cuthill & Espie, 2005; Reuber & Elger, 2003), which is a non-invasive measure of the electrical activity within the brain. However, it requires an episode to occur during monitoring to establish whether there are changes in electrical brain activity during the behaviour. The diagnosis of NEAD requires the observation of behavioural presentations that are inconsistent with epileptic seizures and not associated with electrical activity within the brain during the episode. A further indicator of NEAs can be the lack of response to anticonvulsant medication (Francis & Baker, 1999). An additional method to aid differential diagnosis is the administration of psychological screening tools (Wagner, Wymer, Topping & Pritchard, 2005), such as the Minnesota Multiphasic Personality Inventory (MMPI/MMPI-II; McKinley & Hathaway, 1944) and the Personality Assessment Inventory (PAI, Morey, 1991). These have been found to be useful diagnostic tools when combined with clinical information (Dodrill, 2010; Schramke, Valeri, Valeriano & Kelly, 2007; Wagner et al., 2005). It is suggested all these methods be utilised within the differential diagnosis (Reuber & House, 2002).

There are many challenges in differential diagnosis. Firstly, there is no single semiologic feature shared by all individuals with NEAD, and no set of symptoms allow for the differentiation between NEAs and epileptic seizures (Hoerth et al., 2008), although some indicators have been suggested (Reuber & Elger, 2003). These potentially differentiating indicators can be obtained from the video-EEG, but this requires the patient to experience an NEA/seizure whilst being monitored, which only occurs in one-third of patients (Reuber & Elger, 2003). Additionally, indicators can be obtained from an eye-witness description of the NEA/seizure, but these can be inaccurately recalled (Brown et al., 2011). To this end, it has been suggested that gathering patients' medical, psychiatric and social history may be more useful in the differential diagnosis than the semiologic features (Reuber & Elger, 2003), as individuals with NEAD are more likely to have a history of medical, psychological and social difficulties than individuals with epilepsy (Reuber & Elger, 2003). These are discussed in more detail later in this chapter. Another challenge is that patients having NEAs may also have epileptic seizures. Confirmation of epilepsy on video-EEG cannot completely rule out the presence of NEAD and vice versa. Some epileptic seizures can also be more difficult to distinguish from NEAD, such as frontal lobe epilepsy, which is often characterised by unusual behaviours and strong emotions (Wilkus, Thompson & Vosslet, 1990). A further complication lies within the heterogeneity of NEAD. It is generally accepted that there are different aetiologies of psychological disturbance unique to each patient (Brown et al., 2011; Groppe et al., 2000), but no defining element common amongst individuals with NEAD has been identified.

Considering the similarities between epileptic seizures, the semiology of NEAs and the challenges of differential diagnosis, it is unsurprising that NEAs are frequently misdiagnosed as epileptic seizures (Betts, 1990). This misdiagnosis poses a problem for patients and is costly for services (LaFrance & Benbadis, 2006; Martin, Gilliam, Kilgore, Faught & Kuzniecky, 1998). Individuals with

NEAD often experience a long delay between the onset of NEAs and the accurate diagnosis of NEAD, with one study reporting a 7.2-year-delay between NEA onset and the diagnosis (Reuber, Fernandez, Bauer, Helmstaedter & Elger, 2002; Reuber & House, 2002). This is often accompanied by many years living with a diagnosis of a chronic medical illness, taking harmful antiepileptic medication and occasionally undergoing inappropriate hazardous procedures (Binder & Salinsky, 2007; Moore & Baker, 1997; Reuber & Elger, 2003). These patients also experience the disabilities and social stigma associated with epilepsy during this period, including driving, work and social restrictions (Carton et al., 2003; LaFrance & Benbadis, 2006). Misdiagnosis also prevents the patient's underlying psychological difficulties from being appropriately addressed (Reuber & Elger, 2003).

### **1.9 Psychiatric Classification of NEAD**

There is debate concerning the most useful and reliable psychiatric classification for NEAD (LaFrance et al., 2006). The most common method within the UK is to use the Diagnostic and Statistical Manual of Mental Disorders Version Four Revised (DSM-IV-TR; American Psychiatric Association, APA, 2000) system to classify NEAD. However, clinicians and researchers differ in whether they classify NEAD as a dissociative or a somatoform disorder (Brown & Trimble, 2000; Kuyk, VanDyck & Spinhoven, 1996; Reuber & Elger, 2003). The International Classification of Diseases Version 10 (ICD-10; World Health Organisation, WHO, 1992) classifies NEAD as a dissociative disorder, whereas DSM-IV-TR (APA, 2000) categorises it as a conversion disorder, within the somatoform disorders.

Somatoform disorders are characterised by physical symptoms suggesting a medical condition, but for which no medical condition can be diagnosed (De Gucht & Heiser, 2003). They are instead caused by underlying psychological difficulties. These disorders are in contrast to factitious and malingering disorder, as the symptoms are not voluntarily controlled. Dissociative disorders are characterised by disruption of consciousness, memory, identity or perception (DSM-IV-TR, APA, 2000). Dissociative symptoms can be sudden, gradual, transient or chronic. It has been suggested there are two different types of dissociation. *Detachment* is an altered state of consciousness whereby the person becomes 'detached' from the self and/or world, whereas *compartmentalisation* is the inability to deliberately control processes and/or actions that are usually controllable (Holmes et al., 2005). NEAD may be due to compartmentalisation rather than detachment (Brown et al., 2011; Lawton, Baker & Brown, 2008).

It has been argued, however, that NEAD is a heterogeneous condition, with potentially different mechanisms and processes underlying the disorder (Cragar, Berry, Schmitt & Fakhoury, 2005; Kuyk et al., 1996; Rusch, Morris, Allen & Lathrop, 2001). Some individuals with NEAD seem to experience attacks as a result of dissociation (Alper et al., 1997; Bowman & Markland, 1996; Goldstein & Mellers, 2006; Kuyk et al., 1996), with many individuals with NEAD experiencing high levels of dissociation (Alper et al., 1997; Mazza et al., 2009; Prueter, Schultz-Venrath & Rimpau, 2002). This finding, however, has not always been replicated (Alper et al., 1997; Reuber, House,

Pukrop, Bauer & Elger, 2003). Moreover, high levels of somatoform symptoms have been found within individuals with NEAD (Binder & Salinsky, 2007; Bowman, 2001; Bowman & Markland, 1996; Reuber, House et al., 2003). Other researchers have classified NEAs into posttraumatic NEAs or developmental NEAs (Brown et al., 2011). Posttraumatic NEAs are postulated to be a dissociative response to trauma, whereas developmental NEAs are said to be due to difficulties coping with psychosocial development milestones. Despite this debate of whether to classify NEAD as a dissociative or somatoform disorder, it is recognised that somatisation, conversion and dissociation are highly associated (Guz et al., 2004; Reuber & Elger, 2003; Spitzer, Spelsberg, Grabe, Mundt & Freyberger, 1999). It is unclear, therefore, whether these are driven by the same processes (Brown, Cardena, Nijenhuis, Sar & van der Hart, 2007).

### **1.10 Theoretical models of NEAD**

The earliest explanations of NEAD were derived from a psychodynamic conceptualisation of the disorder, which proposed a role for unconscious conflicts associated with guilt and shame from repressed sexual drives (Myers & Zaroff, 2004). Freud initially proposed these types of NEAs were linked to hysterical personality traits (Freud, 1888/1966), and caused by childhood sexual trauma. Freud later refined his theory to propose NEAs were related to childhood sexual fantasies rather than actual sexual abuse (Rosenbaum, 2000). This association between NEAD and sexual abuse has been demonstrated by many studies (e.g., Cragar et al., 2002) and it has been proposed that NEAs may serve to modify the person's awareness (i.e., to dissociate), in order to manage any perceived threat (Bowman, 1993). Following the links proposed by Freud between NEAD and certain personality types, research into NEAD has demonstrated an association with specific personality types, such as borderline personality disorder (Reuber, Pukrop, Bauer, Derfuss & Elger, 2004).

Following the psychodynamic conceptualisation, behavioural models of NEAD were developed (Ramani et al., 1980), in which NEAs were regarded as a learned response enabling the person to cope with stress. Support for this conceptualisation comes from findings that individuals with NEAD know someone with epilepsy or witnessed a seizure prior to NEAD onset (Bautista, Gonzales-Salazar & Ochoa, 2008; Hopkins, 1989). This may explain why some patients manifest seizures rather than other somatic symptom manifestations. However, other studies have shown that many patients do not know anyone with epilepsy (Moore & Baker, 1997). This conceptualisation also postulates secondary gains (e.g., attention from others or avoidance of a specific situation) may act as reinforcers that serve to perpetuate the difficulty (Alper, 1994).

More recently it has been acknowledged that psychological, social and cognitive factors may be important in the development and maintenance of NEAD. NEAD has been explained within Lazarus and Folkman's Stress Model (1984), suggesting that NEAs are a coping strategy to unmanageable stress (Goldstein, Drew, Mellers, Mitchell-O'Malley & Oakley, 2000; LaFrance & Bjornaes, 2010). Subsequently, Goldstein, Deale, Mitchell-O'Malley, Toone and Mellers (2004) proposed a "fear-avoidance" model, which suggests NEAs are caused by dissociation in response to overwhelming or



feared situations, and NEAs are maintained by a reinforcement cycle of behavioural, cognitive, affective, physiological and social factors. For example, patients may avoid certain behaviours for fear of triggering a NEA, but paradoxically this would result in attention being focused on bodily symptoms, which would consequently increase the fear and arousal experienced by the individual. This is supported by findings that individuals with NEAD demonstrate increased fear sensitivity (Hixson, Balcer, Glosser & French, 2006) and avoidance behaviour (Frances, Baker & Appleton, 1999; Goldstein & Mellers, 2006).

Another model was proposed by Brown et al. (2011). This model describes NEAD within a cognitive psychological framework, whereby NEAs arise from the automatic activation of a well-learned and/or difficult to inhibit 'action programme' triggered by events such as anticipation of further NEAs, bodily hypervigilance and avoidance. It explains how disturbances in high-level attentional systems due to developmental difficulties (e.g., abuse and attachment difficulties) and situational difficulties (e.g., stress) can play a role within NEAD. This model proposes NEAs are dissociative as they involve 'compartmentalisation' of information within the cognitive system (Lawton et al., 2008). This arises when high-level attentional systems are unable to inhibit the automatic activation of a low-level action programme.

### **1.11 Aetiology of NEAD**

As discussed, there are many hypotheses concerning the aetiology of NEAD, including the conversion of arousal into somatic symptoms, a dissociative response to arousal, a learned response, and a form of communication and/or a maladaptive coping behaviour. However, as NEAD occurs within a heterogeneous population, no single mechanism has been identified as contributing to the development or maintenance of the disorder in all cases (Reuber, 2008). Consequently, NEAD may be best understood using a multifactorial model describing the predisposing, precipitating and maintaining factors in the development and maintenance of NEAD (LaFrance & Bjornaes, 2010; Reuber, 2009).

#### **1.11.1 Predisposing Factors**

A number of possible risk factors for NEAD have been identified, including childhood abuse, family dysfunction, genetic factors and physical factors, with most research focusing on the role of childhood abuse (Akyuz, Kugu, Akyuz & Dogan, 2004; Alper, Devinsky, Perrine, Vazquez & Luciano, 1993; Reuber, 2008, 2009; Reuber, Howlett, Khan & Grunewald, 2007). A review of the literature by Cragar et al. (2002) concluded that a history of sexual, physical and/or emotional abuse was reported in 75% of individuals with NEAD compared to 42% of individuals with epilepsy. These findings have been replicated, with estimates ranging from 10-77% (Akyuz et al., 2004; Bowman, 1993; Bowman & Markland, 1996; Fisman, Alves-Leon, Nunes, D'Andrea & Figueira, 2004; Moore & Baker, 1997). However, others have argued for more caution to be taken before concluding that abuse is a predisposing factor to NEAD (Sharpe & Faye, 2006). As highlighted by the variability in the estimates of childhood abuse, there have been concerns regarding the validity and reliability of accurate reporting due to differing definitions of 'abuse', the potential for recall bias and lack of comparison groups (Binzer, Stone & Sharpe, 2004; Sharpe & Faye, 2006). A potential mediating

factor between childhood abuse and NEAD is alexithymia (i.e., difficulties perceiving or feeling emotions) (Bewley, Murphy, Mallows & Baker, 2005; Joukamaa et al., 2008). Similarly, individuals with NEAD can also exhibit emotional dysregulation (i.e., sudden and extreme emotions) (Cragar et al., 2005; Reuber, Pukrop, Bauer, Helmstaedter, Tesselndorf & Elger, 2003), which has been associated with childhood abuse (Breier & Rickards, 2007). It has also been suggested that individuals with NEAD, who have experienced sexual abuse, process information in a hypervigilant manner (Bakvis, Roelofs, Kuyk, Edelbroek, Swinkels & Spinhoven, 2009).

A dysfunctional family environment has been identified as a possible risk factor and may be a mediating factor between childhood abuse and NEAD (Moore, Baker, McDade, Chadwick & Brown, 1994; Reuber, 2008; Sharpe & Faye, 2006). Family problems have been identified as being more prevalent amongst individuals with NEAD than individuals with epilepsy. Wood, McDaniel, Burchfiel and Erba (1998) found families of individuals with NEAD reported more health concerns, distress and criticism than families of individuals with epilepsy. This may contribute to NEAD via family distress, criticism and tendency to somatise. NEAs may develop as a method of communication within the family, allowing the patient's needs to be expressed and met. This is supported by findings that families of individuals with NEAD are more likely to be characterised by "unspeakable dilemmas" (Griffith, Polles & Griffith, 1998), and lack of communication (Krawetz et al., 2001). Higher levels of somatisation have been found within families of individuals with NEAD, potentially highlighting the preponderance to express distress somatically rather than verbally (Wood et al., 1998). These families may also be characterised by high levels of expressed emotion, and individuals with NEAD often perceive their families as less supportive, involved, committed and functioning than individuals with epilepsy and the general population (Griffith et al., 1998; Krawetz et al., 2001; Moore et al., 1994; Salmon, Al Marzooqi, Baker & Reilly, 2003; Stanhope, Goldstein & Kuipers, 2003). Furthermore, individuals with NEAD are more likely to have developed a fearful attachment style from their early experiences in comparison to individuals with epilepsy (Holman, Kirkby, Duncan & Brown, 2008; Salmon et al., 2003).

Gender may be a genetically determined risk factor for developing NEAD, with three times more women experiencing NEAD (Moore & Baker, 1997). It is unclear whether this difference is due to genetics or societal and cultural differences between men and women's expression of emotion (Reuber, 2009). One potential explanation of this gender difference is the association found between sexual abuse and NEAD (Alper et al., 1993). An alternative explanation relates to the gender differences in the acceptability of emotional expression (Francis & Baker, 1999; Reuber & Elger, 2003). For example, Rosenbaum (2000) suggested that NEAs in women are a dissociated defence of expressed rage, fear and helplessness, whereas it was suggested that men are more likely to act out and become aggressive.

Physical factors have also been identified in the development of NEAD. Structural and functional brain abnormalities have been found to be highly prevalent within individuals with NEAD, although no specific pattern of abnormality has been found (Reuber, Fernandez, Helmstaedter, Qurishi &

Elger, 2002). Research has also found individuals with epilepsy are at greater risk of developing NEAD (Reuber, 2009), although the reasons for this are largely unknown. One potential explanation is through alterations in neurological function, whilst an alternative explanation postulates the role of modelling, with individuals with NEAD being more likely to have witnessed a family member having seizures (Bautista et al., 2008).

### **1.11.2 Precipitating factors**

Whilst physical factors have been identified as predisposing factors (op. cit.), some have also been identified as precipitating factors. For example, NEAD can develop following neurosurgery (Reuber, 2009), and head injury has been associated with the onset of NEAD (Barry et al., 1998). Despite this, there is little evidence of actual physical abnormality following head injuries (Reuber, 2009). Significant traumatic or stressful life events, including neurosurgery and head injury, can often be found to be precipitants of NEAD (Binzer et al., 2004, Bowman & Markland, 1999), although many patients often state their NEAs started without any cause (Reuber, 2009). A large proportion of individuals with NEAD report a history of trauma (Duncan & Oto, 2008; Reuber, Howlett et al., 2007). However, these precipitant factors are not specific to NEAD (Reuber, 2009). Additionally, Bakvis et al. (2010) demonstrated NEAs were associated with increased basal cortical levels, suggesting a neurobiological marker for NEAD. However, this effect may be due to the high levels of trauma reported within this population.

The onset of NEAD is often associated with an exacerbation of another form of psychopathology (Reuber, 2009), and many individuals with NEAD have comorbid psychopathology, most commonly other somatoform or dissociative disorders, depression, anxiety and post-traumatic stress disorder (PTSD) (Bowman & Markland, 1996; Fiszman et al., 2004; Owczarek, 2003a, 2003b; Reuber, 2009). Approximately one-third of individuals with NEAD experience depression (Bowman, 2001; Moore & Baker, 1997). Suicide attempts are also common amongst individuals with NEAD (Carton et al., 2003; Moore & Baker, 1997). Levels of depression among this population are similar to levels reported within individuals with epilepsy (Gaitatzis, Trimble & Sander, 2004). Anxiety disorders, including PTSD, are more common amongst individuals with NEAD than individuals with epilepsy (Fiszman et al., 2004; Gaitatzis et al., 2004; Rosenberg, Rosenberg, Williamson & Wolford, 2000), with estimates ranging from 33-47% (Bowman, 2001). The increased instability of emotions, increased suicidal risk and high levels of abuse reported by individuals with NEAD led Lacey, Cook and Salzberg (2007) to suggest personality difficulties underlie NEAD. Individuals with NEAD demonstrate higher levels of personality difficulties compared to individuals with epilepsy and the general population (Gaitatzis et al., 2004; Reuber, 2009), particularly borderline personality disorder (Binzer et al., 2004; Bowman & Markland, 1996; Reuber, Pukrop et al., 2004). It could be argued that high levels of comorbid psychopathology within individuals with NEAD could be due to experiencing NEAD. However, within a sample of patients with newly developed NEAD, van Merode et al. (2004) demonstrated high levels of comorbid psychopathology, suggesting it was not persistent NEAD that produced psychopathology. NEAD may also be a manifestation and/or exacerbation of another psychological disorder rather than being a comorbid

disorder (i.e., NEAD as a symptom rather than a disorder) (Brown et al., 2011; Quigg, Armstrong, Farace & Fountain, 2002; Reuber, 2009).

Reuber (2009) suggests NEAs often have immediate triggers, such as symptoms of panic or sudden sensory or emotional stimulation, such as flashbacks within PTSD or hallucinations within psychosis. This has been supported by evidence of increased fear sensitivity and threat processing in individuals with NEAD compared to individuals with epilepsy, and independent of comorbid psychopathology (Bakvis et al. 2009; Hixson et al., 2006). Bakvis, Spinhoven and Roelofs (2009) found threat vigilance was associated with increased cortisol levels (i.e., neurobiological stress system). This supports Goldstein et al.'s (2004) "fear-avoidance" model. These triggers may ultimately lead to the avoidance of emotion or physical sensations commonly seen in individuals with NEAD (Reuber, 2009).

### **1.1.1.3 Maintaining factors**

A number of factors have been identified in maintaining NEAD once it has developed, with anxiety-driven avoidance being cited as a key maintenance factor (Reuber, Howlett, Khan & Grunewald, 2007). This may explain why individuals with NEAD often cannot report precipitating events as associated with their NEAs. Illness beliefs are also thought to play a role in the maintenance of NEAD. Individuals with NEAD tend to have an external locus of control when describing their health (Goldstein et al., 2000; Stone, Binzer & Sharpe, 2004), describing their health as being determined by uncontrollable and unpredictable factors, being more likely to deny life stresses, and believing psychological factors play less of a role in their NEAs than somatic factors (Stone et al., 2004). This may explain why approximately half of individuals with NEAD refuse psychotherapy (Howlett, Grunewald, Khan & Reuber, 2007). Avoidance also contributes to the social isolation, disability and dependency experienced by individuals with NEAD (Thompson, Isaac, Rowse, Tooth & Reuber, 2009). This may increase the risk of patients becoming depressed, angry and potentially developing other physical symptoms such as pain or fatigue (Reuber, 2009). This "sick role" can also become a part of their self-identify (Reuber, 2009).

NEAD may also be maintained by the misattribution of symptoms to physical causes. Many individuals with NEAD undergo a lengthy period of misdiagnosis (Reuber, Fernandez, Bauer, Helmstaedter & Elger, 2002), and have often formed firm beliefs about a physical cause of their NEAs. This is often reinforced by iatrogenic factors such as continuous investigations, anti-epileptic medication and inappropriate medical interventions (Reuber & Elger, 2003). This misinterpretation of symptoms is supported by evidence of distorted perceptual processing in somatoform dissociation (Brown, Brunt, Poliakoff & Lloyd, 2010). Another proposed explanation is the longstanding suppression of emotions (LaFrance & Bjornaes, 2010), whereby the person does not allow themselves to express certain emotions (e.g., depression, anger), perhaps because this will be against the person's standards/expectations. This may initially be a conscious process, but may become more automatic and less conscious over time.

Stress and coping strategies may also maintain NEAD. Individuals with NEAD have been found to report more stressful life events compared to control participants (Frances et al., 1999; Tojek, Lumley, Barkley, Mahr & Thomas, 2000). However, other studies have found individuals with NEAD were more likely to deny life stresses (Karterud, Knizek & Nakken, 2010; Stone et al., 2004). Furthermore, individuals with NEAD have been found to use more maladaptive, emotion-focused coping strategies rather than adaptive, problem-solving coping strategies (Frances et al., 1999; Goldstein et al., 2000; Jawad et al., 1995). Problem-focused coping has generally been found to be more effective than emotion-focused coping in alleviating stress reactions (Mikulincer, Florian & Weller, 1993), whereby problem-focused coping describes the strategy of dealing with the problem that is causing the distress, and emotion-focused coping is the strategy of regulating one's emotions.

### **1.12 Treatment of NEAD**

Psychological interventions are considered the most appropriate treatment for NEAD (Gaynor, Cock & Agrawal, 2009; LaFrance & Devinsky, 2002), although research into the effectiveness of treatments is limited (LaFrance & Barry, 2005), with a recent Cochrane Review concluding that there was "*no sound evidence on which to base treatment decisions for people with non-epileptic attacks*" (Baker, Brooks, Goodfellow, Bodde & Aldenkamp, 2007a, 2007b). There have been various proposals as to the focus of treatment, such as whether to focus on the trauma that precipitated the NEAs or allowing the patient to learn how to express distress verbally (Bodde et al., 2009b). However, a multiple treatment approach based on idiosyncratic needs of patients may be most effective (LaFrance & Devinsky, 2002; Myers & Zaroff, 2004; Reuber, Burness, Howlett, Brazier & Grunewald, 2007; Rusch et al., 2001). The main treatment approaches are discussed below.

#### **1.12.1 Presentation of NEAD Diagnosis**

The initial step in the treatment of NEAD is confirmation of the diagnosis and an explanation given to the patient (Brown et al., 2011; LaFrance et al., 2006). A clear explanation of the diagnosis has been found to be effective at reducing emergency room visits (Martin et al., 1998), and in leading to the reduction and cessation of NEAs (Aboukasm, Mahr, Gahry, Thomas & Barkley, 1998; Farias, Thieman & Alsaadi, 2003; Reuber & Elger, 2003). The way in which the diagnosis is communicated has been found to have important implications, and has led to the development of specific protocols for presenting the diagnosis (Hall-Patch et al., 2010; LaFrance et al., 2006; Shen, Bowman & Markland, 1990a; Thompson, Osorio & Hunter, 2005). Acceptance of the diagnosis is crucial for patients to accept a referral for psychotherapy (Binder & Salinsky, 2007; Goldstein et al., 2004). Research has also identified that earlier diagnosis and treatment is associated with better prognosis (Moore & Baker, 1997), as is acceptance of their NEAD diagnosis (Ettinger, Devinsky, Weisbrot, Ramakrishna & Goyal, 1999). For patients with comorbid epilepsy it is necessary to explain the nature of the different types of 'seizures' and for them to learn to differentiate between them (Reuber & Elger, 2003).

### **1.12.2 Pharmacology**

As NEAD has a psychological aetiology, anti-epileptic medications do not result in a decrease in NEAs, and may even worsen NEAD (LaFrance & Blumer, 2010). Treatment usually involves the slow withdrawal of any anti-epileptic medication if comorbid epilepsy is not present (Duncan, 2006). The aim of pharmacology in the treatment of NEAD is to treat any underlying difficulty such as anxiety, depression, PTSD and psychoses (Alper, 1994, LaFrance & Barry, 2005). Although limited, some evidence is emerging for the effectiveness of pharmacological treatment for NEAD (LaFrance et al., 2010).

### **1.12.3 Psychodynamic Interventions**

Psychodynamic theory proposes NEAD is caused by unconscious conflicts (Myers & Zaroff, 2004), and the aim of psychodynamic intervention is to help the patient identify these conflicts and establish a more adaptive way of managing them. The effectiveness of psychodynamic interventions for NEAD has not been empirically investigated (LaFrance & Barry, 2005).

### **1.12.4 Behavioural Interventions**

Behaviour theory postulates that NEAs are a conditioned response to secondary gain, and cessation of NEAs is possible by removing this secondary gain. The aim of behavioural therapy in the treatment of NEAD is to prevent the reinforcement of NEAs. For example, behavioural therapy may be particularly useful for patients if their NEAs are reinforced by attention or avoidance as a result of the NEAs. This therapy uses a wide range of techniques to achieve this, such as progressive relaxation and systematic desensitisation. The effectiveness of behaviour therapy for NEAD has not been established.

### **1.12.5 Cognitive-Behavioural Interventions**

The aim of Cognitive-Behavioural Therapy (CBT) is to modify dysfunctional thought processes using behavioural and cognitive change techniques. Depending on the underlying problem, there are a number of different uses of CBT in the treatment of NEAD, such as focusing on negative cycles of maintaining factors such as avoidance, hypervigilance to bodily sensations and negative thoughts (Chalder, 1996; Goldstein et al., 2004, 2010). Additional techniques may be used to enhance awareness of unexpressed emotions, identify stressors and problem-solve alternative coping strategies (Prigatano, Stonnington & Fisher, 2002; Reuber & Elger, 2003). Preliminary evidence (Goldstein et al., 2004, 2010; LaFrance et al., 2009) suggests CBT may lead to a significant reduction in NEAs and improved psychosocial functioning.

### **1.12.6 Family Interventions**

Another suggested intervention approach is Family Therapy (Griffith et al., 1998). The utility of family therapy in the treatment of NEAD is supported by evidence that families of individuals with NEAD often have high levels of expressed emotion, high levels of family dysfunction accompanied by 'unspoken dilemmas' and have difficulties in expressing emotion (Griffith et al., 1998; Krawetz et al., 2001; Moore et al., 1994; Salmon et al., 2003). Experiencing a family member with NEAD may also create anxiety and increase everyday stresses. The aim of this intervention would be to

ensure the family can cope with the increased anxiety and stresses, and ensure they do not reinforce the NEAs, potentially via teaching problem-solving, communication skills and affective responsiveness (LaFrance & Bjornaes, 2010). The effectiveness of Family Therapy for NEAD has not yet been established.

### **1.12.7 Group Interventions**

Another suggested intervention approach is Group Therapy (LaFrance & Barry, 2005). The aim of this intervention would be to increase the patient's support network, decrease social isolation, provide psychoeducation and allow direct experiences of witnessing NEAs and identifying potential triggering factors (LaFrance & Barry, 2005). A number of studies have found group therapy to be effective (Barry et al., 2008; Prigatano et al., 2002; Zaroff, Myers, Barr, Luciano & Devinsky, 2004), although each group used different therapeutic approaches (e.g., psychodynamic, relaxation training, hypnosis). Participants often took part in individual therapy alongside group therapy, making it difficult for any improvements to be fully attributed to the group therapy (Barry et al., 2008).

### **1.12.8 Other Interventions**

Other interventions have been suggested within the literature, including psychodynamic interpersonal therapy (Howlett & Reuber, 2009; Mayor, Howlett, Grunewald & Reuber, 2010), hypnosis (LaFrance & Barry, 2005) and eye-movement desensitisation and reprocessing (Chemali & Meadows, 2004; Kelley & Benbadis, 2007). Other research has demonstrated the effectiveness of multi-disciplinary working in the effective treatment of NEAD (Kuyk, Siffels, Bakvis & Swinkels, 2008). The effectiveness of these interventions for NEAD has not yet been fully established.

### **1.13 Prognosis of NEAD**

Research into the prognosis of NEAD is limited and has often focused on the cessation or reduction of NEAs (Riaz, Comish, Lawton & Scheepers, 1998). However, whilst good prognosis is linked to the cessation of NEAs, other psychosocial outcomes should be taken into account (LaFrance et al., 2006; McKenzie, Oto, Russell, Pelosi & Duncan, 2010; Reuber, Mitchell, Howlett & Elger, 2005), including perceived quality of life (QoL) and functioning, coping style and level of psychopathology (Myers & Zaroff, 2004), given that NEA cessation or reduction may not lead to functional improvement more generally (Walczak et al., 1995).

In a sample of 164 individuals with NEAD, Reuber and colleagues found one-third of patients experienced complete remittance from NEAs approximately four years after diagnosis, which was taken as indicating a poor prognosis. This figure is consistent with other studies (Bodde et al., 2007; Kanner et al., 1999; McKenzie et al., 2010). Factors associated with poorer outcome include longer duration of seizures (Ettinger, Dhoon, Weisbrot & Devinsky, 1999; Guberman, 1982; Kanner et al., 1999; Walczak et al., 1995), recurrent psychopathology and personality disorder (Ettinger, Dhoon et al., 1999; Guberman, 1982; Kanner et al., 1999; McKenzie et al., 2010), having an acute, emotional trauma preceding NEAD onset (Guberman, 1982) and lack of positive relationships (Ettinger, Dhoon et al., 1999). Receiving psychological treatment has also been associated with a

reduction in NEAs (Jongsma, Mommers, Renier & Meinard, 1999; Meierkord et al., 1991), although this has not been a consistent finding (Ettinger, Dhoon et al., 1999; Walczak et al., 1995).

Another factor associated with prognosis is the individual's reaction to the diagnosis, with a poorer outcome being associated with an angry or confused reaction, and better outcomes being associated with a relieved reaction (Carton et al., 2003). Prognosis is better if individuals accept their diagnosis (Ettinger, Devinsky et al., 1999; Thompson et al., 2009). The fact that these reactions play an important role in outcome highlights the importance of exploring the perceptions, understanding and experiences of individuals with NEAD.

#### **1.14 Perceptions and Experiences**

A limited number of studies have explored patient experiences of NEAD, including their perceptions and understanding of their difficulties. Although some patients can experience the diagnosis as a relief from the burden of having epilepsy (Karterud et al., 2010; Thompson et al., 2009), many patients experience negative emotions such as confusion, anger, upset, frustration, disappointment, fear, shame, guilt and despair (Carton et al., 2003; Green, Payne & Barnitt, 2004; Karterud et al., 2010; Thompson et al., 2009). Alongside these negative emotions, only one-third of individuals with NEAD were found to have some understanding of their diagnosis approximately 1-7 years after their diagnosis (defined as awareness of the role of psychological factors) (Carton et al., 2003). Even patients who have some understanding of NEAD still express considerable confusion and misconceptions about the nature of NEAD, particularly when patients are unaware of any underlying cause for their NEAs (Carton et al., 2003; Karterud et al., 2010). These experiences are important to consider, particularly since positive reactions to the diagnosis and understanding of the diagnosis are associated with better prognosis (Ettinger, Devinsky et al., 1999; Green et al., 2004). Furthermore, Karterud et al. (2010) demonstrated many patients became frustrated when their own understanding of their NEAs was not considered, which again was associated with poorer prognosis.

Prior to receiving the diagnosis, individuals with NEAD form hypotheses about the cause of their NEAs (Green et al., 2004; Thompson et al., 2009). These hypotheses lead to different meanings being ascribed to the NEAD diagnosis. Karterud et al. (2010) found patients who believed the cause of their NEAs were due to stress, anxiety and/or trauma, did not perceive a threat to their self-identity upon receiving the diagnosis, and were more readily accepting of the diagnosis. However, it has been argued that individuals with NEAD are generally less readily accepting of a psychological explanation of their condition (Karterud et al., 2010; Stone et al., 2004). Similarly, Karterud et al. (2010) found individuals with NEAD perceived the change from a neurological explanation for their NEAD to a psychological explanation as a threat to their self-identity. Consequently, it has been suggested individuals with NEAD need to integrate the NEAD diagnosis into their sense of self, and redefine themselves and/or re-evaluate their self-identity (Karterud et al., 2010; Thompson, 2009).



Using Interpretative Phenomenological Analysis (IPA; Smith & Osborn, 2003) with individuals with NEAD, Thompson et al., (2009) identified six themes amongst their experiences. These were related to the experience of living with NEAs, difficulties understanding their 'label', being left with a sense of confusion, experiencing a sense of doubt and uncertainty, not feeling like a person and the emotional impact of the diagnosis. Individuals with NEAD felt trapped by their NEAs and described a sense of loss of independence, isolation, helplessness and being unable to move forward with their lives. They also had perceptions of being doubted by medical professionals, society, friends and family, and an overall sense of being 'left in limbo land' by healthcare professionals. Similarly Karterud et al. (2010) found individuals with NEAD reported difficulties in understanding their NEAD diagnosis, a wide-range of emotional reactions and a sense of being abandoned by healthcare professionals. Green et al. (2004) used IPA to investigate illness representations of individuals with NEAD in relation to Leventhal's (1992) self-regulation model. They found individuals with NEAD were particularly confused about the cause of their NEAD and how to 'label' it, which created confusion about the timeline of the disorder and whether it could be controllable and/or curable.

Health-related QoI is a concept used to assess the impact of an illness/disorder (Dodrill, 2010). Individuals with NEAD are more likely than individuals with epilepsy to perceive their health-related QoI as poor (Al Marzooqi, Baker, Reilly & Salmon, 2004; Breier et al., 1998a; Szaflarski & Szaflarski, 2004). This perception persists following the cessation of their NEAs (Ettinger, Devinsky et al., 1999). However, QoI is associated with low mood rather than the NEAs themselves (Dodrill, 2010; Szaflarski et al., 2003; Testa, Schefft, Szaflarski, Yeh & Privitera, 2007), supporting the need for treatment to focus on these difficulties rather than NEA cessation exclusively. Perceptions of neuropsychological functioning have also been investigated. Individuals with NEAD are more likely to report memory and word-finding difficulties compared to individuals with epilepsy (Dodrill, 2010; Fargo et al., 2004). This effect, however, may be due low mood (Dodrill, 2010).

### **1.15 Summary of NEAD Research**

Research into NEAD has focused on the differential diagnosis of NEAD and identifying the associated risk factors, such as abuse and psychopathology (Reuber, 2009). Whilst this is important, there remains a paucity of research exploring the processes involved in the development and maintenance of NEAD, which contributes to the lack of research investigating treatment effectiveness and prognosis. There has been a paucity of studies exploring the experiences and perceptions of individuals with NEAD, despite these factors influencing prognosis (Karterud et al., 2010). Some qualitative studies have explored these experiences and perceptions but have been underpinned by a particular model, or incorporated interview schedules likely to be affected by researcher bias and social desirability factors.

### **1.16 Methodology Debate: Quantitative versus Qualitative Analysis**

The majority of studies within NEAD research have used questionnaire-based designs. Whilst there are advantages to this method (e.g., ease of administration), there are also many disadvantages. Questionnaires are designed to obtain information which is deemed most relevant to the

researcher, creating a potential risk of not asking the most appropriate or useful questions and not giving the person the opportunity or flexibility to convey their true perceptions (Jankowicz, 2004). It also limits how much the participant can respond to the questions and lacks opportunity for clarification of the participants' intended meaning. This poses the risk of the researcher misinterpreting the participants' responses.

Inherent in this discussion is the debate between quantitative and qualitative research, each embedded within different epistemologies (Henwood & Pidgeon, 1992). Quantitative research has historically been influenced by the positivist and empiricist agenda, which emphasises the search for knowledge through objectivity and empirically testable hypotheses. Conversely, the interpretative and constructivist position is seen as embracing the search for rich, qualitative accounts of psychological experiences and focuses on meaning and interpretation. Psychological research, including that on NEAD, has largely been dominated by quantitative methodologies. Over recent years, however, qualitative methods have gained increased popularity within the field of psychology (Madill & Gough, 2008). Research investigating the perceptions and experiences of individuals with NEAD has started to utilise interview-based designs (Carton et al., 2003; Dickinson, Looper & Groleau, 2011; Karterud et al., 2010; Thompson et al., 2009). Whilst interview-based designs can be useful in overcoming some of the difficulties inherent within questionnaire-based designs, there are still some social desirability influences. For example, participants may answer questions in a particular way to avoid being judged by the researcher and/or answer questions in a way they perceive the researchers would like them to answer the questions. Within this debate is the differentiation between nomothetic and idiographic methodology. Nomothetic methodology, usually dominated by questionnaire-based designs, strives to establish a general classification of a cohort of people (e.g., by averaging the attitudes and experiences of all participants). However, this may result in the outcome not being completely true for any one participant. Conversely, idiographic methodology strives to describe each individual's idiosyncratic perspective but is criticised for being non-generalisable, due to the information gathered being unique to each individual.

Consequently, it was important to select a methodology capable of overcoming some of the difficulties inherent within NEAD research. A methodology capable of exploring both the explicit and implicit perceptions and interpretations of participants without imposing interviewer bias is the RGT, developed from the constructivist theory, PCT (Fransella et al., 2004; Kelly, 1955). This technique is able to uncover implicit attitudes that are not likely to be revealed via traditional interviews or questionnaires (Winter, 1992). The RGT can be perceived to be '*qualiquantilogical*', as it incorporates both the quantitative features of numerical data collection and statistical analysis as well as the qualitative features of the detailed information obtained from the participant descriptions, which attempts to stay true to the individual's intended meaning (Ashworth, 2003; Jankowicz, 2004). Additionally, analyses can be used to explore the relationship between constructs and elements within a single grid (i.e., idiographic approach), as well as allowing comparison across multiple grids (i.e., nomothetic approach) (Fransella et al., 2004; Neimeyer,

2002). Considering the proposed heterogeneity of individuals with NEAD, and the relative paucity of research and consensus in our understanding of NEAD, it was important to explore both the individual perspectives and the general (i.e., averaged) perspective of individuals with NEAD. Furthermore, rather than simply exploring *'what'* individuals with NEAD think about their worlds, this technique allows for the exploration of *'how'* individuals with NEAD think about their worlds. For example, it is possible to explore whether individuals with NEAD have 'cognitively complex' construct systems (i.e., whether there is flexibility in their construing) (Bieri et al., 1966).

### **1.17 Personal Construct Theory**

In 1955, George Kelly introduced PCT to provide an alternative explanation for understanding personality and behaviour that was different from then dominant psychodynamic and behavioural theories (see Walker & Winter, 2007, for a review). It was an attempt to describe how people make sense of their world, acknowledging the entire person rather than a fragment of a person's psychological make-up. Kelly postulated that people make sense of the world through their own unique 'filter' (Winter, 1992). This 'filter' consists of constructs, which are ways of perceiving or interpreting situations. Kelly postulated people are scientists trying to give meaning to and predict their environments via a process of construing, whereby they make hypotheses, test them out and revise them based on experiences (Winter, 1992). The philosophical assumption of PCT is *constructive alternativism*, which states there is no objective reality, but we each construct a subjective reality of the world based on the construal of our experiences (Kelly, 1955; Walker & Winter, 2007). PCT suggests that if you want to understand a person, you must know something about the constructs they use (Adams-Webber, 1998; Slater, 1969). Kelly (1955) described a fundamental postulate and 11 corollaries.

#### **1.17.1 Fundamental Postulate and Corollaries**

The fundamental postulate is the basic premise underlying PCT, and assumes that *"a person's processes are psychologically channelized by the ways in which he [sic] anticipates events"* (Kelly, 1955, p.47). This implies that we respond to the world on the basis of how we anticipate the world to be. Kelly (1955) further advocates that any behaviour can be made sense of within the person's construct system. For example, if a person believes that a symptom has a physical/medical cause, they may seek medical intervention and predict the symptom will be alleviated when the physical problem is treated. Alternatively, if the person believes their symptom is caused by a stressful situation, they may attempt to deal with the situation, predicting the symptom will alleviate when the stressful situation is resolved. The corollaries deemed relevant to the current study are individuality, commonality, organisation, dichotomy, experience, sociality and fragmentation corollaries. These are described in further detail below (see Kelly 1955/1963 for review of all corollaries).

#### **1.17.2 Individuality Corollary**

The 'individuality corollary' states that *"person's [sic] differ from each other in their construction of events"* (Kelly, 1955, p.38). This suggests people differ in the way they construe the world, due to having developed their own personal construct system. It implies people can experience the same

events but develop different constructs, and ultimately different personal construct systems (Winter, 1992).

### **1.17.3 Commonality Corollary**

The 'commonality corollary' states that *"to the extent that one person employs a construction of experience which is similar to that employed by another, his psychological processes are similar to those of the other person"* (Kelly, 1955, p.63). This is in contrast to the individuality corollary, and implies that whilst people can differ in their construal of the same event, it is also possible for them to construe different events in a similar way. It is assumed that people who construe events in a similar way would develop similar personal constructs, and may behave in a similar way.

### **1.17.4 Organisation Corollary**

The 'organisation corollary' states that *"each person characteristically evolves, for his convenience in anticipating events, a construction system embracing ordinal relationships between constructs"* (Kelly, 1955, p.39). This implies that personal construct systems are hierarchical, with subordinate (i.e., lower-level) and superordinate (i.e., higher-level) relationships between constructs. The relationship between constructs in a person's construct system will indicate something of the personal meaning of the constructs, the predication they make about the world, and their behaviour (Bieri, 1955).

### **1.17.5 Dichotomy Corollary**

The 'dichotomy corollary' refers to the notion that *"a person's construction system is composed of a finite number of dichotomous constructs"* (Kelly, 1955, p.41). People construe their world through bipolar constructs, and in order to know something, we must also know its opposite. For example, a person can only understand what 'nice' is by understanding the opposite, which might be 'nasty' (Fransella et al., 2004). Each construct has an emergent pole (i.e., a description of similarity between events) and an implicit pole (i.e., a description of contrast between events).

### **1.17.6 Experience Corollary**

The 'experience corollary' states that *"a person's construction system varies as he successively construes the replications of events"* (Kelly, 1955, p.63). This suggests personal construct systems evolve as a result of new experiences. Personal constructs and relationships between them are constantly being tested and are either validated and remain in the personal construct system, or proven to be inaccurate and modified or replaced by other constructs. This continuous refinement of personal constructs allows the person to better anticipate future events.

### **1.17.7 Sociality Corollary**

The 'sociality corollary' states that *"to the extent that one person construes the construction processes of another, he may play a role in a social process involving the other person"* (Kelly, 1955, p.66). This suggests in order to understand the viewpoint of another person, we must understand something about that person's construct system. This does not infer that the person

must construe the world in the same way, but be able to understand how they construe the world. This will allow the person to predict and adjust to another person's behaviour.

#### **1.17.8 Fragmentation Corollary**

The 'fragmentation corollary' states that "*a person may successively employ a variety of construction subsystems which are inferentially incompatible with each other*" (Kelly, 1955, p.5). Therefore, an individual's personal construct system can incorporate several subsystems that are incompatible, which suggests we can sometimes be inconsistent with ourselves.

#### **1.18 Repertory Grid Technique**

In order to know something about a person and their behaviour we need to understand their personal construct system. This can be a difficult task, however, as some constructs may be outside of our conscious awareness (Pervin & John, 2001). Consequently, Kelly (1955) devised a method for exploring people's constructs, the relationships between constructs and for gaining an insight into their overall personal construct system. This is the RGT, derived from Kelly's (1955) Role Construct Repertory Test ('Rep Test') (Winter, 1992). The RGT is a structured interview process which produces a detailed description of an individual's viewpoint. It consists of constructs, elements and ratings (Jankowicz, 2004).

##### **1.18.1 Constructs**

We make sense of our world (i.e., construe) by means of constructs. Kelly (1955) described constructs as "*a way in which some things are construed as being alike and yet different from others*" (Kelly, 1955, p.74). A construct always represents a contrast (i.e., dichotomous corollary). A person can only know what one pole of the construct is by understanding its relation to the other. Some constructs may be highly interconnected (i.e., associated with each other), whereas others may be loosely interconnected (Fransella et al., 2004).

There has been some debate concerning whether constructs should be elicited or supplied. Kelly's (1955) original explanation of the RGT suggested the elicitation of constructs from the person, as this allows the person to give their own verbal labels to the constructs. It is also argued that when constructs are supplied there is a possibility that some important constructs are omitted or the constructs supplied hold less personal meaning (Jankowicz, 2004). As a result, this study elicited constructs from the participants rather than supplying them. The most common method of construct elicitation used within the repertory grid literature is the triadic elicitation method, whereby the person is presented with three elements and asked to specify how two of them are similar and therefore different than the third (Fransella et al., 2004). This will generate one pole of the construct. The second pole of the construct can either be elicited via the 'difference method', whereby the person states in what way the third element is different from the other two, or the 'opposite method', whereby the person identifies the opposite of the word/phrase given for the initial pole elicited. It has been argued that the 'difference method' may give a pole of another construct (Epting, Suchman & Nickeson, 1971). Consequently, this study employed the triadic method of elicitation using the 'opposite method' to elicit the second construct pole.

It may also be necessary to elicit further constructs from earlier constructs through the process of 'laddering' (Hinkle, 1965). 'Laddering' is used for eliciting subordinate constructs (via 'laddering down') and superordinate constructs (via 'laddering up') from the original constructs (Fransella et al., 2004; Hinkle, 1965). Studies have found that ladderred constructs tend to be a valid method for producing more meaningful constructs than the constructs initially elicited (Fransella et al., 2004; Hinkle, 1965; Neimeyer, Anderson & Stockton, 2001). As a result, this laddering process was incorporated within this study.

### **1.18.2 Elements**

Elements are used to identify a set of constructs and are defined as "*the things or events which are abstracted by a construct*" (Kelly, 1955, p.95). They are "*examples of a topic*" (Jankowicz, 2004, p.13) and can be virtually anything we think about, including people, places, situations and objects (Bannister, 1965; Fransella et al., 2004). Choosing the right set of elements is a crucial step in constructing a repertory grid, as they will influence the type of constructs elicited (Haritos, Gindidis, Doan & Bell, 2004). One important rule is that elements should be within the range of convenience of the constructs, which suggests constructs have a limited number of elements that they can be applied to (Fransella et al., 2004). This is illustrated by Brown (1958) by posing the question "Is a boulder sweet or sour?". The choice of elements within this study is described in the next chapter.

### **1.18.3 Ratings**

Each element is *rated* on each construct, so that each of the elements are positioned somewhere between the two poles of a construct. This positioning can be analysed to give insight into how the elements fit into the person's construct system (Fransella et al., 2004). This analysis is based on the premise that mathematical relationships between constructs and elements represent the psychological relationships within a person's construct system (Bannister, 1965; Fransella et al., 2004). There are two main methods of rating elements when constructing repertory grids. The ranking method can be used, whereby elements are ranked in order along each construct. Alternatively, participants can rate each element on a pre-determined numerical scale (e.g., 7-point rating scale) between the two construct poles. This study utilised the rating method, as Fransella et al. (2004) described the ranking method as being too restrictive as they force elements to be distributed evenly across the construct, which may not be the most accurate representation of the person's viewpoint. A 7-point rating scale was used in the current study as this is the most commonly used length within the repertory grid literature, and repertory grids are not affected by the length of the scale used (Metzler, Gorden & Neimeyer, 2002).

### **1.19 Cognitive complexity**

Cognitive complexity refers to the structure of a person's construct system, and describes the capacity to construe behaviour in a multidimensional way (Bieri et al., 1966) Therefore, it is how narrow or broad a person's view is in relation to a particular topic. The level of complexity of a person's construct system (i.e., level of differentiation between constructs) determines the person's

ability to understand different perspectives (Applegate, Kline & Delia, 1991). The greater the cognitive complexity of a personal construct system, the more dimensions an individual has for perceiving others' behaviour and anticipating future events (Bieri, 1955). The cognitive complexity of a person's construct system can be explored using principal components analysis (PCA), with the more components extracted indicating greater cognitive complexity (Baldauf, Cron & Grossenbacher, 2010). Repertory grids with two or more components are deemed to be cognitively complex, whereas repertory grids producing one principal component are generally described as '*monolithic*' (Bell, 2004), and considered to be less cognitively complex. Within the present study, cognitive complexity was measured by the number of principal components needed to explain at least 80% of the variance within the individual grid (Bell, 2004; Fransella et al., 2004). As there is no agreement that one measure of cognitive complexity is more useful or more valid than another (Baldauf et al., 2010; Fransella et al., 2004), this method of obtaining cognitive complexity was used due its use within other studies (Durand, Hare, Hendy & Wittkowski, in press; Woodrow, Fox & Hare, 2010).

## **1.20 Ensuring Quality**

Since there is not one standard form of repertory grid, it poses a problem for making generalisations about their validity and reliability (Winter, 1992). These terms were not a concern of Kelly's (1955), as he argued he was more interested in the consistency and usability of the grids, rather than their reliability and validity (Fransella et al., 2004; Winter, 1992). However, other researchers have investigated the validity and reliability of repertory grid methodology (Adams-Webber, 1970a; Fransella et al., 2004).

### **1.20.1 Validity of Repertory Grids**

Validity can be seen as the usefulness of a technique at increasing our understanding (Bannister & Fransella, 1971). On this basis, it is argued that the RGT is a valid tool. Fransella and Bannister (1977) demonstrated the concurrent and predictive validity of repertory grids, and Fransella et al. (2004) highlight numerous studies that demonstrate repertory grid to be a valid measure in testing PCT hypotheses. Additionally, a measure of validity can be completed via respondent validation (Howitt & Cramer, 2005), whereby the results of the grid are shared with the person and checked whether the grid accurately represents their current construal of the world. Recent studies have also demonstrated the ecological validity of repertory grids (Blundell, Wittkowski, Hare & Wieck, 2011; Durand et al., in press; Woodrow et al., 2010).

### **1.20.2 Reliability of Repertory Grids**

Reliability is generally defined as the "*tendency of a test to produce exactly the same result for the same person at different times*" (Fransella et al., 2004, p.133). Considering the repertory grid is a measure of a person's way of construing a particular topic at one time-point, Kelly (1955) argued a focus on reliability was inappropriate within repertory grid methodology and PCT. Despite this, repertory grid research has demonstrated test-retest correlations of 0.7 to 0.8 (Fransella et al., 2004). In order to ensure reliability and validity within the present study, respondent validation was sought by means of a feedback session, and preparatory work was completed to increase the

researcher's competency in using the RGT. The process was also supervised by a supervisor experienced in this methodology.

### **1.21 Repertory Grid Studies**

The RGT (Kelly, 1955) has been used within many clinical, educational and occupational settings (Fransella et al., 2004; Jankowicz, 2004). Clinically, repertory grids have been used to explore perceptions of people with eating disorders (Feixas, Montebruno, Dada, del Castillo & Compan, 2010; Mottram, 1985), depression (Feixas, Erazo-Cacedo, Harter & Bach, 2008; Hewstone, Hooper & Miller, 1981), self-harm (Parker, 1981), phobias (Winter & Gourney, 1987), thought disorder (Bannister & Fransella, 1971), and health difficulties, such as head and neck cancer, fibromyalgia, chronic pain and irritable bowel syndrome (Large & Strong, 1997; Turpin, Dallos, Owen & Thomas, 2009). They have also been used to explore staff perceptions of patients (Blundell et al., 2011; Ralley, Allott, Hare & Wittkowski, 2009; Woodrow et al., 2010). The RGT has also been used to investigate perceptions of self-identity, cognitive conflicts and cognitive complexity.

#### **1.21.1 Self-Identity**

According to PCT, self-identity is composed of idiosyncratic constructs relating to ourselves and others, and these constructs are organised into a hierarchical network of superordinate and subordinate constructs (Berzonsky & Neimeyer, 1988). Superordinate constructs are the person's core constructs and provide a sense of self-continuity, and are thus considered the person's self-identity (Feixas et al., 2010; Feixas & Saul, 2004). Any change in these 'core' constructs could reflect a change in the entire personal construct system and, therefore, could pose a threat to the person's self-identity (Compan et al., 2011; Feixas & Saul, 2004).

The RGT has been used to measure self-identity by looking at how a person identifies with some people but not with others (Lockhart, 1979). Lack of identification with others has been found within individuals with eating disorders (Mottram, 1985), borderline personality disorders (De Bonis, De Boeck, Lida-Pulik & Feline, 1995; De Bonis, De Boeck, Lida-Pulik, Hourtane & Feline, 1998), and depression (Space & Cromwell, 1980). Another aspect of self-identity can be measured by the discrepancy between how people perceive their current self compared to their past self and ideal self (Higgins, 1987). Discrepancy between these self elements has been associated with poor self-esteem, psychopathology and difficulties adjusting to illness (James & Large, 1992; Ryle & Breen, 1971). In relation to the present study, this raises the question as to whether individuals with NEAD perceive themselves to be similar to their ideal self and/or self before NEAD, or whether they perceive a self-discrepancy.

Repertory grid studies have also been conducted investigating whether people identify with their symptoms/disorder. For example, Fransella (1968) found that people who stutter do not actually identify themselves as stutterers, and they perceived other stutterers to have more negative characteristics. It was also found that stutterers had a highly elaborated system related to stuttering, which suggested that stuttering was a central structure in the person's construct system and, therefore, in their self-identity. Consequently, it was argued that stutterers should be helped



to build a construct system in relation to themselves as fluent speakers. These findings supported earlier work demonstrating how an arsonist did not identify himself as being an arsonist, but instead considered arsonists as being negatively characterised (Fransella & Adams, 1966). Overall, these findings suggest there may be a dichotomy between how people can perceive themselves and their disorder. It also demonstrates how a disorder can become integral to a person's self-identity and how abandoning symptoms can actually threaten a person's self-identity.

### **1.21.2 Cognitive Conflicts**

Internal conflicts play a role within the development of psychological difficulties (Feixas, Saul & Avila-Espada, 2009; Heider, 1958; Higgins, 1987), although different theories use different terminology to describe this conflict. Psychodynamic theory employs the term 'inner conflict' to represent the conflict between inner psychic states (Freud, 1888/1966), whereas social-cognitive theory uses the term 'cognitive dissonance' to highlight internal cognitive dilemmas (Festinger, 1957). According to PCT, difficulties can arise within an individual's personal construct system, and we can understand a person's psychological difficulties by understanding these conflicts and inconsistencies.

The most researched cognitive conflicts are 'implicative dilemmas' (Hinkle, 1965), which are created by a discrepancy between an individual's current and ideal self, but with negative implications associated with being more like the ideal self (Dorough, Grice & Parker, 2007; Feixas & Saul, 2004; Feixas et al., 2009). For example, a person may construe their current self as *lacking in confidence*, yet would like to be *confident*; however, they may also construe *confident* people as *arrogant* (i.e., an undesirable characteristic). Consequently, the person has a dilemma (i.e., becoming confident would imply becoming arrogant), which can prevent the person from becoming their ideal self, and maintain the discrepancy between their current self and ideal self. Similarly, in Fransella's (1968) work with stutterers, it was found that stutterers had a highly elaborated system related to stuttering, which enabled stutterers to anticipate more events than being fluent did. This would reflect a cognitive conflict for the stutterers, whereby becoming more fluent was associated with uncertainty in social situations.

