

**Exploring how males who encounter phenomena they identify as  
'Conversion Disorder'/'Functional Neurological Disorder'  
experience *agency* in their lives.**

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## ABBREVIATIONS

<i>Term:</i>	<i>Abbreviation:</i>
Conversion Disorder	CD
Functional Neurological Disorder	FND
Interpretative Phenomenological Analysis	IPA
Experiences described as CD/FND	EDCD

## ABSTRACT

This research investigates the way that males who identify with the diagnostic label 'conversion disorder/functional neurological disorder (CD/FND)' experience *agency* in their lives. The historical developments, controversies and complexities around 'CD/FND' form the backdrop of this exploration into the lived experience of agency. A sample of eight participants were recruited via social networking sites and charities, and the data was collected through Skype-based interviews and analysed using the qualitative Interpretative Phenomenological Analysis (IPA) approach. The analysis showed the following five main themes: 'paradox of control', 'living within a dualistic framework', 'disconnection from self and others', 'engaged in a battle or fight' and 'meaning and reality as dependent on other people'. These master themes and their related subordinate themes are presented in light of existing research. The findings highlight the difficulty experienced by participants who identify with a diagnostic label that is at odds with a medicalised approach to understanding and treating illness. The limitations of this study and the potential avenues for future research are also discussed.

# 1 INTRODUCTION

This research explores how a particular sample of participants experiences the phenomenon of *agency*. The sample comprises male participants who have experiences that they understand in terms of the diagnostic label 'Conversion disorder/Functional neurological disorder' (CD/FND).

## 1.1 Layout of the introduction and literature review

Following an outline of the research question, a description of the setting out of which this research arose, as well as the developing interests of the researcher in relation to this, are described. A literature review then details the current medical context, including medical classification, comorbidity, controversy and the medical model. This is then drawn from to clarify the decision that is made to refer to a diagnostic framework, as opposed to solely looking at physical phenomena in a non-diagnostic manner.

As this research focuses on an exploration of the ways *agency* is experienced, the relevant literature concerning agency shall be discussed next. An explanation for why this research has specifically targeted a male sample is then discussed.

The history that has resulted in the self-identified diagnosis of 'CD/FND' held by the participants in this study is described next. This is followed by an in-depth look at the areas of trauma, dissociation and emotion.



Finally, discussing the importance of this research and how it fills a gap in the current research concludes the background section.

## **1.2 Research question**

How do males who have experiences described as ‘conversion disorder/functional neurological disorder’ experience the phenomenon of *agency*?

## **1.3 Literature search**

Searches were carried out using Summon, Medline, Embase, PsycINFO, Web of Science, ScienceDirect, PsycNET, and OAJSE from 1965 onwards. The following terms were used in the searches: ‘conversion disorder’, ‘functional neurological disorder’, ‘hysteria’, ‘hysterical conversion’, ‘psychogenic’, ‘non-epileptic attack’, ‘non-epileptic attack disorder’, ‘functional somatization disorder’, ‘functional symptoms’, ‘pseudo seizures’, ‘somatization’, ‘medically unexplained symptoms’, ‘psychosomatic’, ‘conversion’, ‘functional neurological symptoms disorder’, ‘dissociative’, ‘interpretative phenomenological analysis’, ‘qualitative’, ‘dissociative’, ‘men’, ‘males’, ‘agency’, and ‘control’. Titles and abstracts were reviewed, in order to follow-up on relevant publications from references cited. The majority of literature had a quantitative focus and many were medical articles linked to neurology and psychiatry. Articles that were neurobiological were excluded, as this level of biological detail was deemed irrelevant for the focus of this research. A few articles and theses were found that utilised an IPA

method. No literature was found that specifically focused on ways males who identified with 'CD/FND' experience agency.

#### **1.4 Personal introduction and development of research**

The decision to research this particular area was made in the context of work carried out as a trainee-counselling psychologist in the National Health Service (NHS) from February 2013 until August 2015 involving 'patients' who had been diagnosed with 'conversion disorder'. From February 2015, this position developed into a substantive post as a part-time psychological research therapist, contributing to a United Kingdom-wide randomised controlled research trial titled 'CODES' (cognitive behavioural therapy for dissociative (non-epileptic) seizures) (Goldstein et al., 2015). This trial involves the delivery of twelve sessions of cognitive behavioural therapy (CBT) to participants who have been diagnosed with dissociative seizures (Goldstein et al., 2015).

Prior to the placement mentioned above, the researcher had not encountered the term 'conversion disorder' (CD). 'CD' was initially conceptualised to mean that the 'psychological' is 'converted' into the 'physical', which has its roots in the psychoanalytic theories of Sigmund Freud (Freud & Breuer, 1895). For example, a patient that could not relate to feelings of anger whilst simultaneously exhibiting violent seizures was interpreted as suppressing difficult emotions that were manifest physically via their bodies. The fascination that arose around this 'conversion' process stimulated a desire to pursue research in this area.

At the initial stage of embarking on this research process, the plan had been to explore CD in a broad sense. However, what seemed to emerge over time, was the way that patients seemed to grapple with feeling both in and out of control in their lives (cf. the phenomenon of agency), which varied in relation to how they experienced: i) their emotions and thoughts, ii) other people and the NHS/medical system, and iii) their own bodies. There seemed to be something important about how these individuals experienced *agency* in their lives, which is why agency was chosen to be the focal phenomenon of this research. As there also seemed to be much confusion surrounding the way in which these individuals conceptualised 'CD' (for example, they all seemed unclear as to whether they were experiencing something that was physical in a way that they couldn't comprehend or whether it was 'in their minds' or otherwise), this area of research seemed particularly important to pursue.

It was also observed that there seemed to be significantly fewer male patients that had been assigned this diagnostic label and that they seemed to be less able to recognise or identify with emotional states or experiences that one might objectively describe as being traumatic (for example, extreme acts of violence would be discussed with me in a matter of fact way). This observation was part of the reason why a decision was made to solely focus on researching men. Other reasons for this decision were: a) a curiosity about why there seemed to be a smaller ratio of male to female patients and why this appeared to be the case historically (for example: Showalter, 1986, p.129), b) the potential relevance of how men would have a different bodily experience to women, both in terms of physical differences and social ones, c) the sense of agency might also differ between men and women in the context of social constructs, which would make it valuable to focus on males, d) to personally understand the observation made around

the perceived emotional distance exhibited by males, and e) a sole focus on men would allow for homogeneity, which is also a requirement of the Interpretative Phenomenological Analysis (IPA) approach.

Thus, the decision was made to embark on a research study to explore how males who identified with 'conversion disorder' experience agency in their lives. As the main interest was around exploring the lived experience of agency in this context, a qualitative IPA methodology was chosen.

Finally, over the course of conducting this research, the term 'functional neurological disorder' (FND) seemed to be a popular term that was often used in the areas that participants were recruited from. This term is included in the title and body of this work so that all participants could feel the term that they identified with was being used, as well as 'conversion disorder' (as these were the only terms that were used by those involved in the recruitment process). Although these terms refer to the same area, there are subtle differences that can come about in conceptualising them that are relevant, because together they make up current understandings and debates, and this shall be discussed in the literature review below. Finally, as the focus of this research is on how agency is experienced by males who identify with experiences described as 'CD/FND', the acronym 'EDCD' (experiences described as CD/FND) will be used, at times, for ease of reading.

Before discussing the concept of 'agency', the current context of 'CD/FND' will be described, as the interest in the lived experience of agency is in relation to this backdrop.

## 2 MEDICAL DIAGNOSIS AND CLASSIFICATION

### 2.1 Diagnostic classification

'Conversion disorder/Functional neurological disorder' is described as a mental disorder that can be found within certain classification categories in the American 'Diagnostic and Statistical Manual' (DSM) and the European 'International Classification of Diseases' (ICD) (APA, 2013a; WHO, 1992). It is classified in the ICD-10 under 'dissociative (conversion) disorders' with the diagnostic criteria that there be no physical disorder that can account for symptoms and that there be credible links with conversion symptoms and stressful events, difficulties and issues (WHO, 1992). The DSM-5 classifies CD/FND under 'somatic symptom and related disorders' with conversion disorder being bracketed as 'functional neurological symptom disorder'. Here, the diagnostic criteria focus on the relevance of the neurological examination and how psychological components may not be apparent at the time of examination (APA, 2013a).

'Conversion disorder' is but one of many names that has been used to describe symptoms that are described by some as "pseudo-neurological" whereby unconscious psychological processes are thought to give rise to symptoms that are typically neurological in origin; thus being 'converted' into somatic manifestations (Justice-Malloy, 1995; Rowe, 2010; Stonnington, Barry, & Fisher, 2006; White, 1997). With 'functional neurological disorder' the explanation differs in the sense that the focus is on

the brain whereby 'FND' symptoms are due to issues with how the brain is 'functioning' rather than an issue with physical 'structure' (for example, the electro-chemical communication between neurons and brain structures rather than brain anatomy) (Reuber, Mitchell, Howlett, Crimlisk, & Grunewald, 2005; Stone, Carson, & Sharpe, 2005a, 2005b; Stone, Hallett, Carson, Bergen, & Shakir, 2014).

When the fields of psychiatry and neurology separated at the beginning of the twentieth century, many such 'conversion' cases were reported and one of the most commonly used words to describe such phenomena was "hysteria" (Tasca, Rapetti, & Fadda, 2012). Since then, other terms have included: "psychogenic", "medically unexplained symptoms", "functional disorders", "non-organic", and "dissociative disorder" (Rowe, 2010). Symptoms of 'CD/FND' as outlined in diagnostic psychiatric manuals include: i) functional weakness (limb collapse, hip extension/flexion, part of face collapse); ii) functional sensory disturbance (various forms of numbness); iii) non-epileptic attacks (epileptic like attacks); iv) functional movement disorders (tremor, dystonia); v) functional gait disturbance (odd body positions); and vi) sensory (visual, auditory, speech, and balance disturbances) (APA, 2013a; Stone et al., 2005a; WHO, 1992). What is described within the medical field as distinguishing 'CD/FND' from other instances of psychological processes being expressed physically (for example: irritable bowel syndrome, which is linked to the gut and digestion), is the neurological nature of these symptoms (Rowe, 2010). Thus, 'CD/FND' is a specialist branch of "medically unexplained symptoms", which is an umbrella term for any symptom that does not have a physical, pathological explanation. The following are examples of some existing 'medically unexplained symptoms': chronic fatigue syndrome, lower back pain and fibromyalgia (Eriksen, Kerry, Mumford, Lie, & Anjum, 2013).

## **2.2 Comorbidity**

A significant overlap with various other psychiatric symptoms has been demonstrated (which is also suggested by the differing diagnostic terms currently used by the DSM-V and ICD-10) (Reuber et al., 2005; Rowe, 2010). A broad overlay has been shown between 'conversion disorder', 'dissociative disorders', 'borderline personality disorder', 'dysthymic disorder', 'major depression' and 'somatization disorder' (Kundakç & Emre, 2004). Results from a study in Turkey showed that 89.5% of individuals diagnosed with 'conversion disorder' had, at follow-up, at least one other diagnosis involving either 'generalised anxiety disorder', 'undifferentiated somatoform disorder', 'major depression', 'obsessive compulsive disorder', 'dysthymic disorder', 'simple phobia', and 'dissociative disorder not otherwise specified' (Sar et al., 2004). Thus, not only is it difficult to categorise 'EDCD' with the terms 'CD/FND' but there are also many other aspects that are related, which ultimately challenges this categorising approach.

## **2.3 Controversy and stigma**

In line with the complexity mentioned above, individuals diagnosed with 'CD/FND' are found by some medical professionals to provide a fascinating challenge whilst evoking discomfort in others (Owens & Dein, 2006). In addition to this, earlier historical views that raised the notion of feigning in relation to 'CD/FND' symptoms still seem to feature in the attitudes of some medical professionals (Nicholson, Stone, & Kanaan, 2011). A study conducted on neurologists' understanding and attitudes towards 'CD/FND'

demonstrated the following: i) neurologists showed an unwillingness to engage once such 'symptoms' were established; ii) there was a lack of responsibility when the view was that the cause of 'symptoms' was not structural in nature; and iii) they showed an element of disbelief (for example, it had been assumed that malingering was taking place) (Kanaan, Armstrong, Barnes, & Wessely, 2009). This study further showed that there was a tendency for neurologists to view this area as being out of their field of expertise and as something to be moved over to psychiatrists who were seen to be better suited (Kanaan et al., 2009). In an article written by the New York Times, the following quotes were given by neurologists about their patients with 'CD/FND symptoms': "Hysterical patients take a bad rap in the medical profession", "We don't like them", "Somewhere deep down inside, we really think they're faking it", and "The other reason we don't like them is that they don't get better, and when we can't do well by them we don't like them" (Kinetz, 2006, p 6-7). This shows how the views and beliefs held by medical professionals can vary widely and are influenced by earlier historical ideas. This article also highlights how neurologists (albeit not all neurologists) can react to these patients as though they are almost imposters rather than adopting an empathic stance, whereby they can recognise the confusion that must arise for the patient who has been informed that symptoms which had thought to be physical are actually psychological in origin (Peters et al., 2009; Stonnington et al., 2006).