Cognitive conflicts have implications for the treatment of difficulties and have been argued to explain 'resistance'. For example, Winter (1988) found conflicts within people with social phobia created feelings of guilt when their symptoms reduced. Resolution of this conflict is made by 'choosing' the more superordinate of these goals in order to protect the system from becoming invalidated (Feixas et al., 2009). Cognitive conflicts have been found in people with bulimia nervosa (Feixas et al., 2010), social phobia and irritable bowel syndrome (Feixas & Saul, 2004), and the resolution of these dilemmas was associated with improved outcomes. Furthermore, increased somatisation was associated with experiencing implicative dilemmas (Feixas et al., 2007), which may suggest individuals with NEAD experience cognitive conflicts.

### **1.21.3 Cognitive Complexity**

As discussed, cognitive complexity is a summary measure of how broadly or narrowly a person construes their world (Bell, 2004). It has also been linked with psychopathology. For example, Bannister (1962, 1963) found that patients with thought-disorder schizophrenia had very 'loose' personal construct systems (i.e., non-complex and fragmented systems), which would indicate these patients had difficulty in integrating their thoughts or being able to produce specific plans of action. Similarly, 'monolithic' structures (i.e., not very complex) have been found to be associated with more rigid, 'black and white' thinking (Motttram, 1985). This raises a question as to whether individuals with NEAD have less complex personal construct systems.

### **1.22 Choice of Methodology**

Despite patient perceptions having an impact on treatment and prognosis, there is limited knowledge about how individuals with NEAD construe their worlds, themselves and their disorder. Due to this paucity of research, it is recommended an exploratory approach be used (Elliott, Fisher & Rennie, 1999). As a result, a number of recent studies have used qualitative methodologies (e.g., IPA) to explore the subjective perceptions and experiences of individuals with NEAD (Green et al., 2004; Karterud et al., 2010; Thompson et al., 2009). Consequently, in order to expand our knowledge of the perceptions of individuals with NEAD, it was deemed unnecessary to replicate these previous studies by utilising a purely qualitative methodology. It was also considered important to select an exploratory methodology capable of overcoming some of the difficulties inherent within using qualitative methodologies (i.e., social desirability influences and risk of interviewer bias). The RGT was deemed a more appropriate methodology due to its capability to explore both the explicit and implicit perceptions and interpretations of participants without imposing interviewer bias. Furthermore, considering the proposed heterogeneity of individuals with NEAD, and the relative paucity of research and consensus in our understanding of NEAD, it was deemed important to explore the individual perspectives and the general (i.e., averaged) perspective of individuals with NEAD. The RGT was deemed to be particularly useful in being able to meet this aim by combining idiographic and nomothetic approaches. Finally, although this methodology had not previously been used to explore perceptions of individuals with NEAD, studies have utilised the RGT in exploring the perceptions of people experiencing both mental health and physical health difficulties. This methodological approach, therefore, was deemed to be appropriate within this present study.

### **1.23 The Present Study**

In keeping with previous repertory grid studies (e.g., Woodrow et al., 2010), the specific aims of the study are detailed below. These aims were explored individually via analysis of each individual repertory grid. This was followed by a data driven approach (i.e., looking for themes and patterns across the individual grids), which enabled propositions to be developed (Smith, 1997). Multiple grid analyses were then conducted to allow for the study aims and any emerging propositions to be explored at the group-level.

Aim 1. To explore the constructs elicited by individuals with NEAD, and the relationships between the constructs.

Aim 2. To explore the construal of elements (and the relationship between the elements) by individuals with NEAD, specifically looking at the construal of themselves in comparison to:

- a) their ideal self
- b) how they were before NEAD
- c) someone with epilepsy
- d) someone who is uncertain about the cause of their seizures
- e) people with physical health difficulties (i.e., epilepsy and other physical health problems)
- f) people with mental health difficulties (i.e., anxiety, depression and other mental health problems)
- g) people who have experienced difficult/traumatic upbringings
- h) people who are under a lot of stress
- i) people who cope well
- j) people who find it easy to understand their feelings/emotions
- k) people who find it difficult to relate to other people.

Aim 3. To explore the cognitive complexities of individuals' with NEAD construal systems

## **CHAPTER TWO: METHOD**

### **2.1 Outline**

This chapter begins with a description of the study design, including descriptions of the recruitment procedure and the repertory grid procedure.

### **2.2 Study Design**

This study was an exploratory, cross-sectional study using the RGT (Kelly, 1955). The RGT was used to explore the individual and group perceptions of individuals with NEAD.

### **2.3 Ethical Considerations**

The study was peer-reviewed by The University of Manchester ClinPsyD Research Sub-committee. Ethical approval for this study was obtained from a Local Research Ethics Committee (Reference Number: 10/H1017/43) and the local NHS Trust Research and Development Department.

### **2.4 Participants**

#### **2.4.1 Inclusion Criteria**

Inclusion criteria were:

- Confirmed diagnosis of NEAD by a consultant neurologist.
- Aged 16 and over.

- Outpatients on the neuropsychology waiting list for psychological intervention for their NEAD. Participants who had started to be seen by a clinical psychologist within the department by the time of their interview were still included if they were within the assessment phase of their intervention (i.e., intervention had not begun). The rationale for this was psychological intervention could have resulted in cessation of their NEAs, thus potentially affecting the results.

#### **2.4.2 Exclusion Criteria**

Exclusions criteria were:

- Diagnosis of a learning disability (indicated via their medical records). The rationale for this was to minimise difficulties regarding gaining informed consent and difficulties understanding the RGT.
- Non-fluency in English. This was deemed necessary as interpretation services were not available for use within this study.
- If patients had begun psychological intervention (although not assessment) for their NEAD at the time of interview.

#### **2.5 Sample Size**

This study recruited twelve participants, which was deemed an appropriate size due to the exploratory nature of the study and the idiographic approach employed. Previous studies have used similar numbers of participants (Blundell et al., 2011; Durand et al., in press; Ralley et al. 2009; Woodrow et al. 2010).

#### **2.6 Recruitment**

Recruitment was conducted within one NHS Trust locality, which provides specialist outpatient assessment and treatment for NEAD across the North-West of England. Within the Trust, people are assessed and subsequently diagnosed with NEAD by a consultant neurologist within the neurology department. Upon diagnosis of NEAD, patients are referred to the clinical neuropsychology department within the same Trust for individual psychological treatment. Potential participants were identified from the neuropsychology waiting list. Once potential participants had been identified, the researcher posted an information pack to them. This pack contained a participant information sheet (Appendix A), a covering letter (Appendix B), a consent form (Appendix C), and a stamped-addressed envelope (SAE). Participants were required to sign and return the consent form, which only consented for them to be contacted by the researcher by telephone to discuss potential participation.

Once the participant returned the initial consent form, the researcher telephoned the participant to discuss the study. The telephone conversation consisted of explaining the rationale of the study and explaining they could withdraw from the study at any time. They were informed that all information, including audio-taped interviews, would be stored securely and confidentially. They were given opportunity to ask questions. If the patient still wished to participate after the telephone conversation, an appointment was arranged to take place at least 24 hours following

this initial telephone call to allow the participant sufficient time to consider their decision. The appointment was conducted within the clinical neuropsychology service or the patient's home. Domiciliary visits were deemed necessary due to the large geographical area the service encompassed. The researcher followed the Trust's lone-worker policy to ensure safety during all visits.

Recruitment took place over a nine-month period. Fifty-eight individuals with NEAD were invited to take part in the study. Of these, 16 (28%) returned their consent forms to gain further information about participation. Two people were excluded due to ill-health prior to booking an appointment, and one person was not contactable via the telephone number given. The final person who was excluded met with the researcher, but experienced frequent NEAs when being demonstrated the repertory grid procedure. It was jointly decided by the patient and researcher that taking part may be detrimental to her health, and so she was excluded from the study. A total of twelve individuals with NEAD participated in the study. None had a dual diagnosis of NEAD and epilepsy. Ten (83%) were female, and the age range was 17-58 years (mean 36, median 32, SD 13.14).

## **2.7 Preparatory Work**

Preparatory work was conducted before finalising the procedure protocol. In order to develop the researcher's competency in administering the RGT, the procedure (Section 2.9) was practised with three psychology colleagues (one qualified and two trainee clinical psychologists). This allowed the researcher to gain useful feedback on how these colleagues experienced the procedure and to practice entering the grids into the analysis programme Rep IV (Gaines & Shaw, 2005). No changes were made from the preparatory work.

### **2.7.1 Choice of Elements**

One of the initial steps in preparing for a repertory grid study is the selection of elements (Jankowicz, 2004). A review of the literature highlighted key issues pertaining to NEAD, and so it was deemed important to have each of these represented within the elements.

The elements selected were as follows:

- Yourself now
- Ideal self (where you would like to be)
- Yourself before you had seizures
- Someone who has seizures but is uncertain about the cause.
- Someone with epilepsy
- Someone who has a mental health problem
- Someone who has a long-standing, chronic physical illness
- Someone who has experienced a difficult/traumatic upbringing
- Someone who finds it difficult to relate to other people
- Someone who finds it easy to understand their feelings/emotions
- Someone who is under a lot of stress

- Someone who copes well
- Someone who is low in mood
- Someone who is anxious

Within the repertory grid literature, *"yourself now"* and *"ideal self"* are often used to allow the interviewer to see how participants view themselves in comparison to how they would prefer to be (Fransella et al., 2004; Jankowicz, 2004). This has been found to be a good indicator of depression, poor self-esteem, poor QoL, and difficulties in adjusting to illness (Compan et al., 2011; James & Large, 1992; Kempen, Myers, Powell, Selai & Trimble, 1995; Ryle & Breen, 1971). Previous studies have also utilised elements relating to past self (i.e., prior to illness/disorder) (Turpin et al., 2010). Including the element *"yourself before you had seizures"* was considered useful to investigate how the participants' perception of self has changed since the onset of NEAs.

Individuals with NEAD form hypotheses about the cause of their NEAs, which can affect their acceptance of the NEAD diagnosis (Green et al., 2004; Thompson et al., 2009). Having the diagnosis changed from a neurological to a psychological condition can also pose a threat to an individual's self-identity. Consequently, it has been argued that individuals with NEAD need to accept and integrate the NEAD diagnosis into their own sense of self and re-evaluate their self-identity (Karterud et al., 2010; Thompson, 2009). This is important considering acceptance is associated with better prognosis (Green et al., 2004; Thompson et al., 2009). Similarly, patients who believed they had epilepsy rather than NEAD imposed greater life restrictions on themselves and perceived psychological intervention to be ineffective (Dickinson et al., 2011). Very little research has been conducted in this area, therefore it would be useful to explore whether individuals with NEAD are more likely to identify themselves as having epilepsy, physical health difficulties, unidentified causes, or whether they accept the psychological nature of their NEAs. Consequently, the elements *"someone with epilepsy"*, *"someone who has a mental health problem"*, *"someone who has a long-standing, chronic physical illness"*, and *"someone who has seizures but is uncertain about the cause"* were included within the study.

Individuals with NEAD report higher rates of childhood abuse compared to patients with epilepsy (Alper et al., 1993; Cragar et al., 2002), although this has been disputed (Sharpe & Faye, 2006). Consequently, the element *"someone who has experienced a difficult/traumatic upbringing"* was included to assess whether individuals with NEAD perceive themselves to be alike someone who has experienced a difficult/traumatic upbringing, without having to directly ask about such experiences. This is important considering that trauma may be underestimated due to an unwillingness to explicitly disclose such difficulties (Griffith et al., 1998).

High levels of personality difficulties have been found within individuals with NEAD (Binzer et al., 2004; Gaitatzis et al., 2004; Lacey et al., 2007; Reuber, Pukrop et al., 2004). Furthermore, Holman et al. (2008) found individuals with NEAD were more likely than individuals with epilepsy to have insecure attachment styles. Individuals with NEAD, therefore, may have difficulties in their

relationships with others. Consequently, the element *"someone who finds it difficult to relate to other people"* was included to investigate whether patients perceived themselves to have such difficulties.

Reuber and colleagues (2003) argue that individuals with NEAD have a higher tendency to express emotional distress by producing unexplained somatic symptoms, although this has been contested by others (Stone, Smyth, Carson, Warlow & Sharpe, 2006). Similarly, alexithymia has been found to be associated with NEAD (Bewley et al., 2005), whereby patients experience emotions as physiological reactions as opposed to feelings. Others have considered NEAs have a function of sparing the conscious self from confronting negative emotions or experiences (Bodde et al., 2009b). These findings indicate individuals with NEAD may find it difficult to understand their emotions. Consequently, the element *"someone who finds it easy to understand their feelings/emotions"* was included to investigate whether patients perceived themselves to have such difficulties.

It has been postulated that NEAD is a maladaptive coping strategy for unmanageable stress (Goldstein et al., 2000; LaFrance & Bjornaes, 2010). Whilst individuals with NEAD have been found to report high levels of stressful life events (Frances et al., 1999; Tojek et al., 2000), others have found individuals with NEAD were more likely to deny life stresses (Karterud et al., 2010; Stone et al., 2004). Consequently, it was deemed useful to include the element *"someone under a lot of stress"*, to investigate whether individuals with NEAD perceive themselves to be under stress. It would also be useful to understand how individuals with NEAD perceive themselves to be able to cope with stress. Individuals with NEAD have been found to use more maladaptive, emotion-focused coping strategies than adaptive, problem-solving coping strategies (Frances et al., 1999; Goldstein et al., 2000; Jawad et al., 1995). It was, therefore, deemed useful to include the element *"someone who copes well"*.

Depression and anxiety are common disorders associated within NEAD, although it is unclear whether they are a cause or consequence of NEAD, or completely unrelated (Bodde et al., 2009b; Bowman, 2001). It was considered useful to include the elements *"someone who is depressed"* and *"someone who is anxious"* to explore the subjective experiences of depression and anxiety in individuals with NEAD.

## **2.8 Main Study**

The preparatory work allowed for finalisation of the procedure, including the repertory grid interview protocol (Appendix D). All 14 elements were included within the main study. The first two participants were used as pilot participants. This was to allow any necessary changes to be made to the procedure before the remaining participants were interviewed.

### **2.8.1 Pilot Work**

After the first two participants were interviewed, the process was reviewed and the participants were asked to provide feedback as to how they experienced the interview. No modifications to the

procedure were deemed necessary, and so the two participants' data were included in the main study and all analyses. The same procedure was used for all participants within the study.

## **2.9 Procedure**

The overall procedure consisted of one individual appointment lasting approximately 1-2 hours with each participant. This was followed approximately one week later by an optional feedback appointment to discuss the results obtained from the initial appointment. This feedback appointment lasted approximately 20-30 minutes. Each participant completed the interviews within their own home or the clinical neuropsychology department. The initial interview consisted of an explanation of the study rationale and gaining written consent, completion of the repertory grid interview and completion of a demographic questionnaire. All interviews were audio-tape recorded. The interview protocol is highlighted in Appendix D. If the participant completed the appointment within the clinical neuropsychology department, they were reimbursed £10 for their travel and parking expenses.

### **2.9.1 Explanation of Study Rationale and Gaining Consent**

Following an introduction to the researcher, the participant was given an explanation of the study rationale and was instructed to re-read the participant information sheet (Appendix A). Participants were asked to consent to the tape-recording of the session. They were informed all information collected would be stored securely and anonymously. Confidentiality was explained and participants were informed that they could withdraw from the study at any time without giving a reason and this would not have any impact on the care they received by the Trust. They were given opportunity to ask questions. Following this, participants were asked to sign a written consent form (Appendix E) if they agreed to participate. Written informed consent was obtained to audio-tape the interview, to consult their medical records and to publish anonymised quotations from the interview. The interviews were audio-taped if the participant gave consent for this, so the information could be analysed in depth later. This was to ensure the participants' intended meaning was captured and to reduce the risk of being influenced by researcher bias. Access to medical records was deemed necessary to confirm the NEAD diagnosis and gain information about comorbid epilepsy.

### **2.9.2 Repertory Grid Interview Procedure**

The repertory grid interview procedure (Appendix D) was adapted from the protocol used by Woodrow et al. (2010). The steps involved in eliciting the repertory grids were 1) identifying real or hypothetical people for the elements (i.e., role identification), 2) eliciting constructs, and 3) rating the elements. These steps are outlined in more detail below.

#### **2.9.1.1 Materials**

Every participant consented to be audio-taped, and so all interviews were audio-taped. Participants were presented with 14 A5-sized laminated cards, with each of the cards having one of the elements printed on the front (Photograph 1). The top of the laminated cards was used for the participant to write the initials of people they knew that matched the element descriptions.



The initials were wiped off at the end of the interview. Participants were presented with a 7-point visual rating scale to allow for ease of rating elements (Photograph 2). This scale was laminated to allow each construct to be written above the corresponding poles on the scale. The researcher used a blank repertory grid (Appendix F) to capture the constructs and element ratings, and a random number sequence (obtained from [www.random.org/integers](http://www.random.org/integers)) to ensure random elements were selected during the 'triadic elicitation method'. All participants were presented with the same combination of elements during the triadic elicitation procedure.

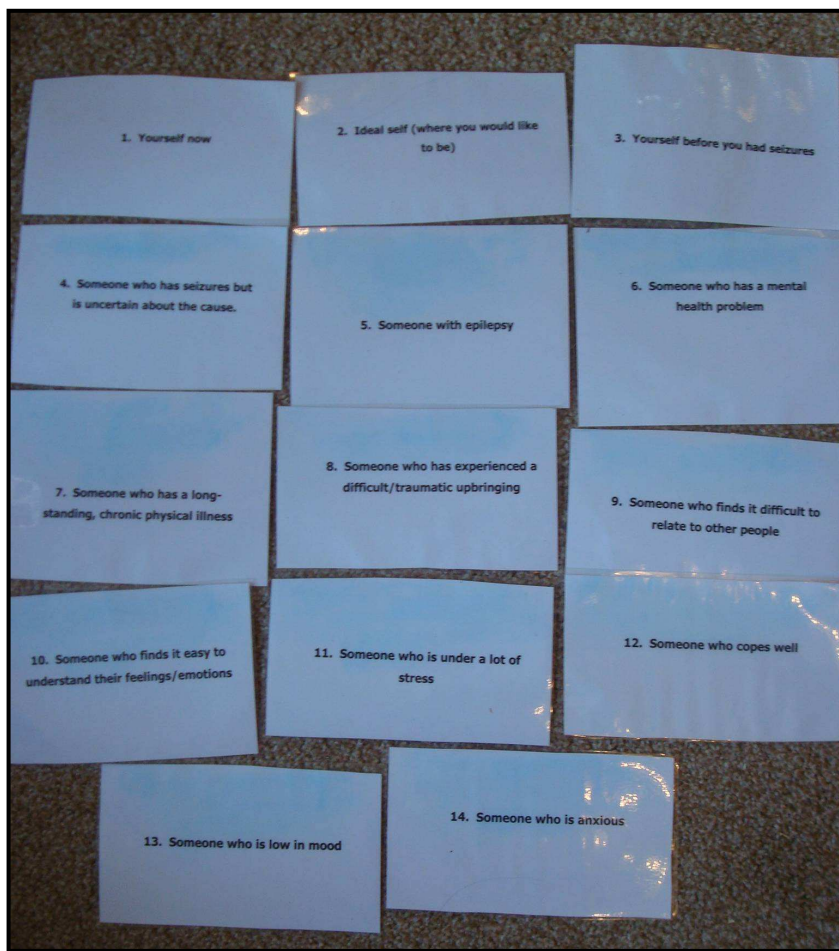
#### **2.9.1.2 Role Identification**

Participants were presented with the 14 element cards (Photograph 1) and asked to think of people that fitted the descriptions. They were asked to write the person's initials on the top of the particular card. If they could not think of a real person fitting the description, they were asked to write what they considered to be the defining characteristics of a person fitting that description on the card. They were not asked to reveal the identity of the people they had chosen. Instead participants were asked to use codes (e.g., initials) to aid their own recall of the chosen people. These initials were wiped off the laminated cards at the end of the interview.

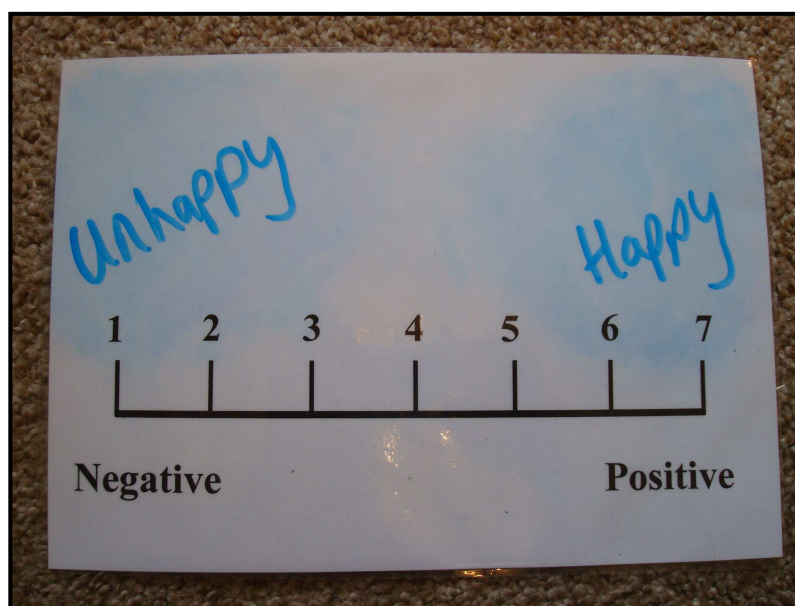
#### **2.9.1.3 Elicitation of Constructs**

As discussed, constructs were elicited using the 'triadic elicitation method' (Jankowicz, 2004). As shown in Photograph 3, this consisted of presenting the participant with a group of three element cards and asking them to think of an important way (e.g., a personal quality) that makes two of the people similar to each other, and hence different from the third person. This generated one pole of the construct, which was a word/phrase to summarise the element similarities. The second pole of the construct was elicited via the 'opposite method', whereby the person identifies the opposite of the word/phrase given for the initial pole elicited. Participants were asked to elaborate on the meaning of each pole and to give behavioural examples of each construct. They were then asked to state which construct pole was the most positive or desirable of the two poles. Using the laddering technique, they were asked to elaborate on the reasons why they had chosen that particular pole as the most positive pole. This may have generated another construct, which was included as another construct if the participants determined it to have a different meaning to the original construct. It was possible for participants to generate several constructs from one triad. Similarly, another triad was presented if the participant could not generate any similarities/differences for a particular triad. This procedure was repeated until the participant could not offer any new constructs. Triads were selected randomly to ensure the order of presentation did not bias the results.

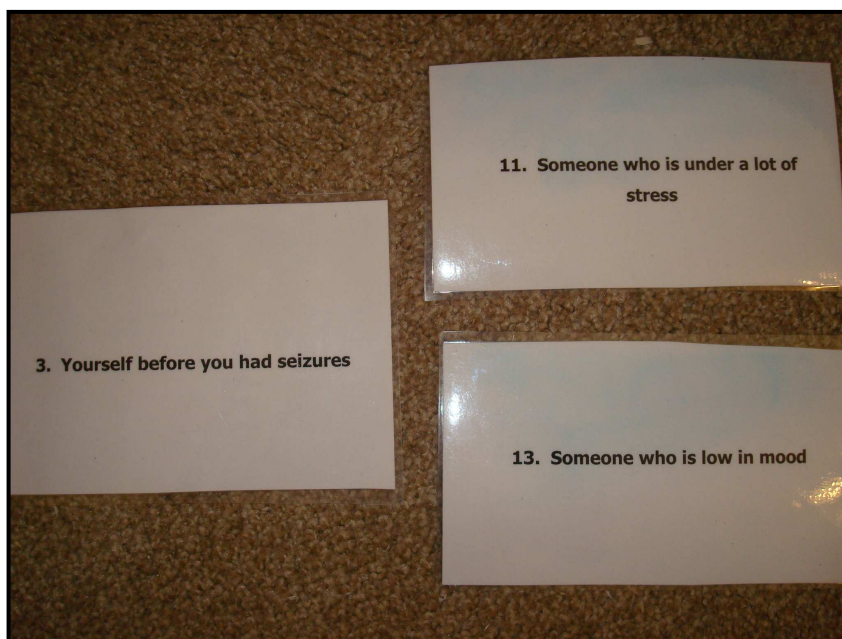
**Photograph 1: The laminated element cards used in the interview**



**Photograph 2: The construct rating scale**



### **Photograph 3: The triadic elicitation technique**



#### **2.9.1.4 Rating Elements**

After all constructs had been elicited, participants were asked to rate the elements against each individual construct. Using a 7-point rating scale (Photograph 2), the positive pole description was written above the number seven on the laminated rating scale (i.e., the right hand side), and the negative construct pole description was written above the number one on the rating scale (i.e., the left-hand side). Participants were asked to rate all 14 elements on this 7-point scale, with seven being the most positive pole of the elicited construct and one being the most negative pole of elicited construct. These ratings were entered onto the blank repertory grid sheet (Appendix F) by the researcher. The participants were unable to see their ratings on the repertory grid sheet to ensure that they were not able to compare their ratings. Participants were then asked whether they were satisfied with their ratings, and were able to change their ratings if they were not satisfied with any. This rating procedure was completed for all constructs elicited.

#### **2.10 Demographic Questionnaire**

A demographic questionnaire devised by the researchers (Appendix G) was completed with each participant at the end of the appointment. This questionnaire captured information about age, gender, marital status, ethnicity, employment status and level of education. It also captured clinical information about age of onset of NEAs and how often they experience NEAs. Their experiences and perceptions of their NEAs were obtained by asking participants whether they had a diagnosis of NEAD and/or epilepsy, and the reasons why they agreed or disagreed with their diagnosis. Two open-ended questions were used to determine what the participant knew about NEAD and what they believed to be the main cause of their NEAs. As the questionnaire was administered verbally by the researcher, the participants' answers to these open-ended questions were captured via audio-tape to allow for qualitative analysis of the responses. This questionnaire

was administered at the end of the interview so to not influence the participant's repertory grid interview.

### **2.11 Analysis of Repertory Grids**

Analyses were carried out by inputting the grid data into a computer statistical analysis package, Rep IV, Research Version 1.12 (Gaines & Shaw, 2005). Individual repertory grids were analysed using hierarchical cluster analysis (HCA) and principal components analysis (PCA). These analyses highlighted the relationships between constructs and between elements for each participant, including the relationships between the constructs and elements. This produced a visual representation (i.e., pringrid) of each individual grid. A data driven approach (i.e., looking for themes and patterns across the individual grids) enabled propositions to be developed (Smith, 1997). These propositions were explored via multiple grid analyses. This produced a Modegrid, which is a composite grid incorporating all the individual grids. This was possible due to the participants using the same 14 elements, allowing constructs to be compared against these elements for all participants. Cognitive complexity for each grid was analysed, with the number of components for each grid representing the level of cognitive complexity of the participants (Baldauf et al., 2010). A SocioNet analysis was also conducted to explore the amount of shared variance between the participants in how they construed the elements.

### **2.12 Feedback**

Participant feedback of the repertory grid is an important aspect of the repertory grid procedure (Tindall, 1994). After the initial appointment, the participants were offered a feedback appointment to discuss the results of their repertory grid analysis. This enabled the participants to comment on whether the findings were an accurate reflection of their perceptions (Fransella et al., 2004) and to comment on the interview process. All participants agreed to complete the feedback appointment. Each tape-recorded feedback appointment lasted 20-30 minutes, and was conducted within the participant's home or within the clinical psychology department. In the session, participants were provided with their pringrid of the analysis. Previous studies have found that participants often describe the process as enjoyable and thought-provoking (Winter, 1992). Despite this, it was recognised that some participants might find it uncomfortable to hear the feedback, and therefore care was taken to deliver all feedback in a respectful, non-judgemental way.

## **CHAPTER THREE: RESULTS**

### **3.1. Overview**

This chapter begins with an overview of the participants' demographic/clinical information before presenting the individual repertory grid analyses. This is followed by the propositions derived from the individual analyses, and the subsequent multiple grid analyses allowing for the aims to be explored at a group level.

### **3.2. Participant Demographic and Clinical Information**

The demographic and clinical information data for each participant are presented in Table 2. All participants had received a firm diagnosis of NEAD via ambulatory-EEG (n=8) or video-EEG (n=4). Although not by design, no participants had a diagnosis of comorbid epilepsy. The majority of the participants agreed with the NEAD diagnosis (n=8), with three being 'unsure' and one participant disagreeing with the diagnosis. Ten participants were female (83%) and two were male (17%). Age range was from 17-58 years (mean 36, median 32, SD 13.14). The most frequently reported age of NEA onset was between 18-30 years old (n=6). Three participants (25%) reported onset between 8-17 years old, and three participants (25%) reported onset between 31-50 years old. Three participants (25%) had previously received a diagnosis of epilepsy. Three participants (25%) were currently taking anti-epileptic medication, and a further five participants (42%) had previously been prescribed anti-epileptic medication.

### **3.3 Individual Repertory Grid Analysis**

Each participant's repertory grid data is presented individually (see Appendix H for individual analysis data). For each individual participant, after a description of the participant's demographic and clinical data, the constructs elicited and the relationships between the constructs are described. Due to high numbers of matched constructs, each matched pair is not individually discussed. This is followed by presentation of the construal of elements and the relationship between the elements, beginning with a description of any emergent element clusters, followed by a comparison of the self and other elements.

Analyses were carried out by inputting the individual grid data into a computer statistical analysis package, Rep IV, Research Version 1.12 (Gaines & Shaw, 2005). This allowed each individual grid to be analysed using hierarchical cluster analysis (HCA) and principal components analysis (PCA). HCA is a statistical technique for highlighting the relationships between constructs and between elements. Rep IV produces a grid of the HCA (see Figure 1 for Participant 1's HCA), which illustrates a hierarchy of the elements and constructs based on the level of association of the elements and constructs. The grid is rearranged so similarly rated constructs and similarly rated elements are placed next to each other. The HCA of the constructs is illustrated by a blue 'dendrogram' (i.e., blue lines that join the constructs), which demonstrates how closely associated (i.e., percentage 'matched') the constructs are. This illustrates how the individual participants think about the world. The HCA also highlights the elements by the red 'dendrogram' (i.e., the red lines that join the elements), which demonstrates how closely associated (i.e., percentage 'matched') the elements are. This illustrates what the participants think about the elements. According to Jankowicz (2004), elements or constructs that match  $\geq 80\%$  are to be considered closely related.

A PCA was also conducted on each individual repertory grid, which examines the patterns of relationships between both elements and constructs and produces a two-dimensional representation (i.e., pringrid) for each grid (see Figure 2 for Participant 1's pringrid). This analysis

**Table 2. Participant Demographic and Clinical Information**

Participant	Age	Gender (M/F)	Marital Status	Ethnicity	Employment Status	Educational Level	Age of seizure onset	Current Frequency of seizures	Comorbid Epilepsy	Previous epilepsy diagnosis	Agreement with NEAD diagnosis	Prescribed anti-epileptic medication
1	52	F	Married	White British	Unemployed	GCSE's/O-levels (or equivalent)	26-30 years old	At least once every three months	No	Yes	Don't know	Yes, but not currently
2	23	F	Single	White British	Unemployed	A-Levels (or equivalent)	8 years or younger	At least once a day	No	No	Yes	No
3	28	F	Co-habiting Partner	White British	Unemployed	A-Levels (or equivalent)	22-25 years old	At least once a week	No	No	Yes	No
4	47	F	Married	White British	Unemployed	None/Less than high school	41-50 years old	At least once a week	No	No	No	Yes, but not currently
5	29	F	Co-habiting Partner	White British	Unemployed	GCSE's/O-levels (or equivalent)	22-25 years old	At least once a fortnight	No	No	Don't know	No
6	35	F	Single	White British	Unemployed	Bachelor's Degree (or equivalent)	31-40 years old	At least once a day	No	No	Yes	Yes, currently
7	48	F	Divorced	White British	Unemployed	None/Less than high school	14-17 years old	At least once a day	No	No	Yes	Yes, but not currently
8	17	F	Single	White British	Student	A-Levels (or equivalent)	14-17 years old	At least once a month	No	No	Yes	No
9	26	F	Single	White British	Unemployed	GCSE's/O-levels (or equivalent)	18-21 years old	At least once a week	No	No	Yes	Yes, currently
10	58	M	Co-habiting Partner	Other White Background	Retired	Master's Degree (or equivalent)	41-50 years old	At least once a week	No	No	Yes	Yes, but not currently
11	26	F	Married	White British	Unemployed	GCSE's/O-levels (or equivalent)	22-25 years old	At least once a week	No	Yes	Don't know	Yes, currently
12	43	M	Single	White British	Unemployed	Bachelor's Degree (or equivalent)	26-30 years old	At least once a week	No	Yes	Yes	Yes, but not currently



groups inter-correlated variables together to produce more distinct variables (i.e., components). The pringrid is plotted within a two-dimensional space to enable clear representation of the relationships between the elements and constructs, although the elements are initially plotted in n-dimensional space, with the axes defined by the two largest principal components. The horizontal line within the pringrid represents the largest component (i.e., accounting for the largest amount of variance). The vertical line represents the next largest component. The PCA was set to power=2 to enable Euclidian distances to be measured (i.e., direct distance between two points) rather than city block metric distances (i.e., distance from two points by moving horizontally or vertically, as if walking along blocks in a city). The Euclidian distances are taken to represent the psychological distances between the constructs and elements (Fransella et al., 2004; Gaines & Shaw, 2005; Kelly, 1955).

In the pringrid, the elements are represented by red dots and red text to identify each element. The constructs are represented by a blue line linked by two blue crosses (x) and by two labels in blue text to identify the bipolar construct labels. Some element names have been abbreviated for ease of representation, for example *someone who has had a difficult/traumatic upbringing* was abbreviated to *traumatic upbringing* and *someone who has a chronic, physical health difficulty* was abbreviated to *chronic illness*. The distance between the elements indicates the level of similarity between them, with closely positioned elements being construed as being similar. Similarly, the closer the constructs are aligned (i.e., the smaller the angle between the construct lines), the closer they are associated (i.e., correlated) with each other. The position of the elements along a construct line indicates the degree to which the element is associated with that construct. Finally, construct line length represents the amount of variance within the ratings on that construct, with longer lines indicating greater variance within the ratings.

The participants elicited a variable number of constructs depending on their ability to elicit a higher number of constructs before becoming 'saturated' (i.e., finding it difficult to generate new constructs). The number of constructs elicited ranged from nine to sixteen, with the majority eliciting at least thirteen constructs (median 13, mode 13).

### **3.3.1 Individual Analysis: Participant 1**

Participant 1 (P1) was a 52-year-old female with a diagnosis of NEAD (see Table 2 for additional demographic information), which started when she was 28 years old. She was initially diagnosed with epilepsy and had previously been prescribed anti-epileptic medication. Her NEAs had reduced in frequency over the years from approximately three per week to one 'period' of NEAs every three months, consisting of approximately three NEAs over a 'few days'. She attributed this reduction in frequency due to a lifestyle change from a 'hectic' lifestyle to a more sedentary lifestyle as a result of the NEAs. She described being unsure as to whether she had NEAD and attributed this to having had many different diagnoses, including epilepsy, migraines and irregular heart beat. Despite this, P1 was also not sure she had epilepsy due to the fact that she had no 'auras' and anti-epileptic medication was ineffective.

P1 had some understanding of NEAD, describing it as being similar to epilepsy but without the "electrical problem", although she did not agree with the "psychological bits". She stated, "I do realise that bad things happen to you and you block them out, but I don't think so. I don't think there is anything in my past". Despite this, P1 recognised stress was a factor in the development of her NEAD: "Stress at work. I was running around like a blue-bottle and I just started falling over when I was busy".

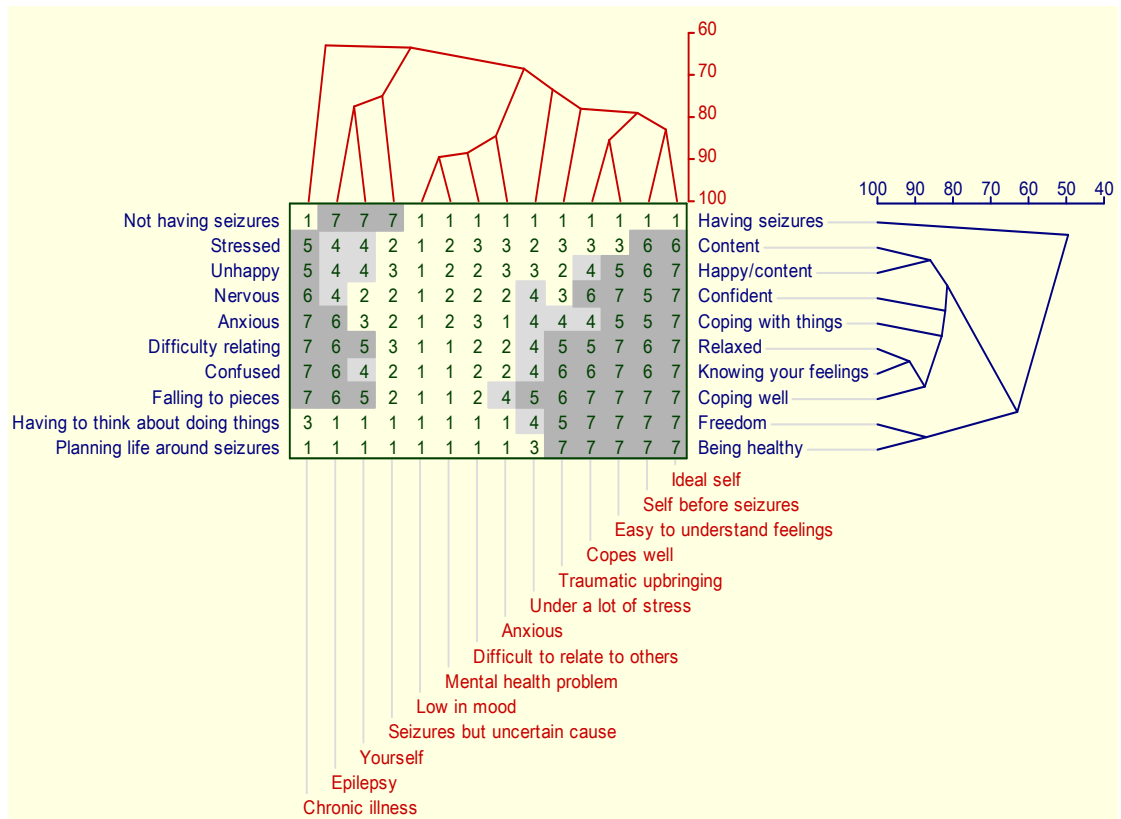
### **3.3.1.1 How does P1 construe her world?**

The results of this analysis are displayed in Figure 1. P1 produced ten pairs of constructs (highlighted in blue writing in Figure 1). During the elicitation procedure for one construct, the only construct P1 was able to produce was ***not having seizures—having seizures***. When describing this construct she stated: "both [elements presented] are similar because they both have seizures, they both have stress and everything else involved with seizures". Consequently, despite this being more of a behavioural and/or physical characteristic, it was deemed important in P1's personal construct system and so was included within the analysis.

The HCA of the constructs is highlighted in Figure 1 by the blue 'dendrogram' (i.e., the blue lines within Figure 1 that join the constructs). This 'dendrogram' shows how closely related (i.e., percentage 'matched') the constructs are. For example, if constructs are matched at 100%, it would illustrate that all the elements for those constructs were rated exactly the same. The overall shape of the construct 'dendrogram' shows one broad cluster incorporating the majority of the constructs and one smaller cluster containing two constructs. There is also one largely independent construct (i.e., not associated with the other constructs). The matched constructs are shown in Table 3 and, as suggested by Jankowicz (2004), only constructs  $\geq 80\%$  are illustrated. The analysis revealed ten matched constructs  $\geq 80\%$ .



**Figure 1. P1's HCA**



**Table 3. P1's construct matches ( $\geq 80\%$ )**

Construct matched with	Construct	Match (%)
Difficulty relating—Relaxed	Confused—Knowing your feelings	91.1
Falling to pieces—Coping well	Confused—Knowing your feelings	87.4
Planning life around seizures—Being healthy	Having to think about doing things—Freedom	86.6
Unhappy—Happy/content	Stressed—Content	85.9
Difficulty relating—Relaxed	Falling to pieces—Coping well	84.6
Difficulty relating—Relaxed	Anxious—Coping with things	82.7
Anxious—Coping with things	Nervous—Confident	81.6
Anxious—Coping with things	Confused—Knowing your feelings	81.6
Unhappy—Happy/content	Nervous—Confident	81.1
Confused—Knowing your feelings	Nervous—Confident	80.1

The main cluster consists of *stress—content*, *unhappy—happy/content*, *nervous—confident*, *anxious—coping with things*, *difficulty relating—relaxed*, *confused—knowing your feelings* and *falling to pieces—coping well*. The majority of constructs within this

cluster express an emotional content and/or reaction (e.g., **unhappy—happy, anxious—coping with things**). This indicates P1 construed her world based largely on emotional qualities (i.e., how she and/or others feel). This larger cluster is also characterised by two constructs describing being able to cope well (i.e., **anxious—coping with things** and **falling to pieces—coping well**). This suggests P1 strongly associated negative emotions with difficulties in coping. A highly matched construct pair is **falling to pieces—coping well** and **confused—knowing your feelings**. **Coping well** was described as getting out and doing things and having a positive outlook. Overall, this indicates P1 construed being unable to identify and understand emotions as having a negative impact on being able to cope, stress levels, inability to relax, confusion and having difficulties relating to other people. The construct pairs **unhappy—happy/content** and **stressed—content** are also highly matched, which suggests P1 construed unhappiness and stressed to be very similar. She commented on how stress and unhappiness can have an impact on her NEAs: "If I'm stressed, I'm more likely to fall over". This would indicate P1 construed having little stress and/or being able to manage stress would have an impact on her happiness, as well as having an impact on the frequency of her NEAs.

The second cluster is characterised by two construct pairs: **planning life around seizures—being healthy** and **having to think about doing things—freedom**. This indicates that being restricted in living a free and healthy life was an important way in which P1 construed her world, although she perceived herself as needing to think and plan due to her NEAD. The only construct not associated with any other construct at  $\geq 80\%$  was **having seizures—not having seizures**. However, this may be due to the dichotomous nature of the ratings given.

### **3.3.1.2 How does P1 construe herself and others?**

Whilst the constructs elicited from P1 informs us about how she thinks about the world, the analysis of the element ratings informs us of what she thinks about the elements (i.e., people, including current herself, past self and ideal self). The HCA shown in Figure 1 also highlights the elements (**written in red**). Similarly, the red 'dendrogram' (i.e., the **red** lines within Figure 1 that join the elements), shows how closely related (i.e., percentage 'matched') the elements are. Table 4 illustrates the elements that were most closely associated ( $\geq 80\%$  matched). Following the HCA, a PCA was conducted to examine the variability in P1's repertory grid. This produced a visual representation (i.e., pringrid) of the clusters (Figure 2). The pringrid supports the inferences drawn from examination of the repertory grid and HCA.

**Table 4. P1's elements matches ( $\geq 80\%$ )**

Element matched with	Element	Match (%)
Someone who has a mental health problem	Someone who is low in mood	89.5
Someone who has a mental health problem	Someone who finds it difficult to relate to other people	88.2
Someone who finds it easy to understand their feelings/emotions	Someone who copes well	85.1
Someone who finds it difficult to relate to other people	Someone who is anxious	84.2
Ideal self (where you would like to be)	Yourself before you had seizures	82.5
Someone who finds it difficult to relate to other people	Someone who is low in mood	81.0
Someone who has a mental health problem	Someone who is anxious	80.3

There are three clusters emerging, along with six independent elements, suggesting P1 largely construed the elements independently of each other. The first cluster is comprised of people experiencing difficulties with mental health (i.e., **someone who is low in mood, someone who has a mental health problem, someone who is anxious** and **someone who finds it difficult to relate to others**), suggesting P1 construed these people in similar ways. In relation to the constructs, P1 construed people experiencing mental health difficulties more negatively in the construct ratings compared to the other elements. The second cluster is comprised of **someone who copes well** and **someone who finds it easy to understand their feelings/emotions**. P1 particularly construed these people as coping well and being free and healthy. The third cluster is comprised of **yourself before you had seizures** and **ideal self**, suggesting P1 construed her ideal self and past self as very similar and construed them positively on the constructs. This indicates P1 was happy with the construal of herself before she developed NEAD. The least associated element was **someone with a chronic, physical health difficulty**. This element was viewed positively in the construct ratings and was highly associated with being able to cope, being relaxed, knowing their feelings and being happy and content. This suggests P1 construed having a chronic, physical illness as being more preferable than having a seizure-related disorder. P1 commented on the validity of this: "*the idea of someone saying I had a heart problem, I honestly thought 'great, give me a pace maker, I'm sorted', you know, it didn't phase me at all the idea of a heart problem*".

Table 5 illustrates P1's construal of her current self, self before NEAD and her ideal self in comparison to each other and the other elements. Despite P1's past self and ideal self being similarly construed, she did not associate her current self with her ideal self (29.5% match) or her past self (38.1% match). These results indicate P1 was not happy with her construal of her current self and also her construal of herself had changed to become more negative since she had developed NEAD. She viewed her current self negatively on the constructs, particularly in relation to having to think and plan her life and feeling nervous and anxious. Her past self was most highly associated with **someone who copes well** (78.9% match) and **someone who finds it easy to**

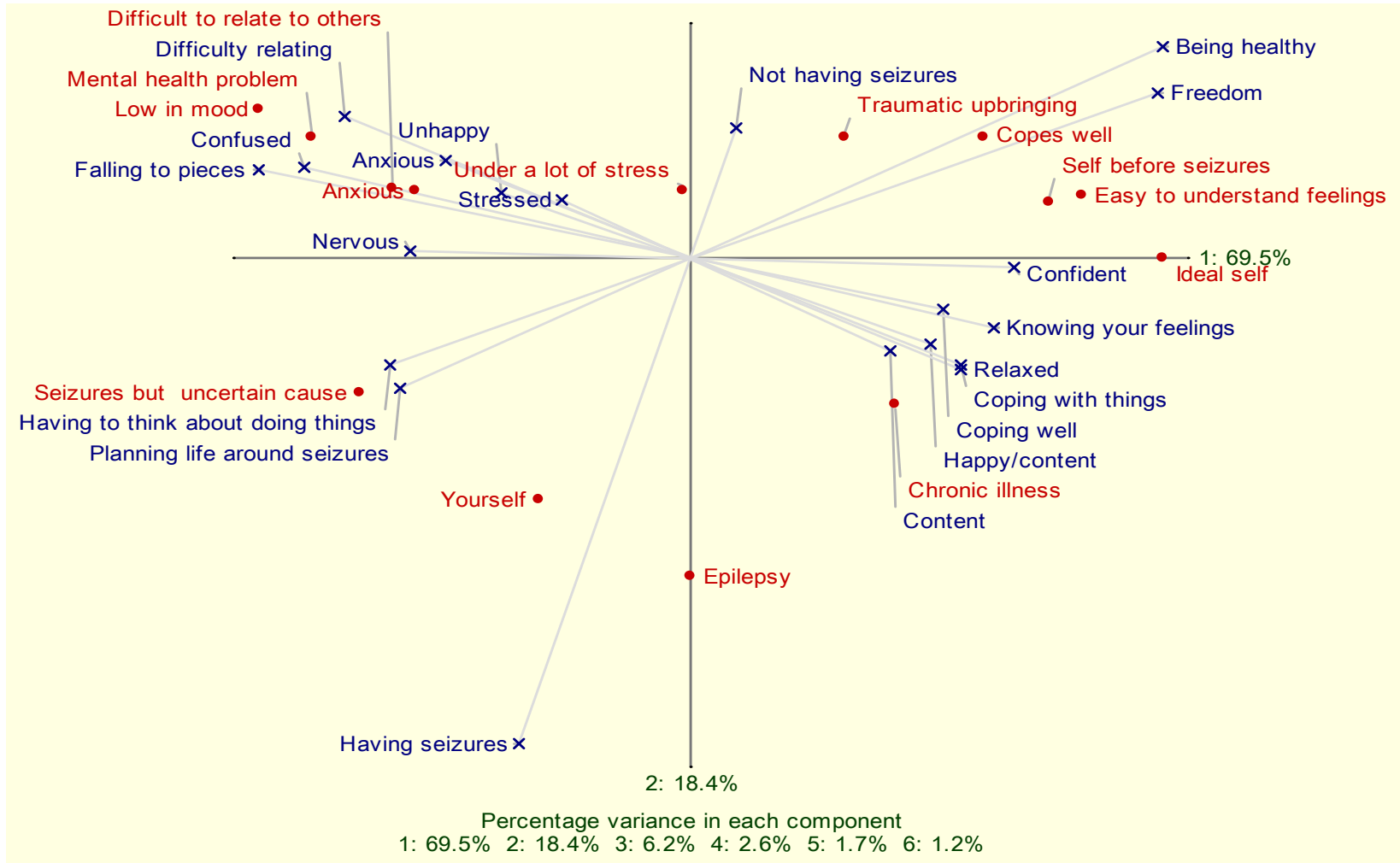


Figure 2: P1's Pringrid

***understand their feelings/emotions*** (78.9% match). When thinking about her current self, however, this association reduced to 39.0% and 34.2% respectively. This indicates a negative shift in how P1 construed her current self in comparison to her past self, suggesting that she now sees herself as not coping or understanding her emotions as well as she used to. The least associated elements with her past self were ***someone low in mood*** (18.4% match) and ***someone with a mental health problem*** (24.0% match). This suggests P1 did not construe herself before NEAD as having any mental health difficulties. However, the association with these elements increased to 47.3% and 51.1% respectively, when compared to her current self. Although this indicates P1 did not currently construe herself as having mental health difficulties, it does indicate a negative shift in how she construed herself, particularly construing her current self to be lower in mood and have more mental health difficulties than before she developed NEAD. She also construed a negative shift from her past self to her current self in relation to the elements ***someone who is anxious*** (34.2% and 60.6% match respectively) and ***someone who finds it difficult to relate to other people*** (31.9 and 58.2% match respectively). P1 did not construe herself to be stressed before or after the onset of NEAD, nor did she construe herself to have had a difficult/traumatic upbringing.

Although not above the 80% cut-off, P1 construed her current self to be most similar to ***someone with epilepsy*** (77.0% match) and ***someone with seizures but uncertain of the cause*** (74.7% match). These results fit with P1's uncertainty about her NEAD diagnosis. P1 particularly construed ***someone with seizures but uncertain of the cause*** as being more negative than her current self. She construed ***someone with epilepsy*** as being more positive than her current self, particularly on the constructs incorporating coping, being confident and knowing their feelings. She particularly commented on how she construed ***someone with epilepsy*** as being more positive: "...this person's [epilepsy] got a diagnosis and doesn't have to worry about people thinking she's making it up".

P1 did not construe her current self to have a chronic, physical health difficulty (49.7% match). Her preference of having a different physical health difficulty compared to a seizure-related difficulty was also supported by P1 construing her ***ideal self*** to be more similar to ***someone with a chronic, physical health difficulty*** (59.9% match) than ***someone who has epilepsy*** (39.0% match) or ***someone who has seizures but uncertain of the cause*** (15.7% match). However, the association between ***ideal self*** and ***someone with a chronic, physical health difficulty*** is still not high, indicating P1 ideally preferred to have no health difficulties.

**Table 5. P1's percentage matches between elements of self and other elements**

	Past self (i.e., before NEAD)	Current self	Ideal self
Past self (i.e., before NEAD)	—	38.1	82.5
Current self	38.1	—	29.5
Ideal self	82.5	29.5	—
<b>Someone with a mental health problem</b>			
Someone with a mental health problem	24.0	51.1	13.2
<b>Someone with epilepsy</b>			
Someone with epilepsy	42.5	77.0	39.0
<b>Someone with seizures but uncertain of the cause</b>			
Someone with seizures but uncertain of the cause	25.3	74.7	15.7
<b>Someone with a chronic, physical health difficulty</b>			
Someone with a chronic, physical health difficulty	58.8	49.7	59.9
<b>Someone low in mood</b>			
Someone low in mood	18.4	47.3	6.8
<b>Someone who is anxious</b>			
Someone who is anxious	34.2	60.6	22.4
<b>Someone who copes well</b>			
Someone who copes well	78.9	39.0	69.7
<b>Someone who finds it easy to understand their feelings/emotions</b>			
Someone who finds it easy to understand their feelings/emotions	78.9	34.2	78.3
<b>Someone under a lot of stress</b>			
Someone under a lot of stress	57.8	59.2	48.1
<b>Someone who finds it difficult to relate to other people</b>			
Someone who finds it difficult to relate to other people	31.9	58.2	21.5
<b>Someone who has had a difficult/traumatic upbringing</b>			
Someone who has had a difficult/traumatic upbringing	68.4	47.3	56.2

**3.3.1.3 Feedback**

The pringrid (Figure 2) allowed the results to be presented to P1 in an understandable format in order to check the validity of the results. She reported the pringrid accurately represented her construal of the elements within the grid. When asked to comment on the repertory grid process, she described it as *'interesting'*.

**3.3.2 Individual Analysis: Participant 2**

Participant 2 (P2) was a 23-year-old female with a diagnosis of NEAD (see Table 2 for additional demographic information), which started when she was approximately 8 years old. She reported experiencing NEAs everyday, with sometimes up to twenty per day. She had never received a diagnosis of epilepsy and agreed with the diagnosis of NEAD. She also had a good understanding of NEAD, describing it as:

*"...it starts off as an emotion in your body, so like stress, excitement, anything like that, the build up on it, and because you don't really know how to release it, your body just builds it up and then it starts to shut itself down, to relax basically".*

### **3.3.2.1 How does P2 construe her world?**

A HCA (Figure 3) was conducted. P2 produced 16 pairs of constructs. Similar to P1, one of the constructs directly referred to her NEAs, particularly the ability of others to understand the nature of her NEAs. When describing **not able to understand NEAs**, P2 stated:

*"People thinking you are putting it on, you're just doing it for attention...even if you have low blood pressure, they understand or if it's a brain tumour, they'll sympathise. But with non-epileptics it's like 'there's nothing wrong with you physically, stop doing it'.*

P2 also construed healthcare professional understanding NEAs as being important by stating: *"I've had an ambulance driver say to my mum 'she's faking it, she's putting it on, there's no need for her to go to hospital.'*

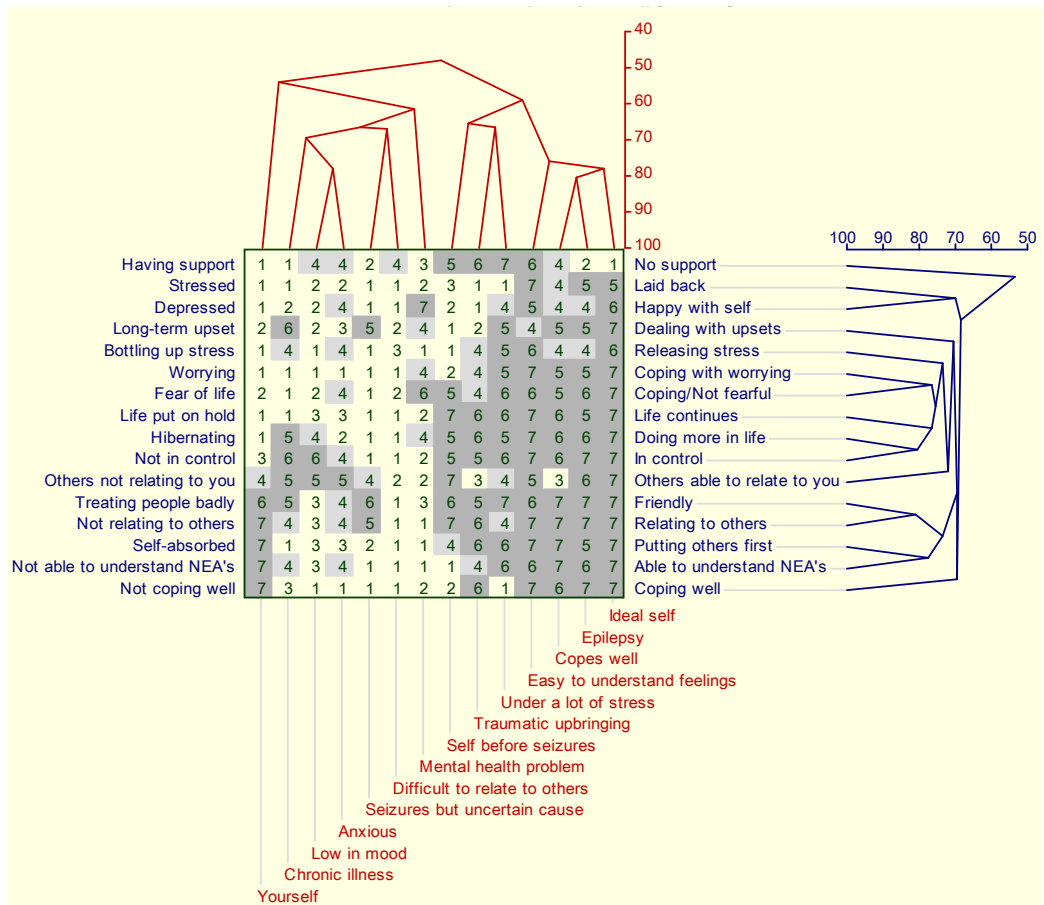
The overall shape of the construct 'dendrogram' shows only two construct pairs are associated above the 80% cut off, suggesting that the majority of constructs are largely independent of each other. The matched constructs ( $\geq 80\%$ ) are shown in Table 6. The first construct pair comprises of **not relating to others—relating to others** and **treating people badly—friendly**. This suggests P2 sees these constructs as being similar. This indicates P2 construed people who were unable to relate to her as being unfriendly. The second cluster comprises of **not in control—in control** and **hibernating—doing more in life**, again suggesting P2 sees these constructs as being similar. P2 described herself as **not in control** due to her NEAD because: *"somebody has to be with you 24/7 wherever you go. Basically supervising everything you do"*. Conversely, she described how she perceived someone with epilepsy to be **in control**:

*"With epilepsy, if you've got the tablets, you can go back to work, you can drive your car, you can do basically anything what you want to do...whereas myself now, there's no control over them. So basically I can't drive, I can't go back to work so there is no life control at all"*.

This indicates P2 construed lack of control in her life as having an impact on her being able to do more in life. The remainder of the constructs were rated independently of each other.

P2 produced a number of constructs related to coping, and described coping as being organised, prepared and flexible enough for dealing with different contingencies, as well as being supported by others. P2 commented on how her mother found **coping with worrying** difficult due to worrying about her daughter's safety. This indicates P2 construed her NEAD as not just having an impact on herself, but also having a negative impact on her family and friends. P2 also produced the construct of **stressed** and continued to explain how she was under a lot of stress before the onset of NEAD. This potentially indicates a mechanism for the development of P2's NEAD (i.e., bottling up stress). She also described how her NEAD increases her current stress levels, potentially highlighting part of a maintenance cycle for P2's NEAD: *"My stress now is I can't go anywhere on my own....the stress of trying to make people understand as well...I just want people to understand"*.

**Figure 3. P2's HCA**



**Table 6. P2's construct matches  $\geq 80\%$**

Construct matched with	Construct	Match (%)
Not relating to others—Relating to others	Treating people badly—Friendly	80.6
Not in control—In control	Hibernating—Doing more in life	80.1

**3.3.2.2 How does P2 construe herself and others?**

The HCA shown in Figure 3 also highlights the elements and shows how closely related they are. As shown in Table 7, only one pair of elements were  $\geq 80\%$  matched. This suggests that the majority of elements within P2's personal construct system are construed differently. Following the HCA, a PCA was conducted to examine the variability in P2's repertory grid. The pringrid (Figure 4) supports the following inferences from examination of the repertory grid and HCA.

**Table 7. P2's element matches  $\geq 80\%$**

Element matched with	Element	Match (%)
Epilepsy	Copes Well	80.0



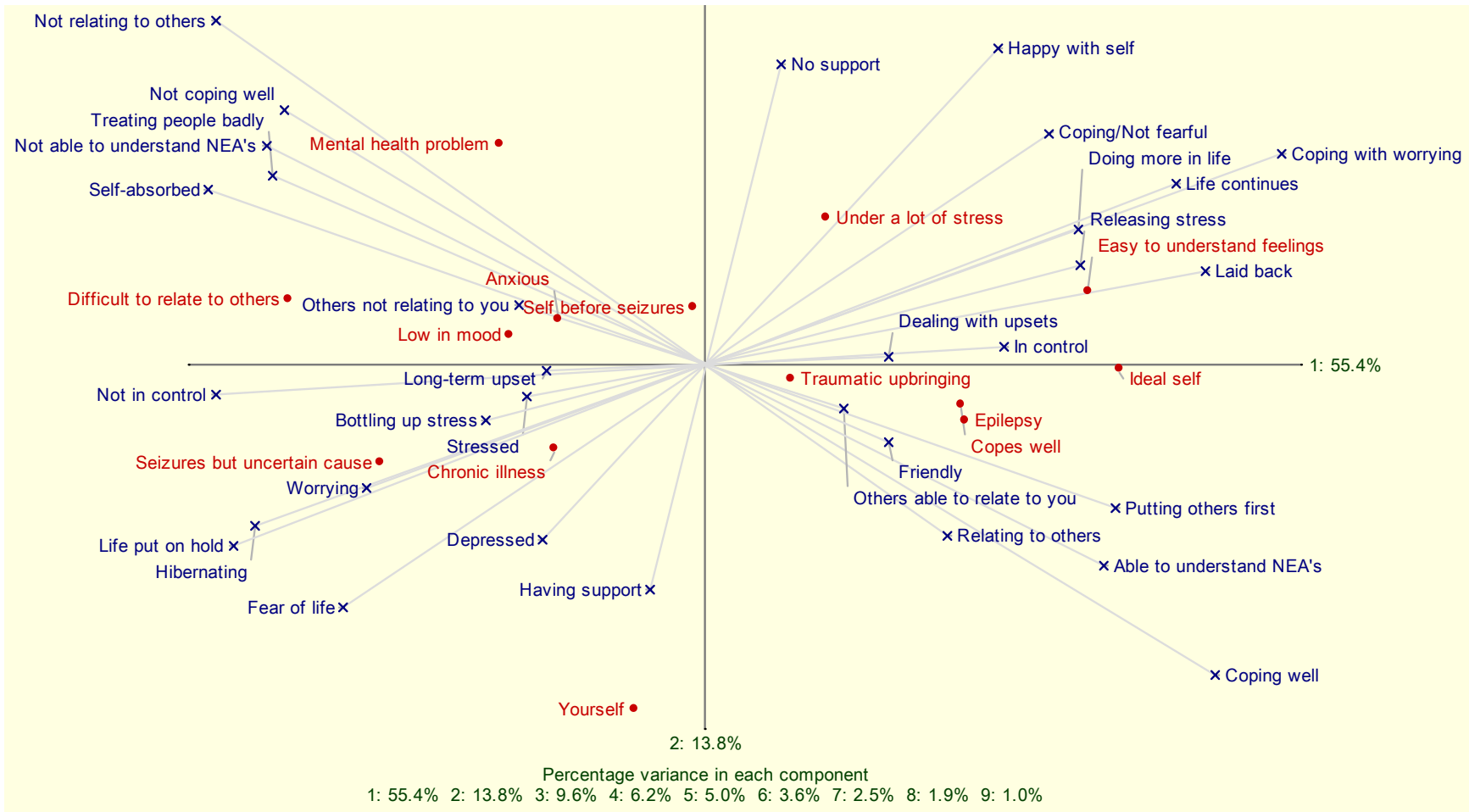


Figure 4: P2's Pringrid

The only elements P2 construed to be highly associated were **someone with epilepsy** and **someone who copes well**. These people were construed positively, particularly seen as being in control, doing more in life, being friendly and relating to others. P2 described being able to cope with epilepsy was due to having medication to control the seizures, as well as having the professional support available.

Table 8 illustrates P2's construal of her current self, self before NEAD and her ideal self in comparison to each other and the other elements. P2 construed her past self, current self and ideal self independently of each other, suggesting that she does not see them as being closely related. The smallest association between these *self* elements was between her current self and ideal self (34.1% match), indicating P2 was not happy with the construal of her current self. She construed her current self to be negatively characterised as not being in control, hibernating, feeling as if life has been put on hold and feeling stressed, depressed and worried. However, her construal of herself was not entirely negative, as she still positively characterised herself as coping well, having support, being friendly and relating to others. P2 did not associate herself before NEAD to be associated with either her current self (46.2 % match) or her ideal self (40.3% match). This indicates a change in how P2 construed herself since she developed NEAD; however, this was not necessarily a negative change. Whilst she construed herself before NEAD as being able to relate to others and feeling as though life was continuing, she also construed her past self as bottling up stress, not coping well, having long-term upset and being depressed and worried. This indicates P2 was not entirely happy with the construal of herself before she developed NEAD. Additionally, P2 construed her current self having support, whereas she construed herself before NEAD as having no support. This indicates a positive change since the onset of NEAD, which may suggest NEAD was associated with some positive consequences for P2.

Additionally, although none of the elements were above the 80% cut-off, a positive shift from her past self to her current self was identified with the elements **someone low in mood** (66.1% and 53.0% match respectively), **someone under a lot of stress** (57.3% and 41.1% match respectively), **someone who is anxious** (63.9% and 55.5% match respectively) and **someone with a mental health problem** (47.6% and 37.2% match respectively). This suggests P2 construed herself to be less depressed, stressed, anxious, and less likely to have a mental health problem since the development of NEAD, although, interestingly, **someone under a lot of stress** was positively construed. Despite these relative shifts, however, P2 did not construe her current self to have any strong association with these elements. This independent construal of her current self may indicate a sense of distinction and/or alienation from others. The least associated element with her past self was **someone who finds it difficult to relate to others** (43.3% match), which suggests P2 construed herself as being able to relate to other people somewhat easily and this had not changed since the development of NEAD (42.6% match), although she would like to increase this ability (10.8% match). The least associated element with her current self was **someone who finds it easy to understand their emotions** (34.4% match). This suggests P2 did not see herself as being able to understand her emotions but ideally would like to

(71.7% match). P2 did not construe her past self or current self to be very good at coping (54.2% and 52.1% match respectively), although ideally would like to be able to cope better (70.5% match). This suggests P2 had always had difficulties with coping. Additionally, P2 did not construe herself to have had a difficult/traumatic upbringing (55.3% match).

P2 did not construe herself to be similar to people with seizure-related disorders or **someone with a chronic, physical health difficulty** (53.6% match). She construed **someone with seizures but uncertain of the cause** more negatively than herself. In contrast, P2 construed **someone with epilepsy** as being more positive than herself. Interestingly, the most highly associated element with P2's ideal self was **someone with epilepsy** (77.6% match). This would suggest P2 did not construe herself as having epilepsy (50.2% match), which fitted with her acceptance of the NEAD diagnosis. It also indicates P2 would prefer to have epilepsy than NEAD, but may also suggest P2 would not like to be 'seizure-free' entirely.

**Table 8. P2 percentage matches between elements of self and other elements**

	Past self (i.e., before NEAD)	Current self	Ideal self
Past self (i.e., before NEAD)	—	46.2	40.3
Current self	46.2	—	34.1
Ideal self	40.3	34.1	—
<b>Someone with a mental health problem</b>			
Someone with a mental health problem	47.6	37.2	28.9
Someone with epilepsy	55.5	50.2	77.6
Someone with seizures but uncertain of the cause	51.9	55.1	20.7
Someone with a chronic, physical health difficulty	50.5	53.6	37.1
Someone low in mood	66.1	53.0	30.9
Someone who is anxious	63.9	55.5	38.2
Someone who copes well	54.2	52.1	70.5
Someone who finds it easy to understand their feelings/emotions	47.8	34.4	71.7
Someone under a lot of stress	57.3	41.1	52.9
Someone who finds it difficult to relate to other people	43.3	42.6	10.8
Someone who has had a difficult/traumatic upbringing	65.1	55.3	48.8

### **3.3.2.3 Feedback**

The Pringrid allowed the results to be presented to P2 to check the validity of the results. P2 reported that the pringrid accurately represented her construal of the elements within the grid. When asked to comment on the repertory grid process as a whole, P2 stated: *"This is quite*

helpful... it shows you what it is, what's bugging me and how to try and stop it" and "I thought it was better than just a questionnaire...made you think more. Made you actually sit down and think about different scenarios in life".

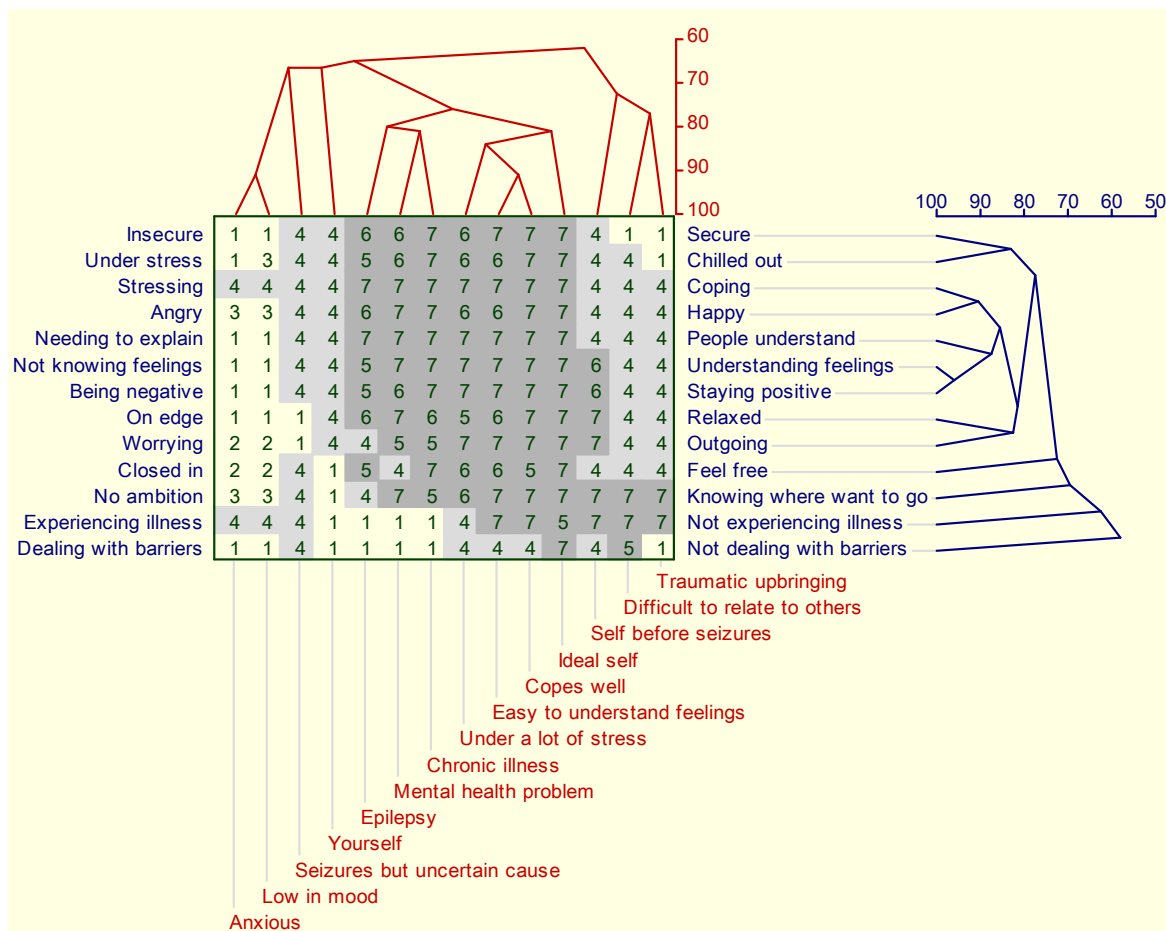
### 3.3.3 Individual Analysis: Participant 3

Participant 3 (P3) was a 28-year-old female with a diagnosis of NEAD (see Table 2 for additional demographic information), although she described initially being misdiagnosed by her GP as having panic attacks. She reported the onset of NEAs approximately 3 years ago. She described experiencing seizures at least once a week. She reported agreeing with the diagnosis of NEAD, but described being unsure what her specific triggers were. P3 had a vague understanding of NEAD, only describing NEAD as not being caused by electrical activity in the brain.

#### 3.3.3.1 How does P3 construe her world?

A HCA was conducted (Figure 5). P3 produced 13 pairs of constructs. Similar to P1 and P2, one of the constructs directly referred to her experiencing NEAs, although she termed the construct *experiencing illness—not experiencing illness*. The overall shape of the construct 'dendrogram' shows one broad cluster incorporating a large proportion of the constructs and one smaller cluster comprising of two constructs. There are also four largely independent constructs (i.e., not associated with the other constructs  $\geq 80\%$ ). The matched constructs ( $\geq 80\%$ ) are shown in Table 9. The analysis revealed 17 matched constructs  $\geq 80\%$ .

Figure 5. P3's HCA



**Table 9. P3's construct matches  $\geq$  80%**

Construct matched with	Construct	Match (%)
Being negative—Staying positive	Not knowing feelings—Understanding feelings	95.5
Angry—Happy	Stressing—Coping	90.0
Needing to explain—People understand	Not knowing feelings—Understanding feelings	87.4
Being negative—Staying positive	Needing to explain—People understand	86.6
Angry—Happy	Needing to explain—People understand	85.2
Under stress—Chilled out	Angry—Happy	82.7
Under stress—Chilled out	Insecure—Secure	82.7
Angry—Happy	Not knowing feelings—Understanding feelings	82.7
On edge—Relaxed	Worrying—Outgoing	82.2
Being negative—Staying positive	Angry—Happy	82.2
On edge—Relaxed	Not knowing feelings—Understanding feelings	81.6
Stressing—Coping	Needing to explain—People understand	81.1
On edge—Relaxed	Being negative—Staying positive	81.1
Being negative—Staying positive	Worrying—Outgoing	81.1
Being negative—Staying positive	Under stress—Chilled out	80.6
Under stress—Chilled out	Not knowing feelings—Understanding feelings	80.1
Under stress—Chilled out	Needing to explain—People understand	80.1

The main cluster comprises of ***stressing—coping, angry—happy, needing to explain—people understand, not knowing feelings—understanding feelings, being negative—staying positive, on edge—relaxed*** and ***worrying—outgoing***. This suggests P3 construes these constructs as being similar. Similar to P1, this cluster is characterised by many constructs expressing an emotional content, suggesting P3 construed her world based on emotional characteristics. P3 described coping as being supported by others, feeling in control and being confident in knowing she was doing the right thing. Positive emotions were associated with ***people understanding*** and not ***needing to explain*** to people, which she described being due to not being judged by others and reassurance that they will know how to help and support her. The most strongly associated construct pair was ***being negative—staying positive*** and ***not knowing feelings—understanding feelings***. P3 commented on how she found it difficult to ***stay positive*** due to her NEAD. She identified a feeling of frustration and anger as a result of not being able to work or go out of the house.

The smaller cluster comprises of ***under stress—chilled out*** and ***insecure—secure***, suggesting P3 construed these constructs to be similar. When discussing ***under stress***, P3 commented on how she did not perceive herself as having any stress before NEAD. However, she also commented on how her stress levels have increased not only as a result of her NEAs, but also due to perceived word-finding difficulties. This suggests a potential mechanism for the development of P3’s NEAD (i.e., bottling up of stress), but also indicates the frustration and additional stressors that may serve to maintain NEAD. P3’s difficulties with stress, frustration and anger were associated with feeling ***insecure***. Conversely, P3 commented on how feeling ***secure*** made her feel calm and appears to be linked to knowing someone is there to help and support her with her NEAD. As illustrated in Figure 5, four constructs are not highly associated with the other clusters of constructs (i.e.,  $\leq 80\%$ ). These are ***closed in—feel free, no ambition—knowing where want to go, experiencing illness—not experiencing illness*** and ***dealing with barriers—not dealing with barriers***.

### **3.3.3.2 How does P3 construe herself and others?**

The HCA shown in Figure 5 highlights the elements and shows how closely related they are. Table 10 illustrates the elements that were most closely associated. A PCA was conducted and the resultant pringrid (Figure 6) supports the inferences drawn from examination of the repertory grid and HCA.

**Table 10. P3’s element matches  $\geq 80\%$**

<b>Element matched with</b>	<b>Element</b>	<b>Match (%)</b>
Low in mood	Anxious	90.8
Easy to understand feelings	Copes well	90.8
Easy to understand feelings	Under a lot of stress	84.0
Mental health problem	Chronic illness	80.9
Ideal self	Copes well	80.9
Ideal self	Easy to understand feelings	80.9
Under a lot of stress	Copes well	80.4

As illustrated in Table 10, there are a small number of elements that are  $\geq 80\%$  matched. This would suggest P3 construed the elements largely independently of each other. There are three small clusters emerging, along with a large number of independent elements. The first cluster comprises of ***ideal self, someone who finds it easy to understand their emotions, someone who copes well*** and ***someone under a lot of stress***. This suggests P3 construed these people in a similar way. In relation to the constructs, P3 construed these people most positively on all the constructs compared to the other elements. The second cluster is comprised of ***someone low in mood*** and ***someone who is anxious***, suggesting P3 construed these elements as being very similar. P3 construed these people more negatively on the construct

ratings compared to the other elements. The third cluster comprises of ***someone with a mental health problem*** and ***someone with a chronic, physical health difficulty***, which suggests P3 construed physical health as having an impact on mental health and/or vice versa. Although not associated above the 80% cut-off, ***someone with epilepsy*** was also slightly associated with this third cluster. Interestingly, these people were construed as being positively characterised. The least associated elements were ***yourself, self before seizures*** and ***someone with seizures but uncertain of the cause***.

Table 11 illustrates P3's construal of her current self, self before NEAD and her ideal self in comparison to each other and the other elements. P3 construed her past self, current self and ideal self as largely independent of each other. The smallest association between these *self* elements was between her current self and her ideal self (33.8% match), which suggests that she was not happy with the construal of her current self. She was more likely to rate her current self neutrally on the constructs, except for seeing herself as having no ambition, experiencing illness, dealing with barriers and feeling closed in. P3 did not construe herself before NEAD to be associated with either her current self (50.2% match) or ideal self (61.6% match). She construed herself before NEAD to be largely neutral in the construct ratings, except for seeing her previous self to be relaxed, outgoing, knowing where she wanted to go in life and not experiencing illness. This suggests P3 construed a negative change since the onset of NEAD. However, P3 still construed herself before seizures to be somewhat more negative than her ideal self, suggesting P3 was not entirely happy with the construal of herself before she developed NEAD.

P3's past self was most associated with ***someone who finds it difficult to relate to other people*** (72.2% match) and ***someone who finds it easy to understand their emotions*** (70.0% match), which suggests P3 construed her previous self to be slightly similar to these people. However, when thinking about her current self, the percentage match with these elements dramatically reduced to 52.4% and 39.4% respectively. This indicates a shift in how P3 construed her current self in comparison to her past self, particularly suggesting that she now finds it more difficult to understand her emotions but more able to relate to other people. The least associated elements with her past self were ***someone who is anxious*** (38.5% match) and ***someone low in mood*** (39.9% match), which suggests P3 did not construe herself to have any previous difficulties with anxiety or low mood. However, the association with these elements increased to 60.5% and 62.7% respectively, when compared to her current self. This also indicates a negative shift in how P3 construed herself compared to her previous self, particularly indicating an increase in low mood and anxiety since the development of NEAD. The least associated elements with her current self were ***someone who copes well*** (38.3% match) and ***someone who finds it easy to understand their emotions*** (39.4% match), which indicates P3 finds it more difficult to cope and understand her emotions than her previous self (68.0% and 70.0% respectively). She also construed ***someone with a mental health problem*** as being positively characterised, although



Figure 6: P3's Pringrid



she did not construe herself or past self as having such difficulties. P3 did not see herself as having had a difficult/traumatic upbringing.

Although not highly associated with any of the elements ( $\geq 80\%$ ), P3 construed her current self to be most similar to *someone with seizures but uncertain of the cause* (66.0% match) and *someone with epilepsy* (64.8% match). She construed *someone with seizures but uncertain of the cause* more neutrally on the ratings, whereas *someone with epilepsy* was rated more positively, particularly being seen as having people understand their difficulties, being able to cope and feeling secure, relaxed and happy. P3 did not construe herself to be similar to *someone with a chronic, physical health difficulty*. Overall, P3 did not see herself as having epilepsy, an unknown cause or a chronic, physical illness, which fitted with her acceptance of the NEAD diagnosis. P3 also construed having a chronic, physical illness as being preferable to have a seizure-related disorder.

**Table 11. P3's percentage matches between elements of self and other elements**

	Past self (i.e., before seizures)	Current self	Ideal self
Past self (i.e., before NEAD)	—	50.2	61.6
Current self	50.2	—	33.8
Ideal self	61.6	33.8	—
<b>Other elements</b>			
Someone with a mental health problem	57.4	53.1	61.9
Someone with epilepsy	55.2	64.8	56.4
Someone with seizures but uncertain of the cause	54.2	66.0	41.0
Someone with a chronic, physical health difficulty	51.5	49.4	63.9
Someone low in mood	39.9	62.7	16.8
Someone who is anxious	38.5	60.5	14.3
Someone who copes well	68.0	38.3	80.9
Someone who finds it easy to understand their feelings/emotions	70.0	39.4	80.9
Someone under a lot of stress	67.3	48.1	79.9
Someone who finds it difficult to relate to other people	72.3	52.4	48.3
Someone who has had a difficult/traumatic upbringing	66.3	54.0	37.3

### **3.3.3.3 Feedback**

P3 reported the pringrid accurately represented her construal of the elements within the grid. When asked to comment on the repertory grid process, P3 described: *"It makes me think about it*

*a lot more. Because it's in front of me, it's easier for me to take in. It is easier to process because it's all there in black and white...it will probably make other people notice a lot more as well".*

### **3.3.4 Individual Analysis: Participant 4**

Participant 4 (P4) was a 47-year-old female with a diagnosis of NEAD (see Table 2 for additional demographic information), which started five years ago. She described experiencing NEAs approximately 3-4 times per week. She had never received a diagnosis of epilepsy, although she reported previously being prescribed anti-epileptic medication. At the time of interview, P4 had begun psychological assessment within the neuropsychology department. She reported disagreeing with the NEAD diagnosis, and instead believed her NEAs were linked to her Dandy-Walker Syndrome, which is a congenital malformation involving the cerebellum. The consultant neurologist was confident her NEAs were due to NEAD rather than her Dandy-Walker Syndrome. P4 reported some understanding of NEAD, stating it was stress-related and not harmful.

#### **3.3.4.1 How does P4 construe her world?**

A HCA was conducted (Figure 7). P4 produced 13 pairs of constructs. Similar to other participants, one of the constructs directly referred to her experiencing NEAs, which she termed ***having seizures—not having seizures***. The overall shape of the construct 'dendrogram' shows all constructs are associated  $\geq 80\%$ . This suggests a very high level of association (i.e., similarity of individual ratings) between the constructs, suggesting P4 primarily construed her world on the basis of a number of similar constructs. Overall, this indicates P4 uses a limited range of constructs to view her world, which is suggestive of a very restricted personal construct system (i.e., not cognitively complex). The matched constructs ( $\geq 80\%$ ) are shown in Table 12.

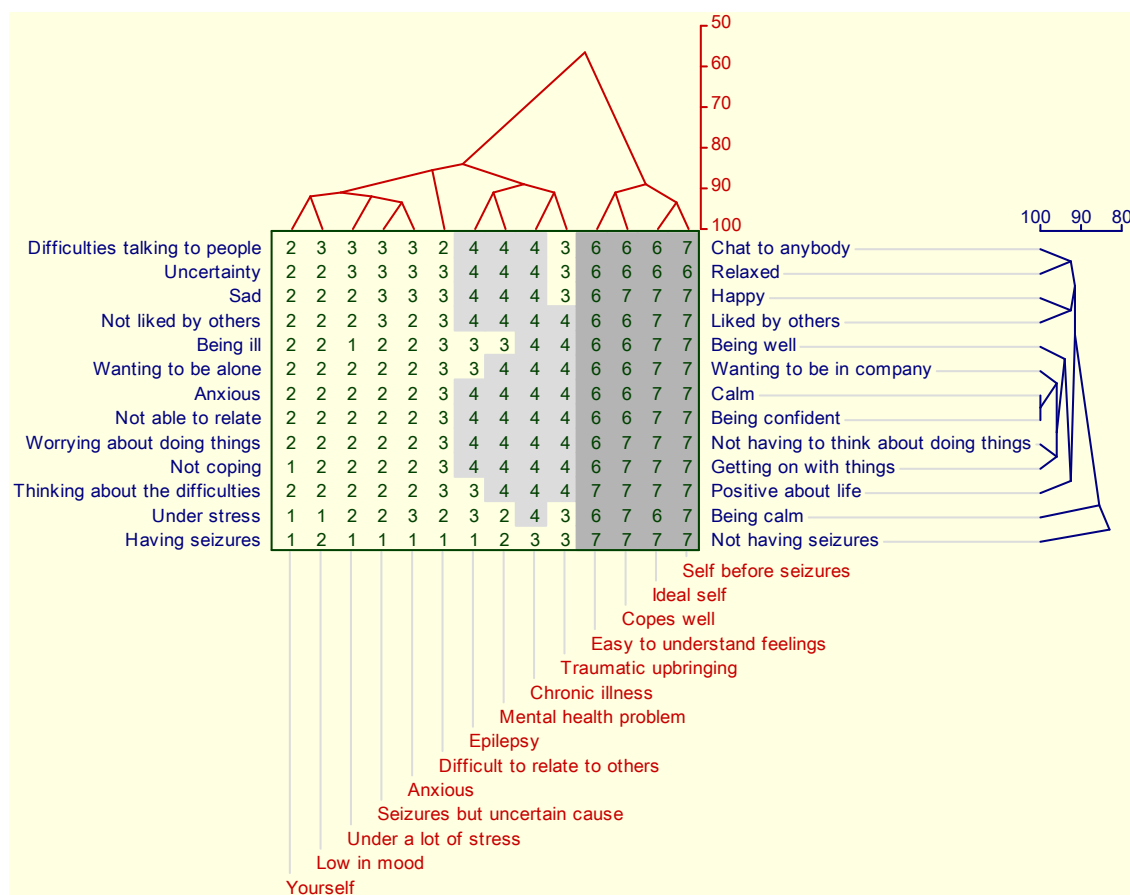
Upon inspection of the repertory grid, the constructs appear to be characterised by themes of being illness-related, having to think about difficulties, emotions, having relationships with others, and coping. P4 discussed how her NEAD and the associated worries impacted on her negative emotions, and also described how her negative emotions can affect her NEAD: *"if you have a lot of stress it can bring the epilepsy on...and can make you have more seizures"*. This suggests a potential maintenance cycle of negative emotions impacting on P4's NEAD. P4 perceived NEAs and negative emotions as impacting on ability to relate to other people. Due to her NEAD and resultant low mood and anxiety, P4 described spending more time on her own, not wanting to socialise as much or getting involved in conversations with others and perceived others not to like her as much. Again, this suggests a potential maintenance cycle of negative emotions and NEAs. P4 also commented on how this difficulty relating to others also extended to her family:

*"It's not just you...it affects all the family and your dynamics of the family change. You go from being mum, to sometimes I feel like I'm the naughty child...or there's always someone watching me"*.

Overall, P4 construed these factors (i.e., having NEAs, thinking about the difficulties, negative emotions and difficulties relating to people) as having an impact on her ability to cope. She described not coping as well as she did prior to the onset of NEAD. It also appears that this

inability to cope is related to her level of uncertainty about NEAD and how to overcome the difficulties.

**Figure 7. P4's HCA**



**Table 12. P4's constructs matches  $\geq 80\%$**

Construct matched with	Construct	Match (%)
Anxious—Calm	Not able to relate—Being confident	100.0
Anxious—Calm	Worrying about doing things—Not having to think about doing things	95.5
Not able to relate—Being confident	Not liked by others—Liked by others	95.5
Wanting to be alone—Wanting to be in company	Not able to relate—Being confident	95.5
Not coping—Getting on with things	Worrying about doing things—Not having to think about doing things	95.5
Wanting to be alone—Wanting to be in company	Anxious—Calm	95.5
Anxious—Calm	Not liked by others—Liked by others	95.5
Worrying about doing things—Not having to think about doing things	Not able to relate—Being confident	95.5
Not coping—Getting on with things	Not able to relate—Being confident	93.7
Anxious—Calm	Not coping—Getting on with things	93.7
Worrying about doing things—Not having to think about doing things	Not liked by others—Liked by others	93.7

Wanting to be alone—Wanting to be in company	Thinking about the difficulties—Positive about life	93.7
Wanting to be alone—Wanting to be in company	Not liked by others—Liked by others	93.7
Being ill—Being well	Wanting to be alone—Wanting to be in company	93.7
Thinking about the difficulties—Positive about life	Worrying about doing things—Not having to think about doing things	93.7
Wanting to be alone—Wanting to be in company	Worrying about doing things—Not having to think about doing things	93.7
Wanting to be alone—Wanting to be in company	Not coping—Getting on with things	92.3
Being ill—Being well	Anxious—Calm	92.3
Thinking about the difficulties—Positive about life	Not able to relate—Being confident	92.3
Sad—Happy	Worrying about doing things—Not having to think about doing things	92.3
Thinking about the difficulties—Positive about life	Not coping—Getting on with things	92.3
Sad—Happy	Not liked by others—Liked by others	92.3
Difficulties talking to people—Chat to anybody	Uncertainty—Relaxed	92.3
Not coping—Getting on with things	Not liked by others—Liked by others	92.3
Thinking about the difficulties—Positive about life	Anxious—Calm	92.3
Being ill—Being well	Not able to relate—Being confident	92.3
Sad—Happy	Anxious—Calm	91.1
Sad—Happy	Not coping—Getting on with things	91.1
Sad—Happy	Not able to relate—Being confident	91.1
Sad—Happy	Uncertainty—Relaxed	91.1
Being ill—Being well	Thinking about the difficulties—Positive about life	91.1
Being ill—Being well	Not liked by others—Liked by others	91.1
Thinking about the difficulties—Positive about life	Not liked by others—Liked by others	91.1
Being ill—Being well	Worrying about doing things—Not having to think about doing things	91.1
Sad—Happy	Thinking about the difficulties—Positive about life	90.0
Being ill—Being well	Not coping—Getting on with things	90.0
Sad—Happy	Difficulties talking to people—Chat to anybody	90.0
Sad—Happy	Wanting to be alone—Wanting to be in company	90.0
Uncertainty—Relaxed	Not liked by others—Liked by others	90.0
Uncertainty—Relaxed	Anxious—Calm	89.1
Uncertainty—Relaxed	Not able to relate—Being confident	89.1

Difficulties talking to people—Chat to anybody	Not liked by others—Liked by others	89.1
Difficulties talking to people—Chat to anybody	Anxious—Calm	88.2
Uncertainty—Relaxed	Worrying about doing things—Not having to think about doing things	88.2
Sad—Happy	Being ill—Being well	88.2
Difficulties talking to people—Chat to anybody	Not able to relate—Being confident	88.2
Uncertainty—Relaxed	Wanting to be alone—Wanting to be in company	88.2
Difficulties talking to people—Chat to anybody	Worrying about doing things—Not having to think about doing things	87.4
Uncertainty—Relaxed	Not coping—Getting on with things	87.4
Difficulties talking to people—Chat to anybody	Wanting to be alone—Wanting to be in company	87.4
Difficulties talking to people—Chat to anybody	Not coping—Getting on with things	86.6
Uncertainty—Relaxed	Thinking about the difficulties—Positive about life	86.6
Under stress—Being calm	Being ill—Being well	86.6
Under stress—Being calm	Not coping—Getting on with things	85.9
Under stress—Being calm	Sad—Happy	85.9
Difficulties talking to people—Chat to anybody	Thinking about the difficulties—Positive about life	85.9
Under stress—Being calm	Worrying about doing things—Not having to think about doing things	85.2
Uncertainty—Relaxed	Being ill—Being well	85.2
Under stress—Being calm	Wanting to be alone—Wanting to be in company	85.2
Under stress—Being calm	Thinking about the difficulties—Positive about life	85.2
Difficulties talking to people—Chat to anybody	Being ill—Being well	84.6
Under stress—Being calm	Anxious—Calm	84.6
Under stress—Being calm	Uncertainty—Relaxed	84.6
Under stress—Being calm	Not able to relate—Being confident	84.6
Under stress—Being calm	Not liked by others—Liked by others	83.9
Under stress—Being calm	Difficulties talking to people—Chat to anybody	83.9
Under stress—Being calm	Having seizures—Not having seizures	82.7
Having seizures—Not having seizures	Being ill—Being well	82.2
Having seizures—Not having seizures	Thinking about the difficulties—Positive about life	81.1
Having seizures—Not having seizures	Wanting to be alone—Wanting to be in company	80.1

### **3.3.4.2 How does P4 construe herself and others?**

The HCA shown in Figure 7 highlights the elements and shows how closely related they are. Table 13 illustrates the elements that were most closely associated. A PCA was conducted and the pringrid (Figure 8) supports the following inferences drawn from examination of the repertory grid and HCA.

**Table 13. P4's elements matches  $\geq 80\%$**

<b>Element matched with</b>	<b>Element</b>	<b>Match (%)</b>
Ideal self	Self before seizures	93.5
Seizures but uncertain cause	Anxious	93.5
Seizures but uncertain cause	Under a lot of stress	92.0
Yourself	Low in mood	92.0
Under a lot of stress	Anxious	92.0
Chronic illness	Traumatic upbringing	90.8
Epilepsy	Mental health problem	90.8
Easy to understand feelings	Copes well	90.8
Under a lot of stress	Low in mood	90.8
Seizures but uncertain cause	Low in mood	89.7
Yourself	Under a lot of stress	89.7
Self before seizures	Copes well	88.7
Mental health problem	Traumatic upbringing	88.7
Ideal self	Copes well	88.7
Mental health problem	Chronic illness	88.7
Yourself	Seizures but uncertain cause	88.7
Low in mood	Anxious	87.8
Yourself	Anxious	86.9
Seizures but uncertain cause	Difficult to relate to others	86.9
Epilepsy	Chronic illness	86.9
Ideal self	Easy to understand feelings	86.9
Self before seizures	Easy to understand feelings	85.4
Difficult to relate to others	Anxious	85.4
Epilepsy	Traumatic upbringing	85.4

Epilepsy	Difficult to relate to others	84.0
Difficult to relate to others	Low in mood	83.3
Difficult to relate to others	Under a lot of stress	83.3
Yourself	Difficult to relate to others	82.7
Traumatic upbringing	Difficult to relate to others	82.7
Mental health problem	Difficult to relate to others	82.7

As illustrated in Table 13, there are a high number of elements that are  $\geq 80\%$  matched. This would suggest P4 construed the elements in very similar ways. There is one main broad cluster and one smaller cluster of elements emerging within the HCA. Despite all the elements within the largest cluster being matched  $\geq 80\%$ , there appears to be two sub-clusters emerging. The first sub-cluster is comprised of ***yourself, someone low in mood, someone under a lot of stress, someone who is anxious*** and ***someone who finds it difficult to relate to other people***. These people are construed most negatively, and suggests P4 perceived herself to be low in mood, under stress, anxious and having difficulties relating to others. The second sub-cluster comprises of ***someone with epilepsy, someone with a mental health problem, someone with a chronic, physical difficulty*** and ***someone who has had a difficult/traumatic upbringing***. Again, this suggests these people are construed similarly and were rated more neutrally on all the constructs. This suggests P4 construed people with mental health difficulties, difficult upbringings, epilepsy and chronic, physical difficulties as being more positively characterised than her current self.

The smaller cluster comprised of ***self before seizures, ideal self, someone who copes well*** and ***someone who finds it easy to understand their emotions***, suggesting these people are construed as being similar. They were construed very positively on all the construct ratings. This also suggests P4 sees her ideal self and past self as very similar (93.5% match), indicating she had a very positive construal of herself prior to the onset of NEAD. However, P4 did not associate her current self with her past self (13.6% match) or ideal self (16.2% match). She rated herself most negatively on all the constructs, indicating that the construal of herself had changed to a very negative construal compared to herself before NEAD. This discrepancy and shift would be indicative of low mood, poor self-esteem and a poor quality of life. This was supported by P4's reported suicidal ideation.

Table 14 illustrates P4's construal of her current self, self before NEAD and her ideal self in comparison to the other elements. It supports the findings P4 construed herself most positively before she developed NEAD, particularly seeing herself as being similar to ***someone who copes well*** (88.7% match) and ***someone who finds it easy to understand their emotions*** (85.4%). However, when comparing this to her current self, this association decreased to 20.6% and 26.2% respectively. This indicates a significant negative shift in the construal of her current

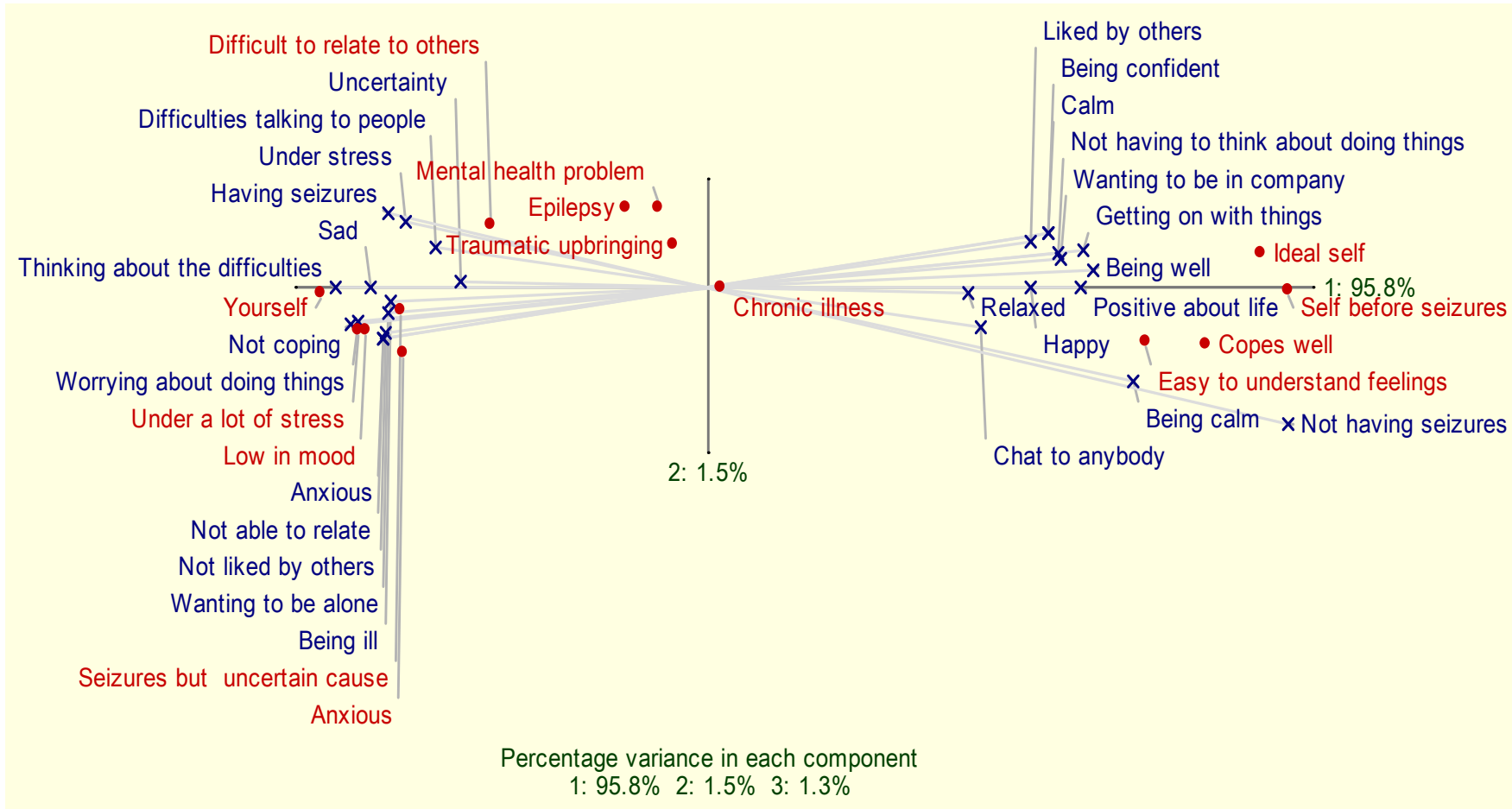


Figure 8: P4's Pringrid



self indicating she now sees herself as not coping well or able to understand her emotions. Additionally, before she developed NEAD, P4 construed herself to be unrelated to **someone under a lot of stress** (17.1% match) and **someone low in mood** (17.6% match). When comparing this to her current self, this association increased to 89.7% and 92.0% respectively. This indicates a significant negative shift in the construal of her current self, particularly seeing herself as being more stressed and low in mood. There has also been a negative shift of her past self construal to her current self construal in relation to the elements: **someone with a mental health problem, someone who is anxious, someone who finds it difficult to relate to other people, someone who has had a difficult/traumatic upbringing** and **someone with a chronic, physical health difficulty**. This suggests P4 construed herself to be more similar to these people than her previous self. Finally, in relation to people experiencing seizures, P4 construed her current self to be very similar to **someone with seizures but uncertain of the cause** (88.7% match) than to **someone with epilepsy** (69.3% match). This would fit with her belief that her NEAs were due to her Dandy-Walker Syndrome. However, she construed these people more positively than her current self due to the support they receive from healthcare professionals and the lack of education healthcare professionals have of NEAD:

*"Nobody knows what [NEAD] is. If I went in saying I had breast cancer, they'd know exactly what was going on. They'd be able to treat me. Or if you went in A&E and said you got epilepsy, 'no problem'. But if you go in and say NEAD they look at you like you've got two heads. If it's not epilepsy, you're making it up. Really you're fighting two battles-your illness when you don't feel well and the system supposed to be helping you".*

**Table 14. P4's percentage matches between elements of self and other elements**

	Past self (i.e., before seizures)	Current self	Ideal self
Past self (i.e., before NEAD)	—	13.6	93.5
Current self	13.6	—	16.2
Ideal self	93.5	16.2	—
Someone with a mental health problem	43.2	68.0	45.9
Someone with epilepsy	40.3	69.3	42.5
Someone with seizures but uncertain of the cause	20.9	88.7	23.1
Someone with a chronic, physical health difficulty	49.6	63.6	51.7
Someone low in mood	17.6	92.0	19.9
Someone who is anxious	20.9	86.9	22.8
Someone who copes well	88.7	20.6	88.7
Someone who finds it easy to understand their feelings/emotions	85.4	26.2	86.9

Someone under a lot of stress	17.1	89.7	19.1
Someone who finds it difficult to relate to other people	28.5	82.7	31.3
Someone who has had a difficult/traumatic upbringing	44.3	68.0	47.1

### 3.3.4.3 Feedback

P4 reported that the pringrid accurately represented her construal of the elements within the grid as well as validating the 'black and white' nature of her construing. When asked to comment on the repertory grid process as a whole, P4 described it as being interesting and stated: "Things like this should be researched because people's attitudes need to change".

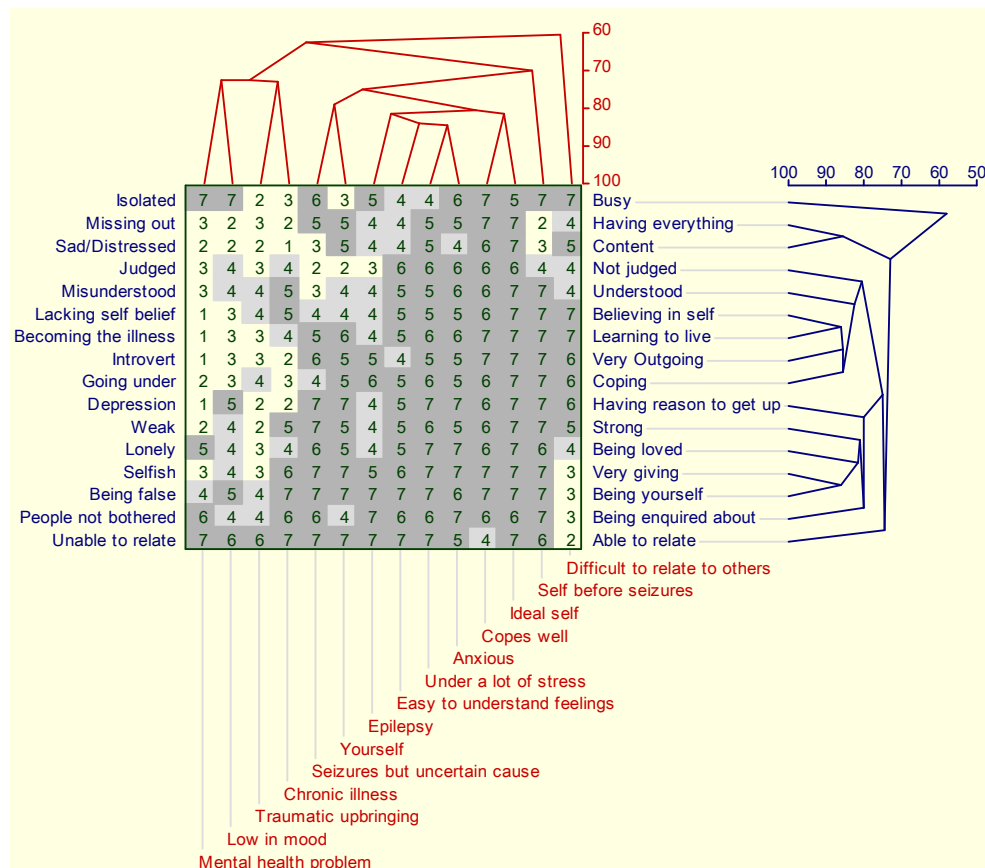
### 3.3.5 Individual Analysis: Participant 5

Participant 5 (P5) was a 29-year-old female with a diagnosis of NEAD (see Table 2 for additional demographic information), which started four years ago. She also had a diagnosis of chronic fatigue syndrome. She experienced NEAs at least once a fortnight. She described being 'unsure' of her diagnosis of NEAD, and questioned whether she had epilepsy instead.

#### 3.3.5.1 How does P5 construe her world?

A HCA was conducted (Figure 9). P5 produced 16 pairs of constructs. One of the constructs directly referred to experiencing NEAs (i.e., **becoming the illness—learning to live**). The overall shape of the construct 'dendrogram' shows three clusters of constructs and a small number of independent constructs. The matched constructs are shown in Table 15.

**Figure 9. P5's HCA**



**Table 15. P5's construct matches  $\geq$  80%**

Construct matched with	Construct	Match (%)
Being false—Being yourself	Selfish—Very giving	85.9
Becoming the illness—Learning to live	Lacking self belief—Believing in self	85.9
Introvert—Very Outgoing	Going under—Coping	85.2
Sad/Distressed—Content	Missing out—Having everything	85.2
Introvert—Very Outgoing	Becoming the illness—Learning to live	85.2
Going under—Coping	Lacking self belief—Believing in self	84.6
Becoming the illness—Learning to live	Going under—Coping	84.6
Becoming the illness—Learning to live	Weak—Strong	82.7
Lacking self belief—Believing in self	Misunderstood—Understood	82.2
Selfish—Very giving	Lonely—Being loved	81.1
Going under—Coping	Misunderstood—Understood	81.1
Becoming the illness—Learning to live	Depression—Having reason to get up	81.1
Introvert—Very Outgoing	Weak—Strong	81.1
Selfish—Very giving	Weak—Strong	80.6
Lonely—Being loved	Weak—Strong	80.6
Introvert—Very Outgoing	Lacking self belief—Believing in self	80.6
Judged—Not judged	Misunderstood—Understood	80.1

The largest cluster of constructs comprises of ***judged—not judged, misunderstood—understood, lacking self belief—believing in self, becoming the illness—learning to live, introvert—very outgoing, and going under—coping***. This indicates P5 construed becoming the illness and not coping as being linked to being judged and misunderstood, lacking in self belief and being introverted. This would indicate P5 perceived the ability to live with and cope with her NEAD as being easier if people were able to understand and not judge her, and her believing in herself. The most strongly associated construct pair within this first cluster was ***becoming the illness—learning to live*** and ***lacking in self belief—believing in self***. This indicates P5 construed someone lacking in self belief as allowing their illness to dominate their lives. The second largest cluster is characterised by ***weak—strong, lonely—being loved, selfish—very giving*** and ***being false—being yourself***. This indicates that these constructs are construed in a similar way. When describing this, P5 described being strong as being determined by having positive relationships, suggesting P5 perceives her support networks as being important in her being able to "*battle through*", as well as being able to accept emotions and problem-solve difficulties.

The smallest cluster is characterised by ***missing out—having everything*** and ***sad/distressed—content***. This suggests P5 construed missing out as having an impact on mood. As illustrated in Figure 9, there are a small number of constructs that are not highly associated with the other cluster of constructs (i.e.,  $\leq 80\%$ ). These are ***isolated—busy***, ***depression—having reason to get up, people not bothered—being enquired about*** and ***unable to relate—able to relate***. When discussing the construct ***depression—having a reason to get up***, P5 stated that she did experience depression but her son was the reason she got up in the morning. This suggests that having a reason to get up in the morning was increasing P5’s feeling of self-worth and helping her to cope with her difficulties. P5 described currently being isolated since she developed NEAD. Despite this, she described how she had come to accept this isolation by being able to enjoy different activities within the house (e.g., watching films).

### **3.3.5.2 How does P5 construe herself and others?**

The HCA shown in Figure 9 highlights the elements and shows how closely related they are. Table 16 illustrates the elements that were most closely associated. A PCA was conducted and the resultant pringrid (Figure 10) supports the inferences drawn from examination of the repertory grid and HCA.

**Table 16. P5’s element matches  $\geq 80\%$**

<b>Element matched with</b>	<b>Element</b>	<b>Match (%)</b>
Under a lot of stress	Anxious	84.4
Easy to understand feelings	Under a lot of stress	83.9
Epilepsy	Easy to understand feelings	81.4
Ideal self	Copes well	81.4
Copes well	Anxious	80.5
Easy to understand feelings	Anxious	80.0

As illustrated in Table 16, there are a small number of elements that are  $\geq 80\%$  matched. One cluster of elements is identified within the HCA, along with a large number of independent elements. This would suggest P5 construed the elements largely independently of each other. This cluster is comprised of ***someone who finds it easy to understand their emotions***, ***someone under a lot of stress***, ***someone who is anxious*** and ***someone who copes well***. This suggests P5 construed these people in similar ways and more positively on the construct ratings. This suggests P5 construed people who are stressed and anxious as still being able to understand their emotions and cope well. ***Someone with epilepsy*** was also closely related to ***someone who finds it easy to understand their emotions***. ***Ideal self*** was highly associated with ***someone who copes well***, which suggests P5 would like to be able to cope better than she currently was able to. Eight elements were not highly associated with the other elements.