This, in turn, would affect the way in which these individuals with 'EDCD' relate to the medical professional as well as how they experience 'agency'. If the channel of communication is one that shifts responsibility away from the medical professional, this may be detrimental for the patient as it could lead to a sense of disempowerment and uncertainty around what the patient holds as possible to achieve (Hallett et al., 2011;



Kanaan et al., 2009). Thus, this power dynamic that is so prominent right from the start can play a role in empowering or disempowering the individual depending on the belief system of the medical professional or society influenced by a Western, biomedical model of 'disease' more generally.

As agency forms a crucial part of how power dynamics consequently unfold, the notion of agency shall be discussed in more detail below.

### **3 AGENCY AND CONTROL**

There have been many attempts to adequately define what is meant by the concept of agency but this area still remains elusive, with remaining challenges and controversies (Emirbayer & Mische, 1998). Although the focus of this research is an exploration into the lived experience of agency, this does not imply that an exhaustive and definitive explanation is required. The descriptions of agency below have been chosen because they have been deemed most relevant in terms of elucidating the research question at hand, which by no means suggests that they are exhaustive.

#### **3.1 Agency and control**

The experience of agency has been referred to as "the feeling that we *control* our own actions, and through them the outside world" (Moretto, Walsh, & Haggard, 2011) and the *perception of control* is "the belief that one can determine one's own internal states and behaviour, influence one's environment, and/or bring about desired outcomes"

(Wallston, Wallston, Smith, & Dobbins, 1987). In terms of this research, the notion of agency has been taken to refer to both the feeling and perception of control and of being the agent of one's life.

### **3.2 Self-agency versus self-ownership**

In terms of movement, the sense of agency refers to the sense that one is the agent of one's own action, which is not an obvious phenomenon and has been shown to involve numerous elements (Voon et al., 2010). In particular, the distinction between the 'sense of self-agency' and the 'sense of self ownership' should be made. The former refers to experiencing one's movements as voluntarily produced, whereas the latter refers to the experiencing the movement as one's own (Gallagher, 2010). Thus, in relation to motor control, self-agency would involve generating a movement whereas self-ownership would be the experience that the movement belongs to the individual. These are usually experienced as combined to bring about an awareness of one's being embodied (Gallagher, 2005, 2010).

### **3.3 Explicit and implicit**

'Sense of agency' can also be explained in terms of 'explicit' or 'implicit'. An implicit sense of agency refers to the general experience of being the agent of one's movement whereas an explicit sense of agency involves conceiving of oneself as an agent on a more conceptual level.

Implicit agency has been measured in 'action-effect binding' tasks involve the following: a) participants first have to voluntarily press a key and then estimate the time at which they did this (with reference to a clock hand that rotates) and do the same with a tone that they hear (which sets the baseline) and b) they have to then estimate either the time that they pressed the key (which was followed by the tone) or the time that they heard the tone (which followed the key press) (Kranick et al., 2013). When the movements were voluntary the effect, the estimated time for the key press was later, whereas the time was judged as earlier for the tone, which demonstrates a 'binding effect' (ibid). When movements were not voluntary and were induced by transcranial magnetic stimulation (TMS) the opposite effect occurred (ibid). In contrast to this, individuals diagnosed with 'CD' showed less of a binding effect for voluntary movements when compared to the controls, which suggests that there may be a decreased sense of agency in this group on an implicit measure (ibid).

Explicit agency differs from this as it has been looked at in terms of how beliefs and social elements form a part of the experience of being an agent in one's life in a more general sense (Gallagher, 2010; Moore, Middleton, Haggard, & Fletcher, 2012). An example of how the sense of self-agency has a social element can be seen in the game poker, whereby playing poker for entertainment versus playing poker for money will influence how bets play out, where players in the latter situation will make very different choices and interact in a more controlled and cautious manner as there is more at stake to lose (Gallagher, 2010). Along these lines, Jean-Paul Sartre described how one's experience changes in a park from being alone to having another person enter the setting, for example: "...everything still exists for me; but everything is traversed by an invisible flight and fixed in the direction of a new object" (cited in

Gallagher, 2010, p.13). In relation to the poker game, the light-heartedness that may feature in a game for entertainment may be replaced by anxiety and emotional distance ('poker face') in a game that involves money. In particular, research involving individuals diagnosed with 'CD/FND' suggests a social component to the symptoms, as it has been shown that such phenomena can be affected by the presence or absence of other people, for example, a tremor can fall in line with the rhythm of tapping of another person (Gallagher, 2010; Kranick et al., 2013).

### **3.4 Agency in social psychology:**

According to Bandura, what it means to be an agent is to be able to affect one's behaviour and to shape one's life situation in a way that is intentional (Bandura, 1989, 2006). Human beings are not passive receptacles that receive stimuli and react involuntarily. Rather, people are active (Bandura, 1989, 2006). They organise their lives and regulate themselves as well as operating in a self-reflective manner (Bandura, 2006). There are four elements that are involved in agency that have been described by social cognitive theory. These are the following: "intentionality", "forethought", "self-reactiveness" and "self-reflectiveness" (Bandura, 1989, 2006). "Intentionality" is an aspect of agency that involves people developing intentions whereby they actively make plans and carry them out. This does not happen in isolation but involves other people as every action occurs in a social context where every choice, decision and execution of this has to bring in other individuals. This means that the intention has to be shared with other people in order to be realised (Bandura, 1989, 2006). The next aspect of agency involves "forethought", which is a forward-looking process that involves individuals setting up future objectives and predicting the likelihood of reaching such

objectives. Depending on the likelihood of reaching such goals for the individual, the behaviour will be directed towards achieving these (Bandura, 2001, 2006). A third aspect of agency as described by social cognitive theory is that of “self-reactiveness”, which is a process whereby people regulate and modify their behaviour and understandings as a result of reassessing and adapting to changes in circumstance (Bandura, 1989, 2006). This is a key part in regaining the initial two aspects of agency: if one adapts then intentionality and forethought become accessible as before, whereas if one does not adapt then this would not open up; the person would be left feeling less about to act as an agent. The final aspect of agency is “self-reflectiveness”, whereby people reflect on the behaviour and decisions that they have made so as to monitor the effectiveness of these, in order to modify their approach to come (Bandura, 2006).

The development of agency is also described as being related to upbringing and parent-child attachments (Bandura, 2001, 2006). A baby does not have the four aspects of agency described above when it comes into the world but rather, the elements of agency are developed in relation to interactions with other people and in particular the parental figure (Bandura, 2001, 2006). The infant’s development of agency involves the initial discovery of cause and effect in the environment: they, too, can cause an effect, which then moves on to the discovery that it is they who are the agent of their own actions. This occurs in the context of the infant receiving feedback and encouragement to engage and learn from their environment, from the figure that they are in a relationship with, for example, a parental figure, and it is these interactions that lead to the infant developing personal agency (Bandura, 2006).

This research addresses the 'explicit' aspects of agency which concern how agency is conceived as opposed to implicitly measured (Moore et al., 2012). In order to explore the lived experience of *agency* in the context of an individual's life, the following areas will be addressed: the individual's experience of agency in relation to their body, mind and other individuals, so as to understand how agency is more broadly experienced in participants lives outside of and including the medical context.

Also, as agency may be experienced in a slightly different way for men in comparison to women, the following discussion will address the decision to research a specifically male population.

## **4 MEN AS AN UNDER-REPRESENTED POPULATION**

As the area of 'CD/FND' has historically been dominated by research involving a female population, this particular piece of work seeks to open up a neglected area concerning males who encounter such phenomena.

### **4.1 Male and female prevalence**

Current studies have shown that there is a higher frequency of female neurological referrals in comparison to males (Carson et al., 2000) and a greater number of women have been shown to experience 'EDCD' (Asadi-Pooya et al., 2013; Bodde et al., 2009; Oto et al., 2005; Van Merode et al., 1997). Historically, experiences described as 'hysteria' were thought to have arisen from problems with the reproductive system and were

described as a “quintessential female malady” (Showalter, 1986, p.129). However, a deeper look into some original sources showed that symptoms of ‘hysteria’ had also been found in children and men (Micale, 1990). In particular, Charcot (1825-1893) was a major influence in challenging this female-orientated perspective as he published more than sixty cases of men who demonstrated ‘hysteria’ in the 1880s and his work was internationally linked with the concept of “male hysteria” (Micale, 1990).

Studies have not fully been able to determine whether the ratio of women to men presenting with ‘CD/FND’ is significantly higher as a result of gender itself or because of other factors that are related to gender (Van Merode et al., 1997). So far, research has not shown significant differences between men and women in relation to demographic factors (age, age of onset, marital status and education), clinical elements, aetiological factors, and social factors (Asadi-Pooya et al., 2013; Oto et al., 2005). It has been suggested that aspects that may be involved in the higher incidence of females with such symptoms may be due to findings that have shown that women, in comparison to men: i) appear to suffer more sexual abuse; ii) are more likely to disclose information and seek help; iii) perceive their bodies differently; and iv) may be more likely to participate in clinical studies (Barsky, Peekna, & Borus, 2001; Van Merode et al., 1997). Thus, this research is specifically aimed at this minority male population so as to further develop knowledge in an area that has not been exclusively addressed in such a way.

## **4.2 Males and trauma**

A study researching male veterans with non-epileptic seizures showed a similar clinical profile to that in the literature regarding women, whereby the group who experienced

non-epileptic seizures showed a higher occurrence of post-traumatic stress disorder (PTSD) in comparison with the male control group (with epileptic seizures) (Dworetzky et al., 2005). Other studies involving veterans have shown that a diagnosis of PTSD precedes the non-epileptic seizure group as well as a history involving 'traumatic brain injury' (Salinsky, Evrard, Storzbach, & Pugh, 2012; Salinsky, Spencer, Boudreau, & Ferguson, 2011).

### **4.3 Sex, gender and society**

Sex differences between men and women refer to biological differences (for example, reproductive organs) whereas gender differences refer to non-biological, socially constructed differences, that involve what it means to operate as a male or female in the context of society (Lyons & Chamberlain, 2006). However, gender differences are not necessarily captured by this description, as biological aspects (physiology, genes, hormones) are shaped by the environment and society, and vice versa (Lyons & Chamberlain, 2006). Thus, the way that these interact will impact on subsequent health.

Historically, it could be said that women have often been viewed as the 'weaker sex', where the medicalised view has upheld the 'healthy' body to be the young, white, male body (Kawakami, 2010). The term 'hysterical' remains a stereotype in society whereby it is used to refer to a woman or child who behaves in an overly emotional manner (Cambridge University Press, 2016; Justice-Malloy, 1995; Showalter, 1986). If the prevalence of women exhibiting symptoms of 'CD/FND' in the Victorian age involved feeling controlled and suppressed (Justice-Malloy, 1995; Tasca et al., 2012), then it could potentially be the case that those men who experience this may feel suppressed by



cultural stereotypes and pressured to fulfil notions of strength and being 'the provider' (Courtenay, 2000). In this sense, focusing on men and their experience of *agency* in the context of 'CD/FND' is particularly interesting, as it involves how men perceive themselves as acting in the world.

#### **4.4 The social construction of masculinity:**

Gender has been shown to have a substantive impact on how people go about their lives in a social sense as well as how institutions are run, whereby men are expected to be non-feminine, able to exercise agency, and responsible for taking care of the household finances (Smiler, 2006). In contrast, women have been described in a way whereby the expectations are for them to be more expressive emotionally, to be responsible for looking after the children, and to hold a greater interest in other people (Smiler, 2006).

When it comes to the health of men, research has shown that men have a reduced life span in comparison with women in the majority of countries on a global scale (Mahalik, Burns, & Syzdek, 2007; Mathers, Sadana, Salomon, Murray, & Lopez, 1999). It has been suggested that those who adopt various social constructs that involve masculinity, comprised of 'risk taking' behaviours and notions that a man should be strong and independent, are less likely to respond to their health needs (Courtenay, 2000; Mahalik et al., 2007). A study that assessed masculinity and the male perception of normal health behaviours, which included 'alcohol use, seatbelt use, tobacco consumption, fights, social support engagement, exercise, diet, and attending medical checks', showed that men based their own health behaviour on what they perceived the normal health behaviour of other men to be (Mahalik et al., 2007). Thus, according to such studies, the

way that men's health is socially constructed seems to place men at a greater level of health risk than women.

In terms of the development and maintenance of gender differences, language can be said to be particularly implicated, as 'masculine and feminine' categories allow for constricted conceptualisations that are acted upon and then linguistically reinforced - thus defining and constructing such differences continuously (Berger, Wallis, & Watson, 1995). In relation to other types of sexuality, apart from heterosexuality (for example, bisexual and homosexual), it can be said that these other types do not conform to the 'masculine and feminine' categories (for example, women can behave in a 'butch' manner and men can behave in a 'camp' way) and thus highlights how the construct of masculinity is in relation to the normative view of heterosexuality (Berger et al., 1995).

In terms of CD/FND, the social construction of masculinity, as outlined above, would be assumed to have a substantial impact on the male sense of agency and self-perception in relation to social norms. As much of the research that was carried out historically with 'male hysteria' by Jean-Martin Charcot and Sigmund Freud was not published, this seems to have served the purpose of maintaining social constructions of masculinity as involving strength and control amongst other attributes (Micale, 2008). This makes it all the more relevant to conduct a study that provides the opportunity to bring out research that has been suppressed in the past.

As there has been much reference to a substantial history surrounding the concept of 'CD/FND' and how the research has involved a female dominance, the following section will concentrate on giving a flavour of this historical backdrop.

## **5 HISTORICAL DEVELOPMENTS AND THEORETICAL EXPLANATIONS OF CD/FND**

There has been a long history of attempts that have been made to provide an explanation for the experiences that are referred to under the heading of 'CD/FND' (Feinstein, 2011; Owens & Dein, 2006; Stone et al., 2005; Tasca et al., 2012). Some of the theories that are addressed in this thesis are the following: psychoanalytic, existential, learning, sociocultural and neurophysiological theories (Owens & Dein, 2006). When the fields of psychiatry and neurology separated at the beginning of the twentieth century, one of the most commonly used words to describe 'CD/FND' was "hysteria" (Rowe, 2010; Stonnington et al., 2006). Despite 'hysteria' being the earliest term that was used, even this term shows how descriptions have changed depending on context (Edwards, 2009).

The Ancient Egyptians and then Ancient Greeks viewed 'CD/FND' as a female condition that was the result of a "wandering uterus (hustera)", which is where the word "hysteria" came from (Owens & Dein, 2006). Hippocrates (c.460 - c.370 BCE) wrote about how breathing was impaired when the dry womb rose to the throat to find moisture and Galen (c.130 AD - c.210 AD) viewed 'hysterical phenomena' as the result of menstrual flow that had been blocked or as the abstinence from sexual intercourse (Edwards, 2009; Singer, 2016). Augustine (354 AD - 430 AD) viewed 'hysteria' as being due to demonic possession (Edwards, 2009; Mendelson, 2016).

## 5.1 Jean-Martin Charcot

Initial findings in the field of neuropathology sought to explain symptoms of 'hysteria' by way of demonstrating neuroanatomical irregularities that were found in neurological disorders (Justice-Malloy, 1995; Pandey, 2012). The absence of such irregularities led to Jean-Martin Charcot's use of the term 'functional' rather than 'structural' to describe these symptoms of 'hysteria' (Nicholson et al., 2011). Charcot was a nineteenth century French neurologist who added significantly to the areas of psychiatry, pathology and medicine. He made many contributions as professor in medicine at the Salpêtrière Hospital in Paris and, amongst other things, he developed the technique of hypnosis whilst working on 'hysteria' and epilepsy (Pandey, 2012). He researched 'hysteria' and demonstrated how it could be induced via hypnosis and he also carried out very popular lectures that were theatrical in nature and popularised hysteria at the time (Justice-Malloy, 1995; Pandey, 2012). Charcot asserted to have shown an isolated and universal form of 'hysteria' that involved four periods of: 1) tonic rigidity; 2) dramatic, circus-like acrobatic movements; 3) vivid expressions of emotion; and 4) a delirium state involving tears and/or laughter where the person returned back to normality (Justice-Malloy, 1995). It has been suggested that the rise of women presenting with 'hysteria' who were admitted to the Sêlpetrière Hospital from 5 in 1841-2 to 500 (which were largely bourgeois women) in the years 1882-3, may have reflected the theatrical presentations of his young female patients (Edwards, 2009; Justice-Malloy, 1995). As the context was one where women were reacting to domestic stress and were culturally perceived to be more frail, such theatrics were thought to have led to 'hysteria' developing into a "cultural hysteria" (Edwards, 2009; Justice-Malloy, 1995).

Interestingly, a recent neurological article has suggested that the ICD-11 should position 'EDCD' in both neurological and psychiatric diagnostic categories (Stone et al., 2014). In the context of history, this seems to show a cycle, as it was Charcot who initially identified 'hysteria' as neurological and later brought it into psychiatry (Justice-Malloy, 1995; Stone et al., 2014). Also, the description provided by Charcot appears to relate particularly to the most recent term 'functional neurological symptom disorder', which is detailed in the DSM-5 (APA, 2013a, 2013b).

## **5.2 Pierre Janet and Sigmund Freud**

The move away from such bodily explanations came in the nineteenth century from the theories of Janet and the psychoanalytic theories of Freud (who was Charcot's student). Janet was a French psychologist, philosopher and psychotherapist who thought that the symptoms of 'hysteria' arose from 'dissociation' due to trauma, whereby conscious experiences were no longer able to come together in a coherent, integrated way and thus became 'dissociated'/separated/unavailable from conscious experience (van der Hart & Horst, 1989; van der Kolk & van der Hart, 1989). Those experiences that were separated were thought to manifest physically in symptoms of 'hysteria' (Nicholson et al., 2011; van der Hart & Horst, 1989). An alternative view proposed by Freud focused on how the repression of traumatic experiences such as childhood sexual abuse were "converted" to hysterical symptoms, as they were too distressing to allow into conscious experience (Freud & Breuer, 1895; Verhaeghe & Masson, 1992).

Freud's account of Dora describes how her loss of voice, appendicitis and a foot that dragged on the floor were symptoms of 'hysteria' (Freud, 1963). Freud thought that the

symptoms of 'hysterical' appendicitis were the result of Dora having read sexual words in the dictionary, which then became a manifestation of her punishing herself for having done so. He saw the dragging of her foot as her desire to fall pregnant with her father's friend (who had tried to seduce her) and that this represented her "false step". He believed that the hysterical symptoms were the result of a mixture of jealousy and desire comprising Dora, her father and this couple (where Dora's father was sexually involved with the female and the man in the couple would make sexual advances on Dora) (Freud, 1963; Stadlen, 1989). Freud starts with the assumption that Dora's symptoms show that she is "ill" (Stadlen, 1989). He then describes how Dora's emotions and physical symptoms show a hysterical response whereby she is "irrational" because of her illness of 'hysteria' (Stadlen, 1989). Thus, Freud took an approach whereby he interpreted the descriptions of his patients as being the result of the expression of repressed sexual desires, which pointed to a pathological illness. Further, he believed that psychoanalytic transference was key in this and subsequently blamed himself for not having seen the transference between himself and Dora as she had left therapy before her symptoms had been removed (Freud, 1963).

It was Freud and Breuer who first devised the word "conversion", which referred to the exchange of a repressed concept for a somatic symptom (Owens & Dein, 2006). These early concepts had a significant impact on theories to follow, and it is the acknowledgement of these that shifted hysteria from a neurological to psychiatric disorder and brought it into the diagnostic classification system, which have used the following terms during their history: 'conversion reaction' (DSM-I, 1952), 'hysterical neurosis (conversion type)' (DSM-II, 1968), 'conversion disorder' (DSM-III, 1980), 'dissociative (conversion) disorder' (ICD-10), 'conversion disorder' (DSM-IV, 1994), and

'somatic symptom and related disorders' (DSM-V, 2013) (Nicholson et al., 2011; Owens & Dein, 2006).

### **5.3 Psychoanalytic research involving pseudoseizures**

The clinical research carried out by Clinical Psychologist Dr Kalogjera-Sackellares, into "pseudoseizures" involved the therapist-client relationship and drew on the theories derived by psychoanalyst Heinz Kohut to show that the following elements of "mirroring", "idealization" and "twinship transference" are exhibited in this client group (Kalogjera-Sackellares, 2004; Kohut, 1971; Siegel, 1996). These three aspects are described as fundamental for the development of "self" (which refers to the stable sense of a unified personality existing) (Kohut, 1971; Siegel, 1996). "Mirroring" is a process where the client will seek acceptance and validation from the therapist, "idealization" is where the client will hold the therapist as a figure of serenity and strength, and "twinship transference" is where similarities are sought out between both in the relationship (Kalogjera-Sackellares, 2004; Kinniburgh & Blaustein, 2010; Kohut, 1971; Siegel, 1996). The way that these aspects are experienced during an individual's upbringing is thought to influence the development of "self" whereby the child learns how to have strength, confidence, courage and resilience when engaging with the world (Kalogjera-Sackellares, 2004; Kohut, 1971). This is compromised when the child does not receive the above-mentioned processes or when trauma is experienced (Kalogjera-Sackellares, 2004; Kinniburgh & Blaustein, 2010).

Two types of trauma have been outlined through the work of Kohut: 1) death or abuse (physical, sexual, emotional) and 2) indifference (Kalogjera-Sackellares, 2004; Kohut,

1971; Schore, 2002). The first lead to conflict and dysfunctional relationships with those who are mourned (Schore, 2002). In the case of abuse, this can involve taking on the behaviour of the aggressor which, in turn, influences how relationships are formed outside of this (Schore, 2002). The second form of trauma involves a lack of nurturing and support where the person can be left feeling as though they are not complete as a person (Schore, 2002; Siegel, 1996). Studies have found that those who fulfilled the processes of “mirroring, idealization and twinship transference” experienced the other person as an extension of their own sense of self, where a merging took place that functioned to meet those needs that had not been met growing up (Kalogjera-Sackellares, 2004; Kohut, 1971). In this case, the other person is treated as an object that is internalised by the client (Kalogjera-Sackellares, 2004). Their own bodies are then also treated as an object whereby, if their needs are refused by the therapist or if their body does not behave as willed, it will undergo “pseudoseizures” that are not under their voluntary control (Kalogjera-Sackellares, 2004). Anger can then arise from the lack of this merger and can have the consequence of other people responding empathically towards them or of creating distance from them (Kalogjera-Sackellares, 2004; Schore, 2002; Siegel, 1996).

#### **5.4 Ludwig Binswanger and Buber**

In contrast to Freud, the existential practitioner and Swiss psychiatrist, Ludwig Binswanger, revealed a different perspective and approach involving the ‘hysterical’ patients that he worked with. In Binswanger’s 1935 clinical case of ‘hysteria’, on which he delivered a lecture in Kreuzlingen at the Bellevue asylum (where he was based), he discussed a viewpoint that differed vastly from that of Freud. Rather than focusing on



transference, he described how the relationship between the doctor and patient needed to involve directness, honesty and most importantly, trust. He thought that the relationship was key and subsequently facilitated the successful use of various other therapies including somatic treatments, psychoanalysis, structured authoritative guidance and morally influenced approaches (Lanzoni, 2004).

Binswanger's case of Ilse showed a 39 year old female who placed her right arm into a stove that was burning whilst in front of her father and then took it out in front of him, proclaiming: "Look, this is to show you how much I love you!" (May, Angel, & Ellenberger, 1958). Binswanger took a very different direction to that used by Freud, whereby he made a phenomenological exploration and derived key themes surrounding Ilse's presentation (Lanzoni, 2004; May et al., 1958). He conceptualised her act as a sacrifice that was situated in her life history, which held her father as the central theme. Thus, he viewed her behaviour as arising from the context of her life rather than from a mental disorder; the problem was one of communication as opposed to an organic or psychiatric interpretation (May et al., 1958).