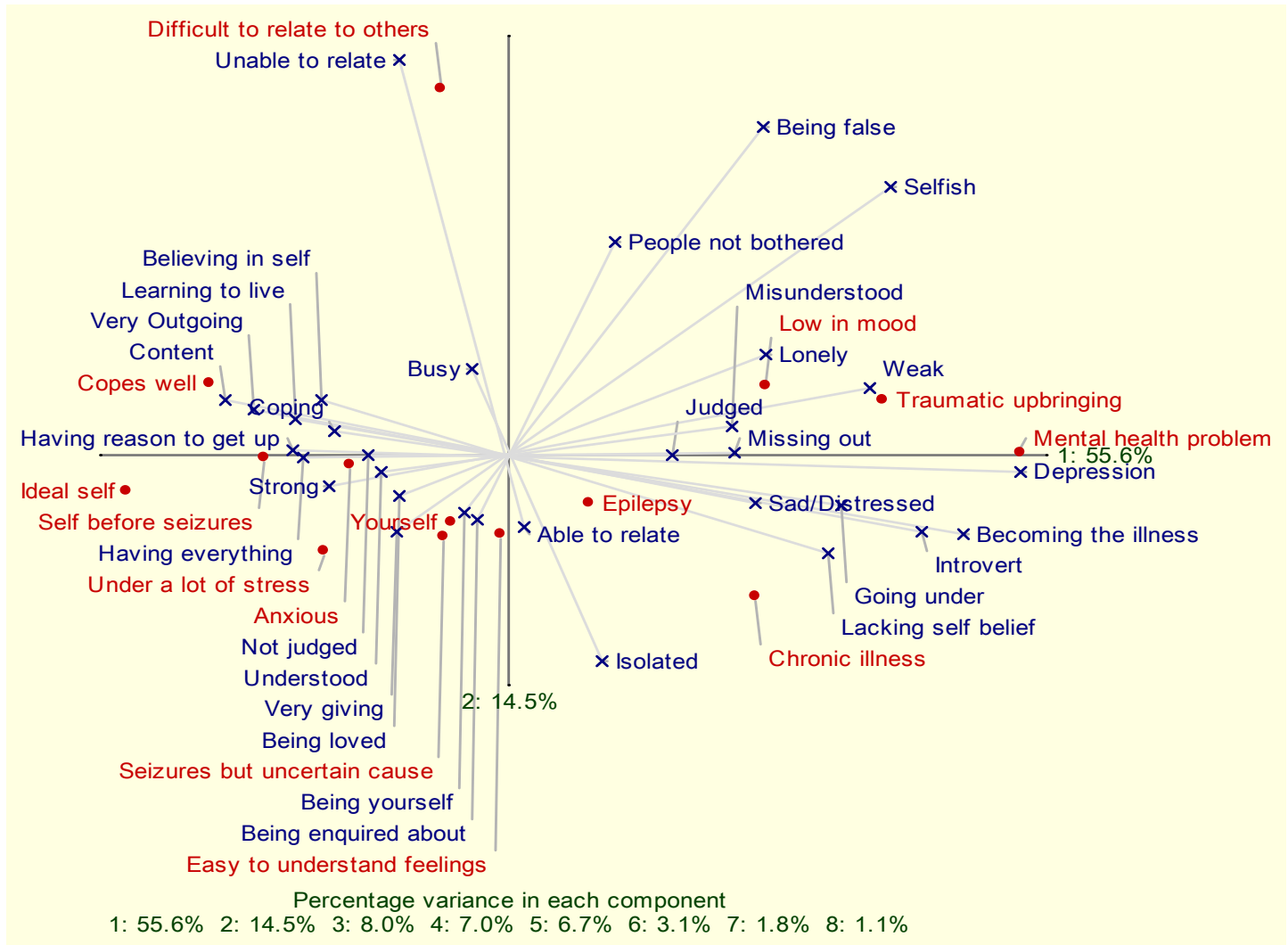


Figure 10: P5's Pringrid

Table 17 illustrates P5's construal of her current self, self before NEAD and her ideal self in comparison to each other and the other elements. P5's independent construal of the elements indicates that she construed her past self, current self and ideal self as largely independent of each other. The association between her current self and her ideal self (65.9%% match) suggests that she construed her current self as slightly distant from her ideal self. P5 rated her current self positively, particularly seeing herself as having a reason to get up, being very giving, being herself, being able to relate to others and learning to live. However, she also rated herself more negatively than her ideal self, particularly seeing herself as judged and isolated. P5 did not construe herself before NEAD to be very similar to her ideal self (70.0% match) or her current self (63.9% match), although she viewed her past self as being slightly more related to her ideal self than her current self. This would suggest P5 had an overall positive construal of herself before she developed NEAD, although this was not as positive as she would have liked, and although she construed her current self to be less positive than herself before NEAD, she still construed herself as being more positively than negatively characterised. This suggests P5 construed a slight change from her past self to her current self, particularly in relation to lacking self-belief and feeling more isolated and misunderstood. She also construed a slight negative shift from her past self to her current self in relation to feeling able to cope well (71.1% and 65.9% match respectively), and she would like to be able to cope better than she currently does (81.4% match).

Although not above the 80% cut-off, P5's past self was most highly associated with **someone who is anxious** (75.0% match) and **someone under a lot of stress** (72.4% match), which suggests P5 construed her previous self to be slightly similar to these people. However, these people are construed positively on all the constructs. She also construed her current self and ideal self to be similar to these people. The least associated element with herself before NEAD is **someone with a mental health problem** (35.3% match). She particularly construed such a person as being very negatively characterised. This had not changed since the development of NEAD (46.6% match), suggesting P5 did not see her past self or current self as having a mental health problem. She also did not see her past self or current self as being similar to **someone low in mood**, **someone who finds it difficult to relate to other people** or **someone who has had a difficult/traumatic upbringing**. This latter finding is particularly interesting, considering P5 reported experiencing a traumatic childhood. When discussing her previous traumas, she stated: "As far as I'm concerned it's gone". P5 perceived a slight shift in being more able to understand her emotions since the onset of NEAD (69.1% to 76.4% match). However, this was not seen as a positive shift, as **someone who finds it easy to understand their feelings/emotions** was rated more neutrally on the construct ratings, and she would like her ideal self to understand her emotions slightly less than she currently did (68.5% match). This may suggest P5 finds managing emotions particularly difficult.

Although not above the 80% cut-off, the most highly associated element with her current self was **someone with seizures but uncertain of the cause** (78.8% match), indicating P5 construed herself to be slightly similar to someone who does not know the cause of their NEAs. She also

construed her current self to be slightly similar to **someone with epilepsy** (75.0%). This fitted with her uncertainty of her NEAD diagnosis. Interestingly, she construed **someone with epilepsy** as being more negatively characterised than **someone with seizures but uncertain of the cause**. Also, despite P5 describing physical health difficulties, she did not highly associate herself with **someone with a chronic, physical health difficulty** (63.0% match). She construed this element largely negatively on the construct ratings, particularly construing them as being sad/distressed, missing out, introvert, depressed, going under and isolated.

**Table 17. P5's percentage matches between elements of self and other elements**

	Past self (i.e., before seizures)	Current self	Ideal self
Past self (i.e., before NEAD)	—	63.9	70.0
Current self	63.9	—	65.9
Ideal self	70.0	65.9	—
<b>Someone with a mental health problem</b>			
Someone with epilepsy	35.3	46.6	28.7
Someone with seizures but uncertain of the cause	65.4	75.0	60.3
Someone with a chronic, physical health difficulty	69.1	78.8	63.4
Someone low in mood	55.5	63.0	46.3
Someone who is anxious	55.7	63.7	45.5
Someone who copes well	75.0	70.8	74.3
Someone who finds it easy to understand their feelings/emotions	71.1	65.9	81.4
Someone under a lot of stress	69.1	76.4	68.5
Someone who finds it difficult to relate to other people	72.4	77.6	79.6
Someone who has had a difficult/traumatic upbringing	60.0	59.8	55.9
	44.1	59.8	39.0

### **3.3.5.3 Feedback**

P5 reported that the pringrid accurately represented her construal of the elements within the grid, and stated: *"I could literally put that in my brain...if you would have asked me the questions about 'where would I be?', you wouldn't have got a true reading. But the way you've done it, you've got a completely true reading because that is how I see myself"*. When asked to comment on the repertory grid process as a whole, P5 described: *"I think it's really helpful. It has made me look at things more in detail. It's made me realise more about myself...it makes you think things that you wouldn't normally do"*.





**Table 18. P6's construct matches  $\geq$  80%**

<b>Construct matched with</b>	<b>Construct</b>	<b>Match (%)</b>
Disability—Able-bodied	Having to rely on others—Independence	92.3
Struggling—Coping	Antisocial—Sociable	92.3
Stressed/Anxious—Level-headed	Isolated—Comfortable	91.1
Struggling—Coping	Sad—Happy	91.1
Sad—Happy	Antisocial—Sociable	90.0
Being negative—Being positive	Isolated—Comfortable	89.1
Antisocial—Sociable	Mentally affected—Not mentally affected	89.1
Antisocial—Sociable	Isolated—Comfortable	89.1
Sad—Happy	Being negative—Being positive	88.2
Isolated—Comfortable	Mentally affected—Not mentally affected	87.4
Being negative—Being positive	Mentally affected—Not mentally affected	87.4
Disability—Able-bodied	Viewed negatively by others—Not judged/Taken on face value	87.4
Being negative—Being positive	Stressed/Anxious—Level-headed	87.4
Being negative—Being positive	Antisocial—Sociable	87.4
Having to rely on others—Independence	Viewed negatively by others—Not judged/Taken on face value	86.6
Sad—Happy	Isolated—Comfortable	86.6
Struggling—Coping	Mentally affected—Not mentally affected	85.2
Sad—Happy	Mentally affected—Not mentally affected	85.2
Disability—Able-bodied	Mentally affected—Not mentally affected	85.2
Struggling—Coping	Isolated—Comfortable	85.2
Having to rely on others—Independence	Mentally affected—Not mentally affected	84.6
Stressed/Anxious—Level-headed	Mentally affected—Not mentally affected	84.6
Antisocial—Sociable	Having to rely on others—Independence	84.6
Struggling—Coping	Being negative—Being positive	83.9
Sad—Happy	Stressed/Anxious—Level-headed	83.9
Antisocial—Sociable	Stressed/Anxious—Level-headed	83.3
Physically affected—Not physically affected	Situation is fixed—Situation is changeable	83.3
Antisocial—Sociable	Disability—Able-bodied	82.7
Struggling—Coping	Having to rely on others—Independence	82.7

Viewed negatively by others—Not judged/Taken on face value	Mentally affected—Not mentally affected	82.7
Isolated—Comfortable	Having to rely on others—Independence	82.2
Struggling—Coping	Disability—Able-bodied	81.1
Physically unhealthy—Physically healthy	Situation is fixed—Situation is changeable	81.1
Sad—Happy	Having to rely on others—Independence	80.6
Isolated—Comfortable	Disability—Able-bodied	80.6
Struggling—Coping	Stressed/Anxious—Level-headed	80.6
Being negative—Being positive	Having to rely on others—Independence	80.1

The first cluster comprises of ***stressed/anxious—level headed, isolated—comfortable, being negative—being positive, sad—happy, struggling—coping, antisocial—sociable, mentally affected—not mentally affected, having to rely on others—independence, disability—able-bodied***, and ***viewed negatively by others—not judged/taken on face value***. This suggests P6 sees these constructs as being similar. A strongly associated construct pair within this first cluster was ***disability—able-bodied*** and ***having to rely on others— independence*** (92.5% match). This indicates P6 construed having a disability as needing to rely on other people. Another strongly associated construct pair was ***struggling—coping*** and ***antisocial—sociable*** (92.5% match). This suggests P6 construed socialising with people as having an influence on ability to cope. Similarly, P6 defined another two constructs as being related to other people (i.e., ***isolated—comfortable*** and ***viewed negatively by others—not judged/taken on face value***), suggesting that social support was important to her, although P6 perceived herself to be viewed negatively by others due to her NEAs. Overall, this cluster indicates P6 sees disability, including her NEAD, as having an impact on her ability to cope and have a sense of independence. This also has an influence on her feeling mentally affected, such as feeling stressed/anxious, sad, isolated, being negative, as well as it impacting on her relationships with others, particularly perceiving herself as being antisocial and viewed negatively by others.

The second cluster is characterised by ***physically affected—not physically affected, situation is fixed—situation is changeable*** and ***physically unhealthy—physically healthy***. This indicates that these constructs are construed in a similar way, suggesting P6 views physical illness as being unlikely to change. Interestingly, however, she construed her current difficulties as being changeable, which may indicate P6 construed her health difficulties as having a psychological cause. This would fit with her acceptance of her NEAD diagnosis.

### **3.3.6.2 How does P6 construe herself and others?**

The HCA shown in Figure 11 highlights the elements and shows how closely related they are. Table 19 illustrates the elements that were most closely associated. A PCA was also conducted

and the pringrid (Figure 12) supports the inferences drawn from examination of the repertory grid and HCA.

**Table 19. P6's element matches  $\geq$  80%**

Element matched with	Element	Match (%)
Ideal self	Easy to understand feelings	93.7
Easy to understand feelings	Copes well	91.1
Self before seizures	Copes well	89.1
Ideal self	Copes well	89.1
Self before seizures	Easy to understand feelings	85.9
Mental health problem	Low in mood	85.9
Mental health problem	Difficult to relate to others	85.2
Ideal self	Self before seizures	83.3
Seizures but uncertain cause	Under a lot of stress	83.3
Under a lot of stress	Low in mood	82.2
Epilepsy	Chronic illness	82.2
Difficult to relate to others	Low in mood	81.6
Mental health problem	Under a lot of stress	81.1
Yourself	Epilepsy	80.1

There are three clusters of elements emerging within the HCA, along with two largely independent elements. The first cluster is comprised of *ideal self, someone who finds it easy to understand their emotions, someone who copes well and self before seizures*. This suggests P6 construed these people in a similar way. She construed these people most positively on all the constructs compared to the other elements. This indicates P6 was happy with the construal of herself prior to the onset of NEAD, particularly seeing her previous self as being able to understand her emotions and cope well. The second cluster of elements comprises of *someone with seizures but uncertain of the cause, someone under a lot of stress, someone low in mood, someone with a mental health problem and someone who finds it difficult to relate to other people*, suggesting that these people were construed in similar ways by P6. She construed these elements more negatively than the other elements. This indicates P6 construed someone experiencing seizures but having an unknown cause as being more likely to be under stress, have difficulties with their mental health, low mood and difficulties relating to others. The third cluster of elements comprises of *someone with a chronic, physical health difficulty, someone with epilepsy and yourself*. This suggests P6 construed these elements in similar ways, and she construed herself as being similar to someone with

epilepsy and someone with a physical illness. These elements were construed as being physically unhealthy, less able-bodied and less independent than the other elements. They were construed more neutrally on the remainder of the constructs, except for **someone with a chronic, physical health difficulty**, who was rated slightly more positively on these remaining constructs. When discussing why she construed **someone with a chronic, physical health difficulty** more positively, she stated:

“...you know exactly what it is, you know exactly what you’re dealing with, you know when things will happen, you’ve got ways of controlling them, you’re under constant medical [provision]”

The independent elements (i.e.,  $\leq 80\%$ ) were **someone who has had a difficult/traumatic upbringing** and **someone who is anxious**, with the former being construed positively and the latter being construed more neutrally.

Table 20 illustrates P6’s construal of her current self, self before NEAD and her ideal self in comparison to each other and the other elements. The results indicate P6 sees her **ideal self** and **self before seizures** as being similar (83.3% match) and viewed them very positively on all the constructs, suggesting P6 was happy with the construal of herself before she developed NEAD. However, P6 did not associate her current self with her past self (48.1% match) or ideal self (33.6% match). She rated herself more negatively on all the constructs, indicating that the construal of herself had changed to a more negative construal compared to herself before NEAD, particularly seeing herself now as being more needing to have to rely on others, having a disability, being viewed more negatively by others and being physically affected. Her past self was most highly associated with **someone who copes well** (89.1% match) and **someone who finds it easy to understand their emotions** (85.9% match), which suggests that she construed herself to be similar to these people before she developed NEAD. These elements are also the most highly associated elements with her ideal self (89.1% and 93.7% respectively), although when comparing this to her current self, this association decreased to 39.6% and 35.8% respectively. This indicates a negative shift in the construal of her current self, indicating that she now sees herself as not coping well or able to understand her emotions. Additionally, before she developed NEAD, P6 construed herself to be unrelated to **someone who is low in mood** (33.3% match) and **someone with a mental health difficulty** (36.7% match). This indicates P6 did not construe herself to have any difficulties with low mood or mental health problems before she developed NEAD. When comparing this to her current self, however, this association increased to 63.8% and 68.5% respectively, indicating a negative shift in the construal of her current self, particularly seeing herself as being slightly more similar to these people than she was previously. There was also a negative shift in the construal of her past self to her current self in relation to the elements: **someone under a lot of stress**, **someone who finds it difficult to relate to other people** and **someone who is anxious**. This suggests P6 construed herself to be more similar to these people than her previous self. However, these associations did not reach the 80% cut off, suggesting P6 did not construe herself as currently having difficulties with stress, low mood, mental health or difficulties relating to others. She also did not see herself as having had a difficult/traumatic upbringing.

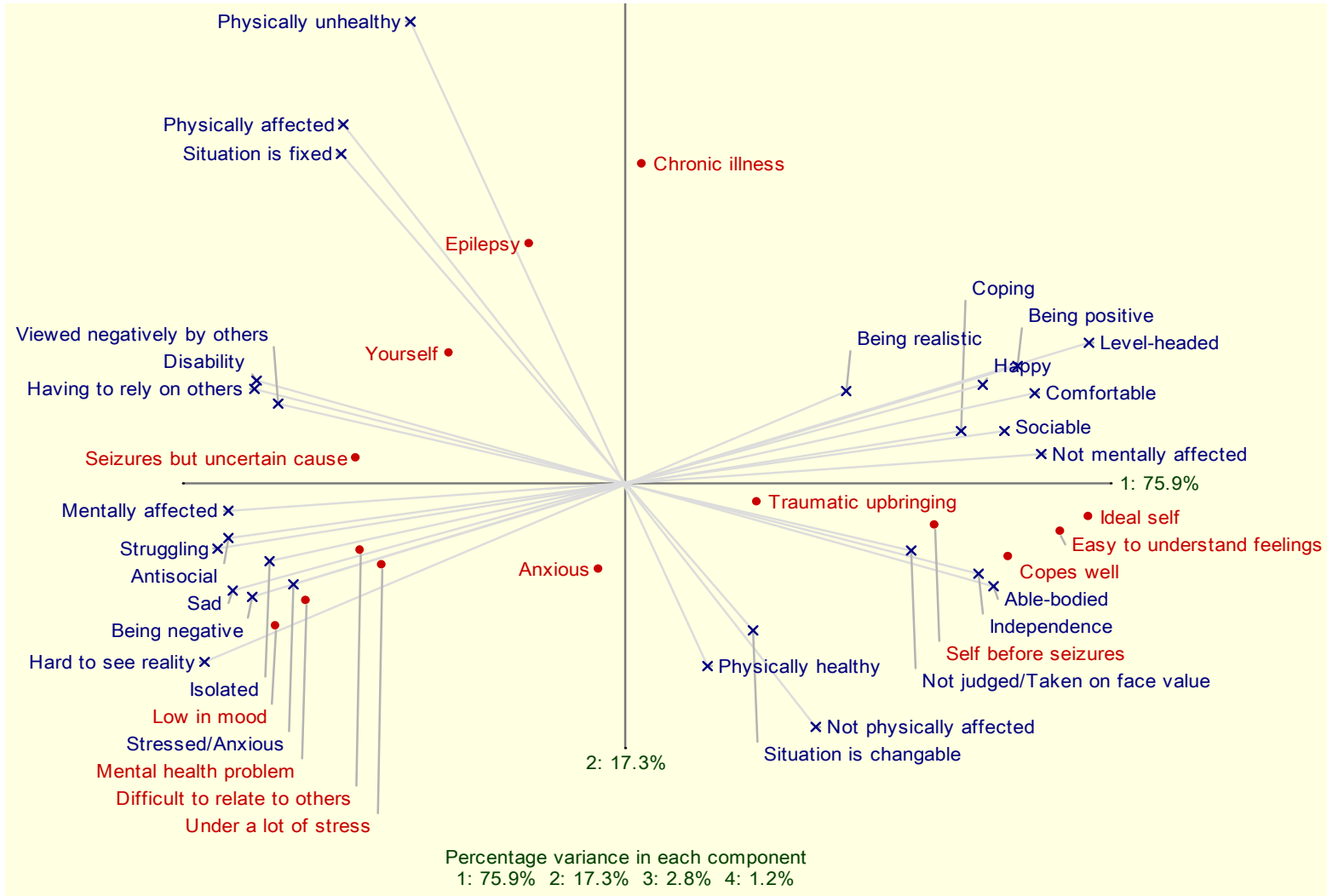


Figure 12: P6's Pringrid

P6 construed her current self to be most associated with *someone with epilepsy* (80.1% match) and slightly associated with *someone with seizures but uncertain of the cause* (76.4% match). P6 commented on this discrepancy between these results and her explicit agreement with her NEAD diagnosis: "...I think even though you're told it's NEAD there's always that little bit of you that doubts it, because it's so strange, because you just don't imagine you're brain can do that to you". Finally, P6 did not construe herself to have a chronic, physical health difficulty, which is particularly interesting considering P6 had mobility difficulties due to her unexplained neurological symptoms.

**Table 20. P6's percentage matches between elements of self and other elements**

	Past self (i.e., before seizures)	Current self	Ideal self
Past self (i.e., before NEAD)	—	48.1	83.3
Current self	48.1	—	33.6
Ideal self	83.3	33.6	—
<hr/>			
Someone with a mental health problem	36.7	68.5	21.8
Someone with epilepsy	49.6	80.1	37.6
Someone with seizures but uncertain of the cause	41.2	76.4	26.3
Someone with a chronic, physical health difficulty	52.4	69.8	42.6
Someone low in mood	33.3	63.8	18.6
Someone who is anxious	64.1	70.8	49.4
Someone who copes well	89.1	39.6	89.1
Someone who finds it easy to understand their feelings/emotions	85.9	35.8	93.7
Someone under a lot of stress	44.4	71.8	28.7
Someone who finds it difficult to relate to other people	41.4	73.6	26.9
Someone who has had a difficult/traumatic upbringing	79.6	64.1	66.4

### **3.3.6.3 Feedback**

P6 reported that the pringrid accurately represented her construal of the elements within the grid. P6 described the process as being useful in showing how she had improved since the onset of NEAD. She also stated: "...there's so many jumbled things going on in your head that sometimes having it written down, physically there in front of you, it makes you feel a little bit more, sort of, level".

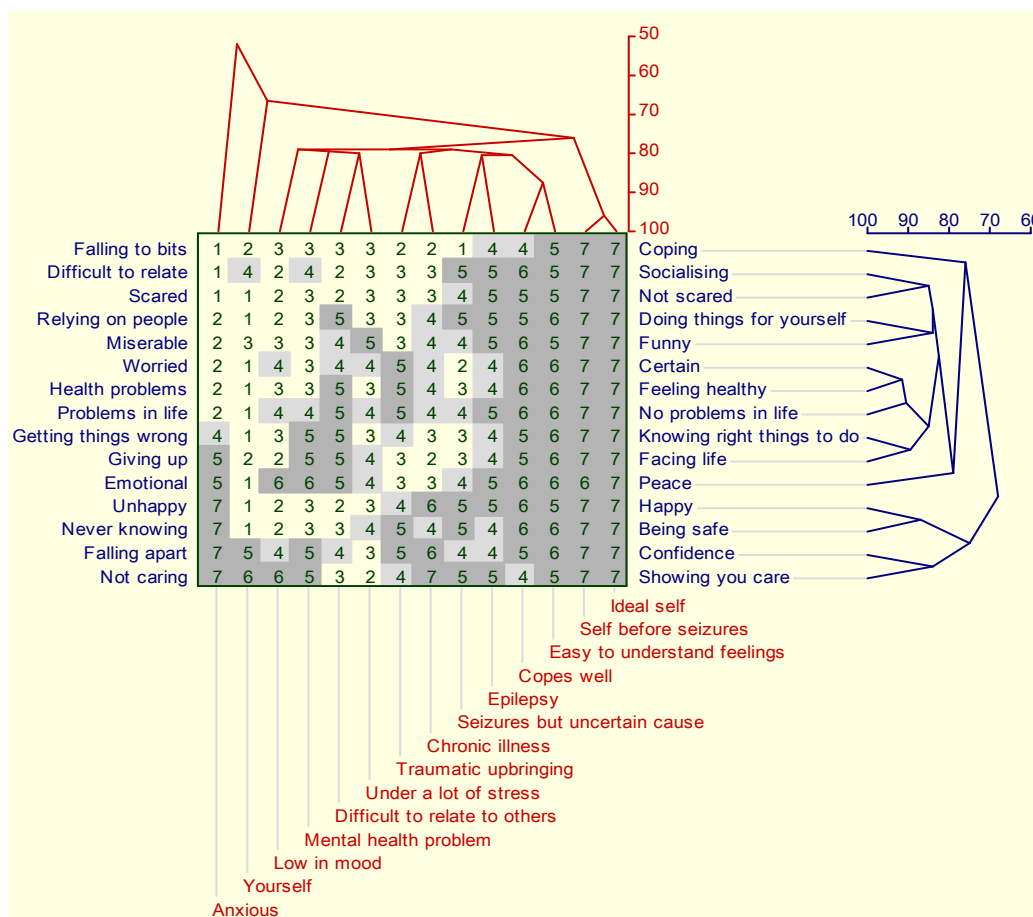
### 3.3.7 Individual Analysis: Participant 7

Participant 7 (P7) was a 48-year-old female with a diagnosis of NEAD (see Table 2 for additional demographic information). She reported the onset of NEAs being when she was 15 years old, but also described periods of her life when she did not experience NEAs. She described experiencing NEAs at least once a day, which varied in frequency from 1-14 per day. She agreed with the diagnosis of NEAD, although described not knowing what the specific causes of her NEAs were. She did, however, believe it could be related to her hormones. P7 had received a diagnosis of NEAD approximately four months prior to the interview via a letter from her neurologist. As a result, she described having no understanding of NEAD.

#### 3.3.7.1 How does P7 construe her world?

A HCA was conducted (Figure 13). P7 produced 15 pairs of constructs. The overall shape of the construct 'dendrogram' shows one main broad cluster incorporating the majority of the constructs and two smaller clusters (i.e.,  $\leq 80\%$ ). The matched constructs ( $\geq 80\%$ ) are shown in Table 21.

**Figure 13. P7's HCA**



**Table 21. P7's construct matches  $\geq 80\%$**

Construct matched with	Construct	Match (%)
Health problems—Feeling healthy	Worried—Certain	91.1
Health problems—Feeling healthy	Problems in life—No problems in life	90.0

Giving up—Facing life	Getting things wrong—Knowing right things to do	89.1
Worried—Certain	Problems in life—No problems in life	88.2
Unhappy—Happy	Never knowing—Being safe	86.6
Health problems—Feeling healthy	Getting things wrong—Knowing right things to do	85.2
Health problems—Feeling healthy	Relying on people—Doing things for yourself	85.2
Getting things wrong—Knowing right things to do	Problems in life—No problems in life	84.6
Difficult to relate—Socialising	Scared—Not scared	84.6
Relying on people—Doing things for yourself	Problems in life—No problems in life	84.6
Relying on people—Doing things for yourself	Scared—Not scared	83.9
Miserable—Funny	Relying on people—Doing things for yourself	83.9
Miserable—Funny	Problems in life—No problems in life	83.9
Not caring—Showing you care	Falling apart—Confidence	83.9
Miserable—Funny	Difficult to relate—Socialising	83.3
Worried—Certain	Getting things wrong—Knowing right things to do	82.7
Miserable—Funny	Worried—Certain	82.2
Miserable—Funny	Scared—Not scared	82.2
Getting things wrong—Knowing right things to do	Relying on people—Doing things for yourself	82.2
Miserable—Funny	Health problems—Feeling healthy	82.2
Falling to bits—Coping	Scared—Not scared	82.2
Getting things wrong—Knowing right things to do	Emotional—Peace	81.6
Health problems—Feeling healthy	Scared—Not scared	80.1

The first cluster of constructs comprises of *falling to bits—coping, difficult to relate—socialising, scared—not scared, relying on people—doing things for yourself, miserable—funny, worried—certain, health problems—feeling healthy, problems in life—no problems in life, getting things wrong—knowing right things to do, giving up—facing life* and *emotional—peace*. This suggests P7 sees these constructs as being highly related. Similar to other participants, one of the constructs referred to health difficulties (i.e., *health problems—feeling healthy*) and the most strongly associated construct pairs within this first cluster were *health problems—feeling healthy* and *worried—certain* (91.1% match) and *health problems—feeling healthy* and *problems in life—no problems in life* (90.0% match). This indicates P7 construed having health problems as being associated with worry and additional difficulties in life, and P7 construed people with health problems (herself included) as being worried, emotional and miserable. It also indicates that her negative emotions were due to



her NEAs having an impact on her ability to relate to other people, needing to rely on others more, presenting additional problems in life, affecting her ability to know what to do and feeling scared. P7 highlighted how she no longer considered herself to be able to relate to others due to her NEAs, how she rarely went out, and how she now had to rely on other people due to her NEAs. P7 construed these difficulties to be highly related to ***falling to bits—coping*** and ***giving up—facing life***. The results also suggest P7 construed these difficulties as too much to cope with and associated them with falling to bits and ultimately "giving up": This was evident during the feedback session, when P7 reported suicidal ideation.

The second cluster is comprised of ***falling apart—confidence*** and ***not caring—showing you care*** (83.9% match). This suggests P7 construed these constructs in similar ways, indicating P7 construed herself as having lost confidence, which was having an impact on her close relationships. The third cluster is characterised by ***unhappy—happy*** and ***never knowing—being safe*** (86.6% match). This indicated P7 often felt unsure of her safety due to her NEAs, which was having an impact on her happiness.

### **3.3.7.2 How does P7 construe herself and others?**

The HCA shown in Figure 13 highlights the elements and shows how closely related they are. Table 22 illustrates the elements that were most closely associated. A PCA was conducted and the resultant pringrid (Figure 14) supports the inferences drawn from examination of the repertory grid and HCA.

**Table 22. P7's element matches  $\geq$  80%**

<b>Element matched with</b>	<b>Element</b>	<b>Match (%)</b>
Ideal self	Self before seizures	95.7
Easy to understand feelings	Copes well	87.1
Epilepsy	Copes well	80.3
Seizures but uncertain cause	Epilepsy	80.3

As illustrated in Table 22, there are a small number of elements that are  $\geq$  80% matched. This would suggest that the elements are largely construed independently of each other. There are two clusters ( $\geq$ 80%) emerging within the HCA and two independent elements. The two independent elements were ***someone who is anxious*** and ***yourself***, indicating that these were not highly associated with the other elements. This suggests P7 did not see herself to be similar to any of the other elements.

The first cluster comprises of ***someone who finds it easy to understand their emotions***, ***someone who copes well***, ***someone with epilepsy*** and ***someone with seizures but uncertain of the cause***. This suggests that these people are construed in similar ways, particularly indicating P7 construed someone with epilepsy and someone with unknown seizures as

being able to cope well and understand their emotions. This appears to be related to being able to control the seizures and having support available. **Someone with epilepsy** received more neutral ratings along the constructs, whereas **someone with seizures but uncertain of the cause** was construed most negatively within this cluster, particularly perceived to be more likely to fall to bits, be worried, have health problems, get things wrong and give up. Additionally, inspection of the 'dendrogram' shows a large cluster of elements (i.e., **someone with a chronic, physical health difficulty, someone who has had a difficult/traumatic upbringing, someone under a lot of stress, someone who finds it difficult to relate to other people** and **someone low in mood**) are matched with this first cluster just below the 80% cut-off. This suggests that these elements were still highly associated with this first cluster, particularly with **someone with seizures but uncertain of the cause**. The second cluster is comprised of **ideal self** and **self before seizures** (95.7%). These elements were rated most positively on all the construct ratings compared to all the other elements. This suggests P7 construed her ideal self and past self as very similar.

Table 23 illustrates P7's construal of her current self, self before NEAD and her ideal self in comparison to each other and the other elements. P7 did not associate her current self with her past self (14.7% match) or ideal self (13.5% match). She rated her current self most negatively on all the constructs compared to the other elements, indicating her construal of herself had changed to a very negative construal compared to herself before NEAD. P7 construed her current self as being negatively characterised as falling to bits, scared, worried, having to rely on people, having health problems, problems in life, getting things wrong, giving up, being emotional, unhappy and never knowing. P7 construed herself before NEAD as being similar to **someone who finds it easy to understand their emotions** (75.7% match) and **someone who copes well** (71.1% match). These elements are also the most highly associated elements with her ideal self (75.3% and 70.8% respectively). When comparing this to her current self, this association decreased to 33.5% and 35.0% respectively. This indicates a negative shift in the construal of her current self, suggesting she now sees herself as not coping or able to understand her emotions. Additionally, before she developed NEAD, P7 construed herself to be most unrelated to **someone who is anxious** (32.4% match) and **someone low in mood** (33.1% match). When comparing this to her current self, this association increased to 51.7% and 66.4% respectively. This indicates a negative shift in the construal of her current self, particularly seeing herself as being more anxious and low in mood than before she developed NEAD. There was also a negative shift from the construal of herself before NEAD to the construal to her current self in relation to the elements: **someone with a mental health problem, someone with a chronic, physical health difficulty** and **someone under a lot of stress**, suggesting P7 construed herself to be more similar to these people than her past self. P7 did not see herself before NEAD as being similar to **someone with a mental health problem, someone under a lot of stress, someone who finds it difficult to relate to other people** and **someone who has had a difficult/traumatic upbringing**. Consequently, P7 did not construe herself to be characterised by these difficulties prior to the development of NEAD.

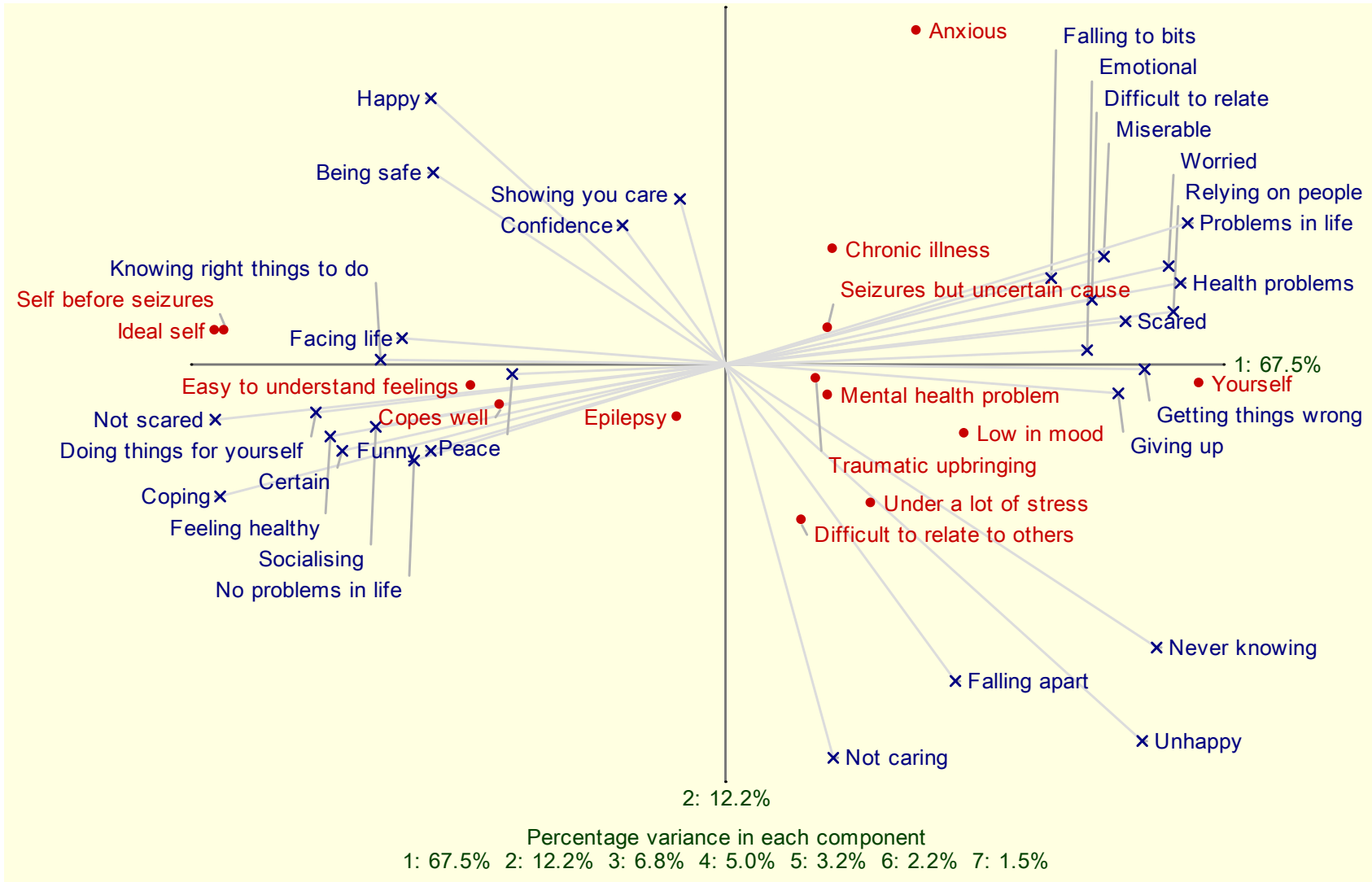


Figure 14: P7's Pringrid

Although there were some relative shifts in how P7 construed herself before NEAD and herself with NEAD, P7 did not construe her current self to be highly associated with any of the elements. She also did not see herself as being *someone with seizures but uncertain of the cause* (59.2% match), *someone with epilepsy* (50.7% match) or *someone with a chronic, physical health difficulty* (60.1% match). This fits with her acceptance of the NEAD diagnosis. P7 frequently stated that she would prefer to have another disorder, such as epilepsy or AIDS: *"I just wish people knew about it. I'd rather have AIDS than what I've got. At least AIDS people understand"*. This wish appears to be driven by lack of understanding of NEAD by other people, which appeared to push her further away from seeking support from others. Despite this, P7 frequently referred to wanting support: *"It's like, everyday, you try looking for somebody to talk to and you're hitting your head against a brick wall and getting nowhere"*.

**Table 23. P7's percentage matches between elements of self and other elements**

	Past self (i.e., before seizures)	Current self	Ideal self
Past self (i.e., before NEAD)	—	14.7	95.7
Current self	14.7	—	13.5
Ideal self	95.7	13.5	—
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Someone with a mental health problem	45.2	60.3	45.1
Someone with epilepsy	58.7	50.7	58.1
Someone with seizures but uncertain of the cause	44.1	59.2	43.2
Someone with a chronic, physical health difficulty	45.1	60.1	43.9
Someone low in mood	33.1	66.4	32.9
Someone who is anxious	32.4	51.7	32.0
Someone who copes well	71.1	35.0	70.8
Someone who finds it easy to understand their feelings/emotions	75.7	33.5	75.3
Someone under a lot of stress	39.6	60.1	38.8
Someone who finds it difficult to relate to other people	43.7	52.9	43.2
Someone who has had a difficult/traumatic upbringing	45.4	57.0	44.2

### **3.3.7.3 Feedback**

P7 became upset during the feedback session, although she stated that this was how she usually felt. After conducting a thorough risk assessment, the researcher discussed P7's difficulties with her supervisor and it was deemed appropriate to move P7 forward on the neuropsychology waiting list. However, whether she would engage with a psychological intervention was questioned when she stated: *"Talking doesn't solve problems. Everybody else gets pills to take, I get somebody to*

waffle on about my past, which I don't really want to go into because my past was a bit horrifying". Interestingly, this comment would suggest P7 had a difficult/traumatic upbringing but she did not construe her current self or past self as being highly associated with this element.

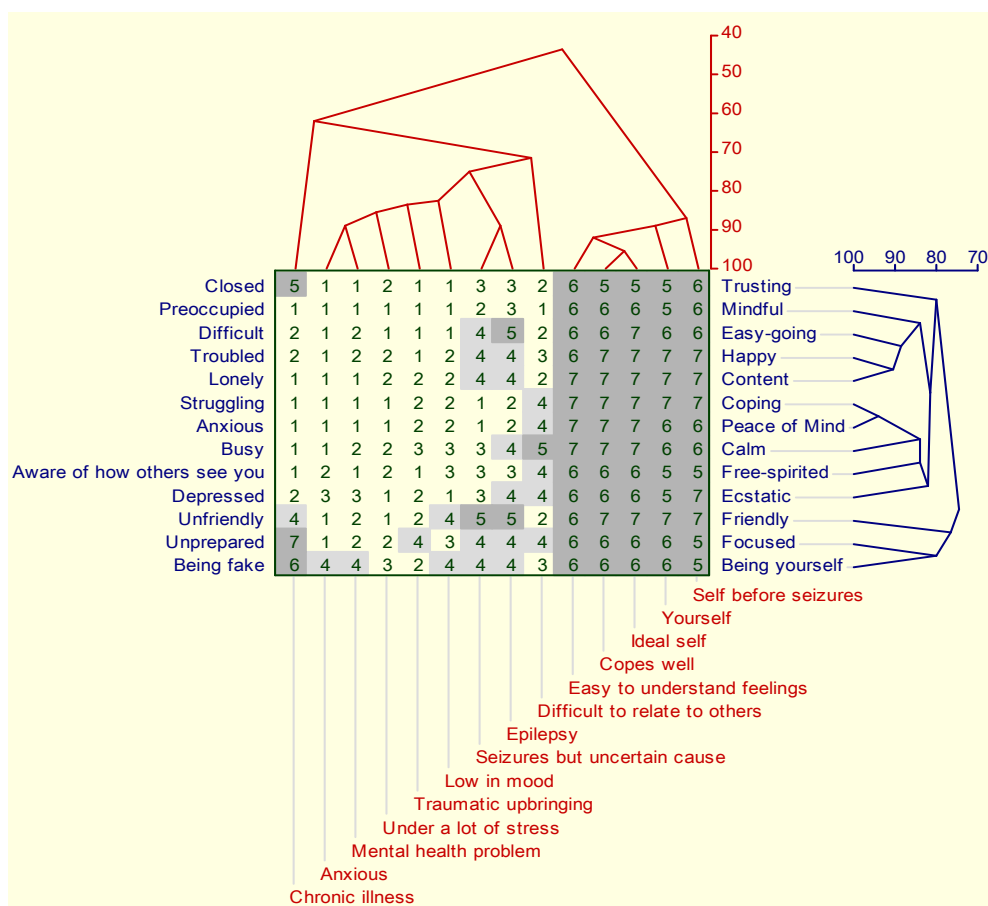
### 3.3.8 Individual Analysis: Participant 8

Participant 8 (P8) was a 17-year-old female with a diagnosis of NEAD (see Table 2 for additional demographic information), which started 3-4 years ago. She described experiencing NEAs at least once every three weeks. She reported agreeing with the diagnosis of NEAD. She described having a limited understanding of NEAD.

#### 3.3.8.1 How does P8 construe her world?

A HCA was conducted (Figure 15). P8 produced 13 pairs of constructs. The overall shape of the construct 'dendrogram' shows one broad cluster, which includes the majority of the constructs and one smaller cluster. The main cluster consists of two sub-clusters. This may indicate P8 uses similar constructs to view her world. The matched constructs ( $\geq 80\%$ ) are shown in Table 24.

**Figure 15. P8's HCA**



**Table 24. P8's construct matches  $\geq 80\%$**

Construct matched with	Construct	Match (%)
Anxious—Peace of Mind	Struggling—Coping	93.7
Troubled—Happy	Lonely—Content	90.0

Troubled—Happy	Difficult—Easy-going	88.2
Lonely—Content	Difficult—Easy-going	85.9
Busy—Calm	Anxious—Peace of Mind	83.9
Busy—Calm	Aware of how others see you—Free-spirited	83.9
Preoccupied—Mindful	Difficult—Easy-going	83.9
Troubled—Happy	Unfriendly—Friendly	83.9
Anxious—Peace of Mind	Aware of how others see you—Free-spirited	83.3
Troubled—Happy	Busy—Calm	83.3
Depressed—Ecstatic	Difficult—Easy-going	82.7
Busy—Calm	Lonely—Content	82.7
Busy—Calm	Struggling—Coping	82.7
Depressed—Ecstatic	Troubled—Happy	82.2
Troubled—Happy	Aware of how others see you—Free-spirited	81.6
Lonely—Content	Preoccupied—Mindful	81.6
Anxious—Peace of Mind	Preoccupied—Mindful	81.6
Preoccupied—Mindful	Aware of how others see you—Free-spirited	81.6
Depressed—Ecstatic	Aware of how others see you—Free-spirited	81.6
Struggling—Coping	Lonely—Content	81.1
Unfriendly—Friendly	Difficult—Easy-going	81.1
Unfriendly—Friendly	Lonely—Content	81.1
Depressed—Ecstatic	Busy—Calm	81.1
Troubled—Happy	Struggling—Coping	80.6
Lonely—Content	Aware of how others see you—Free-spirited	80.1
Struggling—Coping	Aware of how others see you—Free-spirited	80.1
Anxious—Peace of Mind	Lonely—Content	80.1
Troubled—Happy	Preoccupied—Mindful	80.1
Aware of how others see you—Free-spirited	Difficult—Easy-going	80.1

The first sub-cluster within the main cluster of constructs comprises of ***closed—trusting, preoccupied—mindful, difficult—easy-going, troubled—happy*** and ***lonely—content***. This suggests P8 sees these constructs as being related. This cluster comprises of a number of

constructs that refer to being connected to other people, suggesting that interpersonal relationships were important to P8. The second sub-cluster is characterised by ***struggling—coping, anxious—peace of mind, busy—calm, aware of how others see you—free-spirited***, and ***depressed—ecstatic***. This indicates that these constructs are construed in a similar way. P8 described coping as using distraction, planning ahead and acceptance of the difficulties. She also perceived a person to have difficulties coping if their problems have no 'cure'. Interestingly, as she rated herself as being able to cope well, it may suggest that she construed her NEAD as being 'curable'. The highest associated construct pair within this sub-cluster is ***struggling—coping*** and ***anxious—peace of mind*** (93.7% match), which suggests P8 construed struggling as being highly associated with anxiety. Overall, this sub-cluster indicates P8 construed difficulties coping as being accompanied by anxiety, being nervous of how others see them, being depressed and being hectic and busy. Additionally, this sub-cluster was highly associated with the first sub-cluster that had a theme of being connected to other people. This suggests P8 construed being disconnected from people as being accompanied by difficulties in coping and negative emotions, which would indicate P8 construed social support as being an integral aspect of coping well. There are three constructs which are largely independent of the other constructs. These are ***being fake—being yourself, unfriendly—friendly*** and ***unprepared—focused***. Despite this, most constructs are matched close to the 80% cut-off point suggesting an overall high level of association between the constructs.

### **3.3.8.2 How does P8 construe herself and others?**

The HCA shown in Figure 15 highlights the elements and shows how closely related they are. Table 25 illustrates the elements that were most closely associated. The pringrid (Figure 16) supports the inferences drawn from examination of the repertory grid and HCA.

**Table 25. P8's element matches  $\geq$  80%**

<b>Element matched with</b>	<b>Element</b>	<b>Match (%)</b>
Ideal self	Copes well	95.4
Easy to understand feelings	Copes well	92.0
Ideal self	Easy to understand feelings	90.8
Yourself	Copes well	89.7
Seizures but uncertain cause	Epilepsy	88.7
Mental health problem	Anxious	88.7
Yourself	Ideal self	88.7
Self before seizures	Copes well	87.8
Self before seizures	Easy to understand feelings	86.9
Yourself	Easy to understand feelings	86.9

Ideal self	Self before seizures	86.9
Yourself	Self before seizures	86.9
Under a lot of stress	Anxious	85.4
Mental health problem	Under a lot of stress	85.4
Traumatic upbringing	Under a lot of stress	83.3
Traumatic upbringing	Low in mood	82.1
Mental health problem	Traumatic upbringing	82.1
Under a lot of stress	Low in mood	81.5
Mental health problem	Low in mood	80.4

There are three clusters emerging within the HCA, along with two independent elements. The first cluster is comprised of *self before seizures, yourself, ideal self, someone who copes well* and *someone who finds it easy to understand their emotions*. This suggests P8 construed these people as being similar. These people were construed most positively compared to the other elements. This suggests P8 had a positive construal of herself before she developed NEAD, which had not changed with the development of NEAD. The second cluster comprises of *someone who is anxious, someone with a mental health problem, someone under a lot of stress, someone who has had a difficult/traumatic upbringing* and *someone low in mood*. This suggests that these people are construed in similar ways by P8. She particularly construed these people most negatively on all the constructs compared to the other elements. The third cluster is comprised of *someone with seizures but uncertain of the cause* and *someone with epilepsy*, suggesting P8 construed these people in similar ways. These people were construed more neutrally in the majority of construct ratings. The two independent elements were *someone with a chronic, physical health difficulty* and *someone who finds it difficult to relate to other people*. *Someone with a chronic, physical health difficulty* was construed negatively as being preoccupied, lonely, struggling, anxious, busy and being aware of how others see them, but more positively construed as being trusting, focused and being themselves. *Someone who finds it difficult to relate to other people* was construed more neutrally on some of the constructs, although was seen as being closed, preoccupied, difficult, troubled, lonely, unfriendly and being fake.

Table 26 illustrates P8's construal of her current self, self before NEAD and her ideal self in comparison to each other and the other elements. Her past self was most highly associated with *someone who copes well* (87.8% match) and *someone who finds it easy to understand their emotions* (86.9%), suggesting P8 construed her past self to be able to cope well and understand her emotions. These elements are also the most highly associated elements with P8's current self (89.7% and 86.9% match respectively), which suggests P8 still construed herself as being able to cope well and understand her emotions. The small discrepancy between her past





self and current self would suggest P8 did not see her identity as changing as a result of developing NEAD. Additionally, the small discrepancy between her current self and her ideal self indicates P8 was happy with her current self and situation. The least associated elements with P8's self before NEAD were *someone who is anxious* (18.5% match), *someone under a lot of stress* (21.7% match) and *someone with a mental health problem* (23.9% match). She also did not see her past self as being associated with *someone who is low in mood* (30.0% match), *someone who finds it difficult to relate to other people* (43.0% match) and *someone who has had a difficult/traumatic upbringing* (25.2% match). These associations do not change when comparing her current self to these elements, indicating P8 did not see herself, nor had ever seen herself, as having mental health problems, anxiety or mood difficulties, being under stress, having a difficult/traumatic upbringing or difficulties relating to other people. P8 also did not construe herself as being associated with *someone with epilepsy* (56.4% match), *someone with seizures but uncertain of the cause* (48.3% match) or *someone with a chronic, physical health difficulty* (32.4% match). This suggests she did not see herself as having any of these difficulties, which fits with her acceptance of the NEAD diagnosis.

**Table 26. P8's percentage matches between elements of self and other elements**

	Past self (i.e., before seizures)	Current self	Ideal self
Past self (i.e., before NEAD)	—	86.9	86.9
Current self	86.9	—	88.7
Ideal self	86.9	88.7	—
Someone with a mental health problem	23.9	26.8	19.5
Someone with epilepsy	53.5	56.4	49.6
Someone with seizures but uncertain of the cause	44.7	48.3	40.6
Someone with a chronic, physical health difficulty	27.8	32.4	24.0
Someone low in mood	30.0	34.8	27.1
Someone who is anxious	18.5	20.9	13.9
Someone who copes well	87.8	89.7	95.4
Someone who finds it easy to understand their feelings/emotions	86.9	86.9	90.8
Someone under a lot of stress	21.7	25.0	17.4
Someone who finds it difficult to relate to other people	43.0	46.1	40.1
Someone who has had a difficult/traumatic upbringing	25.2	28.7	21.3

### 3.3.8.3 Feedback

P8 reported that the pringrid accurately represented her construal of the elements within the grid. The only element P8 questioned was the positioning of *yourself* from *someone with seizures but uncertain of the cause*, as she expected herself to be closer to having an unknown cause for her NEAs. However, when discussing this in more detail, P8 commented on how this may be representing her having welcomed and readily accepted the diagnosis of NEAD after three years of waiting for a diagnosis.

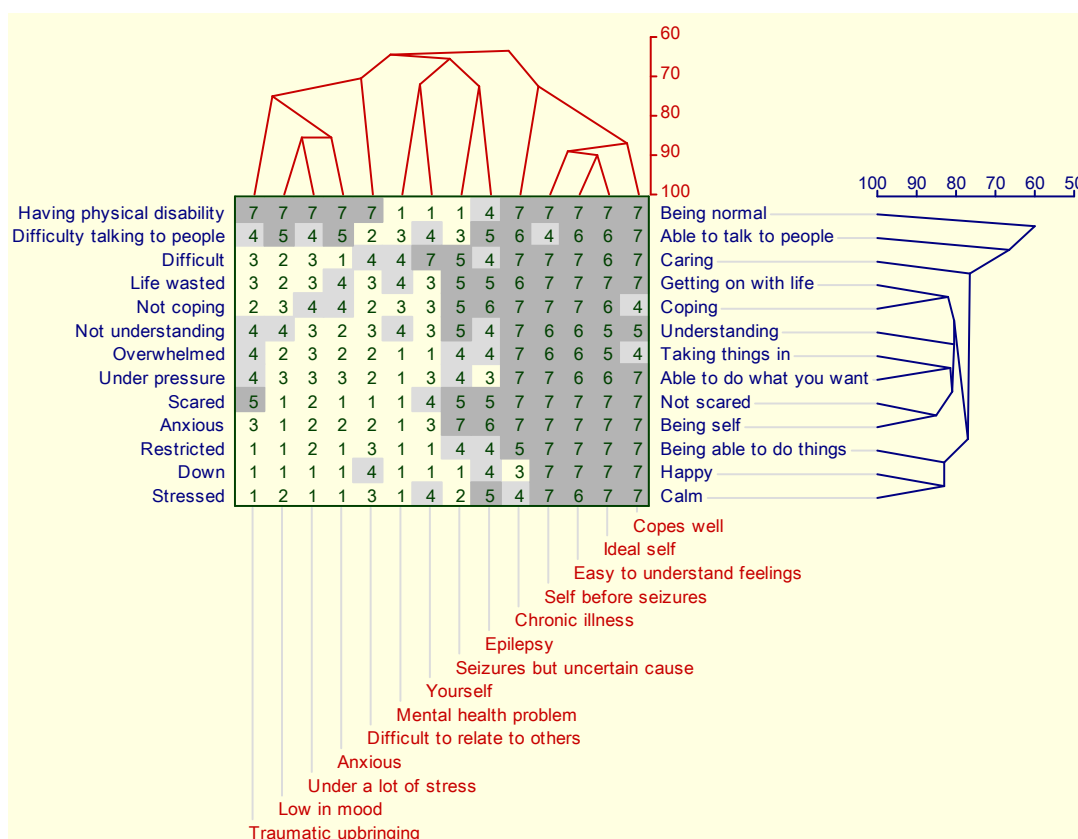
### 3.3.9 Individual Analysis: Participant 9

Participant 9 (P9) was a 26-year-old female with a diagnosis of NEAD (see Table 2 for additional demographic information), which started six years ago. She described experiencing NEAs at least once a week. At the time of the interview, P9 had started psychological assessment within the neuropsychology department. She reported agreeing with the diagnosis of NEAD. When discussing the specific triggers for her NEAs, P9 described stress, low mood and being upset as the cause of her recent 'episodes'. She had a good understanding of NEAD.