Along these lines, the philosopher Martin Buber described two types of relationships: 'I-It' and 'I-Thou' (Buber & Smith, 1937; Hess, 1987; Zank & Braiterman, 2014). The former refers to an interaction whereby the other person is seen in an objectified manner, whereas the latter is a way of engaging in a relationship as advocated by Binswanger, where both parties meet each other in an open and authentic manner (Buber & Smith, 1937; Hess, 1987).

## **5.5 Learning and Sociocultural Theories**

Following on from this, other types of theories that range from learning to neurophysiological explanations came about. According to learning theories, behaviour is shaped by the environment, whereby behaviours that have a positive outcome or reduce negative outcomes are maintained, in contrast to those that lead to negative consequences, which are avoided (Feinstein, 2011). In this sense, 'conversion symptoms' can be seen to be due to the reinforcement of dysfunctional behaviours, for example, receiving attention from playing out a 'sick role' serves to reinforce the behaviour of this role, which continues to receive attention (Owens & Dein, 2006).

On another note, sociocultural theories have described a different view whereby 'conversion symptoms' are seen to be the result of culturally inhibited emotions being expressed (Feinstein, 2011; Schwartz, Calhoun, Eschbich, & Seelig, 2001).

## **5.6 Neurophysiological Theories**

Neurophysiological theories have researched how certain neural circuits may be involved in how voluntary movement does not operate in the typical way with 'CD/FND' (Owens & Dein, 2006). Brain imaging studies have been carried out looking at "hysterical paralysis", which theoretically could come about at any of the following stages: i) 'intention', where the subject wants to move the body part; ii) 'planning', where the muscles have to be prepared to coordinate for movement; or iii) the 'delivery' of this with the actual movement (Hallett et al., 2011; Kinetz, 2006). The brain imaging of a woman who was paralysed on her left side showed that, when she attempted to move her left leg, her right orbitofrontal and right anterior cingulate cortex, as opposed

to primary motor cortex, were activated. As the former areas are associated with action and emotion, whereas the latter is linked to movement, it was thought that the emotional involvement might be implicated in the suppression of the movement (Kinetz, 2006). These kinds of studies are described as being more helpful because they are not based on the “negative proof” (whereby ‘CD/FND’ is defined by what it is not, for example, ‘non-epileptic attack disorder’ refers to seizures in the absence of epilepsy) that this field has mainly been based on (Kinetz, 2006). However, as they have not actually provided firm explanations to account for ‘CD/FND’, they may not necessarily be as helpful as envisioned, as they are alluding to something specific that can explain ‘CD/FND’ when this may not be possible.

Historically, the literature has shown strong links between ‘CD/FND’ and trauma, ‘CD/FND’ and dissociation, and ‘CD/FND’ and emotional expression / suppression / regulation. Thus, the following section is devoted to describing these areas in greater depth.

## **6 TRAUMA, DISSOCIATION, AND EMOTION**

### **6.1 Trauma**

The term ‘trauma’ was derived from ancient Greek, meaning damage or wound, and before the nineteenth century it was used to refer to war wounds (Merriman, 2012). In the nineteenth century trauma became an important area of investigation that arose in the context of people who were described as having ‘hysteria’ (van der Kolk et al.,

1996). The initial research involved Briquet who linked 'hysteria' with childhood trauma, which was then expanded on by Janet and Freud (Crommelinck, 2014; Merriman, 2012; van der Kolk et al., 1996).

According to Janet, an individual who has experienced trauma will have a narrowed attention span, whereby certain memories of the trauma will not have been attended to and thus will not have been integrated with existing knowledge (Janet, 1907). This attentional focus was thought to result in dissociative experiences that act as a psychological defence to protect the individual from overwhelming trauma (Roelofs & Spinhoven, 2007; van der Hart & Horst, 1989). Janet's theory also described how traumatic memories were dissociated from consciousness and became inaccessible to memory (van der Hart & Horst, 1989).

Along a similar vein, Freud (1895) initially described how childhood experiences of sexual abuse were repressed and expressed as 'hysteria' (Freud & Breuer, 1895). He later moved on from this and theorised on how the child would not have had the language to describe the trauma and thus coped with fantasies that acted as a psychic defence against the unacceptable desires that arose from experiencing the trauma (van der Kolk et al., 1996; Verhaeghe & Masson, 1992).

More recent studies have provided support for an association between 'CD/FND' and trauma (Bob, 2008; Roelofs et al., 2002; Roelofs, Spinhoven, Sandijck, Moene, & Hoogduin, 2005; Sar et al., 2004; van der Kolk & van der Hart, 1989). A review of thirty-four papers examining the link between childhood abuse and non-epileptic seizures as well as a meta-analysis, provided support for this relationship (Sharpe & Faye, 2006).

Other findings have shown high levels of physical and sexual abuse in individuals with 'CD/FND' and, in particular, these experiences have been shown to have occurred during childhood (Roelofs et al., 2002; Sar et al., 2004). A further study that looked at thirty-eight patients with a 'CD/FND' diagnosis concluded that almost half of this group reported the following: childhood sexual and emotional abuse, self-harming behaviours, self-neglect and previous suicide attempts (Sar et al., 2004). However, although these links have been found, this does not suggest a causal relation as not every individual diagnosed with 'CD/FND' was shown to have experienced trauma in these studies (Sar et al., 2004). The conceptualisation of trauma, and how something that is experienced as traumatic for one individual may not be the same for another, is also relevant.

It has been argued that numerous events could be considered traumatic and, as a result, it may not be a simple process to provide a straight-forward definition of trauma (as provided in the DSM-5) (APA, 2013b). The main components of trauma have been described as 'disconnection' and 'disempowerment' (Herman, 1998) and the effect of trauma on the individual will differ depending on whether the trauma is simple or complex (whether there was a single event or numerous events across the life span) as well as an individual's context and other individual 'biopsychosocial' differences (Merriman, 2012; Schottenbauer, Arnkoff, Glass, & Gray, 2008).

The association between trauma and 'CD/FND' is particularly relevant in the context of 'CD/FND' being classified as a dissociative disorder in the ICD-10 (WHO, 1992). The reason for this is, if traumatic experiences are involved in dissociative behaviours or experiences, then the argument for supporting the association of trauma in 'CD/FND' would be valid (Sar et al., 2004; van der Hart & Horst, 1989; B van der Kolk, 2001).

However, to the same extent, as it has not been shown that every single individual with a diagnosis of 'CD/FND' has experienced a trauma, this may suggest that what is referred to as dissociative in the ICD-10 may arise in different contexts.

## **6.2 Dissociation**

The term 'dissociation' is not particularly clear-cut and a study looking into 'dissociation' showed how numerous phenomena have been referred to as 'dissociation' (Holmes et al., 2005). According to this review, dissociation can be separated into either that which involves 'detachment' or 'compartmentalisation', the latter of which refers to 'CD/FND' and former to an altered state of consciousness involving feelings of unreality and out-of-body type experiences (Holmes et al., 2005).

Historically the link between dissociation, trauma and 'hysteria' was initially made by Janet in the nineteenth century (Bob, 2008; Janet, 1907; van der Hart & Horst, 1989). In support of 'CD/FND' as coming under a dissociative category in the ICD-10 (WHO, 1992) and showing links with dissociation, is a study that showed that dissociative symptoms were more prevalent in 'CD' and in 'dissociative disorder' in contrast to 'somatisation disorder' and controls (Espirito-Santo & Pio-Abreu, 2009). However, another study showed that the total dissociative symptom score did not differ between 'CD/FND' and somatization disorders (Guz et al., 2004).

In relation to trauma, in the ICD-10 'CD/FND' shows an overlap whereby 'CD/FND' is defined as a dissociative disorder and dissociation is described as something that can be a response to trauma (WHO, 1992). It follows that some cases of 'CD/FND' may be

dissociative responses arising from trauma whereas at other times 'CD/FND' is dissociative responses in the context of some other aspect. Some of the other areas that may come into this are those of emotional regulation and relational attachments.

### **6.3 Emotion**

The ability to regulate emotions has been suggested to involve the following: a) being aware of different emotions and having an understanding of these emotional states, b) having the capacity to be accepting of one's emotions, c) being able to refrain from reacting to negative emotions in a way that compromises one's future plans, and d) being able to interact with others in a way that utilises approaches to regulating emotions that allows for appropriate contextual emotional communication (Gratz & Roemer, 2004).

Studies have shown that individuals diagnosed with 'CD/FND' show higher levels of attention to threatening emotional stimuli and behavioural avoidance of such stimuli, as well showing unusual emotion-movement interactions and enhanced emotion response over time (Aybek et al., 2015; Bakvis et al., 2009; Perez et al., 2015). Difficulties in emotional regulation and the ability to cognitively move between emotional and non-emotional stimuli in tasks, has been demonstrated in individuals with dissociative seizures (Gul & Ahmad, 2014). Interestingly, a study that looked at dissociative seizures showed that such individuals could be divided into two groups, one that showed high levels of emotional dysregulation and another that showed low levels of emotional dysregulation (in comparison to a normal population), whereby the former had greater psychiatric comorbidity and were from a minority socio-demographic population

(Uliaszek, Prensky, & Baslet, 2012). Comparisons on measures of childhood trauma and alexithymia (difficulty in verbally expressing emotion leading to physical expressions of emotion) showed higher levels of both of these in individuals with dissociative seizures (Kaplan et al., 2013). In addition to the above, a qualitative study showed emotional dysregulation, whereby dramatic shifts in emotional states were shown to occur in brief periods of time (Pick, Mellers, & Goldstein, 2016). The tendency to not express or to not identify with negative emotional states was also shown (Pick et al., 2016).

In relation to studies that have shown support for 'CD/FND' and emotional regulation, other work has introduced attachment theory into conceptualising this association. Attachment theory was derived from the work of John Bowlby and simplistically put, it is the idea that infants are born with attachment behaviours that facilitate safety and support for the child, as well as teaching the child how to adaptively function in the world as it develops (Johnson, 2009). The response of the caregiver determines if the child establishes a 'secure' or 'insecure attachment style' ('secure' referring to the child being able to explore and be independent whilst maintaining a level of proximity to the caregiver in contrast to 'insecure' styles which can involve ignoring, desperate clinging and showing angry responses towards the caregiver), all of which can have a significant impact on later development (Dallos, 2006; Johnson, 2009). The "dynamic-maturational model of attachment" can also be used to understand how 'CD/FND' may arise in the context of two innate behaviours that involve the "freeze response" and the "appeasement defence behaviour" (Kozłowska, 2007). For the former, 'CD/FND' was shown to arise in the context of abuse or punishment where the child will protect him/herself by freezing and inhibiting distressing emotional states (for example, paralysis) whereas in the latter, the child will protect him/herself from inconsistent



parental influence through exaggerated behaviour designed to confuse the source of this (for example, seizures), which are dynamic attachment strategies to facilitate survival (Kozłowska, 2007).

Overall, symptoms of 'CD/FND' may involve an interaction between early developmental difficulties and trauma. This might lead to either an exacerbated emotional response to threat or a suppressed/inhibited response, which could trigger dissociative experiences, depending on differing individual contexts and attachment patterns.

## **7 MEDICAL MODEL CONTEXT AND THE GAP IN CURRENT RESEARCH**

### **7.1 An explanation for the reference to the diagnostic terms 'conversion disorder'/'functional neurological disorder'**

As the labels 'CD/FND' were initially encountered within the NHS medical setting that formed the backdrop for the development of this research, the sense that the medical setting actually explains 'CD/FND' by 'un-explaining' it (as it comes under 'medically unexplained symptoms') is held to be particularly important in terms of understanding the lived experience of *agency*. The use of the terms 'CD/FND' is of particular relevance in light of how males with 'EDCD' would only identify with such terms as a result of an association that has come about via medical professionals and/or others who conceptualise such phenomena in relation to this framework. In contrast to this, those individuals with 'EDCD' who have not as yet encountered the terms 'CD/FND' would not

automatically conceptualise their experience in such a way. Rather, their experience could be viewed in various ways, for example, if a person has encountered such phenomena for most of their lives, they might see it as a 'normal' part of how they experience life or, alternatively, a person might view their experience as one that is purely organic (for example, epilepsy). As the aim of this research has been to explore *agency* in relation to identifying with 'CD/FND', the following combinations were all equally relevant when it came to the recruitment of participants: a) males who had been diagnosed with 'CD/FND' and agreed with the diagnosis, b) males who had been diagnosed but did not agree with the diagnosis, or c) males who had not been diagnosed and did identify with 'CD/FND'. In all cases the research interest resided in the fact that participants had been faced with a shift in perception that had moved them away from the standard physical understanding, and how *agency* was experienced in relation to this.

As all labels are a part of language and are used in every sense to categorise and understand the world, the linguistic terms 'CD/FND' also 'explain' phenomena that do not fall under a standard medical-neurological description where symptoms are due to an organic cause. However, the process of providing a medical explanation for something that does not fit the medical model view introduces a contradiction for all those attempting to identify with such terms.

It seems to be because of this, that there is uncertainty about how 'CD/FND' is understood as well as how *agency* is experienced in relation to this. Thus, the researcher's interest has been in how *agency* is experienced in this context, as having

agency would imply having some knowledge of what choices are available and to what extent one can act within the world.

## **7.2 Medical model and mind-body dualism**

The diagnostic terms 'CD/FND' point towards a western dualistic understanding of 'mind and body' as existing separately by way of suggesting that psychological (mind) processes are 'converted' into physical (body) behaviours, or that functional and structural body processes operate separately (Bullington, 2013).

This diagnosis raises the "mind-body problem", which has been pondered by philosophers such as René Descartes whereby the notion of mind as non-physical and body as physical matter were distinguished, leaving an unbridgeable divide (Descartes, 1961). This mind-body division operates in the medical model approach, whereby poor health and disease are conceptualised in terms of physical and bodily problems that require treatment at the level of the physical body. This contrasts with more holistic approaches that take all aspects of a person's life and environment into consideration. For example, Chinese medicine will treat each person based on the manifestation of what they are seeking treatment for in the context of their lives, which includes the environment (elements), their bodies, and philosophical understandings of a holistic system (Hong, 2009). Thus, rather than a broken bone requiring mending (as would be suitable with the medical model), it is the troubles involved in a person's life that are thought to be manifesting physically and need repair.

Along these lines, if mind and body were not seen as separate, then 'physical symptoms' that arose from different sources would not be seen as curious or controversial. The problem emerges in relation to the underlying assumption that certain physical features (for example, neurological structural atrophy) lead to certain physical behaviours, which *should not* come about via an alternative cause. The extent to which individuals (patients and medical professionals) adopt the western dualistic approach would affect how the label of 'CD/FND' is identified with. If mind and body are seen as separate, then the diagnosis would be confusing, as it would imply that the person's experience *should* not be happening (for example, paralysis should only occur when the spine is damaged). In contrast, if mind and body were to be seen as one system that interacted with the world, then a different understanding could be adopted, whereby a person's experience would not be questioned or doubted.

Although a western dualistic medical model permeates current cultural understandings, there is also a history of attempts that have been made to dissolve this. Szasz, in his 1988 book 'Pain and Pleasure', argues against this dualism by describing the problem as one of causation (Szasz, 1988). He refers to the comparison of psychology and physics where both areas can be held to explain an identical object in different ways (Szasz, 1988, 2007). In such an instance, it would not make sense to say that the physical explanation caused the psychological explanation, or vice versa. Rather, both areas can be seen to complement each other at different levels of explanation, whereby one focuses on consciousness, experience and behaviour, and the other looks at particles and laws (Szasz, 1988, 2007). To say that the body causes a mental event or that a mental event causes a bodily consequence is misleading, as these are different types of explanations, from different points of view (Szasz, 1988, 2007). Thus, he views the

mind-body dualism and interaction as firmly held in psychosomatic medicine, psychiatry and medicine (Szasz, 1988, 2007).

In a similar way Laing, in his 1960 book 'The Divided Self', also talks about how the vocabulary used in medicine and psychiatry is one that divides the person or separates the person from their context and the world, whereby they are approached as a biological entity in which mind and body are divided. He described this as an abstraction that encompasses concepts like: 'psychological and physical', 'psyche and soma', personality, self, organism, 'I and You', and 'internal and external' (Laing & David, 2010).

Merleau-Ponty also sought to resolve the western Cartesian dichotomy of mind/body and, in his 1945 work 'Phenomenology of perception', he spoke about the 'body-subject', whereby people are their bodies and not the division of physical objective body and non-physical subjective mind (Bernard, 2004). He described people as 'embodied' in the sense that the world is experienced via the body where every act, intention and experience is as an embodied being experiencing the world, which would not be possible if humans were not embodied (Bernard, 2004; Bullington, 2013; Renolds, 2015).

### **7.3 Gap in current research**

'CD/FND' is a classification that comes from a rich historical backdrop (as described above). The social context, psychiatric classificatory systems and medical model approach has led to the medical profession approaching individuals diagnosed with

'CD/FND' in a way that conceptualises them as unexplainable and as separate, rather than empathising with a patient's experiences and attempting to understand the person in a more 'holistic' manner (APA, 2013a, 2013b; ICD-10 Classification of Mental and Behavioural Disorders Diagnostic criteria for research, 1993; Stone, LaFrance, Levenson, & Sharpe, 2010; WHO, 1992). The research in this area highlights the dominating medical position: the vast majority of studies are quantitative and from the perspective of the medical profession, which has a predominantly neurologic and psychiatric focus (Poole, Wuerz, & Agrawal, 2010; Stone et al., 2005). Although there are neurologists who show a focus on de-stigmatising individuals with a 'CD/FND' diagnosis and aim to bring about greater clarity in the area, the focus remains on a particular perspective as a specific practitioner (Stone, LaFrance, et al., 2010; Stone, Vuilleumier, & Friedman, 2010; Stone et al., 2005). Thus, by focusing research so as to build on the minority qualitative research in this area, the mind-body duality of the medical field will be addressed, alongside giving people who have been labelled with 'CD/FND' a greater voice in this dominant medical setting.

Also, as there is a lack of agency in terms of how people with symptoms of 'CD/FND' feel incapable of preventing or initiating movements when experiencing such phenomena (Kranick et al., 2013; Voon et al., 2010), the notion of agency has been extended to derive a more complete understanding of when agency is and is not experienced. The reasoning behind this has been to understand how agency is experienced in a more holistic way, which is relevant to individuals who have been diagnosed with 'CD/FND' and the medical decision making process involved in this. As the exploration of how males experience agency in the area of 'CD/FND' with an IPA approach has not been attempted before, this study addresses a unique area of inquiry.

## 8 METHODOLOGY

### 8.1 Research Methodology

#### 8.1.1 A qualitative research approach

A qualitative methodological approach was used to explore the research question of the lived experience of *agency* for males who have experiences that are described as and they identify with through the medical label 'CD/FND'.

The majority of existing research of 'CD/FND' has a quantitative focus, with fewer qualitative studies. As this particular area is one that originated within the speciality of neurology (Reuber et al., 2005; Stone et al., 2005a), this would seem unsurprising. However, as individuals who are diagnosed with 'CD/FND' will also frequently be referred to psychiatry, it would seem useful to at least start further exploring the patient's perspective of how this change in direction from a neurological to a psychiatric perspective is experienced (Kanaan et al., 2009). A recent article outlined a qualitative study exploring the subjective experience of patients diagnosed with functional movement disorders; it highlighted the importance and value of continuing contributions of qualitative research to this area (Epstein et al., 2016). With all of this in mind, it was decided that a qualitative approach was most suitable to explore the research question.

Another reason for choosing a qualitative approach over a quantitative approach stemmed from the different assumptions underlying each. Quantitative research assumes the following: i) reality is objective and can be measured through observation, ii) the observer is entirely separate from what is being observed, and iii) research should be unbiased and follow a deductive course (Braun & Clarke, 2013). In contrast, qualitative research assumes that: i) reality is subjective and experienced differently by each individual, ii) the researcher is a part of the research rather than an independent observer, iii) research will be biased as it is context bound (where each individual has a different history with a different set of values, beliefs and ways of approaching the world) and follows an inductive course (Braun & Clarke, 2013; Smith & Osborn, 2007; Smith, Flowers, & Larkin, 2009). As the current research aims to conduct a detailed exploration of the ways agency is experienced by males who have experiences that are described and that they identify with as 'CD/FND', a qualitative approach aimed at exploring the lived experience of this seems most appropriate.

This choice of approach introduced a tension right from the start, as it offers a phenomenological enquiry into an area that is situated within a medical model framework where the majority of existing research has been aimed at providing further clarification within this medical conceptualisation (Hallett et al., 2011). The epistemological problem that this raises is that the term 'CD/FND' exhibits a particular way of categorising experience, whereby the exploration of lived experience in relation to this assumes that something specific is being referred to (for example: 'CD/FND' as a diagnosis), as opposed to a range of physical phenomena (for example: weakness in legs, tremors as phenomena). This epistemological consideration, in turn, is likely to apply to the focal phenomenon under consideration in a similar way, as the experience



of *agency* is interrelated with the different ways 'CD/FND' is conceptualised. Although a qualitative approach contrasts with a diagnostic label of 'CD/FND', it is not at odds with a medical framework or with quantitative methods of inquiry. One reason for this is that the aim has not been to support or refute pre-defined concepts but rather to ask the question in a different kind of way, which addresses the subjective 'lived experience' of *agency* for males who identify with the diagnostic label of CD/FND. Thus, a different perspective is adopted in this research, whereby the focus is informed by participants' description of how *agency* is experienced from the 'inside' as opposed to an observer's objective attempt at understanding via observation from the 'outside' (Biggerstaff, 2008).

### **8.1.2 Why choose the qualitative method IPA?**

There are a number of different types of qualitative methods that differ in the following ways: the research question being asked, epistemological and ontological positions, and the role of the researcher (Lyons & Coyle, 2007). Some of these qualitative methods are: grounded theory, discourse analysis, heuristic enquiry, narrative analysis and interpretative phenomenological analysis (IPA) (Braun & Clarke, 2013; Lyons & Coyle, 2007).

This research aims to explore the phenomenon of *agency* that is to be explored in males who identify with the label 'CD/FND' (where the label refers to motor behaviours and/or sensory experiences that individuals do not feel as though they have conscious control over (Hallett et al., 2011)). The researcher will be included in the research process because an investigation of agency, by way of the relationship that the researcher has with participants and ways of questioning, will always involve the

researcher. Therefore, it is important to recognise and bracket pre-existing assumptions that may arise from researchers' interest and experience in this area (Braun & Clarke, 2013; Smith & Osborn, 2007; Smith et al., 2009). Also, because the researcher is a part of the research, it is especially important that reflexivity forms a part of this process, in terms of how participants' descriptions are understood (Braun & Clarke, 2013).

Reflexivity thus adds to bracketing by making it clearer to separate the researcher's opinion and perspective from those of participants, as well as to highlight how certain lines of questioning may have influenced participants' responses (Smith et al., 2009).

Thus, the choice of method will need to adhere to these research aims.

As the research is phenomenological, discourse analysis was not a suitable method to employ due to its focus on how reality is co-constructed through language rather than from people's lived experience (Lyons & Coyle, 2007; Smith et al., 2009; Smith, Flowers, & Osborn, 1997). Grounded theory was another qualitative approach that was deemed unsuitable for this research because it involves a process whereby a theory will eventually emerge from the data, in contrast to the research in question which intends on exploring specific phenomena (Lyons & Coyle, 2007; Willig, 2001). The heuristic method of inquiry was another phenomenological approach that was considered but decided against. It draws on intuition and the way in which knowledge is tacit and holds that the researcher's role is the central focus, whereby their whole self is used to address the research (Kleining & Witt, 2000; Moustakas, 1994). However, this renders it a less suitable fit for the aim of this research, which is to try and understand participants' experience by means of phenomenological exploration, where the researcher is involved in the process but not central to it. Another phenomenological approach is narrative analysis, which looks at how people's lives are made up of

different types of narratives and the importance of self-exploration in this (Lyons & Coyle, 2007). This approach was not chosen for this research because it is a particular way of deriving meaning through narrative, and as a result excludes other forms that may arise (for example, metaphor). The aim of this research was not to produce a coherent narrative but rather to interpret different accounts of a phenomenon and to stay as close as possible to individual accounts of meaning.