#### 3.3.9.1 How does P9 construe her world?

A HCA was conducted (Figure 17). P9 produced 13 pairs of constructs. Similar to other participants, one of the constructs referred to *having a physical disability*. The overall shape of the construct 'dendrogram' shows one main broad cluster incorporating a large proportion of the constructs, one smaller cluster and three largely independent constructs (i.e.,  $\leq 80\%$ ). The matched constructs ( $\geq 80\%$ ) are shown in Table 27.

**Figure 17. P9's HCA**



**Table 27. P9's construct matches  $\geq$  80%**

Construct matched with	Construct	Match (%)
Scared—Not scared	Anxious—Being self	84.6
Down—Happy	Restricted—Being able to do things	82.7
Stressed—Calm	Down—Happy	82.7
Not coping—Coping	Life wasted—Getting on with life	81.6
Stressed—Calm	Restricted—Being able to do things	81.1
Overwhelmed—Taking things in	Under pressure—Able to do what you want	81.1
Scared—Not scared	Under pressure—Able to do what you want	80.6
Overwhelmed—Taking things in	Not understanding—Understanding	80.1
Under pressure—Able to do what you want	Not understanding—Understanding	80.1
Not coping—Coping	Not understanding—Understanding	80.1

The main cluster of constructs comprises of *life wasted—getting on with life, not coping—coping, not understanding—understanding, overwhelmed—taking things in, under pressure—able to do what you want, scared—not scared* and *anxious—being self*. This suggests P9 sees these constructs as being related. The most strongly associated construct pair within this first cluster was *scared—not scared* and *anxious—being self* (84.6% match). P9 particularly described anxiety and fear of having NEAs when going into new situations and meeting new people. This also suggests P9 construed being comfortable in meeting new people and going into new situations without fear or worry of having an NEA as being indicative of her coping and getting on with life. P9 viewed not coping as being a waste of life, which may indicate that being able to cope is important to her, although her comments suggest that she finds this particularly difficult: *"I go to bed, just shut myself out so you don't have to talk or do anything"*. P9 also associates not being able to cope and wasting life as being related to feeling under pressure from others and not understood by others. This suggests that increasing others' understanding of her difficulties, allowing P9 to talk about her difficulties and feeling more in control of her own life, may increase P9's ability to cope with her NEAD. These difficulties are also related to her feeling overwhelmed, although she described this as being in relation to perceived concentration difficulties. This suggests that other features of NEAD in addition to the NEAs (e.g., subjective memory and concentration difficulties) may have an impact on P9's ability to cope and get on with her life.

The second cluster is characterised by *restricted—being able to do things, down—happy* and *stressed—calm*. This indicates that these constructs are construed in a similar way. This suggests P9 views being restricted due to her NEAs as having an impact on her feeling unhappy and stressed. There are three constructs that are largely independent of the other clusters. These

are *having a physical disability—being normal, difficulty talking to people—able to talk to people* and *difficult—caring*. She also described her NEAs were having an impact on close relationships.

### **3.3.9.2 How does P9 construe herself and others?**

The HCA shown in Figure 17 highlights the elements and shows how closely related they are. Table 28 illustrates the elements that were most closely associated. The pringrid (Figure 18) supports the inferences drawn from examination of the repertory grid and HCA.

**Table 28. P9's element matches  $\geq$  80%**

<b>Element matched with</b>	<b>Element</b>	<b>Match (%)</b>
Ideal self	Easy to understand feelings	89.7
Self before seizures	Easy to understand feelings	88.7
Ideal self	Copes well	86.9
Ideal self	Self before seizures	86.1
Under a lot of stress	Anxious	85.4
Under a lot of stress	Low in mood	85.4
Low in mood	Anxious	84.0
Easy to understand feelings	Copes well	80.9
Traumatic upbringing	Under a lot of stress	80.4

There are two small clusters of elements that are  $\geq$  80% matched and a number of independent elements. The first cluster is comprised of *ideal self, self before seizures, someone who finds it easy to understand their emotions* and *someone who copes well*. This suggests P9 construed these people in similar ways. She construed these people as being more positive on the constructs compared to the other elements. This indicates P9 had a very positive construal of herself before she developed NEAD, and that this was characterised by her feeling able to cope and understand her emotions. The second cluster comprises of *someone low in mood, someone under a lot of stress* and *someone who is anxious*, suggesting these people are construed as being similar. The remainder of the elements were not associated with other elements above the 80% cut-off. P9 construed *yourself, someone with a mental health problem, someone who finds it difficult to relate to other people* and *someone who has experienced a difficult/traumatic upbringing* more negatively on the construct ratings. P9 was also more likely to construe *someone with seizures but uncertain of the cause* and *someone with epilepsy* positively, particularly as being themselves, not being scared, coping and getting on with life. This positivity was related to having control over their seizures. P9 also construed *someone with a chronic, physical health difficulty* positively on the majority of the construct ratings.

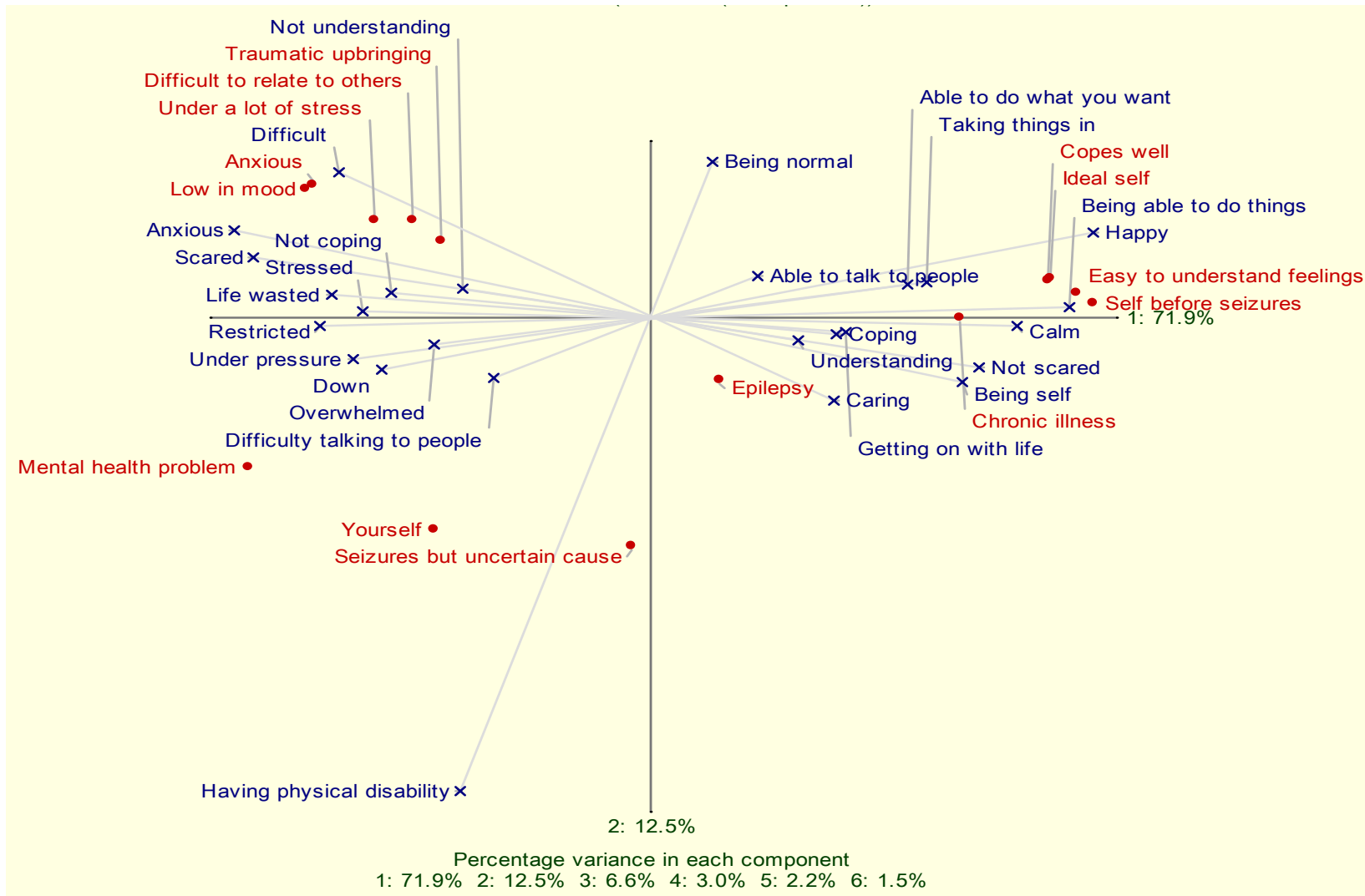


Figure 18: P9's Pringrid

Table 29 illustrates P9's construal of her current self, self before NEAD and her ideal self in comparison to each other and the other elements. P9 did not construe her current self to be similar to any of the other elements, including her **ideal self** (34.5% match) and **self before seizures** (30.8% match). This may indicate a feeling of distinction and/or alienation from other people due to her NEAD. P9 construed herself before NEAD to be similar to her ideal self (86.1% match), suggesting P9 was happy with herself prior to the onset of NEAD. However, P9's construal of herself had changed to a more negative construal compared to herself before NEAD. P9's past self was most highly associated with **someone who finds it easy to understand their emotions** (88.7% match) and **someone who copes well** (77.8% match), but when comparing this to her current self, this association decreased to 31.1% and 35.1% respectively. This indicates a negative shift in the construal of her current self, suggesting that she now sees herself as not coping well or able to understand her emotions.

The least associated elements with P9's past self were **someone with a mental health problem** (17.8% match), **someone who is low in mood** (23.8% match) and **someone who is anxious** (23.8% match). This indicates P9 did not construe herself to have any mental health or emotional difficulties before she developed NEAD. However, when comparing this to her current self, this association increased to 71.5%, 58.1% and 54.7% respectively. This indicates a negative shift in the construal of her current self, particularly seeing herself as having more mental health and emotional difficulties than she had before she developed NEAD. There was also a negative shift of her past self construal to her current self construal in relation to the elements: **someone under a lot of stress**, **someone who finds it difficult to relate to other people** and **someone who has had a difficult/traumatic upbringing**. This suggests P9 construed herself to be more similar to these people than her previous self. These associations, however, did not reach the 80% cut off, suggesting P9 did not construe herself as currently having, nor ever having, difficulties with stress, low mood, anxiety, mental health or difficulties relating to others. She also did not see herself as having had a difficult/traumatic upbringing.

P9 did not construe herself to be similar to **someone with epilepsy** (61.1% match) or **someone with seizures but uncertain of the cause** (65.1% match), which fitted with P9's acceptance of the NEAD diagnosis. Interestingly, P9 construed herself before NEAD (72.3% match) and ideal self (70.4% match) as being similar to **someone with a chronic, physical health difficulty**. However, this reduced when thinking about her current self (38.3% match). This supports the finding P9 construed **someone with a chronic, physical health difficulty** positively and indicates a negative shift in how she construed her current self. It also suggests P9 would prefer to have a physical health difficulty rather than NEAD or another seizure-related disorder. This, again, appeared to be due to the level of control they have in being able to manage their difficulties.

**Table 29. P9's percentage matches between elements of self and other elements**

	Past self (i.e., before seizures)	Current self	Ideal self
Past self (i.e., before NEAD)	—	30.8	86.1
Current self	30.8	—	34.5
Ideal self	86.1	34.5	—
<b>Someone with a mental health problem</b>			
Someone with a mental health problem	17.8	71.5	21.4
<b>Someone with epilepsy</b>			
Someone with epilepsy	60.0	61.1	65.4
<b>Someone with seizures but uncertain of the cause</b>			
Someone with seizures but uncertain of the cause	45.9	65.1	47.3
<b>Someone with a chronic, physical health difficulty</b>			
Someone with a chronic, physical health difficulty	72.3	38.3	70.4
<b>Someone low in mood</b>			
Someone low in mood	23.8	58.1	28.5
<b>Someone who is anxious</b>			
Someone who is anxious	23.8	54.7	29.1
<b>Someone who copes well</b>			
Someone who copes well	77.8	35.1	86.9
<b>Someone who finds it easy to understand their feelings/emotions</b>			
Someone who finds it easy to understand their feelings/emotions	88.7	32.1	89.7
<b>Someone under a lot of stress</b>			
Someone under a lot of stress	31.1	60.8	35.1
<b>Someone who finds it difficult to relate to other people</b>			
Someone who finds it difficult to relate to other people	33.7	59.7	37.5
<b>Someone who has had a difficult/traumatic upbringing</b>			
Someone who has had a difficult/traumatic upbringing	34.3	60.2	38.2

**3.3.9.3 Feedback**

P9 reported that the pringrid accurately represented her construal of the elements within the grid. When asked to comment on the repertory grid process, P9 stated that it had been interesting and useful and also commented on how she would show the pringrid to her psychologist.

**3.3.10 Individual Analysis: Participant 10**

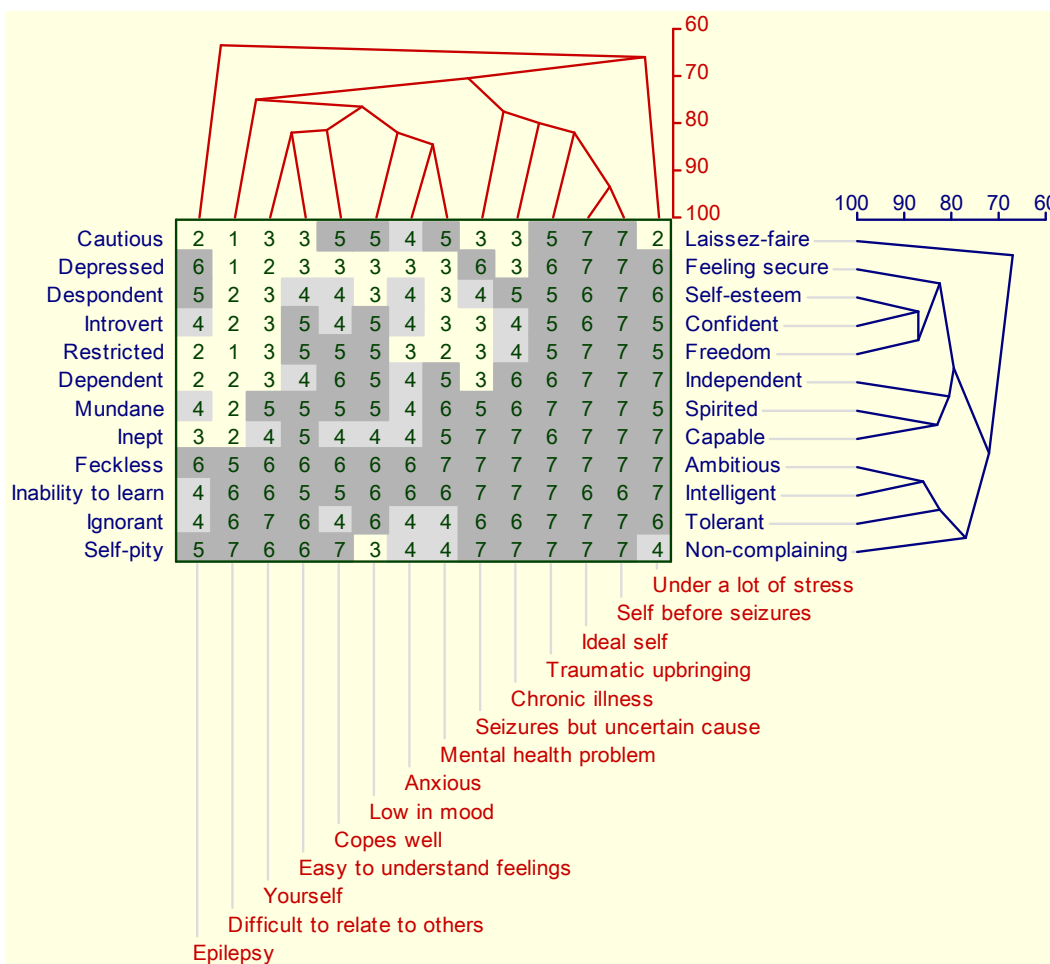
Participant 10 (P10) was a 58-year-old male with a diagnosis of NEAD (see Table 2 for additional demographic information), which started 11 years ago. He described experiencing seizures at least once a week. He reported agreeing with the diagnosis of NEAD. He believed the specific cause of his NEAs was due to having experienced head injuries and psychological trauma. He had some understanding of NEAD.

**3.3.10.1 How does P10 construe his world?**

A HCA was conducted (Figure 19). P10 produced 12 pairs of constructs. The overall shape of the construct 'dendrogram' shows three clusters of constructs and two independent constructs (i.e.,  $\leq 80\%$ ). This indicates P10 uses a differential number of constructs to view his world. The matched constructs ( $\geq 80\%$ ) are shown in Table 30.



**Figure 19. P10's HCA**



**Table 30. P10's construct matches ≥ 80%**

Construct matched with	Construct	Match (%)
Introvert—Confident	Despondent—Self-esteem	86.6
Introvert—Confident	Restricted—Freedom	86.6
Inability to learn—Intelligent	Feckless—Ambitious	85.9
Mundane—Spirited	Inept—Capable	82.7
Inability to learn—Intelligent	Ignorant—Tolerant	82.2
Despondent—Self-esteem	Depressed—Feeling secure	82.2
Dependent—Independent	Mundane—Spirited	80.1

The first cluster of constructs comprises of ***depressed—feeling secure, despondent—self-esteem, introvert—confident*** and ***restricted—freedom***. This suggests P10 sees these constructs as being similar. P10 perceived himself to be restricted since the onset of NEAD, which was impacting on his mood. P10 commented on how he was feeling depressed and had current suicidal ideation. The most strongly associated construct pair within this first cluster was ***introvert—confident*** and ***despondent—self-esteem*** (86.6% match). This indicates P10

views being introvert as being highly associated with despondency. He also described how he lacked confidence and self-belief since the onset of NEAD. P10 described experiencing memory and word-finding difficulties since the onset of NEAD, which he described as having an impact on his self-esteem and confidence. This cluster of constructs suggests P10 construed being restricted due to his NEAD as having an influence on his mood, confidence, self-esteem and self-worth. The second cluster is characterised by ***dependent–independent, mundane–spirited*** and ***inept–capable***. This indicates that these constructs are construed in a similar way. P10 went on to describe how he no longer felt capable in social situations due to his NEAD. As a result, P10 described either avoiding social situations or feel anxious during them. Overall, this cluster indicates P10 construed his dependence on others since the development of NEAD as having an impact on him feeling inept and living a mundane life. The third cluster is characterised by ***feckless–ambitious, inability to learn–intelligent*** and ***ignorant–tolerant***. This indicates that these constructs are construed in a similar way and the ratings suggest P10 construed himself to be positively associated with this cluster of constructs. Another construct that is associated with this cluster, although does not reach the 80% cut-off, is ***self-pity–non-complaining***. This indicates P10 copes with his difficulties by keeping it to himself and "putting on a front" because he construed people who complain as being negatively characterised.

### **3.3.10.2 How does P10 construe himself and others?**

The HCA shown in Figure 19 highlights the elements and shows how closely related they are. Table 31 illustrates the elements that were most closely associated. The pringrid (Figure 20) supports the inferences drawn from examination of the repertory grid and HCA.

**Table 31. P10's element matches  $\geq$  80%**

<b>Element matched with</b>	<b>Element</b>	<b>Match (%)</b>
Ideal self	Self before seizures	93.2
Mental health problem	Anxious	84.0
Ideal self	Traumatic upbringing	82.0
Yourself	Easy to understand feelings	82.0
Low in mood	Anxious	82.0
Easy to understand feelings	Copes well	81.4
Easy to understand feelings	Anxious	80.2
Easy to understand feelings	Low in mood	80.2

As illustrated in Table 31, there are a small number of elements that are  $\geq$  80% matched. This would suggest P10 construed the elements largely independently of each other. There are two clusters emerging within the HCA, along with a number of independent elements. The first cluster is comprised of ***self before seizures, ideal self*** and ***someone who has had a***

**difficult/traumatic upbringing.** This suggests P10 construed these people in similar ways, particularly rating these elements most positively on all the constructs. This indicates P10 had a very positive construal of himself before he developed NEAD. The second cluster comprises of **yourself, someone with a mental health problem, someone who is anxious, someone low in mood, someone who finds it easy to understand their emotions** and **someone who copes well.** This suggests P10 construed these people to be similar. He particularly construed these people as negatively characterised as being depressed and despondent, but also positively characterised as being ambitious and intelligent. This indicates P10 construed his current self as being anxious, low in mood and having difficulties with his mental health, although construed himself as understanding his emotions and coping with these difficulties. The independent elements were **someone with epilepsy, someone who finds it difficult to relate to other people, someone with a chronic, physical health difficulty, someone with seizures but uncertain of the cause** and **someone under a lot of stress.** P10 construed **someone with a chronic, physical illness** and **someone under a lot of stress** as being positively characterised, whereas the others were more negatively characterised.

Table 32 illustrates P10's construal of his current self, self before NEAD and his ideal self in comparison to each other and the other elements. P10 did not construe his current self to be similar to his **ideal self** (50.5% match) or **self before seizures** (47.3% match). This suggests that the construal of himself had changed to a more negative construal compared to himself since the onset of NEAD. Interestingly, P10 construed his **self before seizures** to be more positive than his **ideal self**, which may illustrate his level of hopelessness. When discussing this, P10 said: "it's wondering whether I'll ever get back to there". Although not above the 80% cut-off, his past self was most highly associated with **someone who had a difficult/traumatic upbringing** (78.5% match). This element, including **someone who has a chronic, physical health difficulty** and **someone under a lot of stress** were construed positively. When discussing why he construed these people to be positively characterised, P10 said "I think it toughens you". He did not see his past self as having mental health difficulties, low mood, anxiety, stress or difficulties relating to people. However, although not above the 80% cut-off, most associations increased when comparing the elements to his current self, indicating a negative shift in the construal of his current self, particularly seeing himself as being lower in mood, more anxious, having more mental health problems and more difficulties relating to other people than before he developed NEAD. There was, however, a shift in the association between his current self and **someone who copes well** (73.2% match) and **someone who finds it easy to understand their emotions** (82.0%), suggesting that he saw himself as being more able to cope and understand his emotions since the development of NEAD. This also indicates P10 may not have construed himself as coping well or able to understand emotions before he developed NEAD. Interestingly, P10 construed these elements as being more neutral on the construct ratings and did not associate them with his ideal self. This may suggest that he did not see this as a positive shift and may be indicative P10 finds coping and managing his emotions particularly difficult.

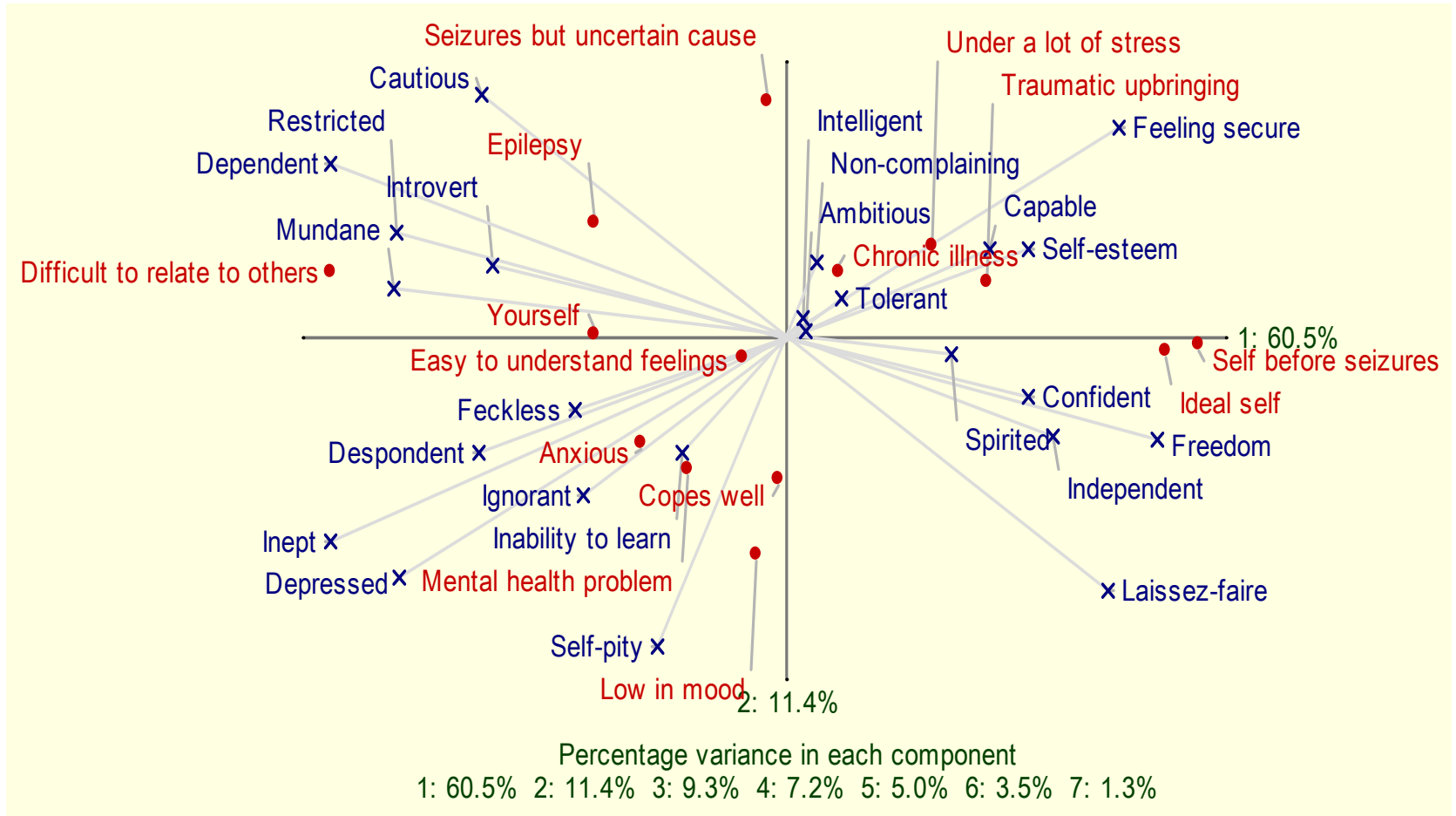


Figure 20: P10's Pringrid

P10 did not construe himself to be very similar to *someone with epilepsy, someone with seizures but uncertain of the cause* or *someone with a chronic, physical health difficulty* (69.6%, 73.6% and 73.6% match respectively), which fits with his acceptance of the NEAD diagnosis. *Someone with epilepsy* and *someone with seizures but uncertain of the cause* were construed negatively. However, P10 described how *someone with epilepsy* was construed as being more positively characterised than his current self: "If someone's got epilepsy, there are certain drugs what can control it...I don't think there is any drugs that [control NEAD]". Overall, this suggests P10 would prefer to have epilepsy than NEAD and would prefer to have a physical-health difficulty than a seizure-related disorder.

**Table 32. P10's percentage matches between elements of self and other elements**

	Past self (i.e., before seizures)	Current self	Ideal self
Past self (i.e., before NEAD)	—	47.3	93.2
Current self	47.3	—	50.5
Ideal self	93.2	50.5	—
<hr/>			
Someone with a mental health problem	50.9	75.5	54.4
Someone with epilepsy	44.7	69.6	46.4
Someone with seizures but uncertain of the cause	57.0	73.6	60.3
Someone with a chronic, physical health difficulty	63.4	73.6	66.0
Someone low in mood	57.2	75.0	60.0
Someone who is anxious	50.7	79.0	53.1
Someone who copes well	60.6	73.2	63.7
Someone who finds it easy to understand their feelings/emotions	59.7	82.0	62.1
Someone under a lot of stress	66.0	60.9	67.4
Someone who finds it difficult to relate to other people	25.8	74.5	28.6
Someone who has had a difficult/traumatic upbringing	78.5	65.3	82.0

### **3.3.10.3 Feedback**

P10 reported that the pringrid accurately represented his construal of the elements within the grid. When asked to comment on the repertory grid process as a whole, P10 described: "...it's actually brought things into perspective of how I look at things".

### **3.3.11 Individual Analysis: Participant 11**

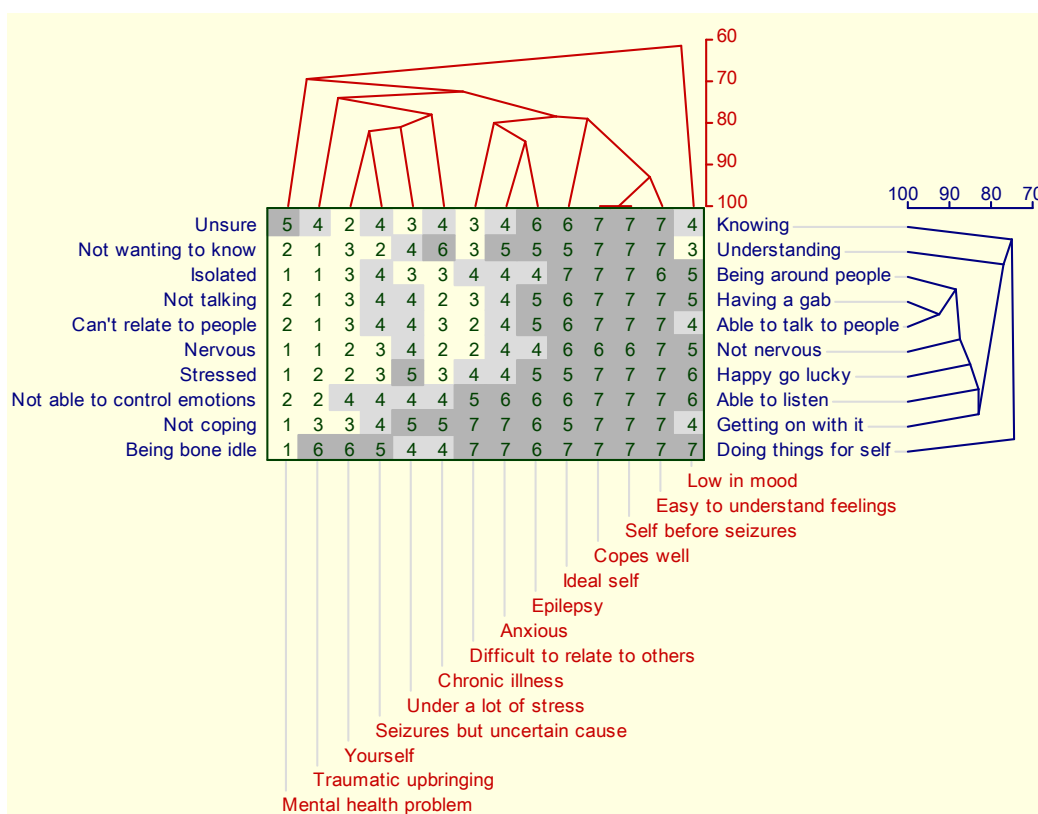
Participant 11 (P11) was a 26-year-old female with a diagnosis of NEAD (see Table 2 for additional demographic information), which started three years ago. She described experiencing NEAs at

least twice per week. She had previously been diagnosed with epilepsy and was currently prescribed anti-epileptic medication. She reported agreeing that she did not have epilepsy. However, she was unsure whether she agreed with the diagnosis of NEAD, largely due to her diagnosis being revealed to her via letter, and consequently had no understanding of NEAD.

**3.3.11.1 How does P11 construe her world?**

A HCA was conducted (Figure 21). P11 produced 10 pairs of constructs. The overall shape of the construct 'dendrogram' shows one cluster of constructs and three largely independent constructs. This may suggest P11 uses similar constructs to view her world. The matched constructs ( $\geq 80\%$ ) are shown in Table 33.

**Figure 21. P11's HCA**



**Table 33. P11's construct matches  $\geq 80\%$**

Construct matched with	Construct	Match (%)
Not talking—Having a gab	Can't relate to people—Able to talk to people	92.3
Not talking—Having a gab	Nervous—Not nervous	88.2
Isolated—Being around people	Not talking—Having a gab	88.2
Nervous—Not nervous	Can't relate to people—Able to talk to people	87.4
Stressed—Happy go lucky	Not talking—Having a gab	86.6
Isolated—Being around people	Can't relate to people—Able to talk to people	85.9
Stressed—Happy go lucky	Nervous—Not nervous	84.6

Isolated—Being around people	Nervous—Not nervous	84.6
Stressed—Happy go lucky	Can't relate to people—Able to talk to people	83.3
Isolated—Being around people	Stressed—Happy go lucky	83.3
Not coping—Getting on with it	Not able to control emotions—Able to listen	82.7
Stressed—Happy go lucky	Not able to control emotions—Able to listen	82.7
Not talking—Having a gab	Not able to control emotions—Able to listen	82.2
Isolated—Being around people	Not able to control emotions—Able to listen	81.6
Not wanting to know—Understanding	Can't relate to people—Able to talk to people	81.6

The only cluster of constructs comprises of ***isolated—being around people, not talking—having a gab, can't relate to people—able to talk to people, nervous—not nervous, stressed—happy go lucky, not able to control emotions—able to listen*** and ***not coping—getting on with it***. This suggests P11 sees these constructs as being similar. These constructs are largely related to relationships with others, suggesting P11 construed her world based on being able to talk to people and relate to people. The results also indicate P11 finds talking to others is important for coping and being happy. The largely independent constructs are ***unsure—knowing, not wanting to know—understanding*** and ***being bone idle—doing things for self***. P11 particularly described herself as being unsure, which was having an impact on how she was able to manage her difficulties:

*“I don't know whether I actually have NEAD properly...because we obviously don't know, we don't know how do deal with the situation and whether we are actually dealing with it right”.*

### **3.3.11.2 How does P11 construe herself and others?**

The HCA shown in Figure 21 highlights the elements and shows how closely related they are. Table 34 illustrates the elements that were most closely associated. The pringrid (Figure 22) supports the inferences drawn from examination of the repertory grid and HCA.

**Table 34. P11's element matches  $\geq$  80%**

<b>Element matched with</b>	<b>Element</b>	<b>Match (%)</b>
Self before seizures	Copes well	100.0
Self before seizures	Easy to understand feelings	92.5
Easy to understand feelings	Copes well	92.5
Epilepsy	Anxious	84.2
Yourself	Seizures but uncertain cause	81.7
Seizures but uncertain cause	Under a lot of stress	81.0

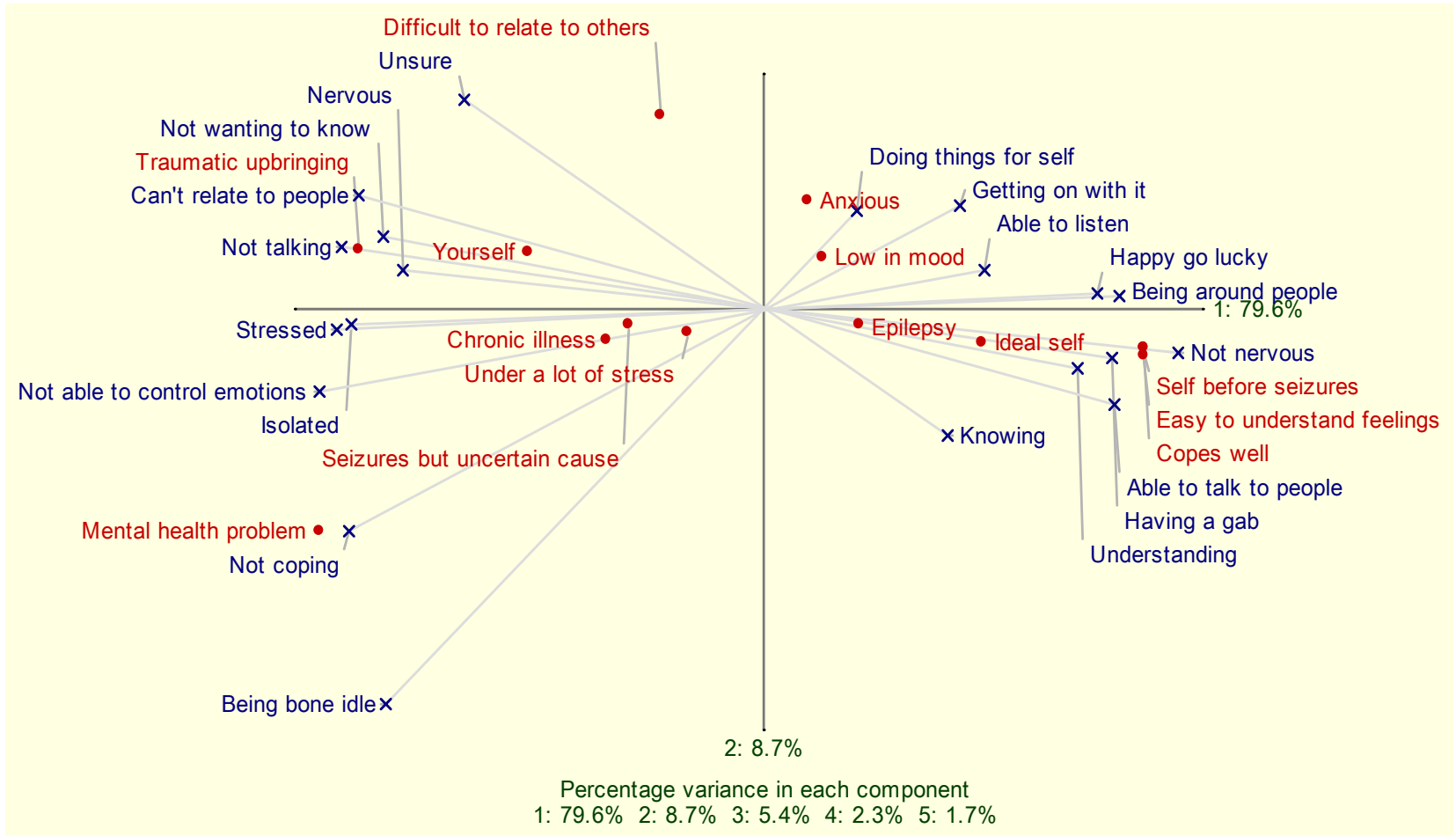


Figure 22: P11 Pringrid



As illustrated in Table 34, there are a small number of elements that are  $\geq 80\%$  matched. This would suggest P11 construed the elements largely independently of each other. There are three small clusters emerging within the HCA along with three independent elements. The first cluster is comprised of ***someone who finds it easy to understand their emotions, self before seizures*** and ***someone who copes well***. This suggests P11 construed these people in similar ways, and these were construed most positively compared to the other elements. This suggests that she construed herself before NEAD as being able to cope well and understand her emotions. The second cluster comprises of ***someone with epilepsy*** and ***someone who is anxious***. Although slightly below the 80% cut-off, ***someone who finds it difficult to relate to people*** is also associated with this cluster. This indicates P11 construed these people to be similar. These people were construed less positively than the elements in the first cluster, but more positively than the majority of the other elements. The third cluster comprises of ***yourself, someone with seizures but uncertain of the cause*** and ***someone under a lot of stress***, suggesting that she construed these people as being similar. This indicates P11 saw herself as being under stress and having an unknown cause to her NEAs. These people were construed more negatively than the elements within the other clusters. The elements most negatively construed compared to all the elements were ***someone with a mental health problem*** and ***someone who has experienced a difficult/traumatic upbringing***. These were construed independently of the other elements. Other independent elements were ***someone who is low in mood***, ***someone who has a chronic, physical health difficulty*** and ***ideal self***. ***Someone low in mood*** was construed slightly positively in the majority of the ratings, whereas ***someone who has a chronic, physical health difficulty*** was construed slightly negatively.

Table 35 illustrates P11's construal of her current self, self before NEAD and her ideal self in comparison to each other and the other elements. P11's independent construal of the elements indicates that she construed her past self, current self and ideal self as largely independent of each other. The discrepancy between her current self and her ideal self (50.6% match) suggests P11 was not happy with her current construal of herself. P11 also construed a discrepancy between her current self and herself before NEAD (34.2% match), indicating that she construed a negative change from her past self to her current self, particularly seeing her current self as being more unsure, nervous, stressed, not coping, isolated, not talking, not wanting to know and not able to relate to others. P11 construed her ideal self to be very positive, although interestingly not as positive as herself before NEAD. P11 construed herself before NEAD as being very highly associated with ***someone who copes well*** (100.0%) and ***someone who finds it easy to understand their emotions*** (92.5% match), which suggests P11 construed her past self to be able to cope well and understand her emotions. However, when comparing this to her current self, this association decreased to 34.2% and 33.8% respectively. This indicates a negative shift in the construal of her current self, suggesting that she now sees herself as not coping well or able to understand her emotions. The least associated elements with P11's past self were ***someone with a mental health problem*** (12.9% match) and ***someone who has had a difficult/traumatic upbringing*** (17.5% match). This indicates P9 did not construe herself to have any mental health

difficulties before she developed NEAD or difficulties during her upbringing. However, when comparing this to her current self, this association increased to 62.4% and 73.6% respectively. This indicates a negative shift in the construal of her current self from her past self. There was also a negative shift in the construal of her past self to her current self construal in relation to the elements: **someone under a lot of stress** and **someone who finds it difficult to relate to other people**. This suggests P11 construed herself to have more difficulties relating to others and being under more stress. Again, however, these associations are not above the 80% cut-off, indicating that she did not construe herself to be characterised by such difficulties. P11 also did not construe herself or her past self as having any difficulties with low mood or anxiety.

P11 did not construe herself to be highly associated with **someone with epilepsy** (60.9% match), but did associate herself to be similar to **someone with seizures but uncertain of the cause** (81.7% match), which fitted with P11's uncertainty about her NEAD diagnosis. She also slightly associated herself with **someone with a chronic, physical health difficulty** (74.7% match). Interestingly, however, P11 construed her ideal self to be similar to **someone with epilepsy** (78.3% match). This may suggest that she did not see her ideal self as being entirely 'seizure-free', and viewed epilepsy as a more positive diagnosis than her current diagnosis.

**Table 35. P11's percentage matches between elements of self and other elements**

	Past self (i.e., before seizures)	Current self	Ideal self
Past self (i.e., before NEAD)	—	34.2	78.9
Current self	34.2	—	50.6
Ideal self	78.9	50.6	—
<b>Someone with a mental health problem</b>			
Someone with epilepsy	69.7	60.9	78.3
Someone with seizures but uncertain of the cause	45.2	81.7	62.0
Someone with a chronic, physical health difficulty	42.0	74.7	53.2
Someone low in mood	61.3	65.0	76.4
Someone who is anxious	61.3	66.7	71.1
Someone who copes well	100.0	34.2	78.9
Someone who finds it easy to understand their feelings/emotions	92.5	33.8	77.6
Someone under a lot of stress	50.3	73.6	62.4
Someone who finds it difficult to relate to other people	44.5	73.6	56.2
Someone who has had a difficult/traumatic upbringing	17.5	73.6	33.1

### 3.3.11.3 Feedback

P11 reported that the pringrid accurately represented her construal of the elements within the grid, and described enjoying the interview process.

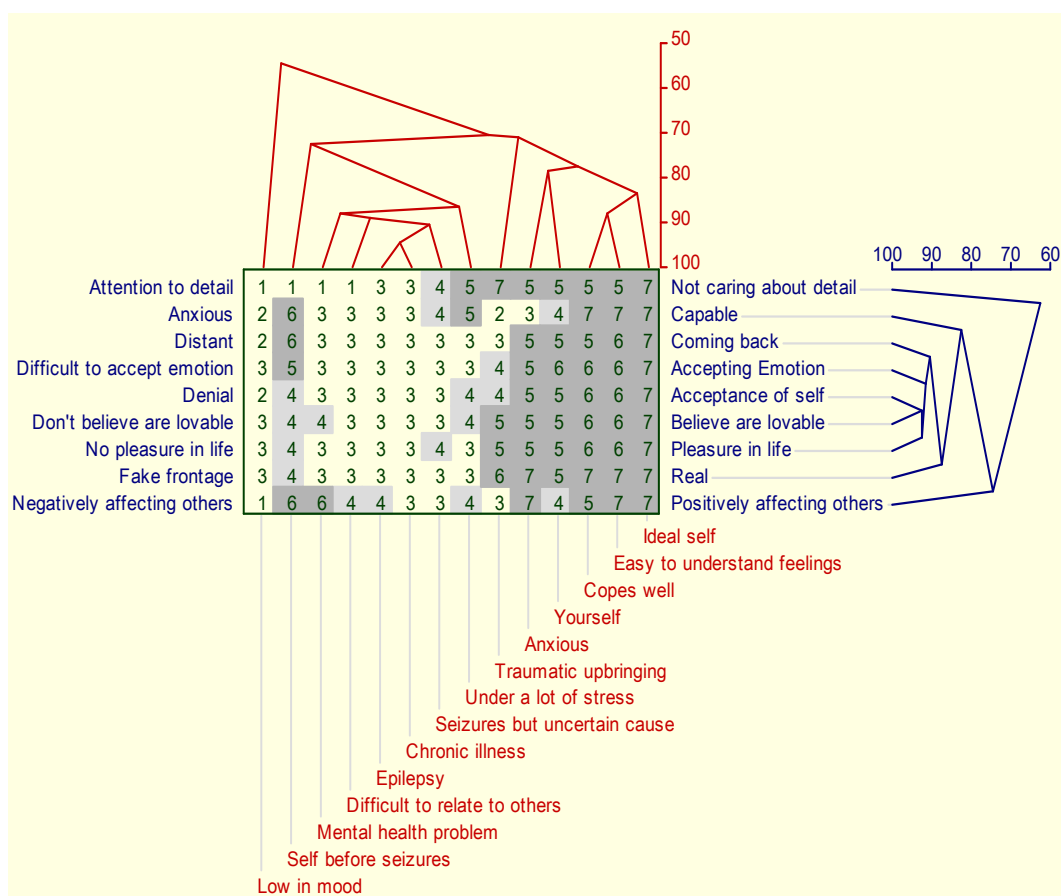
### 3.3.12 Individual Analysis: Participant 12

Participant 12 (P12) was a 43-year-old male with a diagnosis of NEAD (see Table 2 for additional demographic information). He reported the onset of NEAs being 15-16 years ago. He described experiencing NEAs approximately 2-3 times per week. He agreed with the diagnosis of NEAD. He had previously been diagnosed with epilepsy and prescribed anti-epileptic medication. He described having a good awareness of NEAD and described it as being a stress reaction caused by a difficulty which the person cannot cope with, resulting in the brain cutting off to protect the individual. He described the development of his NEAD being due to a period of psychological abuse by a 'friend'.

#### 3.3.12.1 How does P12 construe his world?

A HCA was conducted (Figure 23). P12 produced nine pairs of constructs. The overall shape of the construct 'dendrogram' shows one cluster of constructs and two largely independent constructs. The matched constructs ( $\geq 80\%$ ) are shown in Table 36.

**Figure 23. P12's HCA**



**Table 36. P12's construct matches  $\geq$  80%**

Construct matched with	Construct	Match (%)
Denial—Acceptance of self	Don't believe are lovable—Believe are lovable	92.3
No pleasure in life—Pleasure in life	Don't believe are lovable—Believe are lovable	92.3
No pleasure in life—Pleasure in life	Difficult to accept emotion—Accepting Emotion	91.1
Denial—Acceptance of self	Difficult to accept emotion—Accepting Emotion	91.1
Denial—Acceptance of self	No pleasure in life—Pleasure in life	91.1
Don't believe are lovable—Believe are lovable	Difficult to accept emotion—Accepting Emotion	90.0
Distant—Coming back	Difficult to accept emotion—Accepting Emotion	90.0
Distant—Coming back	Denial—Acceptance of self	88.2
Fake frontage—Real	No pleasure in life—Pleasure in life	87.4
Fake frontage—Real	Don't believe are lovable—Believe are lovable	86.6
Distant—Coming back	No pleasure in life—Pleasure in life	85.2
Distant—Coming back	Don't believe are lovable—Believe are lovable	84.6
Denial—Acceptance of self	Fake frontage—Real	84.6
Fake frontage—Real	Difficult to accept emotion—Accepting Emotion	84.6
Anxious—Capable	Distant—Coming back	82.2
Anxious—Capable	Denial—Acceptance of self	81.6
Negatively affecting others—Positively affecting others	Distant—Coming back	80.6

The cluster of constructs comprises of *anxious—capable, distant—coming back, difficult to accept emotion—accepting emotion, denial—acceptance of self, don't believe are lovable—believe are lovable, no pleasure in life—pleasure in life* and *fake-frontage—real*. This suggests P12 sees these constructs as being similar. One strongly associated construct pair within this cluster was *no pleasure in life—pleasure in life* and *don't believe are lovable—believe are lovable* (92.3% match). This indicates P12 construed experiencing life as being pleasurable if the person is able to accept positive qualities in themselves. Difficulties with self-acceptance and experiencing pleasure in life were also associated with feeling distant, anxious, fake and having difficulties accepting emotions. Overall, this indicates P12 construed the ability to feel pleasure in life and to 'come back' from difficult experiences, such as developing NEAD, as being influenced by feeling certain about yourself and having a feeling of self-worth and self-acceptance despite the difficulties you encounter.

### **3.3.12.2 How does P12 construe himself and others?**

The HCA shown in Figure 23 highlights the elements and shows how closely related they are. Table 37 illustrates the elements that were most closely associated. The pringrid (Figure 24) supports the inferences drawn from examination of the repertory grid and HCA.

**Table 37. P12's element matches  $\geq$  80%**

<b>Element matched with</b>	<b>Element</b>	<b>Match (%)</b>
Epilepsy	Chronic illness	94.4
Seizures but uncertain cause	Chronic illness	90.4
Epilepsy	Difficult to relate to others	88.9
Seizures but uncertain cause	Epilepsy	88.9
Mental health problem	Difficult to relate to others	87.6
Chronic illness	Difficult to relate to others	87.6
Easy to understand feelings	Copes well	87.6
Seizures but uncertain cause	Under a lot of stress	86.4
Epilepsy	Mental health problem	83.3
Ideal self	Easy to understand feelings	83.3
Epilepsy	Under a lot of stress	82.4
Chronic illness	Under a lot of stress	81.6
Chronic illness	Low in mood	81.6
Difficult to relate to others	Low in mood	80.8
Seizures but uncertain cause	Difficult to relate to others	80.8

There are two clusters emerging within the HCA along with five independent elements. The largest cluster is comprised of ***someone with a mental health difficulty, someone who finds it difficult to relate to other people, someone with epilepsy, someone with a chronic, physical health difficulty, someone with seizures but uncertain of the cause and someone who is under a lot of stress.*** This suggests P12 construed these people in similar ways, which are characterised more negatively on all the constructs, although ***someone who is under a lot of stress*** was construed more neutrally than the other elements. The only element that is rated more negatively than those in this cluster is the independent element ***someone who is low in mood.*** This indicates P12 construed people experiencing seizures as being under stress, having difficulties relating to others and having mental health problems. Interestingly, P12 did not construe himself to be similar to these people despite experiencing NEAs.

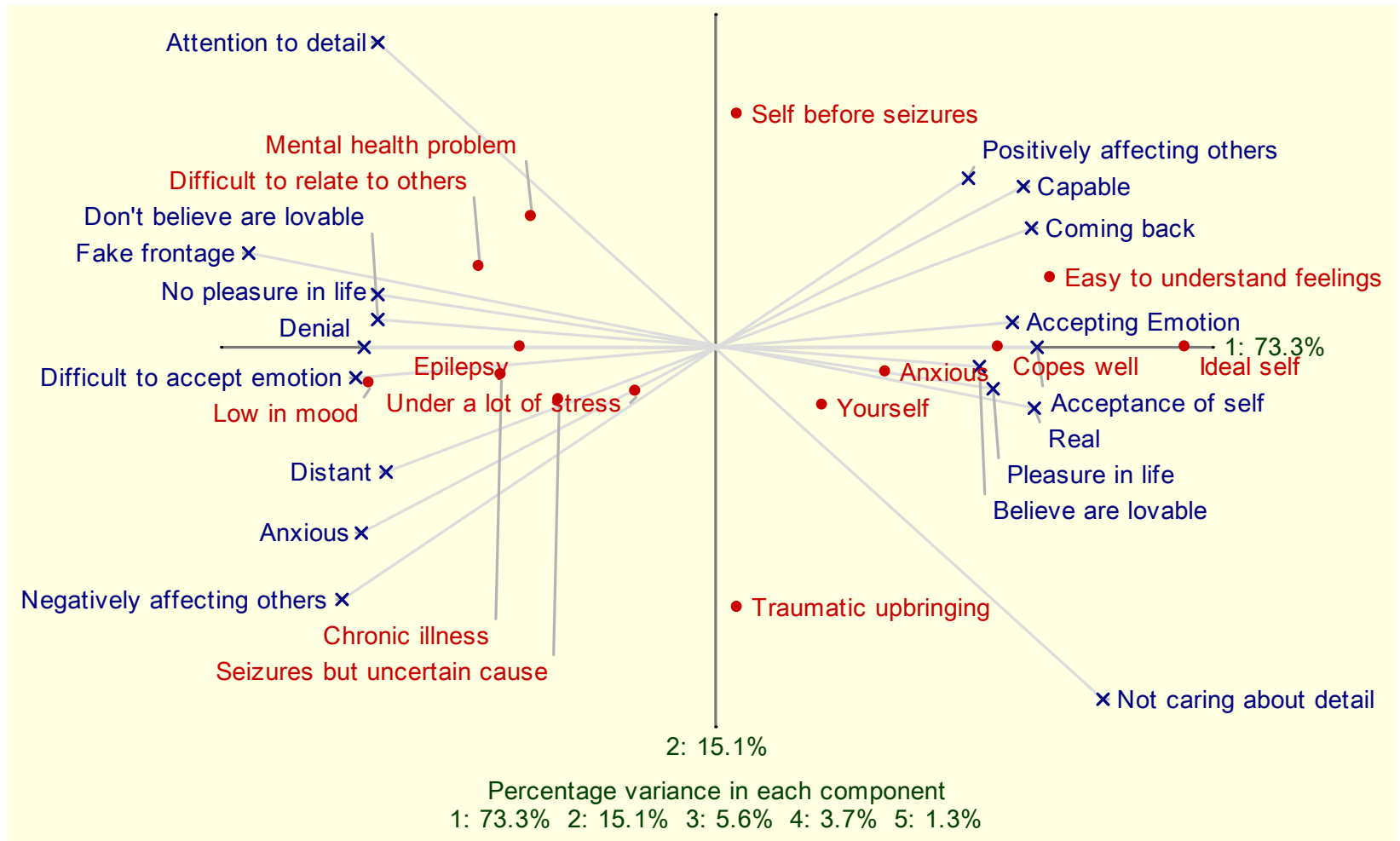


Figure 24: P12's Pringrid

The second cluster comprises of *ideal self, someone who copes well* and *someone who finds it easy to understand their emotions*. This suggests that these people are construed in similar ways by P12. He particularly construed these people most positively on the construct ratings compared to all the other elements. This suggests P12 would like to be able to cope well and understand his emotions better than he currently does. In addition to *someone who is low in mood*, the other remaining independent elements are *self before seizures, someone who has had a difficult/traumatic upbringing, someone who is anxious* and *yourself*. These people were rated more variably on the construct ratings than the other elements. This indicates P12 construed himself before NEAD and his current self to be dissimilar to the other elements and to each other, indicating a sense of distinction and/or alienation. He also described why he construed *someone who had experienced a difficult/traumatic upbringing* as being positive: "I think if you've had a traumatic upbringing, nothing else is going to qualify to that...it becomes almost, sort of good". P12 also construed *someone who is anxious* and *yourself* as being largely positive in the construct ratings. P12 construed his *self before seizures* as being more neutral to positive on the construct ratings.