The approach deemed most appropriate to this investigation is Interpretative Phenomenological Analysis (IPA), which is an approach that was introduced by Jonathan Smith and colleagues in the 1990s and has continued to gain popularity since then (Smith & Osborn, 2007; Smith et al., 2009; Smith, 2011). It is a method that is linked to the field of psychology and has often been applied to health and counselling psychology fields (Clarke, 2009; Pringle, Drummond, McLafferty, & Hendry, 2011). IPA focuses on exploring how individuals understand and bring meaning to their world in relation to themselves and those around them (Smith & Osborn, 2007; Smith et al., 2009). In order to do this, it attempts to examine in detail the way in which individuals experience their world and the explanations they provide for themselves (Smith & Osborn, 2007). The researcher also has a fundamental role in this process of understanding the perspective of an individual; making it a two-fold course in the sense that the researcher has to stay as close to what the person is saying as possible whilst at the same time trying to interpret this (Smith & Osborn, 2007). Thus, IPA differs from more descriptive phenomenological approaches, as it is not just “bearing witness” (Pringle et al., 2011; Smith & Osborn, 2007). Rather, the researcher has an active role in the process, whereby they will attempt to understand how the participant is understanding or making sense of their own experience, which creates a double

hermeneutic (Pringle et al., 2011). In addition to this, IPA has a strong focus on elements of cognition, language, emotion and body in a way that assumes a link between these for people whilst still recognising the complicated nature of this (Smith & Osborn, 2007).

### **8.1.3 Interpretative Phenomenological Analysis**

IPA is a particular approach to conducting qualitative research that has arisen out of the field of phenomenology (Brocki & Wearden, 2006). IPA uses a phenomenological approach that focuses on the meaning of an individual's lived experience (Smith et al., 2009).

**Phenomenology** differs to quantitative approaches that adhere to objective measures as it is about subjective experience and meaning, which means that it can also be used to support and contribute to other areas of research by providing such subjective knowledge (Featherstone, 2010). Phenomenology is a method that focuses on trying to discover what appears to consciousness prior to the influence of any other aspect that may shift this initial 'appearance' (Moran, 2000). Early on it was described as an a priori science of the mental process or insight that could be used to extend outwards to discover broader laws from this (Moran, 2000). The philosopher Edmund Husserl built on this by looking at it as a particular type of descriptive and explorative endeavour to study in detail the phenomena that made up consciousness of individuals (Moran, 2000). This method involved an extreme approach of bracketing of every kind of scientific conceptualisation or theory in order to achieve this (Featherstone, 2010; Moran, 2000). Philosopher Martin Heidegger developed on from this and argued that it was not possible to bracket to such a level as suggested by Husserl, as people need to

hold prior knowledge in order to have any conception of what is being explored (Featherstone, 2010). Thus, the phenomenology of Heidegger moved from Husserl's absolute description towards description as involving interpretation (Moran, 2000). This historical phenomenological movement can be seen in terms of IPA, whereby it supports all description as involving interpretation (Moran, 2000).

IPA thus involves **hermeneutics** whereby it takes participants' interpretation of their experience and the researcher's interpretation of this, and gives a third person view of a first person account (Smith & Osborn, 2007; Smith et al., 2009). An individual's approach to interpreting and making meaning of their own experience is key, whereby the experience is explored as such rather than in a way that imposes predefined categories (Smith et al., 2009). IPA also uses what is referred to as the 'double hermeneutic' whereby the researcher attempts to make sense of how the participant makes sense of their own experience (Smith et al., 2009). However, the problem with interpretation is that the researcher's own views and position can be as much a part of the research process, which can in turn be reflected in the research to a great extent (Brocki & Wearden, 2006). It is for this reason that IPA involves **reflexivity** of the researcher when it comes to carrying out interpretations (which are included in the research) in order to show how results come about in the context of the researcher's own position and interpretative process (Smith & Osborn, 2007; Smith et al., 2009). Importantly, the use of **bracketing** is key in research that uses IPA, as it allows the researcher to recognise his/her assumptions and biases in a way that can be suspended rather than removed (Smith et al., 2009). Bracketing should be brought into all aspects of the research process, for example, when engaging with the participant and the

interview, when analysing and interpreting the data, and when writing up the results (Smith et al., 2009).

IPA is also an **idiographic** approach, as it focuses on the specific rather than the general (Smith & Osborn, 2007). It involves drawing out something particular about an individual's lived experience and then saying something in detail about the participant group (Smith et al., 1997). It aims to understand how the specific can be understood by specific people in a specific context whereby there is always a commitment to analytic depth and detail (Smith & Osborn, 2007; Smith et al., 2009; Smith, 2011). In addition to this, IPA involves **cognition** in the sense that we bring meaning to our experiences through interpretation and communication (Smith et al., 2009). Finally, the researcher is also required to become immersed in each participant's "world" which involves insight, empathy and reflective skills in order to remain as close to what is being communicated as possible (Featherstone, 2010; Smith & Osborn, 2007; Smith et al., 2009).

As this research explores the lived experience of *agency* for men who identify with the label 'CD/FND', IPA has been chosen for this research. As the researcher also works therapeutically with the 'particular' type of group involved in this research, it is paramount that bracketing and reflexivity are brought in at all times, and adhered to as part of the IPA approach. Further, as it is the desire of the researcher to understand as closely as possible how participants experience *agency*, the way that IPA highlights the immersion of the researcher in the experience of each participant is invaluable.

#### **8.1.4 Epistemological and Ontological positions**

As the choice for the use of an IPA approach has been described above, this section attempts to address the epistemological question of 'how we know what we know?' as well as the ontological questions concerning the nature of being (de Gialdino, 2016).

Epistemology questions how and why we can know what we know and how knowledge is created and disseminated (Eriksen et al., 2013). Quantitative scientific knowledge is an approach that attempts to understand reality 'objectively' through what can be directly observed and measured (de Gialdino, 2016). However, as it is based upon the observer's own belief systems and values in conjunction with the use of particular approaches and tools that arise from out of this, the 'objective' can be understood as being 'socially constructed' (de Gialdino, 2016). In contrast to this, the epistemological position of the qualitative IPA approach of this research does not make the assumption of an objectively measurable reality but rather explores how the world is understood or constructed in relation to an individual's lived experience and interaction with the world and other people, which takes into account a variety of different contexts, including culture and language (de Gialdino, 2016). It looks at individual accounts that are gathered by the researcher by means of interpretation in a way that is reflective and transparent in order to maintain the first person perspective (de Gialdino, 2016). Thus, in terms of this research, the epistemological position is one that reveals a) the researcher's own context, beliefs and views, b) those of the individuals whom the researcher has therapeutically worked with, and c) the social environment and assumptions of the NHS, where the researcher works, which adhere to a medical model perspective.

The epistemological positioning of this piece of research is one that sits between the realist and the relativist positions (Mertons, 2014). The realist position holds that the data obtained should give information about how things really are in the world. This assumes that there is a pure or true type of knowledge that can be captured and, as a result, the method used would need to be able to achieve this. For example, research into patients' perceived quality of their healthcare would need to use a method that can derive the true feelings, perceptions and experiences for this group (Mertons, 2014). At the other end of the continuum the relativist position does not hold that true feeling or experience exists but rather that experience is constructed from cultural and discursive factors (Mertons, 2014). IPA would argue that experience is both of these in the sense that there is always an element of interpretation whereby experience is constructed, but to the same extent experience is also undeniably true to the person that is experiencing (Mertons, 2014). As the focus of this research is to explore the lived experience of agency (realist side of continuum) for a group who identifies with a particular medical label (relativist side of continuum), IPA is a very suitable method to achieve this.

Ontology focuses on the nature of reality whereby one's belief systems, history, cultural context and values shape how one perceives reality and, as a result, how one engages with the world. In quantitative research, reality is perceived as holding the belief of subject and object whereby the 'objective' is seen as tangible and observable and as imparting knowledge that holds a truth within this framework (Eriksen et al., 2013; de Gialdino, 2016). In contrast, qualitative research does not view reality as comprised of subject and object but rather as an inter-related, interacting, dynamic process out of which meaning and experience is shaped and constantly re-shaped (Braun & Clarke,



2013; Eriksen et al., 2013; van Deurzen & Adams, 2011; van Deurzen, 2010; de Gialdino, 2016). In this sense, this IPA research is focused on the meaning that people bring to their experience as well as the meaning and interpretation of the researcher and social context that influence how this knowledge is derived, as opposed to 'capturing' a quantifiable 'truth' that can be applied generally (de Gialdino, 2016). In this way, the therapeutic work of the researcher has revealed that some individuals have described feeling a decrease in agency when they have symptoms of 'CD/FND'. This research is aimed at exploring how males with 'EDCD' feel in relation to this and in a broader context in their lives.

In terms of the realist and relativist spectrum mentioned above, a realist ontological position would assume that there are objects that make up the world with a cause and effect relationship that exists between them (Mertons, 2014). A relativist ontological position would argue that the world is not made up of objects and laws but rather can be interpreted in all different sorts of ways (Mertons, 2014). IPA would again sit between these positions whereby, in terms of this research, the realist ontology would be that the experience is concrete to the experiencer, whereas the relativist ontology would point out the interpretative, non-concrete identification with a culturally constructed label (Mertons, 2014).

The researcher's role in relation to the discussed epistemological and ontological positions is again situated in-between the realist and relativist sides. The researcher is involved in capturing the experience of the participant in a way that is as true to the person as can be derived as well as recognising how the researcher co-constructs the data with the participant.

## **8.2 Procedure**

### **8.2.1 Selection of participants**

This study selected a purposeful sample of adults who met the following inclusion criteria: a) participants were male, b) participants had experienced phenomena that they identified under the diagnostic label 'CD/FND', c) participants were able to speak fluent English, d) participants were able to engage fully in the in-depth interviews (which was ascertained through the screening interview), and e) the lower age limit of 18 years was met.

The exclusion criteria were: a) vulnerable participants such as children, individuals with learning disabilities, and older adults with dementia; b) current self-harm and/or suicidal ideation (as there was the possibility that a discussion of past trauma could arise); c) bereavement, where the length of time and inferred vulnerability is judged via the clinical skills of the researcher (as different individuals may take different periods of time to work through this); and d) intoxicated by a substance (this research requires as clear and detailed a description of participants lived experience which could be hampered by intoxication).

### **8.2.2 Interview questions**

A semi-structured interview approach was used in order to have a structure in place that could allow the interview to remain focused (for example, questions relating to agency) whilst also enabling a flexibility that could offer an opening for movement

outside of this to potentially bring about a greater level of depth (see Appendix D). As the research was focused on exploring the experience of *agency* for males with 'EDCD', the questions were constructed to ask about agency in relation to the participant's body, social environment and psychological state or 'inner world'; for example, one of the questions was: "How do you experience agency or control?" This focus was influenced by the researcher's background where the work has involved an approach of psychological formulation using the biopsychosocial model as well as the four dimension philosophical approach of Emmy van Deurzen (physical, personal, social, spiritual) (van Deurzen, 2010). The approach chosen by the researcher fell somewhat between these two approaches as the researcher's direction has been more philosophical than the biopsychosocial model but has not incorporated the 'spiritual dimension' of the other approach.

The interview schedule for the pilot interview began by asking the participant if they were familiar with the terms 'CD/FND' and 'agency' (see Appendix D). After providing clarification on this, the next question was: "Could you tell me a little about what drew you towards participating in my research?" (see Appendix D). These initial questions were followed by a list of questions and prompts intended to direct the interview process in a way that allowed it to flow in a fluid and richly explorative way, where the participant was able to raise the points that he felt were most relevant, and where the researcher's influence was kept at a minimum (see Appendix D). These questions focused on exploring how *agency* was experienced physically, psychologically and socially as well as how phenomena of 'CD/FND' were experienced (see Appendix D). The follow-up questions were designed to move with and be chosen in relation to the flow of the interview (see Appendix D).

Following the pilot interview and subsequent interviews, the interview schedule continued to develop in a way that made adjustments so as to approach the next interview in a way that could continue to derive as much meaning and depth through this learning and modifying process (see Appendix D) (Biggerstaff, 2008; Smith & Osborn, 2007; Smith et al., 2009). The interview criteria set out by Kvale (1996) were used whereby: i) the interviewer should appropriately structure the interview so that it is clear yet communicates a warmth in order to put the interviewee at ease, and ii) the interviewer should reflect back the interviewer's understanding (in order to make sure that what is being communicated is being adequately understood) in a way that allows for the participant to make corrections and provide further clarity (Kvale, 1996).

### **8.2.3 Ethical considerations:**

As this population raises significant ethical issues, this research has followed the Code of Human Research Ethics outlined by the British Psychological Society (British Psychological Society, 2010), as well as the 'Ethical Guidelines for Internet-Based Research' (British Psychological Society, 2013). As sensitive information was predicted to potentially arise from the interview, the interviewer focused on minimising the potential for risk (Rowe, 2010; Sar et al., 2004). Potential risks for this group were thought to include what might happen to: "participants' personal social status, privacy, personal values and beliefs, personal relationships, as well as the adverse effects of the disclosure of illegal, sexual, or deviant behaviour" (British Psychological Society, 2010). All of these elements were held in mind and minimised/eliminated by adhering to the following principles: 'respect, competence, responsibility and integrity, scientific value, social responsibility, and maximising benefits and minimising harm (British

Psychological Society, 2010, 2013) as well as providing a debriefing afterwards (see Appendix C).

The ethical considerations involving 'confidentiality, respect, competence, responsibility, integrity, safety and scientific value' are weaved into the next sections to demonstrate their application and value as appropriate to what is being discussed (British Psychological Society, 2010).

#### **8.2.4 Recruitment of participants**

The decision to recruit eight participants was made at the start as, should any problems have arisen that could lead to the exclusion of data, the sample would still remain within the acceptable requirements where 'six' has been suggested to be a reasonable number of participants to use for doctoral research (Smith & Osborn, 2007; Smith, 2010). The amount of eight was deemed an adequate number because IPA is a qualitative approach that is idiographic and focused on exploring particular phenomena in detail (which is more likely to be achieved by focusing on a small sample in an in-depth manner) (Cooper, Fleischer, & Cotton, 2012a; Smith, 2011).

Upon receipt of ethical approval from Middlesex University, the manager of the charity 'Functional Neurological Disorder (F.N.D) was contacted (<http://www.fndhope.org>) (FNDHope, 2016) to request permission to advertise the research on their website. Once permission was granted and ethical approval provided via Middlesex University and NSPC (see Appendix F, G, H), the participant information sheet was posted on the [fndhope.org](http://www.fndhope.org) website, which included a link to the researcher's website (see Appendix A): <https://sites.google.com/site/fndcresearch/home>. The researcher's email address:

[www.rescd123@gmail.com](mailto:www.rescd123@gmail.com) was included with this so that potential participants could contact the researcher directly.

In addition to advertising through the FND charity, the administrators of various *facebook* groups were approached and permission to advertise was received from the following groups: 'Conversion Disorder Awareness', 'Psychogenic Non-Epileptic Seizures' and 'Just Me – Conversion Disorder', 'Psychogenic Non-Epileptic seizures', 'Living with Non-Epileptic Attack Disorder', 'Conversion Disorder', 'NEAD', 'Functional Neurological Disorder', 'Living with Conversion Disorder' and 'Non-Epileptic Attack Disorder'. As the focus has been internet-related research, the *facebook* group managers were initially contacted so as to not intrude in the private space of the group. The research process ensured that interactions were carried out in such a way that the interaction did not appear in the public space of the group in order to protect the autonomy and confidentiality of the participant (British Psychological Society, 2013).

The groups that identified themselves with the labels 'CD/FND' fell within the following countries: United Kingdom, America, Canada, South Africa and Australia. The decision was made to include all of these groups and potential participants as the focus was on interviewing how males with 'EDCD' experienced agency in their lives. As all of these groups fulfilled this criterion, they were all deemed suitable for interviewing. As this meant that the researcher would potentially not be able to interview participants in person, Skype was used as the platform to conduct the interviews, although the main preference resided in face-to-face where possible. A separate Skype account "researchcd" was set up for this. However, it was acknowledged that Skype is a method of interviewing that will automatically reduce the level of depth and exploration due to

the limited nature of the encounter that involves communication through a screen as opposed in person. As the researcher was accustomed to engaging in therapeutic communications via Skype, this was not seen to be a problem. The process of conducting the interviews supported this as all of the participants engaged to a great level of depth and showed much comfort and immersion in the interview process. The decision was also made to use Skype as it allowed the participant to have a greater level of control whereby they could easily pause the interview or change the situation if this was what they felt to be necessary. As this was a vulnerable participant group, Skype interviewing also introduced a level of safety for these participants.

#### **8.2.5 Pilot study and ethical considerations:**

Upon receipt of an email querying the research, an initial screening interview was arranged where the inclusion and exclusion criteria were discussed in order to determine eligibility, provide an in depth account of the research, and to discuss confidentiality and consent. The following details that were discussed can be seen below.

For the ethical issue of confidentiality, the following was explained to the participants: i) it was explained that the audio-recordings would be transcribed solely by the researcher and that the anonymity of transcripts would be maintained through the use of alternate methods to record participants' identity (for example, acronyms), ii) the use of Skype as the platform to conduct the interviews meant that there would be no possibility that participants could meet each other, iii) transcripts would be analysed privately and information would be held under a protected password in an encrypted form on my personal computer that cannot be accessed by others, iv) recordings would

be listened to with earphones in a private setting, v) the researcher would keep all notes anonymous at all times, vii) audio-recordings would be destroyed once transcribed, and viii) information would be identified solely with a project code and stored on an encrypted USB stick. Results would be provided to the participants either over the phone, via Skype, or in person once completed (should they wish to receive them). It was also explained that the researcher would anonymously store data for four years post DCPsych award in order to allow for the potential for publication, after which transcripts would be destroyed. In addition to this, it was explained that the information would be kept for at least 6 months after the researcher graduated and would be treated as confidential at all times. If the research were to be published in the future, the researcher would make sure that the participants' names and other identifying details would not be used. Finally, it was explained that data would also be stored according to the Data Protection Act and the Freedom of Information Act.

In relation to the ethical consideration of informed consent, the researcher was as clear as possible in regards to explaining what the research involved. The researcher provided a document that clearly outlined the research process in order to allow the participants to decide if the area of research is of interest to them (Appendix A). The name and contact details of the researcher and his/her supervisor were provided in order for participants to be able to get in touch should there be any questions or concerns (see Appendix A). Each participant was required to provide both written and verbal consent to participate and informed consent was obtained verbally at first. The participant was then given the option to choose if they would prefer to contact or be contacted by the researcher within a two-week period or to decide on immediate verbal consent. The next step involved written consent immediately prior to the research



Skype interview. This process of informed consent ensured that the participant had an adequate period of time to decide if he would like to be involved in the research or if he would prefer to withdraw/not become involved without feeling pressured to make a particular decision. As the participants had to give consent to be audio-recorded, transcribed and analysed, the fact that they were given the time and space to make this decision was particularly important.

Recruitment and electronic consent was achieved via email communication and confidentiality was maintained by encrypting the Internet connection of the email service provider, 'gmail', using 'SafeGmail' as well as any messages (cached, stored or archived) from participants. Interviews were held in a private location for both the researcher and the participants, and audio-recordings were made with the researcher's own hand-held recorder (so as to avoid audio recording via Skype where the potential for information to become publically available is greater). Participants' identities were verified via their Skype online visibility as well as by their Skype usernames and email addresses. Potential issues that could arise in relation to privacy in the location were discussed and necessary provisions were agreed on to eliminate this possibility (as well as to avoid interruptions during the interview). In this case, the best attempts were made to ensure that the interview was set for a time when the participant was alone.

Once the signed participant consent form was received from the first participant, the beginning of the Skype interview again reiterated how the participant had the right to withdraw at any time and that confidentiality and privacy would be ensured. The researcher requested permission to audio record the interview with a digital recorder

with the intention of transcribing the interview at a later stage. This procedure was followed for all subsequent interviews.

#### **8.2.6 Interview approach and ethical considerations**

The researcher paid particular attention to the vulnerable nature of the research group. The interview approach and the types of questions that were designed were in accordance with the use of empathic communicative skills to ensure that participants felt at ease at all times. As the nature of the interview was semi-structured, this allowed participants to detail their experience in a way where they could feel as though they were in control of the direction of the interview (and thus more at ease). The researcher used prompt questions to keep participants on track in a way that adhered to this. Thus, any potential for a participant to become anxious was reduced, as either the participant or the researcher was more able to steer away from this if necessary. This was particularly evident in the final ten minutes of the interview where both the researcher and participant steered towards a more positive and safe ending.

The researcher was clear at all times about qualifications and experience in the area under research (where it was explained that the interviewer had two years of experience working with people diagnosed 'conversion disorder' in a therapeutic way in the NHS). Care was taken to inform the participant of every aspect of the research process so that they were informed at all times. In relation to the time and cost involved in the research process, there were no travel costs as the interview took place over Skype.

### **8.2.7 Debriefing**

As it was the researcher's responsibility to ensure the wellbeing of each participant, the fact that the researcher worked as a therapist with this group placed the researcher in a better position to notice and move away from areas that could potentially have induced psychological stress. As this was an internet-related interview, the researcher enquired throughout as to how the participant was doing and whether they were finding the pace and material manageable (British Psychological Society, 2013). The researcher ensured that each participant was 'safe' upon completing the interview by asking the question "How have you found the interview?" The researcher then appropriately and immediately debriefed the participant and concluded the interview once it had been ascertained that the participant was in a safe and calm state to leave without any potential for concern. Upon completion of the interview, the researcher emailed a debriefing form with sources of support. Also, the researcher communicated that she would be available to get in touch with should the participant wish to find out anything further in relation to support or the research. Thus, the researcher's therapeutic skills were used to debrief and ensure the safety of the participant so that, should any situation arise that warranted further intervention (for example, physical injury), the emergency contact details for the specific participant at hand were provided, for example, emergency services close to the participant's location such as the hospital, police department and next of kin. This meant that the researcher knew the name and residence of each participant. These details will be collected via email prior to the interview (ensuring that the necessary encryptions are in place) and destroyed immediately after this.

### **8.2.8 Data analysis**

After the initial pilot interview the researcher proceeded to interview the other seven participants. Once this had been completed the researcher transcribed all eight interviews and moved into the next stage of analysing the data.

The researcher read all of the transcripts over once and then re-read them again making descriptive notes in the left hand margin so as to detail the content (Smith & Osborn, 2007; Smith et al., 2009; Smith, 2011) (see Appendix E). This allowed for the identification of important explanations, characterisations, remarks, and responses of an emotional nature. All transcripts were then re-read for a third time: the focus was on the linguistic detail of the transcript, whereby the way that language was used by each participant was the focus, as opposed to concentrating purely on what was said; for example, pauses, the use of pronouns, and how often things were repeated. The researcher then read them for the fourth time and began interpreting the data so as to devise notes of a conceptual form, which then led into the next stage of deriving themes from the data. Emergent themes were written down in the right hand margin where reflections were made of the first hand words of the each participant (Braun & Clarke, 2013; Lyons & Coyle, 2007; Smith & Osborn, 2007; Smith et al., 2009) (see Appendix E). The researcher focused on 'bracketing' assumptions and judgments at all times by documenting thoughts and reflections in a journal when reading the transcripts in order to remain as close as possible to what was being described in the transcript (Biggerstaff, 2008).

Following this, superordinate themes began to develop and the transcripts were re-read using highlighters to colour code areas that were forming under superordinate themes

as well as to write these themes in highlighted capital letters (see Appendix E). Superordinate themes were written down on a separate piece of paper with all of the emergent themes underneath each area. The researcher did not rush this process but rather took her time to really situate herself in the world of each participant and experience when allowing themes to emerge in her attention. Thus, the interpretative phenomenological analysis of the data approach was followed, which involves various elements such as: i) initially drawing out an in-depth depiction of the participants experience and then moving into an interpretation of the experience, ii) a dedication to developing as close an understanding of the experience of each participant as was possible, iii) looking at the way in which the participant derived meaning in relation to their sense of 'agency' within the context of having experiences described as 'CD/FND' (Smith, 2011). This involved making descriptive notes, focusing on how language was used to communicate what was described, and then interpreting the data. Once this had been completed for all transcripts, superordinate and subordinate themes were derived across all eight participants (see Appendix E).