Table 38 illustrates P12's construal of his current self, self before NEAD and his ideal self in comparison to each other and the other elements. P12's independent construal of the elements indicates that he construed his past self, current self and ideal self as largely independent of each other. The association between his current self and his ideal self (63.6% match) suggests P12 was not entirely happy with his current construal of himself, although he still construed his current self to be positively characterised. P12 did not construe himself before NEAD to be very similar to his ideal self (50.6% match) or his current self (69.6% match), although interestingly he viewed his current self to be more related to his ideal self than his past self, despite the onset of NEAD. This suggests P12 was not entirely happy with the construal of himself before NEAD, although he still construed his past self as being slightly more positively characterised than negatively characterised. He also commented on how his positive construal of current self was related to knowing more about his NEAD diagnosis, and indicated how he had progressed since the initial onset of NEAD:

*"I think it's because now I've been told what it is...so I'm not bothered about it and it's not going to dictate how I live and it's not going to define who I am...there is life for me, there are ways forward whereas before there wasn't...I was uncertain, that's why two years ago I took a massive overdose...that's how bad it was then because I didn't know what was wrong with me...so that's the difference, uncertainty, and now I'm certain".*

P12 also construed a positive change from his past self to his current self, particularly in relation to his ability to accept emotions, accept himself, be real, not attend to detail and have pleasure in life. This indicates P12 construed some positive consequences as a result of NEAD.

P12's past self was most highly associated with *someone with a mental health problem* (72.2% match). However, since this association did not reach the 80% cut-off, it suggests P12 did

not see himself before NEAD as having such difficulties. However, this association reduced when comparing against his current self, indicating a positive shift in the construal of himself compared to his previous self. The most highly associated elements with his current self were **someone who is anxious** (78.5% match) and **someone who copes well** (77.1% match). This is an increase in association from his past self to his current self, again indicating a positive shift in how he construed himself. When discussing the reasons why he construed **someone who is anxious** as being positive, P12 stated: "If anything it can keep you on your toes and I work very well to deadlines...so I use anxiety". There was also a positive shift from his past self construal to his current self construal in relation to **someone who finds it easy to understand their emotions**, suggesting he had difficulties in understanding his emotions prior to the onset of NEAD. However, there was a negative shift in relation to **someone who has had a difficult/traumatic upbringing** and **someone under a lot of stress**. Finally, P12 did not see himself to be highly associated with **someone with epilepsy** (67.6% match), **someone with seizures but uncertain of the cause** (70.6% match) or **someone with a chronic, physical health difficulty** (67.1% match). This fits with P12's acceptance of the NEAD diagnosis.

**Table 38. P12's percentage matches between elements of self and other elements**

	Past self (i.e., before seizures)	Current self	Ideal self
Past self (i.e., before NEAD)	—	69.6	50.6
Current self	69.6	—	63.6
Ideal self	50.6	63.6	—
Someone with a mental health problem	72.2	61.9	33.8
Someone with epilepsy	67.6	67.6	35.0
Someone with seizures but uncertain of the cause	65.8	70.6	38.4
Someone with a chronic, physical health difficulty	65.3	67.1	33.3
Someone low in mood	54.2	54.2	19.3
Someone who is anxious	65.3	78.5	64.9
Someone who copes well	64.4	77.1	77.8
Someone who finds it easy to understand their feelings/emotions	64.9	71.7	83.3
Someone under a lot of stress	66.7	72.8	44.7
Someone who finds it difficult to relate to other people	69.6	62.3	30.4
Someone who has had a difficult/traumatic upbringing	51.3	75.8	49.1



### **3.3.12.3 Feedback**

P12 reported that the pringrid accurately represented his construal of the elements within the grid. When asked to comment on the repertory grid process as a whole, P12 described: *"...it's very good as a map to look at...you can tell through looking and talking, the progress I was making...to see on paper that I have progressed in two years. That I have moved"*.

### **3.4 Cognitive Complexity**

One aim of this study was to explore the cognitive complexities of individuals' with NEAD construal systems. Cognitive complexity is a summary measure of the level of differentiation between the constructs and elements (i.e., how broad or narrow a person construes their world), which can be obtained via PCA. However, as cognitive complexity is a single summary measure, some information is lost in order to obtain this information (Fransella et al., 2004). Each participant's pringrid maps out the first two components, with the largest component being represented by the horizontal line and the next largest component represented by the vertical line. The principal components are displayed at the bottom of each individual participant's pringrid with a cut-off of 80% being used to determine the number of components presented (Jankowicz, 2004). Cognitive complexity was determined by the number of components extracted for each grid (Fransella et al., 2004; Winter, 1992). Two or more components indicates greater cognitive complexity (Bell, 2004), which in relation to PCT would suggest that the participant had the ability to understand different perspectives and anticipate future events (Bieri, 1955). One principal component suggests a 'monolithic' structure, and no principal components indicates a fragmented structure.

Table 39 illustrates the number of principal components that accounted for at least 80% of the variance in each individual participant's grids, including the end of the construct pole which loads most heavily onto each principal component. The results indicate a variable mix of cognitive complexity, which indicates the individuality of the participants' personal construct systems. Two participants' repertory grids (P4 & P8) produced only one principal component (i.e., a 'monolithic' structure). P2 and P5 demonstrated the highest cognitive complexity with four principal components. The majority of the participants' repertory grid variance was explained by two principal components (P1, P3, P6, P9, P11 & P12). The remaining participants' grids were explained by three principal components (P7 & P10). The most closely aligned construct poles indicate the superordinate constructs within the participants' construct systems (Butler, 2006; Neimeyer et al., 2001). The most commonly produced superordinate constructs were related to being ***physically unhealthy and/or having seizures*** (P1, P3, P4 & P6). This indicates that for those individuals, many of the other constructs were subsumed under this construct. Other common superordinate constructs were related to ***interpersonal relationships*** (P2, P5 & P7), ***independence /freedom*** (P1, P9, P10 & P11), ***experiencing emotions*** (P5 & P7) and ***coping*** (P2 & P8).

**Table 39. Principle components analysis for each individual participant's repertory grid**

<b>Grid</b>	<b>Number of components</b>	<b>Variance explained (%)</b>	<b>Total variance explained by components =&gt;80%</b>	<b>End of construct pole most closely aligned with component</b>
<b>P1</b>	1	69.5	69.5	Freedom
	2	18.4	87.9	Not having seizures
<b>P2</b>	1	55.4	55.4	Life continues
	2	13.8	69.2	Not coping well
	3	9.6	78.8	Having support
	4	6.2	85.0	Others able to relate to you
<b>P3</b>	1	67.0	67.0	Secure
	2	19.2	86.2	Not experiencing illness
<b>P4</b>	1	95.8	95.8	Not having seizures
<b>P5</b>	1	55.6	55.6	Depression
	2	14.5	70.1	Unable to relate
	3	8.0	78.1	Busy
	4	7.0	85.1	Judged
<b>P6</b>	1	75.9	75.9	Not mentally affected
	2	17.3	93.2	Physically unhealthy
<b>P7</b>	1	67.5	67.5	Scared
	2	12.2	79.7	Happy
	3	6.8	86.5	Socialising
<b>P8</b>	1	86.9	86.9	Coping
<b>P9</b>	1	71.9	71.9	Being able to do things
	2	12.5	84.4	Being normal
<b>P10</b>	1	60.5	60.5	Freedom
	2	11.4	71.9	Cautious
	3	9.3	81.2	Non-complaining
<b>P11</b>	1	79.6	79.6	Not nervous
	2	8.7	88.3	Doing things for self
<b>P12</b>	1	73.3	73.3	Real
	2	15.1	88.4	Attention to detail

### **3.5 Summary of Individual Analyses and Propositions**

The individual analyses allowed for the exploration of each participant's construct system, and demonstrated the uniqueness of each participant's personal construct system. This was apparent in the variability of cognitive complexity, differing labelling of the constructs and the idiosyncratic nature of the labels (e.g., *laissez-faire*, *funny* and *believe are lovable*). Despite this, a number of similarities between the participants' construct systems were noted, suggesting some themes of construing. In order to explore these themes, constructs were categorised according to the similarity of the construct labels elicited (Jankowicz, 2004). The following construct themes emerged:

1. ***Being physically healthy/able/unaffected*** versus ***Being physically unhealthy/unable/affected***
2. ***Having positive interpersonal relationships*** versus ***Having negative or no interpersonal relationships***
3. ***Positive emotions*** versus ***Negative emotions***
4. ***Having freedom/independence*** versus ***Having to rely on others***
5. ***Coping*** versus ***Not coping***
6. ***Having self-belief/self-confidence*** versus ***Lacking in self-belief/self-confidence***
7. ***Living your life*** versus ***Life put on hold/wasted***

These findings are consistent with the cognitive complexity analyses, as five of these themes (1-5) were identified as common superordinate constructs. Despite this being a useful way of categorising constructs across participants, the meanings, descriptions and behaviours attached to these constructs may be unique to each individual.

The individual analyses demonstrated a number of patterns amongst the participants' construals of themselves and others. Nine participants construed a difference between themselves and their ideal self. This indicates the majority of participants were not happy with how they currently perceived themselves. Nine participants construed their self before NEAD and ideal self to be very highly associated, indicating the majority of the participants construed themselves as being very positively characterised before the onset of NEAD. Similarly, nine participants construed a negative shift from the person they were before NEAD and their current self.

The finding that the majority of participants had a very positive construal of themselves before the onset of NEAD is particularly interesting considering NEAD has a psychological aetiology, and suggests the participants did not acknowledge any such difficulties in the construal of themselves before the onset of NEAD. This is also supported by the finding that none of the participants considered themselves before the onset of NEAD as having mental health difficulties, low mood, anxiety, difficult/traumatic upbringings, experiencing stress or having difficulties relating to others. Additionally, none of the participants (except P4) highly associated their current self with having any of these difficulties, although the majority (except P2 and P12) reported a negative shift towards experiencing these difficulties. Interestingly, P2 and P12 reported a positive shift with the

onset of NEAD. The majority of participants (except P10 and P12) perceived themselves before NEAD as being able to cope well and understand their emotions. Interestingly, P10 and P12 were the only male participants within this study. Despite this, the majority of participants did not construe their current self as being able to cope well or understand their emotions, indicating a negative construal shift since the onset of NEAD. Finally, the finding that the majority of participants did not construe their current self to have associations with any of the other elements may suggest that they construed themselves as being distinct and/or alienated from others.

All the participants (except P6) did not construe themselves as having epilepsy, nor did they (except for P4 & P11) construe themselves as having an unknown cause for their NEAs. However, despite not reaching the 80% cut-off, many participants associated themselves with ***someone with seizures but uncertain of the cause***. This would fit with a large proportion of participants accepting their NEAD diagnosis but being uncertain of the specific causes of their NEAs. None of the participants associated themselves as having a chronic, physical health difficulty, although interestingly many participants construed having a chronic, physical health difficulty as being preferable to having a seizure-related disorder. Additionally, many participants construed having a chronic, physical health difficulty as being preferable to having mental health difficulties.

### **3.5.1 Propositions**

Due to the individual analyses demonstrating potential similarities between the participants, a number of propositions were developed and explored via combining the individual participants' data. This combined the individual repertory grid data to form one composite repertory grid (i.e., Modegrid), which allowed for the initial three aims and the following propositions to be explored at the group level.

Proposition 1: Individuals with NEAD construe themselves to be different from their ideal self. This would be indicated in the Modegrid by a large Euclidian distance (i.e., positioned far apart from each other) between the elements ***yourself*** and ***ideal self***. (NB. A large Euclidian distance is defined as being large relative to the other element distances. Conversely, a small Euclidian distance is defined as being small relative to the other element distances).

Proposition 2: Individuals with NEAD construe their life before they developed NEAD as being positive (i.e., closely related to their ideal self). This would be indicated in the Modegrid by a small Euclidian distance between the elements ***self before seizures*** and ***ideal self***.

Proposition 3: Individuals with NEAD construe their current self to be different from their past self, specifically construing their current self as being more negative. This would be indicated in the Modegrid by a large Euclidian distance between the elements ***yourself*** and ***self before seizures***, with ***yourself*** being positioned within the negative quadrants.

Proposition 4: Individuals with NEAD construe themselves to be more similar to ***someone with seizures but uncertain of the cause*** compared to ***someone with epilepsy***. This would be indicated in the Modegrid by a large Euclidian distance between the elements ***yourself*** and ***someone with epilepsy*** and by a smaller Euclidian distance between ***yourself*** and ***someone with seizures but uncertain of the cause***.

Proposition 5: Individuals with NEAD construe ***someone with a chronic, physical health difficulty*** more positively than someone experiencing seizure-related disorders. This would be indicated in the Modegrid by a large Euclidian distance between the elements ***ideal self*** and ***someone with epilepsy***, and ***between ideal self*** and ***someone with seizures but uncertain of the cause***. However, there would also be a smaller Euclidian distance between ***ideal self*** and ***someone with a chronic, physical health difficulty***.

Proposition 6: Individuals with NEAD construed experiencing physical health difficulties (i.e., ***someone with a chronic, physical health difficulty, someone with epilepsy*** and ***someone with seizures but uncertain of the cause***) to be more preferable than experiencing mental health difficulties (i.e., ***someone with a mental health problem***). This would be indicated in the Modegrid by a smaller Euclidian distance between the elements ***ideal self*** and ***someone with a chronic, physical health difficulty, someone with epilepsy*** and ***someone with seizures but uncertain of the cause***, compared to a larger Euclidian distance between ***ideal self*** and ***someone with a mental health problem***.

Proposition 7: Individuals with NEAD construe a negative shift once they develop NEAD to construe themselves as not being as able to cope or understand their emotions. This would be indicated in the Modegrid by a small Euclidian distance between ***self before seizures*** and the elements ***someone who copes well*** and ***someone who finds it easy to understand their emotions*** and with a larger Euclidian distance between ***yourself*** and the elements ***someone who copes well*** and ***someone who finds it easy to understand their emotions***.

Proposition 8: Individuals with NEAD do not associate themselves with having mental health difficulties, low mood, anxiety, difficult/traumatic upbringings, experiencing stress or having difficulties relating to others, although they do see their current self as being more likely to have these difficulties than themselves before they developed NEAD. This would be indicated in the Modegrid by a large Euclidian distance between ***yourself*** and these six elements but an even larger Euclidian distance between ***self before seizures*** and these six elements.

### **3.6 Modegrid Analysis**

Multiple analyses of the individual participants' repertory grids produced a composite Modegrid (Figure 25), which merges the information from the individual grids based on the most common positions of the elements (see Appendix I for Modegrid analyses data). These analyses were possible due to each individual repertory grid using the same elements, allowing for a comparison

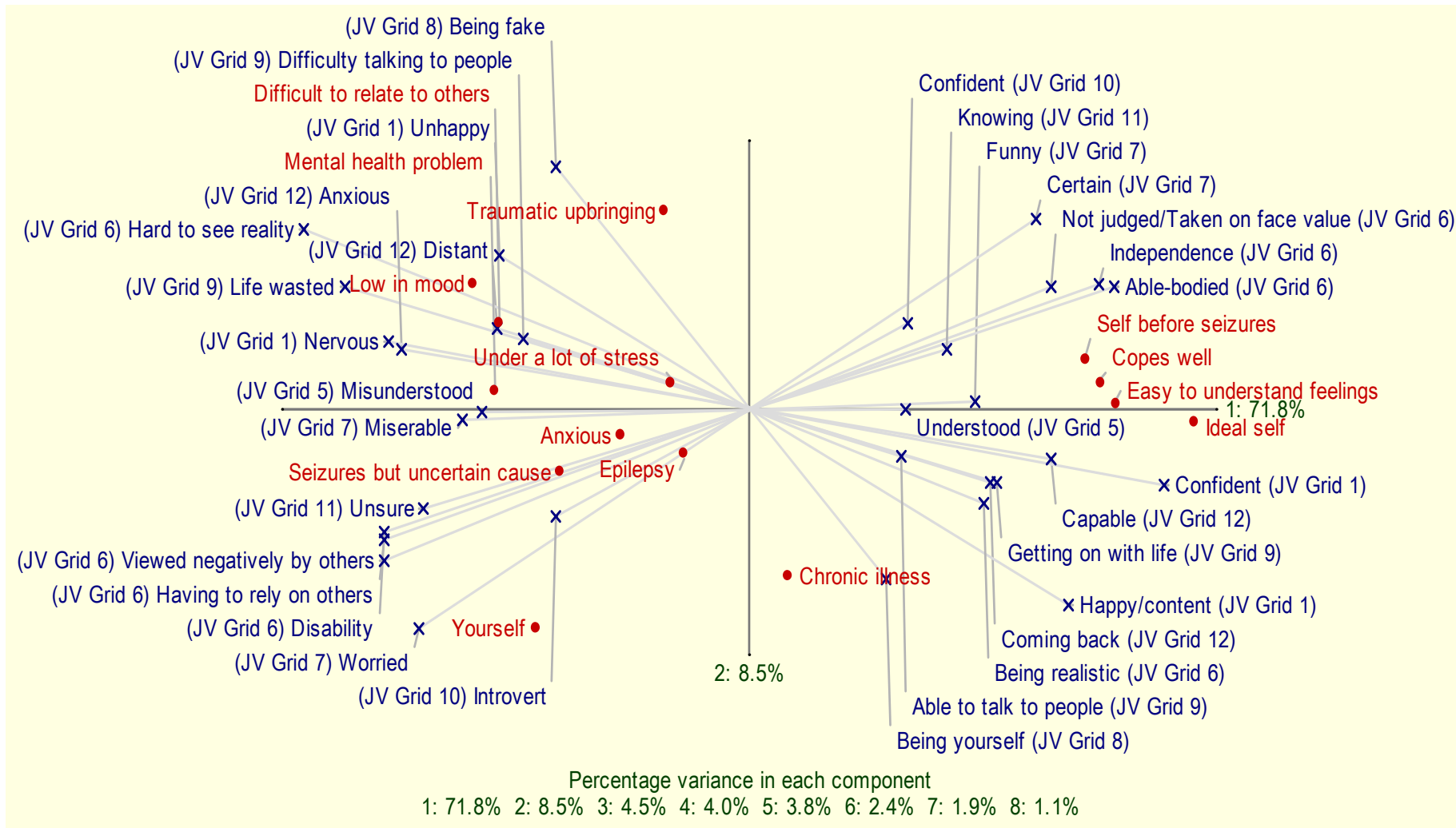


Figure 25. Modegrid

of relationships between the elements across all grids to be explored (Slater, 1969). This allowed for the aims and the subsequent propositions to be explored at the group level. However, combining data in this manner loses a certain amount of individuality and integrity of the data. The data were initially analysed by including all twelve participants' repertory grids. However, it became apparent that due to P4's substantially non-complex personal construct system, the Modegrid essentially incorporated all her data and consequently minimised the data from the other repertory grids, thus distorting the analysis. Consequently, the aims and propositions were explored with the exclusion of P4's repertory grid data (see Appendix J for the Modegrid including P4's data).

The Modegrid (Figure 25) provides a representation of how the elements were construed across the participants (NB. 'JV' within the Modegrid labels refers to the researchers initials, and the grid numbers refer to the participant numbers. For example, 'Grid 1' refers to 'P1'). Although an 80% cut-off was recommended in the individual analyses (Jankowicz, 2004), this resulted in no mode constructs being elicited. When conducting multiple analyses, however, it is recommended this cut-off point be used dynamically to allow for increased exploration of the data (Gaines & Shaw, 2005). Consequently, a 76% cut-off was used to ensure the Modegrid produced enough information to allow for sufficient exploration of the aims and propositions. Sixteen mode constructs were produced using a 76% cut-off point. A 75% cut-off created 32 mode constructs, which was deemed too many to interpret, and a 77% cut-off produced nine mode constructs, which was deemed too few to adequately explore the aims and propositions.

Following the PCA, two principal components were extracted that explained at least 80% of the variance (Table 40), indicating a cognitively complex structure (Bell, 2004). The first component explained the majority of the variance and is indicated by the horizontal axis of the Modegrid. The construct pole most closely aligned to this component is ***confident***. This principal component can differentiate between elements that were rated more positively by participants from elements that were construed more negatively by participants.

**Table 40: Modegrid PCA**

<b>Number of components</b>	<b>Variance explained (%)</b>	<b>Total variance explained by components <math>\geq 80\%</math></b>	<b>End of construct pole most closely aligned with component</b>
1	71.8	71.8	Confident
2	8.5	80.3	Being fake

The elements ***ideal self, self before seizures, someone who copes well*** and ***someone who finds it easy to understand their feeling/emotions*** were located within close proximity to each other and towards the preferred construct poles. ***Someone with a chronic, physical health difficulty*** was located within the positive side of the Modegrid, although this was to a lesser extent than these other elements, suggesting this person is construed as being characterised

by both positive and negative characteristics. The elements ***yourself, someone with seizures but uncertain of the cause, someone with a mental health problem, someone who finds it difficult to relate to other people*** and ***someone low in mood*** were located towards the least preferred construct poles. ***Someone under a lot of stress, someone who has epilepsy,*** and ***someone who is anxious*** were also located within the negative side of the Modegrid, although to a lesser extent than these other elements.

### **3.6.1 Construal of current self, self before seizures and ideal self**

***Ideal self*** was construed very positively (i.e., within the right hand side of the Modegrid), whereas ***yourself*** was construed negatively (i.e., within the left hand side of the Modegrid), resulting in a large Euclidian distance (i.e., positioned far apart). Subsequently, proposition one was supported. The participants particularly construed their ideal self as being confident, not being judged, getting on with life, being happy/content, being realistic, capable, having independence, being certain and able-bodied. The participants construed their current self as being nervous, viewed negatively by others, having a wasted life, being unhappy, having difficulties in seeing reality, being anxious, having to rely on others, being worried and having a disability. ***Ideal self*** and ***self before seizures*** were construed positively, as both were positioned to the right hand side of the Modegrid, which resulted in a small Euclidian distance (i.e., positioned closely together). The participants construed themselves before NEAD as having the same characteristics as their ideal self, suggesting the participants did not see themselves before NEAD as having many difficulties. Subsequently, proposition two was supported. ***Self before seizures*** was located within the right hand side of the Modegrid, whereas ***yourself*** was positioned within the left hand side of the Modegrid, which resulted in a large Euclidian distance between these elements. This is indicative of a negative shift in how the participants construed themselves since the onset of NEAD. Subsequently, proposition three was supported.

### **3.6.2 Construal of self and other disorders**

The Modegrid shows a slightly larger Euclidian distance between ***yourself*** and ***someone with epilepsy*** than between ***yourself*** and ***someone with seizures but uncertain of the cause***. This indicates the participants construed themselves as being more similar to ***someone with seizures but uncertain of the cause*** than to ***someone with epilepsy***. They construed ***someone with epilepsy*** more positively than themselves and ***someone with seizures but uncertain of the cause***. This is illustrated by ***someone with epilepsy*** being positioned more centrally within the Modegrid. Subsequently, proposition four was supported. However, ***yourself*** was not located very closely to these elements, suggesting the participants did not entirely construe themselves as having epilepsy or having an unknown cause for NEAs. This fits with the majority of participants accepting the NEAD diagnosis yet still remaining unsure as to the specific causes/triggers of their NEAs. Also, ***yourself*** was positioned in isolation from the other elements and positioned outside the construct lines, which indicates a construal of themselves as being distinct/alienated from other people. This may be due to their acceptance of their NEAD diagnosis. ***Someone with a chronic, physical health difficulty*** was located within the right-hand side of the Modegrid, resulting in a relatively large Euclidian distance from ***yourself***, which indicates the



participants did not construe themselves to have a physical health difficulty. **Someone with a chronic, physical health difficulty** was positioned to the right hand side of the Modegrid resulting in a smaller Euclidian distance to the **ideal self** element compared to **someone with epilepsy** and **someone with seizures but uncertain of the cause**, which were positioned to the left hand side of the Modegrid, resulting in a larger Euclidian distance from the **ideal self** element. This suggests that the participants construed having a physical health difficulty to be preferable to having a seizure-related disorder. Subsequently, proposition five was supported. Additionally, **someone with a mental health problem** was positioned within the left hand side of the Modegrid, and there was a larger Euclidian distance between **someone with a mental health problem** and **ideal self** than between **ideal self** and **someone with a chronic, physical health difficulty**, **someone with epilepsy** or **someone with seizures but uncertain of the cause**. This indicates the participants construed experiencing physical health difficulties as preferable to experiencing mental health difficulties, thus supporting proposition six.

### **3.6.3 Construal of self and other elements**

The Modegrid shows a small Euclidian distance between **self before seizures** and the elements **someone who copes well** and **someone who finds it easy to understand their emotions**, but with a large Euclidian distance between **yourself** and these elements. This suggests the participants construed themselves prior to the development of NEAD as being able to cope well and understand their emotions, but they no longer construed themselves as coping well or understanding their emotions. This illustrates a negative shift in the construal of themselves since the onset of NEAD. Consequently, proposition seven was supported. Proposition eight was also supported. The Modegrid demonstrated a large Euclidian distance between **self before seizures** and six elements that have been linked with the development and/or maintenance of NEAD (i.e., **someone who has a mental health problem**, **someone low in mood**, **someone who is anxious**, **someone who has had a difficult/traumatic upbringing**, **someone under a lot of stress** and **someone who finds it difficult to relate to other people**). This indicates that the participants did not construe themselves before NEAD as being characterised by such difficulties. The Modegrid also revealed relatively smaller Euclidian distances between **yourself** and these elements. This indicates the participants did not associate their current self with having any of these difficulties, but perceived their current self as being more likely to experience these difficulties since the onset of NEAD.

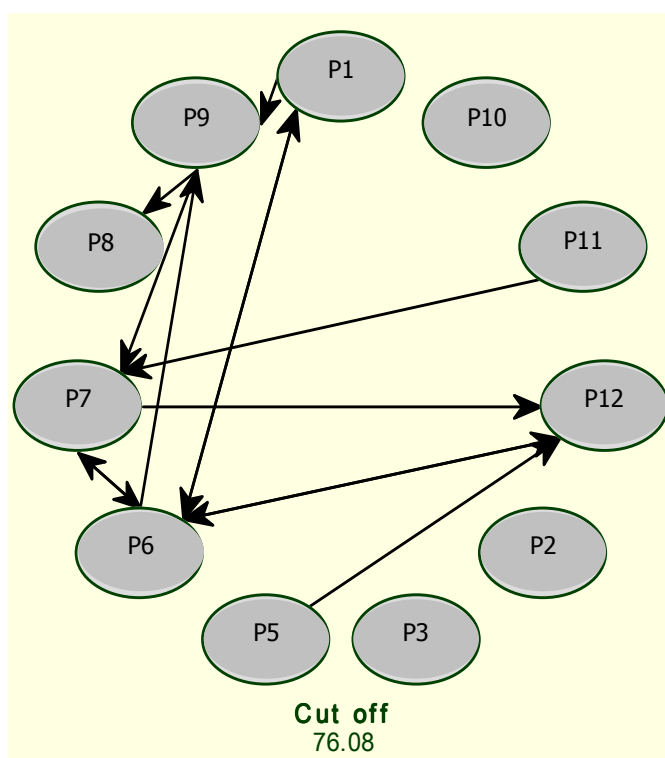
Although P4's data was excluded from these analyses, the Modegrid incorporating her data (Appendix J) supported most propositions. The only difference was within proposition eight, whereby the Modegrid incorporating P4's data demonstrated the participants construed themselves as being similar to **someone who is anxious** and **someone under a lot of stress**. This reflects the higher level of anxiety and stress P4 was experiencing compared to the other participants.

### **3.7 SocioNet Analysis**

A SocioNet analysis was produced to explore the degree to which participants might be able to understand the organisation of each others' personal construct systems. The SocioNet analysis examines the similarity of element clusters between each pair of individual repertory grids. Relationships are illustrated via arrows within the SocioNet grid. No arrow depicted between two participants indicates there is no shared structure of elements (i.e., no shared understanding). A participant with no connection to an arrow is thought to have a unique personal construct system. A bi-directional arrow between two participants indicates a shared understanding of their personal construct systems. A uni-directional arrow leading from one participant (A) to another (B) indicates that B's personal construct system can be subsumed under A's personal construct system but not the other way around (i.e., A can understand B's personal construct system, but B cannot understand A's personal construct system).

The SocioNet analysis is illustrated in Figure 26. As with the Modegrid, P4's data were excluded. The standard 80% cut-off did not produce any arrows, indicating that the participants did not have a shared understanding of each others construct systems. Only a 76% cut-off was deemed to hold sufficient data for meaningful interpretation. The SocioNet grid shows P2, P3 and P10 had no shared personal construct system with other participants. Three participants (P5, P8 & P11) had only one link to another participant. P6 was the most able participant to understand other participants' construct systems, and had the most reciprocation of understanding from others. Overall, this indicates no shared understanding amongst the participants, which suggests a high degree of variability in the participants' ways of construing.

**Figure 26. SocioNet analysis**



## **CHAPTER FOUR: DISCUSSION**

### **4.1 Overview**

This discussion begins by reviewing and interpreting the findings in relation to the research aims, before considering the implications for future research and clinical practice, and the methodological strengths and limitations of the present study.

### **4.2 Summary of results in relation to aims/propositions**

One aim of this study was to explore the constructs elicited by individuals with NEAD. Despite some common themes being identified, each participant's construct system was idiosyncratic. This uniqueness was supported when exploring the cognitive complexities of the participants' construct systems, as the analyses revealed wide variability of cognitive complexity amongst the participants. Additionally, the participants had no shared understanding of each other's ways of construing. The superordinate nature of the themes also indicates they were 'core' to many participants' self-identity. Most participants evaluated themselves and others on the basis of being physically healthy (e.g., not having NEAs), having positive relationships, having independence/freedom, experiencing positive emotions and coping.

Another aim was to explore how the participants construed other people, including their current self, self before NEAD and ideal self. The Modegrid revealed commonalities in how they construed themselves and others, enabling eight propositions to be explored (Section 3.5.1). All propositions were supported via the Modegrid. Discrepancies between the participants' view of their current self compared to their ideal self and their self before NEAD were revealed. The participants did not identify their current self or self before NEAD as being associated with any of the factors identified within the research literature as playing a role in the development and/or maintenance of NEAD. Consequently, they did not identify themselves, previously or currently, experiencing mental health problems, low mood, anxiety, stress, difficulties relating to other people or experiencing a difficult/traumatic upbringing. However, they construed themselves as being less able to cope well or understand their emotions since the onset of NEAD. It was also revealed that the participants did not identify themselves with the other elements (i.e., people). The participants did not perceive themselves as having epilepsy, a physical health difficulty, or having an unknown cause to their NEAs, which suggests they identified with having NEAD. Finally, the participants construed experiencing physical health difficulties to be preferable to experiencing mental health difficulties, and also preferred to experience another physical health difficulty than a seizure-related disorder.

### **4.3 Interpretation of findings in relation to personal construct theory**

The participants' unique ways of construing their world suggests the participants within the current study were a heterogeneous group, with different mechanisms underlying their behaviour. This illustrates the '*individuality corollary*' of PCT (Kelly, 1955). PCT would postulate individuals with NEAD can experience similar events involved in the development of NEAD (e.g., stress, trauma), yet develop different underlying construct systems. Similarly, the '*sociality corollary*' states that to understand another person's viewpoint, we must understand something about that person's

construct system. The current findings suggest the participants would find it difficult to understand other participants' ways of construing and, therefore, had difficulties in understanding each others experiences. Conversely, the '*commonality corollary*' suggests it is possible for people to construe events in similar ways. This corollary proposes that if people construe events in the same way, they are likely to behave in the same way. This was evident by some themes emerging from the data. However, the '*individuality corollary*' suggests that whilst people can use similar verbal labels for constructs, they may not necessarily result in similar ways of construing. This would suggest caution is taken when interpreting the construct themes revealed within the present study. It also highlights the need to work idiosyncratically with individuals with NEAD, eliciting their own constructs rather than supplying constructs or gaining predetermined information via questionnaires. This has implications for future research, as the majority of previous studies have utilised questionnaire-based designs, which may be missing important issues for individuals with NEAD, and masking the individual differences between patients. This may also explain why there have been some discrepancies amongst the previous research.

According to PCT's '*experience corollary*', people are constantly refining their construct systems by incorporating new information and experiences into them. PCT would suggest that the current participants' personal construct systems are constantly being tested and will remain in the personal construct system if validated, or will be modified or replaced if proven inaccurate. This corollary was illustrated within the present study by many participants producing constructs relating to their NEAD. This suggests the development of NEAD had resulted in a change to the participants' construct systems, and NEAD had become a core aspect of some participants' self-identity. Finally, the '*fragmentation corollary*' suggests personal construct systems can incorporate several incompatible subsystems (Kelly, 1955). This was evident for the participants who construed positive consequences as a result of their NEAD. For example, P2 construed herself as having increased support since the onset of NEAD. This may create two incompatible goals within her construct system (e.g., wanting cessation of her NEAs, but also wanting to maintain her current level of support). These incompatible goals may perpetuate P2's difficulties (Feixas et al., 2004).

#### **4.4 Exploring the cognitive complexities of individuals with NEAD**

Another aim was to explore the cognitive complexities of the participants' construct systems. The analyses revealed variability between the participants' levels of cognitive complexity. This indicates the participants' construct systems were made up of differing structures (Bell, 2004), and supports the heterogeneity of the participants' construct systems. As non-complex construct systems are associated with psychological difficulties (Adams-Webber, 2003; Bannister & Fransella, 1971; Mottram, 1985), it was hypothesised that individuals with NEAD may demonstrate non-complex construct systems. This was not supported, as the majority of the participants demonstrated cognitive complexity, with some participants demonstrating highly complex construct systems. Additionally, some of the participants demonstrating higher cognitive complexity described struggling with their NEAD (e.g., P10), which suggests that complex construing did not necessarily buffer against these difficulties. Two participants (P4 & P8) demonstrated a 'monolithic' structure,

suggesting these participants construed their world more rigidly (Mottram, 1985), and would find it difficult to understand and predict situations (Bell, 1988; Bieri, 1955). Consequently, these participants may find it difficult to predict and cope with their NEAs. They may also have difficulties in predicting others' responses to their NEAD, which may impact on their interactions with others. This was particularly evident for P4 who had an extremely 'monolithic' structure and described struggling with her NEAD. However, this did not account for P8's experiences, as she described coping well. This may suggest that non-complex construing can be indicative of psychological difficulties (e.g., P4), but may also serve a protective function (e.g., P8).

Overall, the cognitive complexities of the participants did not demonstrate a clear pattern, with both complex and non-complex construing being associated with the presence of NEAD and with difficulties coping with NEAD. However, considering the unusually high complex construing found within some participants compared to other repertory grid studies (e.g., Woodrow et al., 2010), further research may be worth exploring the possibility of a non-linear relationship between psychological difficulties and cognitive complexity within individuals with NEAD.

#### **4.5 Exploring the Constructs**

##### **4.5.1 Idiosyncratic Construing**

As discussed, the participants' idiosyncratic construing indicates different psychological processes underlying their NEAD, supporting the argument that individuals with NEAD form a heterogeneous group with differing underlying mechanisms unique to each individual. This is consistent with other findings demonstrating individuals with NEAD form a heterogeneous group in relation to semiology, neurological, psychiatric and psychosocial factors (Baslet, Roiko & Prensky, 2010; Duncan & Oto, 2008; Groppel et al., 2000; Kuyk et al., 1996; Lesser, 1996; Rusch et al., 2001).

Currently, ICD-10 (WHO, 1992) classifies NEAD as a dissociative disorder, whereas DSM-IV-TR (APA, 2004) categorises it as a somatoform disorder. Whilst these psychiatric classifications can help clinicians make sense of NEAD, help determine treatment and plan services, the heterogeneity of the present sample does not support the usefulness of psychiatric classification system for individuals with NEAD (LaFrance et al., 2006). Other models of NEAD have been suggested, and although this study did not explicitly test any model, there were findings consistent with some models. For example, some participants identified the impact of stress on the development of their NEAD, suggesting NEAs may have been a coping strategy to unmanageable stress for some participants (Goldstein et al., 2000; LaFrance & Bjornaes, 2010). The 'fear-avoidance' model (Goldstein et al., 2004) was also indicated, with some participants commenting on their lack of independence/freedom due to fear of having a NEA. Also, despite the majority of participants construing negative consequences as a result of their NEAD, three participants (25%) construed some positive consequences (e.g., increased support, increased acceptance of self). Behavioural theory suggests these positive consequences act as reinforcers to perpetuate NEAD (Alper, 1994).

Overall, these findings support the idea that there may be no single mechanism or factor contributing to the development or maintenance of NEAD in all cases (Reuber, 2009). Instead, the current findings support Reuber's (2009) multi-factorial model of individually formulating the patient's difficulties and tailoring interventions when working with individuals with NEAD (LaFrance & Bjornaes, 2010; Reuber, 2009). There may, however, be an alternative explanation for the participants' idiosyncratic construing. Although no research has investigated potential stages of NEAD, studies within the clinical health psychology field have found patients often go through different stages of denial, anger, depression and partial acceptance (Hendler, 1981). These potential stages were indicated by P8 and P12 when commenting on how, despite their current positive construals, they initially struggled with their NEAD. Subsequently, the 'heterogeneity' of the participants may be explained by the participants being at different stages of their 'journey'. More longitudinal studies would be useful to investigate this potential explanation.

#### **4.5.2 Themes**

Despite the uniqueness of the participants' personal construct systems, some similarities in their ways of construing were identified via identification of similar constructs labels and the Modegrid analysis (Jankowicz, 2004). The positive poles of these themes were ***being physically healthy*** (e.g., not experiencing NEAs), ***having positive relationships, having independence /freedom, experiencing positive emotions, coping, having self-belief/confidence*** and ***being able to live life***. Subsequently, the participants evaluated themselves and others on the basis of these characteristics. The themes identified (except for *having self-belief/confidence* and *being able to live life*) were identified as superordinate constructs in the majority of participants construct systems. These superordinate constructs provide a sense of self-continuity and, therefore, are considered the person's self-identity (Feixas et al., 2010; Feixas & Saul, 2004).

Previous studies have highlighted the need for individuals with NEAD to integrate the diagnosis into their self-identity (Karterud et al., 2010). Interestingly, constructs relating to NEAD were superordinate for five participants, suggesting NEAD had become integrated within their self-identity (Compan et al., 2011; Feixas & Saul, 2004). Despite this, however, these participants were still struggling with their NEAD. One explanation for this inconsistency is highlighted within Fransella's (1968) work with stutterers. She found stutterers had highly elaborated construct systems relating to their stuttering, and they lacked other constructs relating to being a fluent speaker. This may suggest that for some participants their NEAD had become their life, and they lacked a sense of being a person without their NEAD. Consequently, abandoning the symptoms may actually threaten their self-identity (Fransella, 1968). This would fit with previous findings that adoption of the 'sick' role may become an important part of individuals' with NEAD self-identity (Reuber, 2009). Instead, Fransella's (1968) work suggests these participants need to build a construct system relating to themselves without NEAD. Whilst it may be important for individuals with NEAD to incorporate their NEAD into their self-identity, they must also ensure they maintain a construct system in relation to themselves as people who are more than just their NEAD.

The current themes support previous research investigating the experiences of individuals with NEAD. The positive construct poles are presented here, although many participants construed themselves negatively on these constructs. The majority of participants produced constructs relating to ***independence/freedom***. Similarly, Thompson et al. (2009) found participants felt trapped by their NEAs, and described a loss of independence. They also described the individuals' lives taking on a '*static quality*', which fitted with the current theme of ***being able to live life***, whereby many participants construed their lives as being put on hold. Thompson et al. (2009) found their participants perceived their NEAD to be doubted by professionals, friends and family. Similarly, three participants within the current study produced constructs relating to people understanding their difficulties and not being judged, which appeared to be related to the theme ***having positive relationships***. All the participants within the current study produced constructs relating to ***experiencing emotions***, which is consistent with previous research (Carton et al., 2003; Green et al., 2004; Karterud et al., 2010; Thompson et al., 2009). Thompson et al. (2009) also identified themes relating to the experience of living with NEAs and self-doubt, which were also identified within the current study (i.e., ***being physically healthy/not experiencing NEAs*** and ***having self-belief/confidence***). Finally, the importance of ***coping*** has also been found by other studies (Karterud et al., 2010).

Overall, the current themes identified are consistent with previous studies, adding to the validity of the current findings. Subsequently, these themes appear to be common amongst individuals with NEAD, and may explain some of the participants' behaviour. It also suggests potential implications for clinical practice by targeting intervention towards modifying these constructs. It is important to note, however, that although certain themes were identified, the individual meanings may be different across participants. For example, coping appeared to have different meanings, with some participants describing problem-focused coping strategies, and others describing emotion-focused coping strategies. The relative importance of the constructs may also have differed between participants. For example, P1 demonstrated two superordinate themes relating to having *independence/freedom* and *not having seizures*, suggesting these were core to her self-identity. However, even though P7 produced constructs relating to the themes *independence/freedom* and *not having seizures*, her superordinate constructs were related to *experiencing emotions* and *having positive relationships*.

#### **4.6 Exploring construals of self and others**

##### **4.6.1 Construals of self, self before NEAD, and ideal self**

The majority of NEAD participants construed their current self negatively, whereas they construed their ideal self positively. This indicates the participants construed themselves differently than they would like to be. The participants construed themselves before NEAD as having the same characteristics as their ideal self, indicating the participants construed their current self differently (i.e., more negatively) than they were prior to their NEAD. They particularly construed themselves as being less able to cope and understand their emotions since the onset of NEAD. Overall, these findings suggest that the current participants were very unhappy with their current self and

situation. This was supported by three participants describing current suicidal ideation, and another two participants describing depression. It also indicates that the majority of participants construed a negative shift from the person they were before NEAD to their current self. This is consistent with evidence suggesting individuals with NEAD often perceive a *'loss of a previous way of life'* (Thompson et al., 2009). Interestingly, the findings also revealed many participants had an idealised construal of themselves prior to NEAD. Although this is a retrospective construal, it may suggest the participants were experiencing a sense of grief for their past self.

Although no studies have explored self-discrepancies in relation to NEAD, other studies have demonstrated similar findings with patients with physical illnesses. Turpin et al. (2009) found patients with head and neck cancers construed their ideal self as being very similar to their pre-cancer self, and far removed from their current self. Discrepancies between these self elements have been linked to depression, poor self-esteem, poor QoL, and difficulties in adjusting to illness (Compan et al., 2011; James & Large, 1992; Kempen et al., 1995; Ryle & Breen, 1971). Considering all these factors have been demonstrated within individuals with NEAD (Bowman, 2001; Bowman & Markland, 1996; Carton et al., 2003; Karterud et al., 2010; Moore & Baker, 1997; Szaflarski & Szaflarski, 2004; Thompson et al., 2009), these self-discrepancies may play an important role within NEAD, and suggests the importance of acknowledging perceived self-discrepancy within the treatment of individuals with NEAD.

Despite the majority of participants experiencing negative self perceptions, the findings revealed some participants construed their NEAD as having positive consequences (e.g., receiving more support and acceptance of self). These participants were less likely to perceive themselves as having mental health difficulties. Patients with chronic fatigue syndrome and chronic pain also describe positive changes due to their illness, such as greater understanding of self and others, better relationships, the discovery of new options in life, 'new insights' into their lives, increased self-respect and personal integrity (James & Large, 1992). This may be a common reaction when faced with life-changing circumstances. However, although cognitive conflicts were not directly measured, these positive consequences suggest cognitive conflicts were present for these participants. As discussed, P2's construct system appeared to have two incompatible goals (i.e., wanting cessation of her NEAs but also wanting to maintain her current level of support). Positive consequences and potential cognitive conflicts may be important factors for some individuals with NEAD, which other methodologies may have overlooked, particularly since standardised measures tend to focus on negative rather than positive changes.

#### **4.6.2 Construals of self compared to the other elements**

The participants did not construe themselves as having a chronic, physical health difficulty, epilepsy or having an unknown cause for their NEAs. This suggests the participants identified with having NEAD. However, they were more likely to identify with having an unknown cause to their NEAs, which may be due to most participants reporting being unsure about the specific aetiology of their NEAs. This acceptance of the NEAD diagnosis is consistent with previous findings



(Karterud et al., 2010). However, the participants did not identify their current self or self before NEAD with any of the factors found to be associated with NEAD. This suggests that whilst the participants agreed with their NEAD diagnosis 'label', they were less readily accepting of the psychological factors that characterise this diagnosis. The participants separated their current self from the majority of other elements, which indicates the participants did not identify with other people, and thus construed themselves to be distinct/different or 'alienated' from others (Feixas et al., 2004; Mottram, 1985; Woodrow et al., 2010). This fits with previous findings that individuals with NEAD often feel isolated (Thompson et al., 2009). The potential explanations for these findings shall be discussed.

#### **4.6.3 Non-identification with NEAD factors**

There are a number of potential explanations for the participants not identifying with the associated NEAD factors. It may indicate the participants were not experiencing any of these difficulties. Inconsistent with this explanation, however, is that many participants described previous and current stresses, low mood, suicidal ideation and/or traumatic experiences. This is a common finding within the literature, whereby participants acknowledge the presence of difficulties within their lives but fail to acknowledge their role within NEAD (Karterud et al., 2010). It could be argued the findings are a product of the methodology employed. However, the participants commented on the validity of the findings, suggesting this may not be a sufficient explanation. Another explanation could be lack of awareness and/or insight into their difficulties. This would suggest participants were unaware of any stresses and/or emotional difficulties. Whilst this may be possible for some participants, other participants were able to identify potential factors contributing to their NEAD, such as stress and 'bottling up' emotions. This suggests some participants had awareness of these difficulties.

Another explanation may be that the participants were engaging in a process of denial and/or suppression of these difficulties, due to these difficulties being too threatening to their self-identity. The current findings extend this argument by suggesting that rather than explicitly denying or suppressing the occurrence of their difficulties, some participants may be more likely to deny or suppress any identification with the difficulties (i.e., not allowing the difficulties to be accommodated within their self-identity). For example, whilst P5 described a history of trauma, she did not identify herself as being similar to someone with these experiences. This suggests P5 was able to acknowledge her earlier trauma but was not identifying with being a victim of this abuse and did not perceive this trauma as contributing to her NEAD. P5 construed herself positively, whereas she construed someone with a traumatic upbringing very negatively. This may suggest that identifying with her traumatic upbringing would cause a threat to her self-identity.

As discussed, non-identification with identified NEAD factors may serve to protect the participants' self-identity, particularly if the identified factors are construed more negatively than their current self. This suggests, however, that the current diagnostic and treatment process may perpetuate difficulties within individuals with NEAD. The Modegrid demonstrated that the participants

construed people with low mood, mental health difficulties and difficulties in relating to other people more negatively than their current self. It also revealed that having a physical difficulty was more acceptable than having a mental health difficulty. However, this suggests the participants were faced with a conflict, whereby accepting a mental health explanation for their NEAD would mean characterising themselves more negatively within their personal construct system. Similarly, participants construed their current self and people with an unknown cause to their seizures as being similar in relation to how negatively they were construed. However, they perceived people having an unknown cause for their seizures as being less distinct and/or alienated than having a NEAD diagnosis. Therefore, giving the NEAD diagnosis to a patient who is uncertain about the cause of their NEAs may result in the person feeling less able to identify with others. Additionally, the participants construed people who have epilepsy more positively than their current self, particularly as having more control over their seizures and having their difficulties understood by others. Therefore, for those participants who previously believed they had epilepsy, receiving a NEAD diagnosis produced a negative shift in how they perceived themselves, particularly perceiving themselves as being less in control and less understood by others. These findings are comparable to Fransella's (1968) work with stutterers, whereby the stutterers acknowledged they had difficulties speaking but did not identify themselves as being stutterers. Instead, they construed stutterers more negatively than their current self. It appears a similar process may be occurring for some participants within the present study.

These findings suggest full acceptance of their NEAD diagnosis may be detrimental to individuals' with NEAD self-identity. However, considering NEAD diagnosis and treatment is geared towards acknowledgement of psychological difficulties, attempts to convince individuals with NEAD of this may produce the resistance and lack of engagement observed within this patient population (Howlett et al., 2007). These findings also reveal a discrepancy between our theoretical perceptions of individuals with NEAD compared to the actual perceptions of individuals with NEAD, and raises an ethical question as to whether to highlight potential underlying difficulties with patients and risk them disengaging from therapy. Considering the Modegrid revealed people with anxiety, stress and traumatic upbringings were construed less negatively than people with a mental health difficulty, low mood and/or difficulties relating to others, it suggests these factors (i.e., anxiety, stress and trauma) may be a more acceptable explanation for individuals with NEAD.

#### **4.6.4 Acceptance of NEAD diagnosis versus non-acceptance of psychological factors**

As discussed, it may be possible that the participants did not identify with the NEAD factors due to protecting their self-identity. However, it does not explain why the participants identified with their 'label' of NEAD, but did not accept the underlying factors of the label. One explanation may be the lack of understanding of NEAD described by the participants, as understanding is associated with diagnosis acceptance (Green et al., 2004). It may also reflect the need for this patient population to receive a medical 'label' for their difficulties, despite not understanding or fully accepting the underlying aetiology. This is consistent with evidence from studies investigating medically unexplained symptoms, suggesting these patients seek to understand their symptoms in medical

terms (Clements, Sharpe, Simkin, Borrill & Hawton, 1997; Peters, Stanley, Rose & Salmon, 1998; Stenner, Dancer & Watts, 2000). This need for a medical explanation is supported within the current study by the participants construing having a physical health difficulty as being closer to their ideal self than other more psychological factors (e.g., mental health, low mood).

Despite this potential need for a medical label, Thompson et al. (2009) found receiving a 'label' only provided meaning for patients who were aware of underlying causes of their NEAs. As discussed, the current study suggests that presence of potential underlying factors in a patient's life (e.g., trauma, stress) may be insufficient for the patient to accept the NEAD diagnosis without the patient specifically identifying with these factors. This may explain why individuals with NEAD often acknowledge experience of psychosocial problems, but are less willing to accept the link between these problems and their NEAD (Karterud et al., 2010). Consequently, exploration should be made into patient acceptance of the underlying factors of NEAD rather than acceptance of the NEAD 'label'.

#### **4.6.5 Shift towards identifying with NEAD factors**

Although most participants did not associate their current self with having any of the difficulties associated with NEAD, they construed a negative shift towards experiencing these difficulties since the onset of NEAD. One explanation for this finding is that the participants perceived their difficulties as being a consequence of NEAD rather than involved in the development and/or maintenance of NEAD. However, it has been argued that persistent NEAD is not the cause of psychopathology (van Merode et al., 2004). This may suggest the current participants had become more aware of an underlying psychological difficulty as a result of their NEAD, which may have contributed to the negative construal shift. Although more research exploring these potential explanations is needed, the former explanation appears more plausible within the context of the current study, particularly considering the qualitative information provided by some of the participants: *"Before I had seizures, I was reasonably together...I didn't have any sort of issues, I was quite happy with myself. I had no general worries, I coped with things. I didn't have major things to deal with."* (P1). Alternatively, the participants may experience both explanations (i.e., more aware of an underlying psychological difficulty *and* perceiving difficulties as a consequence of NEAD), but potentially perceiving these difficulties as being unrelated.

#### **4.6.6 Sense of distinction/difference or alienation**

One explanation for the participants' construing themselves as being distinct/different or alienated is that they have always had this sense of distinction/alienation. However, this does not fit with the participants' construals of their past self as being able to identify with other people. Another explanation may be inherent in the nature of the disorder and the diagnostic process. Individuals with NEAD often have no knowledge of NEAD prior to their diagnosis, and many continue to be confused as to the nature of their NEAD post-diagnosis (Carton et al., 2003). Additionally, individuals with NEAD may not know anybody else with a diagnosis of NEAD (Prigatano et al., 2002), and diagnosis is often accompanied by loss of contact with their neurologist (Kanner, 2008). These factors may contribute to having a lack of frame of reference for their current difficulties and

potential future (Green et al., 2004), which may result in a sense of alienation. Consistent with Karterud et al.'s (2010) findings, this would suggest support from other individuals with NEAD would be beneficial via group-based therapy, educational booklets and websites/forums for individuals with NEAD. However, the participants did not have a shared understanding of each other's construct systems, which does not support the use of group-based interventions, particularly as differences in construct systems often lead to communication difficulties between people (Pervin & John, 2001). More research is needed to investigate the effectiveness of group interventions, and whether some individuals with NEAD would benefit more from group settings than others (i.e., those with more shared understanding).

This sense of distinction may also be due to a lack of self-integration (i.e., fragmentation). As discussed, it is important for individuals with NEAD to incorporate their NEAD within their self-identity, ideally without it becoming too all-encompassing (Fransella, 1968). However, fragmentation can occur if the onset of NEAD invalidates the person's construct system (Walker & Winter, 2007). The current findings may be due to some participants having difficulties in accommodating the NEAD diagnosis into their construct systems, and thus self-identity. This is supported by the Modegrid showing that the '*yourself*' element is isolated from most constructs (i.e., positioned outside the construct lines). This suggests this self element did not fit inside the participants' construal systems (Woodrow et al., 2010), and would suggest the participants did not have a coherent sense of self. This fits with the finding that individuals with NEAD often perceive themselves to lose the sense of feeling like a person (Thompson et al., 2009). This lack of self-integration may cause many difficulties, such as the ability to make future plans, interact with others and having self-belief, and may explain the high rates of personality disorder found within this patient population. Similar to the previously discussed mechanism, it could be postulated that this may be an attempt at protecting the integrity of their construct system, and thus their self-identity (Walker & Winter, 2007). It could also be argued that this distinction/difference could reinforce patients' sense of helplessness (i.e., 'nobody can help me'), which has clinical implications for engaging individuals with NEAD.

This lack of identification with others is not unique to individuals with NEAD (Feixas et al., 2004; Mottram, 1985). Subsequently, no firm conclusions can be made. The lack of identification could reflect borderline personality traits or depression within the participants (De Bonis et al., 1995; Space & Cromwell, 1980). Again, it is also important to acknowledge the heterogeneity of the present sample, as the '*yourself*' element was not isolated for some participants, suggesting that these participants had no difficulties with their self-identity.

#### **4.6.7 Construals of the individual factors within NEAD**

##### **4.6.7.1 Childhood Trauma**

As discussed, studies have demonstrated a high frequency of childhood abuse in individuals with NEAD (Alper et al., 1993; Cragar et al., 2002). However, none of the participants identified themselves as having had a difficult/traumatic upbringing, which is inconsistent with these previous

findings. One explanation is that the current participants had not experienced difficult/traumatic upbringings. Although childhood trauma was not directly assessed, a number of participants voluntarily described having a *'happy childhood'*. This supports Sharpe and Faye's (2006) appeal for more caution to be made before concluding that abuse is a common predisposing factor for NEAD. Despite this, two participants described a history of abuse, although did not identify themselves as having had difficult/traumatic upbringings. As discussed, it appears that for P5, identifying with her traumatic upbringing would cause a threat to her self-identity. The explanation for P7 not identifying with her traumatic upbringing is less clear, as she construed herself more negatively than all the other elements (including someone with a difficult/traumatic upbringing). It may be that P7 was struggling to incorporate her NEAD diagnosis within her personal construct system, or it may be that the distinction/alienation she currently felt was better than identifying with her difficult past. The differences between P5 and P7's difficulties may also reflect them being at different stages of their 'journey'. However, these findings may also be due to the participants not wanting to 'disclose' such experiences within the current setting.

#### **4.6.7.2 Personality Disorder**

High levels of personality difficulties have been found within individuals with NEAD compared to individuals with epilepsy and the general population (Binzer et al., 2004; Gaitatzis et al., 2004; Lacey et al., 2007; Reuber, Pukrop et al., 2004), suggesting individuals with NEAD may have difficulties with relationships. However, the participants did not see themselves as having any difficulties with relating to others, suggesting they did not perceive themselves as having personality difficulties. However, caution should be taken when interpreting this finding since no previous research has explored whether people with a diagnosis of personality disorder actually identify themselves as having difficulties relating to others.

#### **4.6.7.3 Anxiety and Depression**

Depression and anxiety are common psychiatric disorders associated within NEAD, although it is unclear whether they are a cause, consequence or unrelated to NEAD (Bodde et al., 2009b; Bowman, 2001). Considering most participants did not identify with being low in mood, it may indicate very few difficulties within the current sample. However, three participants volunteered information about current suicidal ideation, and a further two participants described current depression. It appears, therefore, that the participants did not identify with experiencing low mood despite explicitly acknowledging difficulties. As discussed, this may be due to protecting their self-identity, particularly considering people experiencing low mood were construed very negatively. It was also interesting to note that experiencing anxiety was construed more positively than being low in mood, and participants were more likely to identify with having anxiety than low mood. This suggests an anxiety-based explanation for their NEAD was more acceptable for some participants. However, caution should be taken in the interpretation of these findings as no standardised measures were used.

#### **4.6.7.4 Stress and Coping**

NEAD has been described as a coping strategy for unmanageable stress (Goldstein et al., 2000; LaFrance & Bjornaes, 2010). The participants did not construe themselves as experiencing stress, which is consistent with findings that individuals with NEAD are more likely to deny life stresses (Karterud et al., 2010; Stone et al., 2004). This may be due to not actually experiencing stress, or lacking insight and/or identification with the stresses they are experiencing. Individuals with NEAD have also been found to use more escape-avoidant coping strategies rather than problem-solving coping strategies to cope with stresses (Frances et al., 1999; Goldstein et al., 2000; Jawad et al., 1995). However, the current findings suggest the participants often construed coping differently, with some participants describing problem-focused strategies (e.g., problem-solving), and others describing more emotion-focused strategies (e.g., avoidance and acceptance). The majority of participants did, however, construe themselves as being less able to cope than they were able to before NEAD. This suggests that the participants perceived this difficulty to be a consequence of NEAD and/or a consequence of acknowledging underlying difficulties.

#### **4.6.7.5 Emotions**

It has been argued that individuals with NEAD have a higher tendency to express emotional distress as unexplained somatic symptoms (Bewley et al, 2005; Reuber, House et al., 2003), although others have contested this (Stone et al., 2006). Others have considered NEAD to be a dissociative disorder, with its function to spare the conscious self from confronting negative emotions or experiences (Bodde et al., 2009b). These explanations suggest individuals with NEAD have difficulties in understanding their emotions. The present findings confirm this, as the majority of participants construed themselves as being unable to understand their emotions. However, they did not construe themselves as having such difficulties before the onset of NEAD. Again, this suggests that the participants perceived this difficulty to be a consequence of NEAD and/or a consequence of acknowledging underlying difficulties.

### **4.7 Implications for Clinical Practice**

#### **4.7.1 Diagnosis**

The findings support the notion that there is no single mechanism or factor underlying NEAD, and thus the NEAD diagnosis may not offer any insight into the underlying aetiology of this patient population (Hoerth et al., 2008, Reuber, 2008, 2009). Moreover, the findings suggest the diagnostic system may maintain patients' difficulties. As having a physical health difficulty was construed to be preferable to a mental health difficulty, it indicates that receiving a NEAD diagnosis (i.e., a psychiatric explanation for their NEAs) may create a threat to their self-identity, causing them to perceive themselves more negatively and feel less able to identify with others. This may explain why patients often do not agree with any psychological explanation of their NEAs, and why they often do not engage in psychological intervention. This raises an ethical question as to whether to uncover underlying difficulties with these patients and risk them disengaging from services. However, it is acknowledged that avoidance of these underlying difficulties may be the

cause of their NEAs, and so not facing these issues may also result in continued NEAs. Similarly, not giving a label to their NEAs can be just as confusing as receiving the NEAD diagnosis.

These findings support the argument that forcing individuals with NEAD to accept the diagnosis can be detrimental to the patient (Kanner, 2003; Karterud et al., 2010). This highlights the need for the diagnosis to be approached gradually to allow for the gradual modification of the patients' construct systems to incorporate their NEAD, without the sudden, overwhelming threat to their self-identity. It also highlights the need for integrated working between neurologists, psychologists and other MDT members to support the patient to modify their construct systems, and foster the need for patients to incorporate and/or retain important constructs unrelated to their NEAD (Fransella, 1968; Karterud et al., 2010; Thompson et al., 2009). Additionally, the current findings revealed that a more plausible explanation for patients may be to highlight factors associated with anxiety, stress and/or trauma. Despite this, it was also suggested that acceptance of their diagnosis may be associated with how much they identify with the difficulty rather than the mere occurrence of the difficulty within their lives. As these factors may be fundamental to engagement, acceptance of the NEAD diagnosis and better prognosis, it is important to have an understanding of the patient's self-perceptions and self-identity.

#### **4.7.2 Intervention**

Due to the largely idiosyncratic construals of the participants, it would indicate that a '*one size fits all*' approach would be highly ineffective. This may partly explain why the effectiveness of treatments within NEAD has been extremely limited (Brooks, Goodfellow, Bodde, Aldenkamp & Baker, 2007). The findings support the idea that treatment should be based on the idiosyncratic needs of the individual patient. Despite this, the construct themes revealed within the current study may highlight effective strategies for a large proportion of individuals with NEAD. For example, modifying the construct ***having positive relationships*** may require supporting individuals with NEAD to foster their social interactions (e.g., increase social skills and confidence in social situations). However, considering these common constructs are embedded within a wide range of other idiosyncratic constructs, it highlights the need to formulate the individual patient's difficulties based on the entire construct system rather than a few common constructs. Another potential explanation for these idiosyncratic construals was the idea of different stages of NEAD. Although further research is necessary to establish this, it may highlight the need to tailor intervention according to the different stages of the individual patient's 'journey'. Additionally, this may also support the need to consider different stages of motivation/change, and may indicate the potential usefulness of utilising motivational interviewing techniques with individuals with NEAD (Prochaska & DiClemente, 2005).

The findings revealed a self-discrepancy between how the participants construed themselves compared to their past self (i.e., before onset of NEAD), which may suggest that intervention aimed at addressing this sense of grief may be helpful. Acknowledgement of these self-discrepancies may also allow the patient and clinician to work towards reducing this discrepancy

(Higgins, 1987). As discussed, the current findings also suggest that intervention with individuals with NEAD should focus on constructing a cohesive self-identity, which incorporates their NEAD but also emphasises themselves as more than just their NEAD (Fransella, 1968; Karterud et al., 2010). Additionally, the presence of cognitive conflicts may explain the lack of engagement with psychological intervention, and would suggest intervention aimed at addressing these conflicts would be beneficial.

The nature of individuals' with NEAD feeling of being distinct/alienated potentially suggests the usefulness of increasing group activities for individuals with NEAD (Compan et al., 2011). Similarly, some participants mentioned how having support from other individuals with NEAD would be useful. Interestingly, these participants demonstrated the most shared understanding within the SocioNet analysis (e.g., P6). Support groups for individuals with NEAD would foster this need for having positive relationships and interactions with others without the fear of being judged. This would also help individuals with NEAD to use each other for educational support and finding out strategies for how other individuals with NEAD cope with their difficulties. However, the finding that there was no shared understanding amongst the participants may suggest that group work may not be effective, or may only be effective for individuals with NEAD who have capacity to understand other people's perspectives. This lack of identification with others can also be modified by cognitive interventions aimed at the individuals with NEAD learning to perceive themselves as similar to others (Space & Cromwell, 1980).

The current findings also suggest the need for more service-related interventions. Firstly, the participants construed people with epilepsy as being more in control and better understood than individuals with NEAD. Considering individuals with epilepsy were construed as being closer to their ideal self than their current self, it would suggest that making individuals with NEAD feel more in control and understood would be useful at improving their self-esteem and QoL. This may be achieved by methods such as increased healthcare staff training and education of NEAD, and increased public awareness of NEAD (O'Sullivan, Sweeney & McNamara, 2006). Secondly, the findings also suggest that upon receiving the NEAD diagnosis, patients are faced with a threat to their self-identity. However, diagnosis may be followed by a referral to a clinical psychology department waiting list and accompanied by loss of contact with their neurologist (Kanner, 2008). Therefore, there is often a reduction of support during this vulnerable period. As argued by others (Karterud et al., 2010; Thompson et al., 2009), this highlights the need for integrated working between healthcare professionals involved in their care. Finally, similar to previous research (Carton et al., 2003; Karterud et al., 2010; Thompson et al., 2009), it was found that the majority of participants had a poor understanding of NEAD, particularly of the underlying causes of their NEAD. On some occasions, the participants' medical records stated that the participant had been given an explanation of NEAD during their previous neurology appointment. However, it may be that the level of stress, compounded by some potentially reported memory difficulties, may render this process more difficult to understand and retain. It highlights an area for consideration within



services, particularly considering understanding of the diagnosis has been found to be effective in reducing NEAs (Farias et al., 2003; Reuber & Elger, 2003).

### **4.7.3 Repertory Grid Technique as a Clinical Tool**

The researcher found the RGT to be a useful and efficient way of measuring the perceptions of individual patients. Repertory grid methodology has been used on a clinical basis to explore patients' personal construct systems to help guide formulation and intervention (Slater, 1969), and has been used as an outcome measure following intervention (Winter, 1992). Although the RGT may not be used as a diagnostic tool, it may be an important clinical tool for the idiosyncratic formulation and treatment of individuals with NEAD. For example, although the researcher did not conduct the interviews in a clinical capacity, the usefulness of the repertory grid methodology in aiding formulation and guiding intervention for individual participants was observed. For example, P3 construed positive emotions as being highly associated with people being understanding and supportive. This may suggest that working together with P3 to try to increase the understanding of her family and friends may be beneficial to her mood. P4's repertory grid revealed her predominant 'black and white' style of thinking, which may suggest cognitive-behavioural therapy aimed at modifying this thinking style will be beneficial for P4. Finally, since P8 placed a high value on feeling connected to people, intervention may incorporate her maintaining and/or increasing her current levels of social support. Interestingly, P8 commented on her current ability to cope well with her NEAD was fostered by the planning and joint support of her school/college, friends and family. This provides some support for systemic intervention (e.g., involving family/friends, education and employment) in the management of NEAD. Despite these advantages, it is important to note that the RGT can be a distressing process, particularly when patients become aware of any self-ideal self discrepancy (Higgins, 1987; Turpin et al., 2009). It would, therefore, be important to consider the ethics of conducting a repertory grid with individual patients, and where indicated, to receive appropriate supervision.

## **4.8 Methodological Considerations**

The RGT was deemed appropriate to explore the subjective experiences and perceptions of individuals with NEAD. The next two sections highlight the methodological strengths and limitations of the present study.

### **4.8.1 Methodological Strengths**

#### **4.8.1.1 Subjective Perceptions**

The flexible nature of the RGT allowed the individuals with NEAD to use their own idiosyncratic language and valued perceptions to illustrate their construal of themselves, others and their disorder. This ensured that the participants generated their own perceptions rather than having perceptions imposed upon them (Bannister, 1965). This is a significant difference from the largely quantitative methodologies that have previously been utilised within the NEAD literature, which could arguably be forcing the researcher's own interpretation of the world onto the individuals with NEAD. These idiosyncratic meanings explored within this technique made it a user-friendly and

ecologically valid tool for assessing the subjective perceptions of participants. Furthermore, the technique enabled the exploration of *'what'* (i.e., via exploration of their valued constructs) and *'how'* (i.e., how they rated themselves and others on their valued constructs) individuals with NEAD think about their worlds, which using a purely qualitative or quantitative methodology would have been unable to achieve (Jankowicz, 2004; Winter, 1992). It was also possible to explore their personal construct systems as a whole, such as whether individuals with NEAD have flexibility in their construing (i.e., cognitive complexity; Bieri et al., 1966) or shared understanding of each other's ways of viewing the world (Applegate et al., 1991).

#### **4.8.1.2 Idiographic and Nomothetic Design**

The joint idiographic and nomothetic nature of the methodology was considered a strength of the present study. The RGT incorporated both the quantitative features of numerical data collection and statistical analysis (Fransella et al., 2004), as well as the qualitative features of the detailed information obtained from the participant descriptions (Ashworth, 2003). The idiographic focus of the methodology enabled the individual perspectives to be explored, without losing sight of each individual participant. However, the nomothetic (i.e., averaged) perspective of the individuals with NEAD allowed for the exploration of further propositions to be investigated. It also enabled exploration as to whether participants were able to have a shared understanding of each others' difficulties. Previous research has predominantly utilised questionnaire-based, nomothetic techniques to investigate different aspects of NEAD, which arguably do not allow for the finer nuances to be explored in the experience of individuals with NEAD. This is particularly important considering the idiographic analysis within the present study was able to reveal the heterogeneity of the participants' construing, which the nomothetic analysis would have overlooked.

#### **4.8.1.3 Researcher Bias**

As succinctly phrased by P6, *"if you would have asked me the questions about 'where would I be?', you wouldn't have got a true reading"*. This highlights the difficulties inherent in researching patient perceptions, particularly the patient's need to portray themselves in a socially desirable manner. However, the nature of the RGT enables the researcher to explore both the explicit and implicit perceptions of participants whilst minimising interviewer bias (Fransella et al., 2004; Kelly, 1955; Winter, 1992). This was found to be particularly significant within the present study, considering it revealed that some participants construed implicit gains as a result of their NEAD diagnosis. Furthermore, as the interpretation of the repertory grids is inherent within the statistical analysis (i.e., the pringrids are directly produced from the statistical analysis), it minimises the likelihood of researcher bias.

#### **4.8.1.4 Qualitative Information**

Qualitative information was captured via tape-recordings of all interviews and feedback sessions. The participants' qualitative information supported the analyses conducted, which validates the results found as being an accurate representation of the participants perceptions rather than being an artefact of the methodology (Howitt & Cramer, 2005). The richness of the data gathered was considered a strength of the present study. However, due to the vast amount of data produced,

only a limited number of participant quotes have been illustrated throughout the results section, resulting in a significant amount of information being lost within the analysis. Consequently, it would have been useful to have utilised a combined methodology of RGT and another qualitative method (e.g., IPA). This merging of methodologies has been utilised in previous studies (e.g., Turpin et al., 2009) and has been found to be useful in extending and enriching the understanding of participants' perceptions and experiences.

#### **4.8.1.5 Feedback**

Repertory grid studies have consistently found the process to be enjoyable and thought-provoking for participants (Winter, 1992; Woodrow et al., 2010). In support of this, the majority of participants within the current study described the process as being interesting and enjoyable, with many describing wanting to show their pringrid to other healthcare professionals to help others understand their perspective. However, three participants became distressed when talking about their current difficulties. Interestingly, the researcher found the nature of the pringrid useful in managing the participants' distress, by focusing the participant's attention on one of their bipolar constructs and aiding problem-solving and goal-setting. For example, if the participant specifically focused on the bipolar construct *difficulty talking to people—able to talk to people*, they were able to think of small steps to help move themselves towards their ideal self. Subsequently, these participants were able to focus on this one component of the grid more easily and with less distress than looking at the pringrid as a whole. However, this raises an ethical question of the utilisation of this technique with distressed patients, and particularly whether this process is more (or less) distressing for patients than taking part in other methodologies (e.g., questionnaire-based or interview-based).

#### **4.8.1.6 Validity**

Since there is no standard form of repertory grid, it poses a problem for making generalisations about their validity (Winter, 1992). Despite this, validity has been described within PCT as the usefulness of a technique, and its capacity to increase our understanding (Bannister & Fransella, 1971; Fransella et al., 2004). The current study achieved this aim by increasing our knowledge of how individuals with NEAD construe themselves and others within their world. On this basis, the present study can be determined to be valid. In support of this, a further validity check was sought by means of respondent validation, which is an integral process within repertory grid methodology (Tindall, 1994). During each individual participant's feedback meeting, the participant reported that their pringrid accurately represented their experiences and perceptions. All participants reported finding the repertory grid process beneficial as it allowed them to think about themselves in more detail and 'put things into perspective', which demonstrates the ecological and face validity of the RGT used. Finally, the study's validity was strengthened via the triangulation of participant feedback, qualitative information gathered throughout the interviews and the statistical analyses. Again, this supports that the findings were 'true' to the participants' construct systems rather than an artefact of the technique itself (Howitt & Cramer, 2005).

## **4.8.2 Methodological Limitations**

### **4.8.2.1 Generalisability**

The current findings represent the construals of twelve individuals with NEAD on the waiting list of a particular neuropsychology service within the North-West of England. Consequently, the idiographic nature of the methodology utilised within this study does not allow the findings to be generalised across other individuals with NEAD or other services. Despite this, the non-reductionist nature of the methodology was considered a strength of this exploratory study. Additionally, the present study was cross-sectional in nature, and therefore only gives one 'snapshot' in time of the participants' dynamic and flexible construct systems (Large & Strong, 1997). Subsequently, it would be interesting to utilise a longitudinal design to explore the participants' journey in their adjustment and/or development of their construct systems since the onset of NEAD. It may also be useful in recording changes in personal construct systems before and after intervention (Large, 1985a, 1985b)

### **4.8.2.2 Sample Demographics**

Although the small sample size reduces the generalisability of the findings, it was deemed an appropriate size for the aims of this exploratory study (Durand et al., in press; Fransella et al., 2004; Woodrow et al., 2010). The current sample was considered to be representative of individuals with NEAD in terms of age of NEAD onset (Alper, 1994), gender (Alper, 1994; Lesser, 1996; Moore & Baker, 1997), and previous misdiagnosis of epilepsy (Betts & Boden, 1992). One participant had a further diagnosis of chronic fatigue syndrome, and another participant had additional unexplained neurological symptoms. This is consistent with studies indicating other unexplained symptoms are common in individuals with NEAD (Bowman & Markland, 1996; Mogleby et al., 2002).

Although not intentional, none of the participants had a comorbid diagnosis of epilepsy. This may not be representative of individuals with NEAD, as 10-60% of individuals with NEAD also have comorbid epilepsy (Abubakr et al., 2003; Betts, 1990; Betts & Boden, 1992; Devinsky et al, 1996). However, this 'pure' group of individuals with NEAD could arguably be considered a strength of the study. This may be due to patients with comorbid epilepsy not being willing to participate in 'NEAD research', or maybe it represents lack of referrals of patients with comorbid epilepsy to the neuropsychology department. It is a strength of the present study that all diagnoses had been made by an experienced consultant neurologist. However, it is worth noting that misdiagnosis can be common (Brown et al., 2011), and confirmation of NEAD on ambulatory-EEG and/or video-EEG cannot completely rule out the presence of epilepsy (and vice versa).

### **4.8.2.3 Sample Recruitment**

Due to the sample being recruited from a specialist neuropsychology service waiting list, there may have been an element of recruitment bias, as these patients may be more likely to have chronic difficulties and experience increased psychological and social difficulties compared to community samples. Although the present sample may not be representative of individuals with NEAD within

the community, recruitment from a community sample would have posed problems relating to accuracy of diagnoses. Additionally, as some participants experience a cessation of NEAs upon the diagnosis of NEAD (Reuber & Elger, 2003), these patients may not have been referred to the neuropsychology service. As previously discussed, it may also be possible that the individuals with NEAD go through different stages of adjusting to their NEAD, such as denial, anger, depression and acceptance (Hendler, 1981), and so the present sample may represent patients within similar stages, such as anger and depression rather than denial and acceptance. Alternatively, the heterogeneity finding within the present study may represent each patient being at a different stage of adjusting to their NEAD diagnosis. Finally, as all the participants volunteered to take part in the study, it may be that these patients were more psychologically minded and/or open to self-exploration than other individuals with NEAD. Alternatively, the current sample of individuals with NEAD may have been less psychologically minded, and maybe volunteered to take part to express their dissatisfaction with their current NEAD diagnosis. However, this latter explanation may be less plausible due to the majority of participants explicitly agreeing with their NEAD diagnosis.

#### **4.8.2.4 Data Analysis**

As discussed, nomothetic methodology aims at making classifications of a group of people by averaging their experiences and perceptions. Consequently, caution must be taken when interpreting the results of the multiple grid analyses due to the reductionism of the rich data to form generalisations (Leach, Freshwater, Aldridge & Sunderland, 2001; Ralley et al., 2009). This can lead to information being lost and the findings not being representative of any single participant's experiences. Similarly, a common criticism of repertory grids is the lack of a standardised measure to compare the results against, which can lead to misinterpretation of the findings (Rawlinson, 1995). Therefore, it would have been useful to include standardised measures within the current study to check the present findings, particularly measures of depression and anxiety within the current sample of individuals with NEAD.

#### **4.8.2.5 Elements**

As repertory grids are conducted in relation to a specific topic, we are only able to explore a small part of a person's construct system. Subsequently, the elements supplied within the present study were deliberately chosen on the basis of previous research into NEAD and previous repertory grid research, which would limit the material produced by the participants. However, this was deemed to be less restrictive than a questionnaire-based design. It is also important to note that the findings may have been impacted by the negative connotations of the supplied elements, which may have increased the participants need to protect their self-identity. The present study also assumes that participants used similar rating styles when rating the elements (Leach et al., 2001), which could potentially have an impact on the composite analyses (i.e., when the element ratings are combined). Finally, it may have been possible for different meanings to be ascribed to the elements. For example, one participant may have selected a person with severe and chronic mental health difficulties when thinking about the element *someone with a mental health problem*, whereas another participant may have selected someone with mild/moderate mental health difficulties. These differences may have had an impact on the findings.

Upon reflection, a number of other elements would have been useful to include within the present study. For example, *someone who has NEAD* was decided to be excluded from the current study due to the anticipated difficulties of the participants identifying another person as having a diagnosis of NEAD, and to reduce the possibility of participants requesting information about NEAD during the elicitation process. However, this may not have posed a problem and would have been a useful element to incorporate within the study. It would also have been useful to incorporate more self elements within the present study to potentially highlight the patient's journey (Turpin et al. 2009), such as *self five years before seizures, self one year before seizures, self when seizures started* and *self in five years time*. However, similar to the *self before seizures* element used within the present study, it is acknowledged that these elements are rated retrospectively, which could have an impact on findings. As discussed, a more longitudinal design may be beneficial, which would also help reduce this retrospective rating bias.

#### **4.9 Researcher's Reflections**

##### **4.9.1 Risk Issues**

Previous research has demonstrated that up to one-third of individuals with NEAD experience depression (Bowman 2001; Moore & Baker, 1997), with suicide attempts being relatively common amongst individuals with NEAD (Carton et al., 2003; Lacey et al., 2007; Moore & Baker, 1997; Thompson et al., 2009). Although the current study did not explicitly measure levels of depression and/or suicidal ideation using standardised tools, three participants expressed suicidal ideation and a further two participants described current difficulties with depression. This implies that at least 42% of the current sample described current difficulties. A further two participants reported previous suicidal attempts with no current suicidal ideation. The current rates of suicidal ideation found within the present study appeared to be similar to previous findings (Lacey et al., 2007). However, as suicidal ideation was not directly assessed within the present study (i.e., participants readily volunteered this information), no firm conclusions can be drawn. It may be possible that some participants were experiencing similar thoughts but did not want to discuss this with the researcher. Upon participants revealing current or previous suicidal ideation, the researcher conducted a thorough risk assessment to determine the participant's safety. All participants who reported current suicidal ideation stated they had no plans to act on their thoughts and identified protective factors for minimising this risk. They were made aware of the pathways to follow should these thoughts increase or felt they were at risk of harming themselves. The researcher also discussed individual risk with her supervisor, and for one participant it was deemed appropriate to offer a sooner psychological assessment appointment within the neuropsychology department.

##### **4.9.2 Reflexivity**

It was important to acknowledge the power imbalance between the researcher and participants within the study, particularly as a number of participants expressed negative beliefs and emotions towards healthcare professionals. It was important for the researcher to take a non-expert role.

Similar to pure qualitative methodological approaches, the methodology used within the present study adopted the premise that the researcher is an integral component of the research process, and that complete neutrality and objectivity is not possible (Neimeyer, 2002). The interview itself takes part within an interaction between the researcher and participant and, therefore, will have an impact on the findings. Reflexivity refers to the *"acknowledgment by the researcher that his/her own actions and decisions will inevitably impact upon the meaning and context of the experience under investigation"* (Horsburgh, 2003, p.308). Reflexivity can be enhanced by the researcher being clear about his/her own personal, disciplinary and theoretical perspectives.

Consequently, the principal researcher of this study is a 25-year-old, single, White-British female from a working-class background. During the production of this thesis, she was completing her final year of a three-year doctorate in clinical psychology at The University of Manchester. Before commencing the course, the researcher had experience of working within a clinical health in-patient setting. Her interest in NEAD was borne out of her interest and experience in the interaction between physical and mental health, and not wanting to *'lose sight'* of the patient/client. The study was initially designed to be a quantitative study, but due to recruitment difficulties as a result of the highly specialist population, it was changed to the current repertory grid design. Upon reflection, the researcher deemed this new design to be a more appropriate methodology for the research aims, despite her initial anxieties at the change. This perspective represents the filter through which the results were construed, and subsequently reported. Therefore, this current study can be deemed to be the researcher's construal of the participants' construals (Kelly, 1955), which is recognised as a limitation of the present study.

#### **4.10 Implications for Future Research**

As far as the researchers are aware, this study was the first to utilise repertory grid methodology with individuals with NEAD. As such, the findings of this study are deemed to be exploratory. It was evident that there were a number of key findings that nomothetic, questionnaire-based designs would have overlooked, such as the heterogeneity amongst the participants and the positive consequences of NEAD. Consequently, it may be fruitful for further research to continue to explore perceptions of individuals with NEAD using this methodology. It may also be useful for future studies to use combined methodology, such as RGT with IPA or grounded theory (Glaser & Strauss, 1967), as this may provide greater richness of data and increase the validity of the findings (Turpin et al., 2009). The current participants and researcher found the RGT to be a useful tool to allow for the assessment and formulation of individual difficulties. It may, therefore, be useful for future studies to evaluate the effectiveness and usefulness of the RGT as a clinical tool. Additionally, as the present study did not employ standardised measures, it was not possible to compare the results of the repertory grid analyses against these measures. It may be useful for future research to check whether the results from standardised measures and results from repertory grid match, particularly considering the discrepancy found within the current study between talking about experiencing difficulties with low mood but not identifying with being low in mood. This may provide better understanding of the lack of identification with psychological

factors found within the present study, and also would help evaluate the usefulness of using standardised measures within this patient population.

Due to the exploratory nature of the study and the small sample size, future research could investigate the generalisability of the present findings within larger samples of individuals with NEAD and within different services. If these findings are replicated with different individuals with NEAD and within different settings, this would increase the generalisability of the present findings, and would provide further support for investigating specific findings in greater detail. Further research could, therefore, focus on one or more of the current findings in greater detail. For example, it was suggested that the development of NEAD led to changes within the participants' construct systems. However, as construct systems are continuously being modified by experiences (Kelly, 1955; Large & Strong, 1997), it may be useful to investigate the nature of these construct system changes throughout the course of the journey from pre-diagnosis to post-therapy. This may highlight potential stages of NEAD, and may help clinicians and researchers understand any changes within patient constructs that are associated with better prognosis. Similarly, it was also found that some participants had incorporated their NEAD into their self-identity. According to Fransella (1968), people who incorporate their symptoms into their self-identity may find it difficult to abandon the symptoms due to the subsequent threat to their self-identity. It may therefore, be postulated that those patients who have incorporated NEAD into their self-identity may demonstrate poorer prognosis. More longitudinal studies would be necessary to establish the effect of patient construct systems on prognosis.

According to the fragmentation corollary within PCT, and supported by previous research investigating cognitive conflicts, people can have incompatible subsystems within their personal construct system. The current study demonstrated that cognitive conflicts may be pertinent to individuals with NEAD, particularly for patients who construe positive consequences from their NEAD. However, the findings also suggest that conflicts occur when clinicians attempt to diagnose and modify patients' illness beliefs. Future research would be useful to further explore the effect of diagnosis and psychological treatment on patients' self-identity, as well as investigating the presence of cognitive conflicts within individuals with NEAD. It would also be useful to investigate the hypothesis that acceptance of a psychological aetiology to their NEAD is more likely if the patient identifies with the difficulty, rather than simply acknowledging the occurrence of the difficulty in their life. Similarly, it would be useful to tease apart the reasons for the negative shift in the participants identifying with the factors associated with NEAD, such as whether they perceive the shift as a consequence of NEAD or as a consequence of realising the underlying difficulty.

It has been argued that conflicts addressed during the therapy process may lead to better prognosis, and so future research could investigate the effectiveness of interventions aimed at addressing cognitive conflicts. The importance of identifying potential cognitive conflicts is a premise of some interpersonal therapies, such as cognitive-analytical therapy (CAT; Ryle, 1995).



Consequently, it may be useful for future research to investigate the effectiveness of CAT within this patient population. Similarly, the present study identified themes amongst the participants' construct systems, which were consistent with previous findings. Future studies could explore the effectiveness of intervention, when the intervention is based on modifying these particular construct themes. If this is effective, it would support the use of a manualised treatment approach. However, the current findings suggest the heterogeneity of the construct systems would be more important to address. Consequently, it could be investigated whether modification of these more idiosyncratic constructs leads to better prognosis. This would support the usefulness of a more individualised treatment approach. Considering the current participants did not demonstrate any shared understanding, more research may be useful in establishing the effectiveness of group interventions and/or whether some patients are more likely to benefit from particular interventions on the basis of their capacity to understand others' experiences.

The present study revealed that individuals with NEAD may have a self-ideal self discrepancy and often feel distinct/alienated from others. More research would be beneficial exploring the potential role of self-identity difficulties, such as lack of self-integration, within individuals with NEAD. This study would also postulate that considering the patient's self-identity within therapy, such as being able to construct a new sense of self that does not focus on NEAD, would lead to better engagement and prognosis. It may be useful for future research to explore this possibility. The study also demonstrated that participants had an idealised construal of their past self. The potential grief reaction and adjustment difficulties associated with grief reactions may be worth exploring with individuals with NEAD.

As this study only incorporated perceptions of individuals with NEAD, no conclusions can be made as to whether their ways of construing are different from the general population or other patient populations (e.g., individuals with epilepsy and/or other individuals with somatoform disorders). Future research may compare the construct systems of individuals with NEAD with other groups to explore any differences that may be used to differentiate between the groups. For example, it may be postulated that individuals with NEAD have different ways of construing in comparison to individuals with epilepsy. This appears to be supported by evidence that individuals with NEAD could be distinguished from individuals with epilepsy via interactional and linguistic analysis (Plug, Sharrack & Reuber, 2009; Reuber, Monzoni, Sharrack & Plug, 2009), which suggests potential differing personal construct systems underlying their behaviour and interactions with others. These previous studies found that individuals with NEAD were less likely to volunteer information and make more redundant speech. The findings from the present study would hypothesise that this type of speech may be due to ongoing cognitive conflicts during interaction with healthcare professionals. Future research could explore this further. Additionally, other repertory grid studies have investigated the perceptions of staff regarding different clients (Blundell et al., 2011; Ralley et al., 2009; Woodrow et al., 2010). Consistent with other studies, the present study found that individuals with NEAD often perceive a discrepancy between how healthcare professionals treat individuals with NEAD and individuals with epilepsy. Similarly, Shneker and Elliott (2008) found

healthcare professionals often have misperceptions that NEAs are voluntary. It would, therefore, be useful to investigate the perceptions of healthcare professionals who work with individuals with epilepsy and NEAD (e.g., neurologists, epilepsy nurses, psychologists and accident and emergency staff).

Finally, the relationship between cognitive complexity and NEAD did not demonstrate a clear pattern of results. However, future research may be useful to explore the impact of higher cognitive complexity on individuals' with NEAD ability to cope with their NEAD, and explore whether there is a non-linear relationship between cognitive complexity and NEAD and/or difficulties coping with NEAD. It may also be beneficial to establish the impact of cognitive complexity on prognosis. It could be postulated that those with higher cognitive complexity may construe their difficulties in a more flexible way, which may have implications for their adaptability and willingness to understand the importance of psychological intervention within their NEAD. If this is the case, then ways to increase cognitive complexity may be a useful intervention for individuals with NEAD.

#### **4.11 Conclusions**

This exploratory study investigated the subjective perceptions of individuals with NEAD using repertory grid methodology from PCT (Kelly, 1955). The current study adds to the limited evidence-base exploring patient perceptions and experiences of NEAD (Carton et al., 2003; Karterud et al., 2010), and increases our understanding of the construal of patients with this complex disorder. As far as the researchers are aware, this was the first study to incorporate the repertory grid methodology to explore the perceptions of individuals with NEAD, and adds to the wide range of clinical applications using this methodology.

In line with PCT, the current study maintained focus on each individual participant's experiences and perceptions. Despite some themes being identified, the findings revealed the uniqueness of the participants' ways of construing. This finding, along with the varied levels of cognitive complexity and lack of shared understanding found amongst the participants, reflects the heterogeneity of individuals with NEAD. This highlights the importance of idiosyncratic formulation and intervention when working with individuals with NEAD. The participants' construals indicated that most were very unhappy with their current self and situation and no longer perceived themselves to be the person they were before NEAD. They also felt distinct and/or alienated. Conversely, some participants were happy with how they perceived themselves and some construed positive consequences as a result of their NEAD. The findings also revealed that whilst most participants agreed with their NEAD diagnosis 'label', they were much less readily accepting of the psychological factors that characterise this diagnosis. Finally, physical health difficulties were construed as being preferable to mental health difficulties.

The potential explanations for these findings have been explored, but it was particularly interesting to note how the current diagnostic and treatment system for individuals with NEAD may serve to

perpetuate their difficulties, particularly in relation to threatening their sense of self. However, it is important to acknowledge the exploratory nature of the present study, and thus further research investigating the current findings in greater depth is necessary.

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## **Appendices**

### **Appendix A – Participant Information Sheet**

#### **The experience of non-epileptic attack disorder (NEAD): A repertory grid study examining NEAD patient’s construal of their disorder**

**Please read this sheet carefully.**

I am asking if you would like to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information and decide whether or not you wish to take part. Ask us if there is anything that is not clear or if you would like more information.

#### **What is the study about?**

This study will look at in people’s experience of non-epileptic attack disorder (NEAD).

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

If you decide to take part you will be asked to sign a consent form, and be given a copy of it to keep. You are free to withdraw from the study at any time without giving a reason, and it will not affect the standard of care you receive.

#### **What does the study involve?**

The study involves completing an interview (with one researcher) asking questions about how you see yourself compared to others. It should last approximately 1 hour. You will be given the option to either complete the interview within your own home or within the Clinical Neuropsychology Department at \_\_\_\_\_. If you come to the department, you will then be reimbursed (up to a maximum £10) for your travel/parking expenses.

You will also be given an option of having a second appointment with the same researcher to feedback the results of the initial interview. Again, this can be conducted either within your own home or within the Clinical Neuropsychology Department at \_\_\_\_\_. Again, if you come to the department, you will then be reimbursed (up to a maximum £10) for your travel/parking expenses.

#### **What will happen to me if I decide that I might like to take part?**

If you might want to take part in the study, please complete the enclosed “Consent to be Contacted Form” and return it in the pre-paid envelope provided. A member of the research team will then contact you via telephone to give further information about the study and answer any questions you may have. If you then agree to take part in the study an appointment time will be arranged to take place, depending on your preference, either within your own home or at the Clinical Neuropsychology Department at \_\_\_\_\_.

The interview will be conducted by a researcher. You will be provided with descriptions, such as “someone with epilepsy” or “yourself before you developed seizures”, and will be asked to compare ways in which these are similar or different from each other and yourself now. You will not be asked to name real people. This will last approximately 1 hour. The interview will be audio-taped, which will then be stored securely and confidentially within the Clinical Neuropsychology Department at \_\_\_\_\_, and destroyed when the study is finished. Once the interview is complete, a few questions about yourself (e.g., your age, marital status and employment status), and also about your condition (e.g., how long you have suffered with NEAD, whether you are receiving any medication) will be asked. You will also be asked whether it would be possible for the researchers to access your medical notes to gather more medical information about your condition.

#### **What are the likely benefits?**

The study will add to our understanding of non-epileptic attack disorder (NEAD). It will help to indicate more clearly the experiences of people with non-epileptic attack disorder (NEAD).

**Will personal details be kept confidential?**

All information that is collected about you during the course of the research will be kept strictly confidential and anonymous. This means that only a number (not your name) will be stored on any information you give, to ensure your identity remains private. The audio-tape will be transcribed with all names omitted, will be stored in a locked filing cabinet, and will be destroyed after the study finishes. With your permission, we would like to inform your GP (and neurologist, if applicable) if you agree to take part in the study.

**What if I change my mind?**

You do not have to take part in this study. If you have agreed to take part, you can stop at any time without giving any reasons. This will have no effect on any services you are receiving.

**Who can I talk to for further information?**

If you would like further information about the study, please complete the enclosed "Consent to be Contacted Form" and return it in the pre-paid envelope provided. A member of the research team will then contact you via telephone to give further information about the study and answer any questions. Any further queries, please contact the researcher on 0161 306 0400.

**What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 2757583 or 0161 2758093 or by email to [research-governance@manchester.ac.uk](mailto:research-governance@manchester.ac.uk).

**PLEASE DO NOT HESITATE TO ASK IF YOU HAVE ANY QUESTIONS**  
**Thank you for reading this information sheet**

## **Appendix B – Covering Letter**

Dear Patient,

I am a doctoral student at The University of Manchester, and I am conducting a research study as part of the requirements of my training, investigating patients' experiences of non-epileptic attack disorder (NEAD). As you are a patient of the clinical neuropsychology department at \_\_\_\_\_, I would like to invite you to take part in this research study.

Please read the enclosed participant information sheet carefully, which describes what the study involves in more detail. If you might like to take part, please complete the enclosed "Consent to be Contacted Form" and return it in the pre-paid envelope provided. I will then contact you via telephone to give you further information about the study and answer any questions you may have. Thank you for your consideration.

With kind regards,

Jennifer Vaughan  
Trainee Clinical Psychologist

Under the supervision of Dr. Helen Caswell  
Clinical Neuropsychologist



**Appendix C - Consent to be Contacted Form**

**Project: The experience of non-epileptic attack disorder (NEAD): A repertory grid study examining individuals with NEAD' construal of their disorder**

Researcher's: Jennifer Vaughan (Trainee Clinical Psychologist)  
Dr Helen Caswell (Clinical Neuropsychologist)  
Dr. Richard Brown (Clinical Psychologist)  
Dr. Dougal J. Hare (Clinical Psychologist)

If you would like to take part in the study please insert your details below and return this form in the pre-paid envelope provided. A member of the research team will contact you to discuss participation and/or answer any questions you may have.

Please tick

I agree that the researchers may contact me via telephone to discuss participation in the study. I understand that I am only consenting to be contacted so that I can obtain further information about the study and to have the opportunity to have any questions answered. It does NOT mean I am consenting to take part in the study.

Full Name (*please print*).....

Address.....

Telephone Number (*essential*).....

Specify any preferable times/days to be contacted.....

Date.....

Signed.....

## **Appendix D: Interview Protocol (adapted from Woodrow et al., 2010)**

### **Materials:**

Participant information sheet  
Consent form  
Electronic voice recorder (+ spare batteries)  
Blank audio-cassette tape  
Cards with the 14 elements written on them  
A laminated scale running from one to seven  
Random number sequence  
Blank repertory grid  
Example of pringrid  
Pens  
Diary  
Tissues  
Reimbursement money and receipt (if applicable)

### **Introduction:**

Hi. My name is XXX. Thank you for agreeing to meet with me today. To begin with, can you please read over the participant information sheet? I'm supervised by XXX who works at XXX. However, anything you say to me will be anonymised, so no one but me will know what you have said. The only exception to this would be if I became worried that you might harm yourself or anyone else.

To help me remember the detail and meaning of what you say, I would like to record this session. You can ask for the recording to be stopped at any time. I am the only person who will have access to the recording. I'm going to tell you about my research so that you can decide whether you would like to take part. We have between an hour and an hour and half booked in today but it's fine if you want to stop before that.

If you are happy to carry on, could you please sign the consent form?

### **Presenting the research:**

The aim of the research is to explore how people with non-epileptic attack disorder (NEAD) perceive their disorder and other aspects of their life. If you agreed to take part, you would be asked to think of 14 different people, which match particular descriptions. These can be real people that you know, a celebrity, or even an imaginary/made-up person.

Once you have picked the 14 people, you will be shown three people at a time and asked to think about a way in which they are similar or different to each other. When you have thought of something, you will be then asked to tell me its opposite. For example, I would give you three people to think about and you might think that two are funny. That would be the similarity. Then I would ask you to tell me what the opposite of funny was for you. You might say 'boring', or 'serious' or 'inappropriate'. After this, I will then ask you to rate all 14 people with regard to what you have said.

I am interested in what you think so there are no right or wrong answers. And the process will become clearer once we go through it. You can stop, take a break or withdraw from the study at any time.

At the end of the interview, we will have a grid of numbers indicating how you rated different people with regard to the different qualities/characteristics. After I have analysed these ratings on a computer, I would then like to come back and let you see the results so you can tell me if it fits with your views. The computer will produce a 'mental map' of your views based on the ratings you have given, and will look something like this (show example of pringrid). Some people have found this process interesting and informative at how they see themselves and their experiences.

Do you have any questions about that?

*Start Audio-tape*

**Eliciting elements (i.e., 'people'):**

Ok, the first step is to think about these people (*show cards of 14 elements*) and to ask you to think of someone for each card. 'Yourself now', 'Yourself before seizures' and 'Ideal self' (*point to these three card*) refers to yourself at different time points and how you would like to be. The others need you to identify someone you know who fits the heading, or *imagine* what a person would be like that fitted that description. When you think of someone, just write their initials on the back of the card or some other way of identifying them by.

*Go through all 14 elements.* I would like you to think about those people you have chosen. Do you think those people are typical of the description on the cards? *If participant says yes – continue. If they say no, ask them to also think of someone more typical of the description and add that to the appropriate card.*

*If the participant is unable to think of someone for a card, they can be asked to imagine a person that matches the description (an imaginary person). The participant would be excluded from the study if they could not think of people to assign three or more descriptions to.*

**Eliciting constructs (i.e., qualities/characteristics):**

Ok, I'm going to show you three of the cards and I would like you to tell me a way in which two of the people are similar and therefore different from the third. If you want a different set of three cards at any point, for any reason, just let me know and I'll change them. (*Give out three cards, working through the list of randomly generated combinations provided on a separate sheet*). So, how are two of these people the same and therefore different from the third?

*If participant struggles to think of anything ask if they understand. If they do but find it difficult ask if they would like to change the cards. If they seem unsure of what is being asked remind them that there is no right or wrong answer and give this example – 'for example, maybe two are funny and the other is not.'* Wait for response. *If participant still cannot do it, go through instructions and example again.*

*When participant gives a construct, get a behavioural example by responding:*

Ok, so what does (*insert construct*) look like? What kind of person is like that? and/or "What does that look like?."

That's great. What is the opposite of *answer*? I know it might seem obvious to you, but can I check which one of those things (X or Y) is more positive? That's great. So we have *X* at one end (*put X at one end of scale on the blank repertory grid, with the more positive response going on the right*) and *Y* at the other end (*put Y at other end of scale*).

*Ladder-up to obtain any superordinate constructs:* Can I just check with you, why it is more positive for you to be *X* rather than *Y*? What is important about being *X*? If participant gives another construct, following the same procedure as above (i.e., Ok, so what does (*insert construct*) look like? What kind of person is like that? and/or "What does that look like?." That's great. What is the opposite of *answer*? I know it might seem obvious to you, but can I check which one of those things (X or Y) is more positive? So we have *X* at one end (*put X at one end of scale on the blank repertory grid, with the more positive response going on the right*) and *Y* at the other end (*put Y at other end of scale*).

*Give next randomised card set. Continue eliciting constructs until no new constructs are elicited, or until approximately 15-20 constructs have been elicited. Offer a break at this point.*

**Rating elements:**

Ok, so now can we go through all the 14 people and can you tell me where you would rate them on a scale of one to seven. *Start by writing the first bi-polar construct elicited on a laminated scale so they can always see their construct. Read out each element description and remind them of the person they picked as matching that description and put a score in for the construct (e.g., thinking about someone who copes well, you decided your mum was someone who particularly copes well, where would you rate them on this scale?)*

Here is how that looks (*show repertory grid to them*). Does that seem ok? *Make any changes required. Continue rating each element again each of the bi-polar constructs elicited.*

**Demographics:**

Before we finish, can I ask you some basic information? *Complete demographics sheet. Continue to audio-tape.*

**Debrief:** *At the end of the session:*

Thank you very much for going through that with me. How do you feel? Did you enjoy the session? Now we have this grid, I'm going to go and put the information into the computer. That will put the results into a table and plot the information on a pringrid (*show example of pringrid again*). Would you like to meet again so that I can go through those results with you? Does that sound ok? Do you have any questions? Thank you very much for your time. I'll stop the recording now.

Stop Audio-tape

*(Arrange feedback appointment; give money reimbursement and receipt to sign if necessary).*

**Feedback Session**

Thank you for meeting with me again. This appointment is to discuss the results from last session and to see whether it fits with your views. *Check if still ok to audio-tape. If ok, start audio-tape. Show the repertory grid (biplot) and describe the constructs that were close to each other, the elements that were close to each other, and then the two together.*

—If people are close together, it means they tended to receive similar ratings to each other, and if the words or phrases are close together, it means they tended to receive similar ratings to each other ||

—If a person is close to one end of a pole, it means they tended to get ratings towards that end of the pole on the rating scale ||  
Describe the grid.

— Does this sound right to you? Does it make sense? Is there anything that strikes you, or surprises you? Is there anything you do not agree with? Do you have any questions and/or any further comments? Again, thank you for taking part in this study.

**Appendix E – Participant Written Consent Form**

Name of participant: .....

**Project: The experience of non-epileptic attack disorder (NEAD): A repertory grid study examining individuals with NEAD' construal of their disorder**

Researcher's: Jennifer Vaughan (Trainee Clinical Psychologist)  
Dr Helen Caswell (Clinical Neuropsychologist)  
Dr. Richard Brown (Clinical Psychologist)  
Dr. Dougal J. Hare (Clinical Psychologist)

Please tick

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

Please tick

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

Please tick

I agree for the researchers to inform my neurologist and/or GP that I am taking part in the study.

Please tick

I agree for the interview to be audio-taped. I have been made aware that this data will be stored securely and confidentially, and will be destroyed upon completion of the study.

Please tick

I agree to the publication of direct quotations from the interview. I have been made aware that these quotations will be fully anonymised and confidentiality will be maintained.

Please tick

I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

Please tick

I agree to take part in the study.

.....  
Name of participant (print)

.....  
Signed

.....  
Date

.....  
Name of researcher (print)

.....  
Signed

.....  
Date

**Appendix F– Blank Repertory Grid Recording Sheet**

Negative Pole	1. Yourself now	2. Ideal self (where you would like to be)	3. Yourself before you had seizures	4. Someone who has seizures but is uncertain about the cause.	5. Someone with epilepsy	6. Someone who has a mental health problem	7. Someone who has a long-standing, chronic physical illness	8. Someone who has experienced a difficult/traumatic upbringing	9. Someone who finds it difficult to relate to other people	10. Someone who finds it easy to understand their feelings/emotions	11. Someone who is under a lot of stress	12. Someone who copes well	13. Someone who is low in mood	14. Someone who is anxious	Positive Pole

## **Appendix G - Socio-Demographic and Clinical Information Questionnaire**

Participant Identification Number:.....

Date:.....

1. **Age** (in years): \_\_\_\_\_
2. **Gender** (please circle)            male / female
3. **Marital Status** (please circle)  
single / married / separated / divorced / widowed / other, specify \_\_\_\_\_

4. **Ethnicity** (please tick)
  - \_\_\_\_\_ British
  - \_\_\_\_\_ Irish
  - \_\_\_\_\_ Any other white background
  - \_\_\_\_\_ White and Black Caribbean
  - \_\_\_\_\_ White and Black African
  - \_\_\_\_\_ White and Asian
  - \_\_\_\_\_ Any other mixed background
  - \_\_\_\_\_ Indian
  - \_\_\_\_\_ Pakistani
  - \_\_\_\_\_ Bangladeshi
  - \_\_\_\_\_ Any other Asian background
  - \_\_\_\_\_ Caribbean
  - \_\_\_\_\_ African
  - \_\_\_\_\_ Any other black Background
  - \_\_\_\_\_ Chinese
  - \_\_\_\_\_ Any other Ethnic group
  - \_\_\_\_\_ I did not wish to disclose

5. **Which of the following best describes your current employment status?** (please tick)
  - \_\_\_\_\_ Full-time Employment
  - \_\_\_\_\_ Part-time Employment
  - \_\_\_\_\_ Unemployed
  - \_\_\_\_\_ Student
  - \_\_\_\_\_ Retired
  - \_\_\_\_\_ Other, specify \_\_\_\_\_

6. **What is highest level of education you achieved?** (please tick)
  - \_\_\_\_\_ None/Less than high school
  - \_\_\_\_\_ GCSE's/O-Levels (or equivalent)
  - \_\_\_\_\_ A-Levels (or equivalent)
  - \_\_\_\_\_ Bachelor's Degree (or equivalent)
  - \_\_\_\_\_ Master's Degree (or equivalent)
  - \_\_\_\_\_ Doctorate (or equivalent)
  - \_\_\_\_\_ Other, specify \_\_\_\_\_

7. **Approximately how old were you when you first developed your condition?**
  - \_\_\_\_\_ 8 years old or younger
  - \_\_\_\_\_ 9 – 13 years old
  - \_\_\_\_\_ 14 – 17 years old
  - \_\_\_\_\_ 18 – 21 years old
  - \_\_\_\_\_ 22 – 25 years old
  - \_\_\_\_\_ 26 – 30 years old
  - \_\_\_\_\_ 31 – 40 years old
  - \_\_\_\_\_ 41 – 50 years old
  - \_\_\_\_\_ 50 years old or older
  - \_\_\_\_\_ Unknown

**8. How often do you currently experience seizures?**

- At least once a day
- Once a week
- Once a fortnight
- Once a month
- Once every three months
- Once every six months
- Once per year
- Less than once per year

**9a. Have you received a diagnosis of epilepsy?** (please circle)

Yes / No / Don't Know

**9b. Do you agree with this diagnosis?** (please circle)

Yes / No / Don't Know

**9c. If so why/why not?**

---

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**10. Do you have a diagnosis of non-epileptic attack disorder (NEAD)** (please circle)

Yes / No / Don't Know

**10b. Do you agree with this diagnosis?**

Yes / No / Don't Know

**10c. If so why/why not?**

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**11. Have you ever been prescribed anti-epileptic medication?** (please circle)

Yes, currently / Yes, but not currently / No

**12. What do you know about NEAD?**

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**13. In your opinion, what do you believe is the main cause of your seizures?**

---

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## **Appendix H – Individual Repertory Grid Analysis Data**

### **P1's HCA Data**

#### **Elements**

- 1 = Yourself now
- 2 = Ideal self
- 3 = Yourself before you had seizures
- 4 = Someone who has seizures but is uncertain about the cause
- 5 = Someone with epilepsy
- 6 = Someone who has a mental health problem
- 7 = Someone who has a chronic, physical health difficulty
- 8 = Someone who has experienced a difficult/traumatic upbringing
- 9 = Someone who finds it difficult to relate to other people
- 10 = Someone who finds it easy to understand their feelings/emotions
- 11 = Someone who is under a lot of stress
- 12 = Someone who copes well
- 13 = Someone who is low in mood
- 14 = Someone who is anxious

#### **Element matches**

*	1	2	3	4	5	6	7	8	9	10	11	12	13	14
*****														
1 *	100	29	38	75	77	51	50	47	58	34	59	39	47	61
2 *	29	100	83	16	39	13	60	56	21	78	48	70	7	22
3 *	38	83	100	25	43	24	59	68	32	79	58	79	18	34
4 *	75	16	25	100	57	65	33	40	67	23	56	30	63	65
5 *	77	39	43	57	100	38	63	48	47	42	57	43	33	47
6 *	51	13	24	65	38	100	31	41	88	21	61	30	89	80
7 *	50	60	59	33	63	31	100	54	41	59	62	56	25	42
8 *	47	56	68	40	48	41	54	100	49	68	73	78	39	49
9 *	58	21	32	67	47	88	41	49	100	28	68	37	81	84
10 *	34	78	79	23	42	21	59	68	28	100	59	85	16	30
11 *	59	48	58	56	57	61	62	73	68	59	100	67	56	68
12 *	39	70	79	30	43	30	56	78	37	85	67	100	26	39
13 *	47	7	18	63	33	89	25	39	81	16	56	26	100	76
14 *	61	22	34	65	47	80	42	49	84	30	68	39	76	100

#### **Constructs**

- 1 = Unhappy—Happy/content
- 2 = Stressed—Content
- 3 = Difficulty relating—Relaxed
- 4 = Anxious—Coping with things
- 5 = Having seizures—Not having seizures
- 6 = Planning life around seizures—Being healthy
- 7 = Having to think about doing things—Freedom
- 8 = Falling to pieces—Coping well
- 9 = Confused—Knowing your feelings
- 10 = Nervous—Confident

#### **Construct matches (reverse match on diagonal and below)**

*	1	2	3	4	5	6	7	8	9	10
*****										
1 *	44	86	77	80	40	59	67	70	73	81
2 *	48	47	71	78	38	57	62	64	69	73
3 *	40	44	28	83	39	57	63	85	91	79
4 *	43	46	34	36	41	56	63	73	82	82
5 *	46	49	37	41	0	38	41	45	42	45

6 \* 32 35 26 31 24 3 87 57 61 65  
 7 \* 33 37 28 31 25 8 10 63 67 75  
 8 \* 38 42 25 33 28 22 24 20 87 74  
 9 \* 39 43 27 32 33 22 24 23 24 80  
 10 \* 41 46 34 37 35 24 25 31 31 33

**P1's PCA Data**

**Percentage variance in each component**

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>%</b>	69.50	18.36	6.21	2.60	1.72	1.17
<b>Cumulative %</b>	69.50	87.85	94.07	96.66	98.28	99.56

**Construct loadings on each component**

<b>Construct</b>	<b>Component</b>					
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>1</b>	1.67	-.065	-0.22	0.86	0.22	0.25
<b>2</b>	1.27	-0.65	-0.44	0.83	-0.51	-0.20
<b>3</b>	2.39	-1.07	-0.06	-0.22	-0.02	-0.00
<b>4</b>	1.99	-0.88	-0.73	-0.17	0.21	-0.60
<b>5</b>	0.85	2.59	-1.39	-0.08	-0.19	0.04
<b>6</b>	2.94	1.44	1.20	0.11	-0.14	-0.29
<b>7</b>	2.97	1.15	0.53	0.17	0.25	0.08
<b>8</b>	2.65	-0.60	-0.05	-0.33	-0.52	0.51
<b>9</b>	2.66	-0.69	-0.11	-0.52	-0.19	-0.09
<b>10</b>	2.34	-0.09	-0.43	-0.06	0.71	0.23

**P2's HCA Data**

**Elements**

- 1 = Yourself now
- 2 = Ideal self
- 3 = Yourself before you had seizures
- 4 = Someone who has seizures but is uncertain about the cause
- 5 = Someone with epilepsy
- 6 = Someone who has a mental health problem
- 7 = Someone who has a chronic, physical health difficulty
- 8 = Someone who has experienced a difficult/traumatic upbringing
- 9 = Someone who finds it difficult to relate to other people
- 10 = Someone who finds it easy to understand their feelings/emotions
- 11 = Someone who is under a lot of stress
- 12 = Someone who copes well
- 13 = Someone who is low in mood
- 14 = Someone who is anxious

**Element matches**

*	1	2	3	4	5	6	7	8	9	10	11	12	13	14
*****														
1 *	100	34	46	55	50	37	54	55	43	34	41	52	53	56
2 *	34	100	40	21	78	29	37	49	11	72	53	71	31	38
3 *	46	40	100	52	56	48	51	65	43	48	57	54	66	64
4 *	55	21	52	100	37	55	65	46	67	22	41	37	64	66
5 *	50	78	56	37	100	41	52	63	26	73	59	80	48	53
6 *	37	29	48	55	41	100	53	45	61	31	48	41	60	64
7 *	54	37	51	65	52	53	100	53	55	35	50	49	69	68
8 *	55	49	65	46	63	45	53	100	43	60	66	71	60	60
9 *	43	11	43	67	26	61	55	43	100	17	37	28	65	65
10 *	34	72	48	22	73	31	35	60	17	100	59	76	37	42

11	*	41	53	57	41	59	48	50	66	37	59	100	68	55	63
12	*	52	71	54	37	80	41	49	71	28	76	68	100	48	53
13	*	53	31	66	64	48	60	69	60	65	37	55	48	100	78
14	*	56	38	64	66	53	64	68	60	65	42	63	53	78	100

**Constructs**

- 1 = Stressed—Laid back
- 2 = Depressed—Happy with self
- 3 = Not coping well—Coping well
- 4 = Bottling up stress—Releasing stress
- 5 = No support—Having support
- 6 = Not in control—In control
- 7 = Hibernating—Doing more in life
- 8 = Not relating to others—Relating to others
- 9 = Others not relating to you—Others able to relate to you
- 10 = Not able to understand NEAs—Able to understand NEAs
- 11 = Treating people badly—Friendly
- 12 = Worrying—Coping with worrying
- 13 = Self-absorbed—Putting others first
- 14 = Life put on hold—Life continues
- 15 = Long-term upset—Dealing with upsets
- 16 = Fear of life—Coping/Not fearful

**Construct Matches (reverse match on diagonal & below)**

*	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	
*****																	
1	*	21	70	60	68	45	54	61	48	57	55	45	73	55	61	59	64
2	*	32	30	50	66	50	54	62	43	56	54	48	73	50	57	68	74
3	*	27	38	12	58	50	57	60	64	53	69	56	63	69	55	54	56
4	*	35	41	34	34	47	62	66	51	59	66	53	73	60	64	70	65
5	*	53	55	40	61	35	49	47	53	63	52	56	41	44	36	65	46
6	*	39	45	31	41	53	27	80	67	72	69	69	59	65	69	60	65
7	*	36	41	30	40	57	30	29	62	65	62	64	71	63	76	64	73
8	*	41	52	25	46	45	32	35	21	69	65	81	51	73	62	53	57
9	*	48	56	44	56	53	42	47	40	47	59	69	54	60	63	64	63
10	*	36	42	23	37	47	31	36	30	47	22	66	61	77	58	62	60
11	*	48	52	33	50	47	34	38	27	45	33	28	53	69	61	62	61
12	*	26	30	25	32	57	35	30	38	51	32	41	21	64	71	65	76
13	*	36	44	22	39	54	32	35	26	46	25	31	30	21	69	53	64
14	*	30	38	28	36	63	29	28	30	43	33	34	26	27	19	53	75
15	*	44	44	41	45	49	47	46	49	58	42	47	40	49	47	42	62
16	*	37	36	35	43	61	39	36	41	52	39	42	30	36	30	50	33

**P2's PCA Data**

**Percentage variance in each component**

	1	2	3	4	5	6	7	8	9
%	55.44	13.80	9.61	6.18	4.99	3.65	2.47	1.87	1.03
Cumulative %	55.44	69.23	78.84	85.01	90.00	93.65	96.12	97.99	99.02

**Construct loadings on each component**

	1	2	3	4	5	6	7	8	9
1	1.84	0.34	0.33	0.29	-0.80	-0.45	-0.25	0.71	-0.60
2	1.24	1.32	1.26	-0.22	-0.46	0.38	-0.56	-0.19	-0.12
3	2.52	-1.51	0.34	-0.78	-0.74	-0.82	0.29	-0.12	0.18
4	1.62	0.43	0.41	-0.24	1.05	-0.36	0.14	0.82	0.40
5	-0.037	-1.41	1.66	0.56	-0.54	-0.03	-0.09	-0.16	0.33
6	2.13	0.13	-0.13	0.90	0.74	-0.64	-0.41	-0.43	-0.18
7	2.23	0.80	0.02	0.52	0.14	-0.68	0.50	-0.60	-0.02

<b>8</b>	1.99	-1.37	-0.69	0.53	-0.44	0.33	0.27	0.23	-0.08
<b>9</b>	0.89	-0.28	-0.10	1.51	-0.18	0.10	-0.49	0.28	0.32
<b>10</b>	2.27	-1.13	0.38	-0.63	0.93	0.12	-0.72	-0.13	-0.10
<b>11</b>	1.67	-0.73	-0.07	0.49	0.16	1.02	0.42	-0.15	-0.21
<b>12</b>	2.47	0.90	0.44	0.57	-0.20	0.09	0.43	0.05	-0.04
<b>13</b>	2.46	-0.86	-0.86	-0.76	0.09	0.45	-0.29	-0.04	-0.01
<b>14</b>	2.55	0.96	-1.14	0.36	-0.16	0.16	0.17	0.04	0.25
<b>15</b>	0.93	0.05	1.62	0.34	0.67	0.49	0.59	0.10	-0.13
<b>16</b>	1.91	1.27	0.16	-0.27	-0.60	0.49	-0.30	-0.15	0.39

**P3's HCA Data**

**Elements**

- 1 = Yourself now
- 2 = Ideal self
- 3 = Yourself before you had seizures
- 4 = Someone who has seizures but is uncertain about the cause
- 5 = Someone with epilepsy
- 6 = Someone who has a mental health problem
- 7 = Someone who has a chronic, physical health difficulty
- 8 = Someone who has experienced a difficult/traumatic upbringing
- 9 = Someone who finds it difficult to relate to other people
- 10 = Someone who finds it easy to understand their feelings/emotions
- 11 = Someone who is under a lot of stress
- 12 = Someone who copes well
- 13 = Someone who is low in mood
- 14 = Someone who is anxious

**Element matches**

*	1	2	3	4	5	6	7	8	9	10	11	12	13	14
*****														
1 *	100	34	50	66	65	53	49	54	52	39	48	38	63	61
2 *	34	100	62	41	56	62	64	37	48	81	80	81	17	14
3 *	50	62	100	54	55	57	52	66	72	70	67	68	40	39
4 *	66	41	54	100	58	48	47	63	69	46	52	43	66	64
5 *	65	56	55	58	100	80	79	50	50	60	70	59	41	39
6 *	53	62	57	48	80	100	81	46	47	65	73	66	30	27
7 *	49	64	52	47	79	81	100	40	42	65	76	65	26	23
8 *	54	37	66	63	50	46	40	100	77	48	49	44	60	61
9 *	52	48	72	69	50	47	42	77	100	54	55	52	57	55
10 *	39	81	70	46	60	65	65	48	54	100	84	91	24	22
11 *	48	80	67	52	70	73	76	49	55	84	100	80	29	27
12 *	38	81	68	43	59	66	65	44	52	91	80	100	21	19
13 *	63	17	40	66	41	30	26	60	57	24	29	21	100	91
14 *	61	14	39	64	39	27	23	61	55	22	27	19	91	100

**Constructs**

- 1 = On edge—Relaxed
- 2 = Being negative—Staying positive
- 3 = Under stress—Chilled out
- 4 = Angry—Happy
- 5 = Worrying—Outgoing
- 6 = No ambition—Knowing where want to go
- 7 = Experiencing illness—Not experiencing illness
- 8 = Dealing with barriers—Not dealing with barriers
- 9 = Closed in—Feel free
- 10 = Stressing—Coping
- 11 = Insecure—Secure
- 12 = Needing to explain—People understand
- 13 = Not knowing feelings—Understanding feelings

**Construct matches (reverse match on diagonal and below)**

* 1 2 3 4 5 6 7 8 9 10 11 12 13
*****
1 * 22 81 74 76 82 68 46 48 70 71 72 78 82
2 * 26 24 81 82 81 71 48 50 78 77 78 87 96
3 * 32 31 32 83 73 62 44 54 76 77 83 80 80
4 * 33 33 37 37 74 70 47 47 78 90 76 85 83
5 * 28 29 36 38 29 71 56 54 72 71 69 73 80
6 * 28 28 37 35 31 21 62 47 69 68 54 66 71
7 * 42 42 51 51 38 29 19 58 53 44 37 41 46
8 * 43 43 44 54 42 43 34 24 60 42 49 45 48
9 * 37 36 40 43 40 37 46 45 40 73 72 76 76
10 * 32 31 34 34 35 32 49 55 40 29 72 81 77
11 * 25 24 27 31 30 34 49 40 34 29 18 80 78
12 * 24 23 28 29 29 28 45 45 34 27 22 20 87
13 * 24 23 29 31 28 27 42 43 35 29 23 22 22

**P3's PCA Data**

**Percentage variance in each component**

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>%</b>	66.99	19.22	5.13	3.25	1.63	1.24
<b>Cumulative %</b>	66.99	86.21	91.33	94.59	96.22	97.45

**Construct loadings on each component**

<b>Construct</b>	<b>Component</b>					
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>1</b>	2.47	0.08	-1.00	-0.42	0.33	0.25
<b>2</b>	2.48	0.10	-0.05	-0.10	0.06	-0.49
<b>3</b>	2.18	-0.53	0.64	-0.24	0.06	0.35
<b>4</b>	1.74	-0.48	0.01	0.30	-0.04	0.27
<b>5</b>	2.15	0.71	-0.56	-0.72	-0.28	0.16
<b>6</b>	1.56	1.53	-0.52	0.78	0.35	0.19
<b>7</b>	0.11	2.92	0.00	-0.03	-0.59	-0.08
<b>8</b>	1.14	1.51	1.32	-0.42	0.50	0.13
<b>9</b>	1.85	0.24	0.46	0.84	-0.12	-0.07
<b>10</b>	1.62	-0.57	0.07	0.36	-0.40	0.44
<b>11</b>	2.72	-0.96	0.46	-0.28	-0.45	-0.14
<b>12</b>	2.56	-0.50	-0.03	0.33	0.05	-0.22
<b>13</b>	2.54	-0.00	-0.17	-0.04	0.19	-0.41

**P4's HCA Data**

**Elements**

- 1 = Yourself now
- 2 = Ideal self
- 3 = Yourself before you had seizures
- 4 = Someone who has seizures but is uncertain about the cause
- 5 = Someone with epilepsy
- 6 = Someone who has a mental health problem
- 7 = Someone who has a chronic, physical health difficulty
- 8 = Someone who has experienced a difficult/traumatic upbringing
- 9 = Someone who finds it difficult to relate to other people
- 10 = Someone who finds it easy to understand their feelings/emotions
- 11 = Someone who is under a lot of stress
- 12 = Someone who copes well
- 13 = Someone who is low in mood
- 14 = Someone who is anxious

**Element matches**

*	1	2	3	4	5	6	7	8	9	10	11	12	13	14
*****														
1 *	100	16	14	89	69	68	64	68	83	26	90	21	92	87
2 *	16	100	93	23	42	46	52	47	31	87	19	89	20	23
3 *	14	93	100	21	40	43	50	44	29	85	17	89	18	21
4 *	89	23	21	100	77	75	71	73	87	33	92	28	90	93
5 *	69	42	40	77	100	91	87	85	84	51	73	47	72	76
6 *	68	46	43	75	91	100	89	89	83	55	71	50	71	73
7 *	64	52	50	71	87	89	100	91	78	62	67	56	67	71
8 *	68	47	44	73	85	89	91	100	83	56	70	51	71	72
9 *	83	31	29	87	84	83	78	83	100	41	83	35	83	85
10 *	26	87	85	33	51	55	62	56	41	100	30	91	30	33
11 *	90	19	17	92	73	71	67	70	83	30	100	24	91	92
12 *	21	89	89	28	47	50	56	51	35	91	24	100	25	28
13 *	92	20	18	90	72	71	67	71	83	30	91	25	100	88
14 *	87	23	21	93	76	73	71	72	85	33	92	28	88	100

**Constructs**

- 1 = Under stress—Being calm
- 2 = Sad—Happy
- 3 = Difficulties talking to people—Chat to anybody
- 4 = Uncertainty—Relaxed
- 5 = Having seizures—Not having seizures
- 6 = Being ill—Being well
- 7 = Wanting to be alone—Wanting to be in company
- 8 = Thinking about the difficulties—Positive about life
- 9 = Anxious—Calm
- 10 = Not coping—Getting on with things
- 11 = Worrying about doing things—Not having to think about doing things
- 12 = Not able to relate—Being confident
- 13 = Not liked by others—Liked by others

**Construct Matches (reverse match on diagonal & below)**

*	1	2	3	4	5	6	7	8	9	10	11	12	13
*****													
1 *	29	86	84	85	83	87	85	85	85	86	85	85	84
2 *	35	39	90	91	76	88	90	90	91	91	92	91	92
3 *	40	44	48	92	75	85	87	86	88	87	87	88	89
4 *	42	46	51	52	74	85	88	87	89	87	88	89	90
5 *	21	27	32	33	11	82	80	81	78	79	78	78	76
6 *	33	38	43	45	24	35	94	91	92	90	91	92	91
7 *	35	39	44	46	26	37	38	94	96	92	94	96	94
8 *	32	36	41	43	23	34	35	32	92	92	94	92	91
9 *	36	40	45	46	27	37	39	36	39	94	96	100	96
10 *	32	36	41	43	24	34	36	33	36	33	96	94	92
11 *	34	38	43	45	25	36	37	34	37	34	36	96	94
12 *	36	40	45	46	27	37	39	36	39	36	37	39	96
13 *	37	40	45	47	28	38	40	37	40	37	39	40	41

**P4's PCA Data**

**Percentage variance in each component**

	<b>1</b>	<b>2</b>	<b>3</b>
<b>%</b>	95.78	1.54	1.30
<b>Cumulative %</b>	95.78	97.33	98.63

**Construct loadings on each component**

Construct	Component		
	1	2	3
1	2.46	-0.49	-0.38
2	2.24	-0.02	-0.34
3	1.85	-0.25	-0.32
4	1.73	-0.05	-0.37
5	3.04	-0.64	0.52
6	2.38	0.11	0.29
7	2.28	0.18	0.21
8	2.52	-0.02	0.21
9	2.26	0.32	0.03
10	2.48	0.23	-0.14
11	2.38	0.22	-0.02
12	2.26	0.32	0.03
13	2.18	0.28	-0.04

**P5's HCA Data**

**Elements**

- 1 = Yourself now
- 2 = Ideal self
- 3 = Yourself before you had seizures
- 4 = Someone who has seizures but is uncertain about the cause
- 5 = Someone with epilepsy
- 6 = Someone who has a mental health problem
- 7 = Someone who has a chronic, physical health difficulty
- 8 = Someone who has experienced a difficult/traumatic upbringing
- 9 = Someone who finds it difficult to relate to other people
- 10 = Someone who finds it easy to understand their feelings/emotions
- 11 = Someone who is under a lot of stress
- 12 = Someone who copes well
- 13 = Someone who is low in mood
- 14 = Someone who is anxious

**Element matches**

*	1	2	3	4	5	6	7	8	9	10	11	12	13	14
*****														
1 *	100	66	64	79	75	47	63	60	60	76	78	66	64	71
2 *	66	100	70	63	60	29	46	39	56	69	80	81	46	74
3 *	64	70	100	69	65	35	56	44	60	69	72	71	56	75
4 *	79	63	69	100	74	49	62	53	58	73	75	67	66	73
5 *	75	60	65	74	100	61	72	69	60	81	72	64	72	71
6 *	47	29	35	49	61	100	63	69	42	54	43	36	72	46
7 *	63	46	56	62	72	63	100	73	49	75	61	50	71	60
8 *	60	39	44	53	69	69	73	100	55	65	52	43	72	52
9 *	60	56	60	58	60	42	49	55	100	61	59	65	61	63
10 *	76	69	69	73	81	54	75	65	61	100	84	70	71	80
11 *	78	80	72	75	72	43	61	52	59	84	100	76	60	84
12 *	66	81	71	67	64	36	50	43	65	70	76	100	53	80
13 *	64	46	56	66	72	72	71	72	61	71	60	53	100	63
14 *	71	74	75	73	71	46	60	52	63	80	84	80	63	100

**Constructs**

- 1 = Introvert—Very Outgoing
- 2 = Sad/Distressed—Content
- 3 = Missing out—Having everything
- 4 = Being false—Being yourself
- 5 = Selfish—Very giving
- 6 = Unable to relate—Able to relate

- 7 = Becoming the illness—Learning to live
- 8 = Lonely—Being loved
- 9 = Isolated—Busy
- 10 = Weak—Strong
- 11 = Judged—Not judged
- 12 = People not bothered—Being enquired about
- 13 = Going under—Coping
- 14 = Lacking self belief—Believing in self
- 15 = Misunderstood—Understood
- 16 = Depression—Having reason to get up

**Construct matches (reverse match on diagonal and below)**

*	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
*****																
1 *	35	74	73	62	69	50	85	73	64	81	66	63	85	81	74	80
2 *	45	44	85	51	58	44	70	67	56	67	73	55	74	70	69	65
3 *	47	47	47	57	64	50	69	72	58	69	72	61	71	68	69	65
4 *	35	49	45	17	86	77	66	74	57	73	57	80	67	63	69	65
5 *	35	48	45	21	23	69	74	81	59	81	62	77	71	68	73	74
6 *	44	56	50	20	26	16	52	67	53	60	51	74	57	52	60	52
7 *	34	44	46	31	31	40	30	75	62	83	68	64	85	86	77	81
8 *	44	54	51	33	34	36	41	42	70	81	73	80	76	71	79	75
9 *	43	55	54	36	39	39	42	43	30	66	61	67	64	62	65	61
10 *	39	51	51	32	33	38	37	43	44	38	68	71	79	80	78	80
11 *	53	55	57	47	47	51	49	53	54	54	50	65	71	73	80	61
12 *	45	58	54	27	32	29	42	41	40	43	53	33	69	65	74	61
13 *	40	49	52	36	38	42	38	47	47	44	54	45	42	85	81	75
14 *	40	51	53	38	39	45	37	48	48	43	52	47	43	40	82	70
15 *	48	57	58	39	41	44	44	50	50	49	55	47	49	48	50	68
16 *	30	41	41	26	26	33	27	35	36	31	46	37	35	36	42	20

**P5's PCA Data**

**Percentage variance in each component**

	1	2	3	4	5	6	7	8
%	55.63	14.49	8.00	7.02	6.71	3.06	1.83	1.09
Cumulative %	55.63	70.12	78.12	85.14	91.85	94.91	96.73	97.82

**Construct loadings on each component**

Construct	Component							
	1	2	3	4	5	6	7	8
1	-2.11	0.44	0.02	0.30	0.33	0.50	0.01	0.06
2	-1.67	0.36	-0.44	0.45	-0.85	0.22	-0.18	-0.21
3	-1.37	-0.05	-0.29	0.70	-1.13	0.14	0.42	0.01
4	-0.96	-1.33	0.01	-0.01	0.20	0.19	0.20	-0.12
5	-1.56	-1.19	0.16	0.08	0.17	-0.24	0.28	0.19
6	0.41	-1.61	-0.06	0.24	0.01	0.19	-0.44	-0.36
7	-2.12	0.41	-0.33	-0.11	0.33	-0.15	0.16	0.12
8	-1.17	-0.50	0.58	0.05	-0.47	-0.27	-0.14	0.16
9	-0.43	1.01	1.78	0.01	-0.11	0.23	0.02	-0.21
10	-1.71	-0.35	0.31	0.04	0.55	-0.15	0.28	-0.42
11	-0.98	-0.01	0.05	-1.05	-0.94	-0.53	-0.13	-0.14
12	-0.44	-0.96	0.68	-0.52	-0.22	0.55	0.04	0.33
13	-1.61	0.28	-0.39	-0.23	0.10	0.57	-0.45	0.08
14	-1.61	0.53	-0.51	-0.76	0.46	0.07	0.18	-0.16
15	-1.12	-0.18	-0.02	-0.96	-0.07	0.02	-0.15	0.03
16	-2.30	0.10	0.29	0.73	0.42	-0.59	-0.46	0.15



## **P6's HCA Data**

### **Elements**

- 1 = Yourself now
- 2 = Ideal self
- 3 = Yourself before you had seizures
- 4 = Someone who has seizures but is uncertain about the cause
- 5 = Someone with epilepsy
- 6 = Someone who has a mental health problem
- 7 = Someone who has a chronic, physical health difficulty
- 8 = Someone who has experienced a difficult/traumatic upbringing
- 9 = Someone who finds it difficult to relate to other people
- 10 = Someone who finds it easy to understand their feelings/emotions
- 11 = Someone who is under a lot of stress
- 12 = Someone who copes well
- 13 = Someone who is low in mood
- 14 = Someone who is anxious

### **Element matches**

*	1	2	3	4	5	6	7	8	9	10	11	12	13	14
*****														
1 *	100	34	48	76	80	69	70	64	74	36	72	40	64	71
2 *	34	100	83	26	38	22	43	66	27	94	29	89	19	49
3 *	48	83	100	41	50	37	52	80	41	86	44	89	33	64
4 *	76	26	41	100	69	77	56	57	77	29	83	34	76	66
5 *	80	38	50	69	100	57	82	64	63	39	61	42	52	64
6 *	69	22	37	77	57	100	43	53	85	24	81	30	86	69
7 *	70	43	52	56	82	43	100	62	50	44	50	46	40	56
8 *	64	66	80	57	64	53	62	100	58	68	59	72	49	78
9 *	74	27	41	77	63	85	50	58	100	30	80	35	82	73
10 *	36	94	86	29	39	24	44	68	30	100	32	91	21	53
11 *	72	29	44	83	61	81	50	59	80	32	100	37	82	71
12 *	40	89	89	34	42	30	46	72	35	91	37	100	27	57
13 *	64	19	33	76	52	86	40	49	82	21	82	27	100	63
14 *	71	49	64	66	64	69	56	78	73	53	71	57	63	100

### **Constructs**

- 1 = Struggling—Coping
- 2 = Sad—Happy
- 3 = Being negative—Being positive
- 4 = Antisocial—Sociable
- 5 = Hard to see reality—Being realistic
- 6 = Stressed/Anxious—Level-headed
- 7 = Isolated—Comfortable
- 8 = Disability—Able-bodied
- 9 = Having to rely on others—Independence
- 10 = Physically unhealthy—Physically healthy
- 11 = Viewed negatively by others—Not judged/Taken on face value
- 12 = Mentally affected—Not mentally affected
- 13 = Physically affected—Not physically affected
- 14 = Situation is fixed—Situation is changeable

### **Construct Matches (reverse match on diagonal & below)**

*	1	2	3	4	5	6	7	8	9	10	11	12	13	14
*****														
1 *	35	91	84	92	78	81	85	81	83	56	77	85	65	67
2 *	35	33	88	90	76	84	87	78	81	52	76	85	62	62
3 *	36	34	33	87	78	87	89	80	80	51	79	87	59	58
4 *	35	34	35	34	77	83	89	83	85	55	79	89	65	64
5 *	36	36	35	36	30	71	76	71	72	57	75	76	58	64
6 *	34	33	32	33	35	28	91	77	77	47	75	85	56	54
7 *	36	35	34	35	36	32	34	81	82	52	79	87	61	60

8 \* 38 38 37 37 39 36 38 36 92 65 87 85 75 71  
 9 \* 38 38 38 38 40 37 38 37 38 65 87 85 77 72  
 10 \* 44 47 47 44 41 48 47 39 40 23 67 55 77 81  
 11 \* 42 42 40 41 40 39 41 40 41 40 41 83 74 72  
 12 \* 35 34 33 34 35 32 34 35 36 43 38 32 65 64  
 13 \* 42 44 45 42 45 45 45 38 38 31 41 41 31 83  
 14 \* 42 44 47 43 42 47 46 41 41 30 43 42 34 32

**P6's PCA Data**

**Percentage variance in each component**

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
<b>%</b>	75.93	17.33	2.82	1.18
<b>Cumulative %</b>	75.93	93.27	96.09	97.27

**Construct loadings on each component**

<b>Construct</b>	<b>Component</b>			
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
<b>1</b>	2.29	0.38	-0.58	-0.24
<b>2</b>	2.30	0.67	-0.58	0.10
<b>3</b>	2.35	0.74	0.20	0.18
<b>4</b>	2.39	0.35	-0.33	-0.17
<b>5</b>	1.98	0.88	0.64	-0.46
<b>6</b>	2.44	0.77	0.13	0.17
<b>7</b>	2.35	0.55	0.10	-0.12
<b>8</b>	2.27	-0.67	0.20	0.03
<b>9</b>	2.22	-0.60	-0.07	0.16
<b>10</b>	0.92	-2.04	0.54	-0.29
<b>11</b>	1.96	-0.48	0.63	0.44
<b>12</b>	2.50	0.19	0.09	0.06
<b>13</b>	1.45	-1.92	-0.45	0.32
<b>14</b>	1.27	-1.51	-0.33	-0.41

**P7's HCA Data**

**Elements**

- 1 = Yourself now
- 2 = Ideal self
- 3 = Yourself before you had seizures
- 4 = Someone who has seizures but is uncertain about the cause
- 5 = Someone with epilepsy
- 6 = Someone who has a mental health problem
- 7 = Someone who has a chronic, physical health difficulty
- 8 = Someone who has experienced a difficult/traumatic upbringing
- 9 = Someone who finds it difficult to relate to other people
- 10 = Someone who finds it easy to understand their feelings/emotions
- 11 = Someone who is under a lot of stress
- 12 = Someone who copes well
- 13 = Someone who is low in mood
- 14 = Someone who is anxious

**Element matches**

* 1	2	3	4	5	6	7	8	9	10	11	12	13	14	
*****														
1 *	100	14	15	59	51	60	60	57	53	33	60	35	66	52
2 *	14	100	96	43	58	45	44	44	43	75	39	71	33	32
3 *	15	96	100	44	59	45	45	45	44	76	40	71	33	32
4 *	59	43	44	100	80	75	79	76	69	63	75	67	68	64
5 *	51	58	59	80	100	78	75	76	74	77	76	80	68	56

6 *	60	45	45	75	78	100	72	76	79	67	77	66	79	65
7 *	60	44	45	79	75	72	100	80	67	62	69	64	72	68
8 *	57	44	45	76	76	76	80	100	77	67	79	69	73	63
9 *	53	43	44	69	74	79	67	77	100	67	80	66	73	55
10 *	33	75	76	63	77	67	62	67	67	100	61	87	54	50
11 *	60	39	40	75	76	77	69	79	80	61	100	65	74	57
12 *	35	71	71	67	80	66	64	69	66	87	65	100	55	49
13 *	66	33	33	68	68	79	72	73	73	54	74	55	100	60
14 *	52	32	32	64	56	65	68	63	55	50	57	49	60	100

**Constructs**

- 1 = Falling to bits—Coping
- 2 = Giving up—Facing life
- 3 = Miserable—Funny
- 4 = Health problems—Feeling healthy
- 5 = Worried—Certain
- 6 = Getting things wrong—Knowing right things to do
- 7 = Not caring—Showing you care
- 8 = Difficult to relate—Socialising
- 9 = Unhappy—Happy
- 10 = Falling apart—Confidence
- 11 = Never knowing—Being safe
- 12 = Relying on people—Doing things for yourself
- 13 = Scared—Not scared
- 14 = Problems in life—No problems in life
- 15 = Emotional—Peace

**Construct Matches (reverse match on diagonal & below)**

*	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
*****															
1 *	35	74	77	76	78	76	53	76	60	58	62	75	82	73	66
2 *	45	44	78	78	76	89	61	72	71	72	77	78	74	77	79
3 *	46	51	49	82	82	79	62	83	70	69	72	84	82	84	73
4 *	42	46	47	40	91	85	58	75	70	68	74	85	80	90	73
5 *	42	47	47	41	40	83	58	73	69	67	72	80	79	88	74
6 *	45	45	51	45	45	45	62	73	72	73	77	82	77	85	82
7 *	55	53	55	54	54	53	35	60	68	84	64	58	55	60	65
8 *	43	49	47	46	47	49	52	40	67	65	67	79	85	75	66
9 *	47	45	48	44	45	45	42	46	33	74	87	71	69	69	68
10 *	56	51	56	52	52	52	41	54	43	44	75	65	60	69	71
11 *	48	44	49	44	45	45	46	47	36	45	36	73	69	73	71
12 *	42	46	46	42	43	45	53	44	43	53	44	40	84	85	72
13 *	38	46	45	42	42	45	54	40	42	55	44	40	36	79	67
14 *	45	48	48	42	42	46	53	47	45	52	45	43	43	42	79
15 *	48	47	52	47	47	46	49	52	46	51	46	47	48	46	42

**P7's PCA Data**

**Percentage variance in each component**

	1	2	3	4	5	6	7
%	67.49	12.21	6.82	5.03	3.24	2.20	1.50
Cumulative %	67.49	79.70	86.51	91.54	94.78	96.99	98.49

**Construct loadings on each component**

Construct	Component						
	1	2	3	4	5	6	7
1	-2.01	-0.54	0.27	-0.78	0.02	-0.21	0.29
2	-1.73	0.15	-0.64	-0.38	-0.71	-0.49	-0.06
3	-1.63	-0.48	0.50	0.19	-0.13	-0.09	0.24
4	-2.06	-0.39	-0.22	0.15	0.60	-0.17	-0.23

<b>5</b>	-1.99	-0.46	-0.23	-0.02	0.75	-0.10	0.35
<b>6</b>	-1.85	0.04	-0.63	-0.36	-0.09	-0.11	-0.25
<b>7</b>	-0.39	1.35	0.76	-0.90	0.34	0.29	-0.16
<b>8</b>	-1.73	-0.33	1.19	0.04	-0.51	-0.05	0.04
<b>9</b>	-1.72	1.55	0.07	0.64	0.03	0.25	0.16
<b>10</b>	-0.81	1.10	0.10	-0.50	0.24	-0.43	-0.11
<b>11</b>	-1.75	1.15	-0.46	0.68	-0.16	-0.20	0.22
<b>12</b>	-2.07	-0.26	0.15	0.34	-0.12	0.15	-0.68
<b>13</b>	-2.20	-0.25	0.61	0.21	-0.15	0.24	0.07
<b>14</b>	-1.88	-0.59	-0.21	0.18	0.36	0.22	-0.12
<b>15</b>	-1.39	-0.07	-0.85	-0.57	-0.34	0.81	0.18

**P8's HCA Data**

**Elements**

- 1 = Yourself now
- 2 = Ideal self
- 3 = Yourself before you had seizures
- 4 = Someone who has seizures but is uncertain about the cause
- 5 = Someone with epilepsy
- 6 = Someone who has a mental health problem
- 7 = Someone who has a chronic, physical health difficulty
- 8 = Someone who has experienced a difficult/traumatic upbringing
- 9 = Someone who finds it difficult to relate to other people
- 10 = Someone who finds it easy to understand their feelings/emotions
- 11 = Someone who is under a lot of stress
- 12 = Someone who copes well
- 13 = Someone who is low in mood
- 14 = Someone who is anxious

**Element matches**

*	1	2	3	4	5	6	7	8	9	10	11	12	13	14
*****														
1 *	100	89	87	48	56	27	32	29	46	87	25	90	35	21
2 *	89	100	87	41	50	20	24	21	40	91	17	95	27	14
3 *	87	87	100	45	54	24	28	25	43	87	22	88	30	18
4 *	48	41	45	100	89	71	69	68	69	42	69	42	75	64
5 *	56	50	54	89	100	66	63	64	71	51	62	50	69	59
6 *	27	20	24	71	66	100	67	82	69	22	85	21	80	89
7 *	32	24	28	69	63	67	100	66	59	27	65	25	68	62
8 *	29	21	25	68	64	82	66	100	74	24	83	23	82	78
9 *	46	40	43	69	71	69	59	74	100	43	68	42	74	65
10 *	87	91	87	42	51	22	27	24	43	100	21	92	29	17
11 *	25	17	22	69	62	85	65	83	68	21	100	19	82	85
12 *	90	95	88	42	50	21	25	23	42	92	19	100	29	15
13 *	35	27	30	75	69	80	68	82	74	29	82	29	100	76
14 *	21	14	18	64	59	89	62	78	65	17	85	15	76	100

**Constructs**

- 1 = Depressed—Ecstatic
- 2 = Troubled—Happy
- 3 = Busy—Calm
- 4 = Anxious—Peace of Mind
- 5 = Struggling—Coping
- 6 = Unfriendly—Friendly
- 7 = Lonely—Content
- 8 = Preoccupied—Mindful
- 9 = Aware of how others see you—Free-spirited
- 10 = Being fake—Being yourself
- 11 = Unprepared—Focused
- 12 = Closed—Trusting

13 = Difficult—Easy-going

**Construct Matches (reverse match on diagonal & below)**

```

* 1 2 3 4 5 6 7 8 9 10 11 12 13
*****
1 * 36 82 81 79 78 74 79 79 82 73 70 77 83
2 * 32 23 83 80 81 84 90 80 82 71 71 77 88
3 * 35 27 28 84 83 76 83 75 84 69 71 70 79
4 * 28 21 23 15 94 70 80 82 83 63 65 73 76
5 * 25 18 20 12 10 70 81 80 80 62 64 71 76
6 * 35 25 30 25 22 24 81 71 73 75 76 74 81
7 * 29 20 24 18 15 23 16 82 80 66 67 74 86
8 * 30 23 27 18 16 26 19 18 82 63 64 80 84
9 * 39 31 34 26 24 35 28 29 36 70 69 76 80
10 * 52 43 48 42 39 42 41 44 53 54 80 73 69
11 * 46 38 41 35 33 36 35 38 47 51 41 76 70
12 * 38 31 37 28 26 33 28 27 38 49 41 32 79
13 * 32 24 29 22 20 26 21 22 32 45 39 31 23

```

**P8's PCA Data**

**Percentage variance in each component**

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>%</b>	86.87	5.69	2.91	1.57	1.02
<b>Cumulative %</b>	86.87	92.56	95.47	97.04	98.06

**Construct loadings on each component**

<b>Construct</b>	<b>Component</b>				
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>1</b>	2.16	-0.29	-0.22	0.69	0.43
<b>2</b>	2.83	0.11	-0.38	-0.06	-0.05
<b>3</b>	2.53	-0.71	0.17	-0.40	0.24
<b>4</b>	2.97	-0.71	0.61	0.06	-0.11
<b>5</b>	3.18	-0.69	0.56	0.11	-0.11
<b>6</b>	2.57	0.84	-0.33	-0.50	-0.14
<b>7</b>	3.04	-0.06	-0.47	-0.26	-0.03
<b>8</b>	2.71	-0.01	-0.29	0.23	-0.09
<b>9</b>	2.15	-0.51	-0.01	-0.15	-0.33
<b>10</b>	1.19	0.75	0.16	0.38	-0.59
<b>11</b>	1.59	1.06	0.93	-0.31	0.35
<b>12</b>	2.06	0.95	0.32	0.42	0.05
<b>13</b>	2.68	0.38	-0.64	0.04	0.27

**P9's HCA Data**

**Elements**

- 1 = Yourself now
- 2 = Ideal self
- 3 = Yourself before you had seizures
- 4 = Someone who has seizures but is uncertain about the cause
- 5 = Someone with epilepsy
- 6 = Someone who has a mental health problem
- 7 = Someone who has a chronic, physical health difficulty
- 8 = Someone who has experienced a difficult/traumatic upbringing
- 9 = Someone who finds it difficult to relate to other people
- 10 = Someone who finds it easy to understand their feelings/emotions
- 11 = Someone who is under a lot of stress
- 12 = Someone who copes well
- 13 = Someone who is low in mood

14 = Someone who is anxious

**Element matches**

*	1	2	3	4	5	6	7	8	9	10	11	12	13	14
*****														
1 *	100	34	31	65	61	72	38	60	60	32	61	35	58	55
2 *	34	100	86	47	65	21	70	38	37	90	35	87	29	29
3 *	31	86	100	46	60	18	72	34	34	89	31	78	24	24
4 *	65	47	46	100	72	57	56	58	50	47	56	45	47	49
5 *	61	65	60	72	100	51	63	60	58	63	60	60	53	54
6 *	72	21	18	57	51	100	26	59	64	20	67	20	66	64
7 *	38	70	72	56	63	26	100	47	36	76	42	66	34	34
8 *	60	38	34	58	60	59	47	100	68	36	80	37	75	72
9 *	60	37	34	50	58	64	36	68	100	34	76	36	74	70
10 *	32	90	89	47	63	20	76	36	34	100	33	81	26	26
11 *	61	35	31	56	60	67	42	80	76	33	100	33	85	85
12 *	35	87	78	45	60	20	66	37	36	81	33	100	28	27
13 *	58	29	24	47	53	66	34	75	74	26	85	28	100	84
14 *	55	29	24	49	54	64	34	72	70	26	85	27	84	100

**Constructs**

- 1 = Stressed—Calm
- 2 = Down—Happy
- 3 = Restricted—Being able to do things
- 4 = Scared—Not scared
- 5 = Anxious—Being self
- 6 = Having physical disability—Being normal
- 7 = Overwhelmed—Taking things in
- 8 = Under pressure—Able to do what you want
- 9 = Not coping—Coping
- 10 = Life wasted—Getting on with life
- 11 = Not understanding—Understanding
- 12 = Difficulty talking to people—Able to talk to people
- 13 = Difficult—Caring

**Construct Matches (reverse match on diagonal & below)**

*	1	2	3	4	5	6	7	8	9	10	11	12	13
*****													
1 *	22	83	81	71	70	42	68	73	67	71	67	65	69
2 *	18	11	83	63	63	42	66	66	60	66	60	57	58
3 *	22	16	17	74	77	43	75	76	70	75	69	62	66
4 *	24	22	21	16	85	43	75	81	71	76	73	66	74
5 *	24	22	19	17	15	42	74	77	75	79	72	64	71
6 *	34	27	30	30	31	4	50	56	51	53	52	60	43
7 *	37	31	31	31	31	36	38	81	77	73	80	69	64
8 *	34	30	30	28	28	31	39	35	76	80	80	76	73
9 *	38	35	34	33	31	36	43	42	39	82	80	74	70
10 *	35	31	31	30	28	34	43	39	41	37	80	76	76
11 *	45	41	40	38	38	41	49	47	50	49	54	76	76
12 *	45	42	43	41	41	35	53	48	51	49	59	51	66
13 *	32	31	30	27	27	37	43	37	41	37	45	49	28

**P9's PCA Data**

**Percentage variance in each component**

	1	2	3	4	5	6
<b>%</b>	71.92	12.49	6.61	3.03	2.16	1.47
<b>Cumulative %</b>	71.92	84.42	91.02	94.05	96.22	97.69

**Construct loadings on each component**

Construct	Component					
	1	2	3	4	5	6
1	2.60	-0.08	-1.09	-0.21	-0.28	0.13
2	2.83	0.63	-1.31	0.27	0.15	-0.08
3	2.98	0.11	-0.41	0.44	0.20	-0.13
4	2.88	-0.52	0.59	-0.61	-0.08	-0.40
5	2.91	-0.70	0.52	0.26	-0.13	-0.55
6	1.02	2.88	0.24	-0.21	0.22	0.02
7	1.97	0.30	1.01	0.20	0.37	0.03
8	2.21	0.36	0.54	-0.52	-0.04	0.06
9	1.77	-0.21	0.60	0.86	-0.25	0.59
10	2.05	-0.19	-0.08	0.41	-0.20	-0.01
11	1.36	-0.24	0.55	-0.04	0.39	0.39
12	1.05	0.48	0.22	-0.37	-1.07	0.25
13	1.97	-1.06	-0.37	-0.74	0.45	0.50

**P10's HCA Data**

**Elements**

- 1 = Yourself now
- 2 = Ideal self
- 3 = Yourself before you had seizures
- 4 = Someone who has seizures but is uncertain about the cause
- 5 = Someone with epilepsy
- 6 = Someone who has a mental health problem
- 7 = Someone who has a chronic, physical health difficulty
- 8 = Someone who has experienced a difficult/traumatic upbringing
- 9 = Someone who finds it difficult to relate to other people
- 10 = Someone who finds it easy to understand their feelings/emotions
- 11 = Someone who is under a lot of stress
- 12 = Someone who copes well
- 13 = Someone who is low in mood
- 14 = Someone who is anxious

**Element matches**

*	1	2	3	4	5	6	7	8	9	10	11	12	13	14
*****														
1 *	100	50	47	74	70	75	74	65	75	82	61	73	75	79
2 *	50	100	93	60	46	54	66	82	29	62	67	64	60	53
3 *	47	93	100	57	45	51	63	78	26	60	66	61	57	51
4 *	74	60	57	100	70	70	77	75	58	75	70	68	65	71
5 *	70	46	45	70	100	67	60	58	63	71	60	66	64	76
6 *	75	54	51	70	67	100	73	67	59	74	65	76	78	84
7 *	74	66	63	77	60	73	100	80	54	80	76	76	70	72
8 *	65	82	78	75	58	67	80	100	43	74	75	72	69	65
9 *	75	29	26	58	63	59	54	43	100	62	43	57	56	66
10 *	82	62	60	75	71	74	80	74	62	100	71	81	80	80
11 *	61	67	66	70	60	65	76	75	43	71	100	66	68	67
12 *	73	64	61	68	66	76	76	72	57	81	66	100	76	78
13 *	75	60	57	65	64	78	70	69	56	80	68	76	100	82
14 *	79	53	51	71	76	84	72	65	66	80	67	78	82	100

**Constructs**

- 1 = Introvert—Confident
- 2 = Despondent—Self-esteem
- 3 = Cautious—Laissez-faire
- 4 = Restricted—Freedom
- 5 = Inability to learn—Intelligent
- 6 = Ignorant—Tolerant
- 7 = Dependent—Independent

- 8 = Mundane—Spirited
- 9 = Self-pity—Non-complaining
- 10 = Depressed—Feeling secure
- 11 = Feckless—Ambitious
- 12 = Inept—Capable

**Construct Matches (reverse match on diagonal & below)**

```

* 1 2 3 4 5 6 7 8 9 10 11 12
*****
1 * 56 87 78 87 62 67 79 77 60 76 60 73
2 * 57 54 71 79 63 66 77 76 63 82 61 77
3 * 53 56 42 78 53 57 73 72 53 67 51 64
4 * 50 52 46 42 56 62 79 73 56 71 53 70
5 * 54 52 54 51 28 82 66 74 74 55 86 74
6 * 52 52 53 48 32 31 66 76 77 59 77 73
7 * 50 49 45 43 41 43 36 80 60 67 64 78
8 * 53 52 48 48 39 40 42 40 70 69 75 83
9 * 53 49 51 48 31 31 42 39 24 55 73 67
10 * 50 47 48 45 48 47 45 46 45 35 55 71
11 * 47 45 47 45 23 27 35 32 25 40 16 72
12 * 51 47 49 45 35 38 39 39 37 41 30 33

```

**P10's PCA Data**

**Percentage variance in each component**

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>
<b>%</b>	60.51	11.38	9.28	7.21	4.98	3.49	1.33
<b>Cumulative %</b>	60.51	71.89	81.17	88.38	93.35	96.84	98.17

**Construct loadings on each component**

<b>Construct</b>	<b>Component</b>						
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>
<b>1</b>	1.40	-0.29	-0.30	-0.30	-0.49	-0.09	0.13
<b>2</b>	1.43	0.45	-0.46	-0.13	-0.24	0.36	0.06
<b>3</b>	1.64	-1.08	0.16	-0.48	0.72	-0.27	-0.15
<b>4</b>	1.98	-0.46	0.23	-0.30	-0.62	0.00	0.09
<b>5</b>	0.33	0.30	0.45	0.71	0.06	-0.21	-0.34
<b>6</b>	0.68	0.44	0.78	-0.07	-0.49	-0.73	-0.07
<b>7</b>	1.87	-0.60	0.22	0.58	-0.19	0.54	-0.30
<b>8</b>	1.46	-0.16	0.21	0.14	0.47	-0.16	0.35
<b>9</b>	0.42	0.84	1.12	-0.85	0.25	0.47	-0.05
<b>10</b>	1.87	0.98	-1.02	-0.35	0.24	-0.22	-0.25
<b>11</b>	0.61	0.18	-0.05	0.32	0.28	-0.00	0.09
<b>12</b>	1.71	0.64	0.24	0.77	0.19	0.03	0.27

**P11's HCA Data**

**Elements**

- 1 = Yourself now
- 2 = Ideal self
- 3 = Yourself before you had seizures
- 4 = Someone who has seizures but is uncertain about the cause
- 5 = Someone with epilepsy
- 6 = Someone who has a mental health problem
- 7 = Someone who has a chronic, physical health difficulty
- 8 = Someone who has experienced a difficult/traumatic upbringing
- 9 = Someone who finds it difficult to relate to other people
- 10 = Someone who finds it easy to understand their feelings/emotions
- 11 = Someone who is under a lot of stress
- 12 = Someone who copes well



13 = Someone who is low in mood

14 = Someone who is anxious

**Element matches**

```

* 1 2 3 4 5 6 7 8 9 10 11 12 13 14
*****
1 * 100 51 34 82 61 62 75 74 74 34 74 34 65 67
2 * 51 100 79 62 78 28 53 33 56 78 62 79 76 71
3 * 34 79 100 45 70 13 42 18 44 93 50 100 61 61
4 * 82 62 45 100 72 61 74 67 75 45 81 45 74 72
5 * 61 78 70 72 100 40 68 46 69 70 75 70 78 84
6 * 62 28 13 61 40 100 61 69 46 13 55 13 39 39
7 * 75 53 42 74 68 61 100 63 72 42 78 42 61 72
8 * 74 33 18 67 46 69 63 100 63 18 59 18 49 50
9 * 74 56 44 75 69 46 72 63 100 43 73 44 70 80
10 * 34 78 93 45 70 13 42 18 43 100 51 93 61 61
11 * 74 62 50 81 75 55 78 59 73 51 100 50 75 76
12 * 34 79 100 45 70 13 42 18 44 93 50 100 61 61
13 * 65 76 61 74 78 39 61 49 70 61 75 61 100 76
14 * 67 71 61 72 84 39 72 50 80 61 76 61 76 100

```

**Constructs**

- 1 = Isolated—Being around people
- 2 = Stressed—Happy go lucky
- 3 = Not wanting to know—Understanding
- 4 = Not talking—Having a gab
- 5 = Unsure—Knowing
- 6 = Not coping—Getting on with it
- 7 = Not able to control emotions—Able to listen
- 8 = Nervous—Not nervous
- 9 = Can't relate to people—Able to talk to people
- 10 = Being bone idle—Doing things for self

**Construct Matches (reverse match on diagonal & below)**

```

* 1 2 3 4 5 6 7 8 9 10
*****
1 * 35 83 77 88 74 72 82 85 86 64
2 * 37 35 78 87 74 76 83 85 83 65
3 * 39 39 35 77 75 74 77 76 82 58
4 * 37 37 39 36 77 71 82 88 92 62
5 * 45 44 44 43 42 69 76 72 79 62
6 * 38 37 37 39 43 29 83 66 70 74
7 * 38 38 39 38 44 35 36 75 80 76
8 * 37 37 39 37 45 41 40 35 87 57
9 * 37 38 38 37 43 40 39 37 36 60
10 * 35 35 39 37 40 28 30 40 39 18

```

**P11's PCA Data**

**Percentage variance in each component**

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>%</b>	79.57	8.73	5.36	2.28	1.74
<b>Cumulative %</b>	79.57	88.29	93.66	95.94	97.68

**Construct loadings on each component**

<b>Construct</b>	<b>Component</b>				
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>1</b>	2.29	0.10	-0.39	-0.03	-0.44
<b>2</b>	2.26	0.12	-0.10	-0.20	0.64
<b>3</b>	2.07	-0.38	1.10	-0.15	-0.33

<b>4</b>	2.29	-0.33	-0.44	-0.14	0.03
<b>5</b>	1.44	-0.96	0.07	0.91	0.15
<b>6</b>	1.82	0.93	0.91	0.10	0.24
<b>7</b>	1.98	0.35	0.02	-0.08	-0.09
<b>8</b>	2.31	-0.25	-0.43	-0.23	0.15
<b>9</b>	2.25	-0.60	-0.13	-0.13	-0.18
<b>10</b>	1.41	1.40	-0.45	-0.44	-0.19

**P12's HCA Data**

**Elements**

- 1 = Yourself now
- 2 = Ideal self
- 3 = Yourself before you had seizures
- 4 = Someone who has seizures but is uncertain about the cause
- 5 = Someone with epilepsy
- 6 = Someone who has a mental health problem
- 7 = Someone who has a chronic, physical health difficulty
- 8 = Someone who has experienced a difficult/traumatic upbringing
- 9 = Someone who finds it difficult to relate to other people
- 10 = Someone who finds it easy to understand their feelings/emotions
- 11 = Someone who is under a lot of stress
- 12 = Someone who copes well
- 13 = Someone who is low in mood
- 14 = Someone who is anxious

**Element matches**

*	1	2	3	4	5	6	7	8	9	10	11	12	13	14
*****														
1 *	100	64	70	71	68	62	67	76	62	72	73	77	54	78
2 *	64	100	51	38	35	34	33	49	30	83	45	78	19	65
3 *	70	51	100	66	68	72	65	51	70	65	67	64	54	65
4 *	71	38	66	100	89	75	90	70	81	50	86	55	75	60
5 *	68	35	68	89	100	83	94	66	89	47	82	51	78	61
6 *	62	34	72	75	83	100	79	56	88	48	72	49	70	61
7 *	67	33	65	90	94	79	100	67	88	45	82	50	82	58
8 *	76	49	51	70	66	56	67	100	58	55	70	62	56	71
9 *	62	30	70	81	89	88	88	58	100	44	74	48	81	57
10 *	72	83	65	50	47	48	45	55	44	100	56	88	32	75
11 *	73	45	67	86	82	72	82	70	74	56	100	60	65	64
12 *	77	78	64	55	51	49	50	62	48	88	60	100	38	73
13 *	54	19	54	75	78	70	82	56	81	32	65	38	100	45
14 *	78	65	65	60	61	61	58	71	57	75	64	73	45	100

**Constructs**

- 1 = Attention to detail—Not caring about detail
- 2 = Negatively affecting others—Positively affecting others
- 3 = Anxious—Capable
- 4 = Distant—Coming back
- 5 = Denial—Acceptance of self
- 6 = Fake frontage—Real
- 7 = No pleasure in life—Pleasure in life
- 8 = Don't believe are lovable—Believe are lovable
- 9 = Difficult to accept emotion—Accepting Emotion

**Construct Matches (reverse match on diagonal & below)**

*	1	2	3	4	5	6	7	8	9
*****									
1 *	30	58	62	67	75	72	75	74	70
2 *	49	38	74	81	78	74	75	78	76
3 *	47	45	40	82	82	71	78	78	80

4 \* 50 47 48 50 88 79 85 85 90  
 5 \* 46 50 49 53 53 85 91 92 91  
 6 \* 40 44 47 48 47 38 87 87 85  
 7 \* 47 52 52 55 55 47 55 92 91  
 8 \* 48 51 52 55 55 48 56 55 90  
 9 \* 48 50 49 52 53 47 54 54 51

**P12's PCA Data**

**Percentage variance in each component**

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>%</b>	73.29	15.10	5.55	3.68	1.33
<b>Cumulative %</b>	73.29	88.39	93.94	97.62	98.95

**Construct loadings on each component**

<b>Construct</b>	<b>Component</b>				
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>1</b>	1.86	-1.69	0.16	-0.58	0.15
<b>2</b>	1.61	1.08	-0.80	-0.63	-0.03
<b>3</b>	1.71	0.89	1.05	-0.23	-0.23
<b>4</b>	1.67	0.64	0.01	0.15	0.43
<b>5</b>	1.74	-0.00	0.08	-0.05	-0.00
<b>6</b>	2.02	-0.41	-0.48	0.42	-0.35
<b>7</b>	1.59	-0.25	0.03	-0.31	-0.03
<b>8</b>	1.55	-0.14	-0.08	0.10	-0.16
<b>9</b>	1.69	0.15	0.06	0.49	0.26

**Appendix I – Modegrid Principal Component Analyses Data**

**Percentage variance in each component**

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>
<b>%</b>	71.77	8.49	4.49	4.03	3.80	2.43	1.89	1.09
<b>Cumulative %</b>	71.77	80.26	84.75	88.78	92.59	95.01	96.90	97.99

**Construct loadings on each component**

	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>Component</b>
<b>1</b>	1.54	0.06	0.27	0.85	-0.34	-0.13	0.29	-0.00	Miserable—Funny (P7)
<b>2</b>	1.99	0.69	0.06	-0.31	0.04	-0.23	0.26	-0.07	Viewed negatively by others—Not judged/taken on face value (P6)
<b>3</b>	1.26	0.01	-0.24	-0.24	-0.58	0.35	0.08	0.27	Misunderstood—Understood (P5)
<b>4</b>	1.48	-0.39	-0.94	-0.03	-0.21	0.30	-0.08	0.09	Distant—Coming back (P12)
<b>5</b>	1.95	-0.50	0.17	0.40	0.52	0.21	-0.34	-0.05	Life wasted—Getting on with life (P9)
<b>6</b>	1.70	-0.88	0.04	0.28	-0.46	0.17	-0.25	0.16	Unhappy—Happy/content (P1)
<b>7</b>	2.03	-0.69	0.38	-0.41	-0.34	-0.30	-0.35	-0.38	Hard to see reality—Being realistic (P6)
<b>8</b>	1.93	-0.29	-0.59	0.45	0.08	-0.37	0.54	-0.30	Anxious—Capable (P12)
<b>9</b>	1.14	-0.30	0.45	-0.91	0.33	0.21	0.42	0.02	Difficulty talking to people—Able to talk to people (P9)
<b>10</b>	2.14	0.64	-0.44	-0.24	0.27	-0.02	-0.24	0.12	Having to rely on others—Independence (P6)
<b>11</b>	1.85	1.02	0.45	0.27	-0.18	-0.01	0.09	0.34	Worried—Certain (P7)
<b>12</b>	1.05	0.49	0.28	-0.18	-0.78	0.51	0.10	-0.35	Introvert—Confident (P10)
<b>13</b>	2.31	-0.37	0.59	-0.07	0.08	-0.47	-0.12	0.25	Nervous—Confident (P1)
<b>14</b>	1.00	-1.03	-0.08	-0.13	0.31	0.23	0.44	0.18	Being fake—Being yourself (P8)
<b>15</b>	2.18	0.61	-0.61	-0.31	0.17	-0.23	-0.22	-0.06	Disability—Able-bodied (P6)
<b>16</b>	1.56	0.41	0.29	0.38	0.73	0.65	-0.07	-0.21	Unsure—Knowing (P11)