### **8.3 The participants**

The age of each participant, country of residence, type of 'EDCD', ethnicity, relationship status and employment status have been detailed below. The demographic of age was chosen as the general age of onset for men has been identified in the range of 20-50 years old (Hallett et al., 2011; Reuber et al., 2005; Stonnington et al., 2006). The country demographic reflects how the specified countries all held the same diagnostic label and criteria and how the ethnicity of 'CD/FND' has leaned towards Caucasian. As the

'symptoms' of 'CD/FND' are not uniform across individuals, the details of this are provided. Relationship and employment statuses have also been included. All participants are male, with one participant being transgender.

#### 'Aston'

The interviewee is a 38-year-old Caucasian male residing in Australia with a self-reported diagnosis of 'Conversion Disorder'. Aston reported experiencing the following signs and symptoms: 'seizures', 'legs collapsing', 'visual disturbances', 'headaches', 'amnesia', and 'dissociation of identity'. He is employed and married.

#### 'Byron'

The interviewee is a 40-year-old Caucasian male residing in Ireland with a self-reported diagnosis of 'Functional Neurological Disorder'. Byron reported experiencing the following signs and symptoms: 'weakness and numbness in legs' that can result in his body collapsing. He is not employed and is in a long-term relationship.

#### 'Cecil'

The interviewee is a male in his twenties residing in England with a self-reported diagnosis of 'Non-Epileptic Attack Disorder'. Cecil reported experiencing the following signs and symptoms: 'seizures', 'amnesia', 'dissociative episodes where functioning but unaware of this', 'body freezing', 'weakness in limbs', 'tremors' and 'ticks'. He is not employed and is not in a relationship.

#### 'Daniel'

The interviewee is in his twenties residing in England with a self-reported diagnosis of 'Non-Epileptic Attack Disorder'. Daniel reported experiencing the following signs and symptoms: 'seizures'. He is not employed and is in a long term relationship.

'Ethan'

The interviewee is a 49-year-old male residing in England with a self-reported diagnosis of 'Functional Neurological Disorder'. Ethan reported experiencing the following signs and symptoms: 'seizures', 'weakness and numbness of limbs', 'spasticity of limbs' and 'tremors'. He is not employed and is not in a relationship.

'Flick'

The interviewee is a 43-year-old male residing in England with a self-reported diagnosis of 'Functional Neurological Disorder'. Flick reported experiencing the following signs and symptoms: 'visual disturbances' and 'spasms around midsection'. He is not employed and is in a long-term relationship.

'Gavin'

The interviewee is a 43-year-old male residing in England with a self-reported diagnosis of 'Functional Neurological Disorder'. Gavin reported experiencing the following signs and symptoms: 'legs collapsing', 'loss of ability to talk' and 'partial paralysis of areas of body'. He is not employed and is in a long-term relationship.

'Harry'

The interviewee is a 34-year-old male residing in South Africa with a self-reported diagnosis of 'Conversion Disorder'. Harry reported experiencing the following signs and

symptoms: 'paralysis (full or partial)' and 'seizures'. He is not employed and is in a long-term relationship.

## **9 ANALYSIS**

Five superordinate themes have been developed across participants in the analysis of this data, beneath each of which there is a cluster of a range of three to five subordinate themes. Brief overviews of superordinate and subordinate themes are initially provided. Following on from this, an account of what the findings suggest overall are given and an in-depth analysis of each theme is detailed in accordance with IPA (Smith et al., 2009).

### **9.1 Overview of themes:**

The following five superordinate themes were derived: 'paradox of control', 'living within a dualistic framework', 'disconnection from self and others', 'engaged in a battle or fight', and 'meaning and reality as dependent on other people'. These superordinate themes have clusters ranging from three to five subthemes, which can be seen in Table 1 as follows.



Table 1: Overview of super-ordinate and sub-ordinate themes

<b>Super-ordinate themes</b>	<b>Sub-ordinate themes</b>
Paradox of control	1. Re-conceptualising control
	2. Body disconnected
	3. Centrality of conscious mind
	4. Being experienced by others
	5. Potentiality woven in time
Living within a dualistic framework	1. Identities in conflict
	2. Mind-body duality
	3. Something becoming and nothing unbecoming
	4. Conscious- unconsciousness separation
Disconnection from self and others	1. Body as distorting perception
	2. 'I' isolate, 'you' isolate, 'we' isolate
	3. Trust in mistrust
	4. This body of mine is not me in authenticity
	5. Dissevering anger
Engaged in a battle or fight	1. Fighting to not lose oneself
	2. Stuck in frustration
	3. Battling undesired aspects of self
Meaning and reality as dependent on other people	1. Expecting one's power to be provided by another
	2. Knowledge being the door to acceptance
	3. Responsibility as residing outside oneself
	4. The underlying desire for cohesion

## 9.2 Summary of findings:

A brief account of the overall findings is given before moving into a detailed analysis of each superordinate and subordinate theme. The rationale of this is to provide a contextual frame that will enable the reader to have an informed understanding of the detailed sections of the analysis to follow.

The overall findings have shown that the participants appear to approach the world in a way whereby the notion of duality holds centre stage. This dualistic framework is one that seems to be applied to the mind, body, self, and other people, whereby the separation between dual parts comes across as a disconnection that is in opposition rather than in parallel. For example, the body is seen as working against the best interests and desires of the person concerned.

This goes beyond 'mind-body' dualism in the sense of mind and body being viewed as separate areas that work together, as mind and body have become opponents engaged in a battle. As the notion of a battle generally implies that it is possible for one side to win and prevail over the other side, the experience of mind and body in opposition may lead to frustration. The consequence of not integrating the experience of mind and body, or of not resolving the battle, may be to experience the self as divided.

The participants also show a disconnection between themselves and other people, whereby they seem to view other people as holding the power to further widen the gap of disconnection between self and other. This in turn may have the effect of widening the gap in their experience of self.

The sense of agency seems to involve a 'push-pull' dynamic as the participants simultaneously engage with, and isolate themselves from, other people. Over time, agency seems to become more and more focused on the environment that is within immediate reach, whereby the level of interaction with others is controlled so as to avoid potentially feeling out of control in relation to other people.

### **9.3 Superordinate themes**

A brief description of the meaning behind the terms that have been chosen is given below.

#### **9.3.1 Superordinate theme 1: Paradox of control**

The term 'paradox' "refers to a situation or statement that seems impossible or is difficult to understand because it contains two opposite facts or characteristics" (Cambridge University Press, 2016). The analysis of the eight interview transcripts appears to show that the participants feel both in control and not in control of their bodies, minds and social interactions. The following five subordinate themes are discussed: 're-conceptualising control', 'body disconnected', 'centrality of conscious mind', 'being experienced by others', and 'potentiality woven in time'.

##### **9.3.1.1 Subordinate theme 1: 'Re-conceptualising control'**

This subordinate theme explores how the participants experiences of 'EDCD' seems to raise the question of what it means to be in control of one's life, in the context of having

previously assumed that control was something that was automatic. This previous assumption seems to have shifted following the onset of 'EDCD'. For Harry, this leads to the realisation that his previous experience of feeling in control may not have actually been control at all. He seems to utilise this re-conceptualisation of control so as to draw on a newfound sense of control.

*"I was under the impression I'm, like best of all, with a halo, running around and being an angel and helping everyone. And at the end of the day I had made the biggest massive mistake of thinking in that manner, where I'm having this power trip, when in actual fact I never had it. Where now I've got it. Yah. That, the idea of control is what we have before CD, and once you have CD you actually now realize what control is." (Harry: lines 5-21, p 40)*

Aston describes how he feels as though he is in control but also recognises that he may not actually be in control. This idea of control as potentially being an illusion seems to also be pushed away in order to re-establish control. There also seems to be the sense that although his 'conscious mind' might not be under his control in the way he had assumed before having 'EDCD', it still remains his only avenue from which to exercise any kind of control.

*"I believe I have control. I probably don't! Well I thought I had control of my mind and body prior to the incident and that incident proved that I don't. I should be able to go to bed at night and not worry about breaking my nose or hurting my neck. But if I don't deal with it then what's going to happen next?" ('Aston': lines 20-13, p 23-24)*

Daniel seems to compensate for the areas that he does not feel in control of by exercising greater control in the areas that give him the sense of being in control, for example, choosing whom to see, when to go outside, and how much to do. This seems to have the overall effect of leaving him feeling both more in control and less in control.

*"I'm able to have quite a lot of control in my life, in in the extent that I can decide to not go out today, I can I can decide say, you know, I can I control how to say, I'm only going to um a tackle this amount of tasks today. The flip side of it is that I, the reason I have so much control over those things, is because I have so 'little' control over."* (Daniel: lines 16-2, p 13-14)

Byron shows a re-conceptualisation of how he previously viewed conscious awareness/experience/mind in relation to control. He seems to hold his 'conscious mind' as an almost central aspect of control that needs to be maintained and exercised as much as possible in order to prevent the demise of those aspects that he does not feel in control of. There is the sense that his 'conscious mind' is constantly paying attention to any signs that could suggest that further control may be taken away.

*"I need to be as sharp as possible try stave it off as long as possible."* (Byron: line 15, p 20)

Overall, the participants seem to experience their bodies as behaving in a way that they cannot control when they experience 'EDCD'. This seems to make them aware that they no longer have the level of control that they had originally believed themselves to have. Thus, they all show a revision of how they had previously conceptualised control.

### 9.3.1.2 Subordinate theme 2: 'Body disconnected'

This subordinate theme explores how the participants all seem to experience their bodies as behaving in a way that they cannot control since the development of 'EDCD'. They seem to feel as though their bodies have taken on a 'life of their own', whereby they feel powerless to intervene. This seems to result in the 'conscious mind' feeling disconnected from the body.

Cecil describes an experience where his body has behaved in a disconnecting way that led to him feeling alienated from it. He consciously viewed his arms twisting to the point where he experienced pain, but was unable to stop this from happening. His body does not seem to be his own when he experiences it as behaving in such a way, and his mind also seems to "twist" alongside his body in a state of confusion. This also suggests a sense of powerlessness in relation to his experience, as well as confusion around a self-inflicted pain that is not experienced as intentional.

*"I used to get points where my legs would just twist, my arm would twist round to the point of where it were really hurting but there's nothing I could've done to put a stop to it. It, kind of like, "what's going on?", I'm not mentally doing this." (Cecil: lines 4-10, p 21)*

Gavin describes his body in a way where he almost seems to experience himself as a puppet that he cannot control. His ability to verbally communicate disappears and he experiences his body as being controlled by something outside of his experience of self. His description of feeling "stuck in cement" could show how he may feel trapped and powerless, whereas his experience of "other times I've fallen to the floor" could be viewed as showing that he may feel as though he is being controlled by something that

does not come from him. Again there is a sense of alienation and disconnection in relation to his body.

*“I couldn’t get words out. My face looks like I’ve had a stroke. A bad one comes. I’ve actually had no movement in my legs. It was like I was stuck in cement. Other times I’ve fallen to the floor. It’s just been nuts, kind of scared to go out because obviously you don’t want that happening when you’re outside.”* (Gavin: lines 22-8, p 2-3)

Gavin describes being aware of what is happening but of not being able to stop the process, which seems to lead to the experience of alienation and disempowerment.

*“I’m not in control of what’s happening. Most of the time I normally know what’s going on um but ‘x’ does say that sometimes I like, I’m just like, you know I’m not there like, you know what I mean? But I am internally. I know what’s happening, I just can’t. It’s like someone has just shut down something but inside is still working.”* (Gavin: lines 7-16, p 8)

Ethan discusses instances where being out of control involves being in control, and where being in control involves being out of control, for example, by no longer “fighting” for control but rather “working with it” makes the ‘EDCD’ easier to bear. In this case, there seems to be an understanding in part that, although he experiences his body in a disconnected way through how it behaves, it is the “working” with his body that reduces the ‘EDCD’ and consequent pain and distress that arises from this.

*“Working, not fighting, working. If you fight it, it gets worse and worse and you get angry and it doesn’t work. So you have to work with it, you have to be conscious.”* (Ethan: lines 14-16, p 19)

Overall, the participants seem to experience their bodies as behaving in a distressing and often painful way, which leaves them feeling as though their bodies do not belong to them. They all experience confusion and alienation in relation to this, but only some show a partial realisation of needing to work with their body rather than fight against it.

#### *9.3.1.3 Subordinate theme 3: ‘Centrality of conscious mind’*

This subordinate theme explores how the participants seem to experience their ‘conscious experience/mind’ as central and as where the locus of control should reside. However, the ‘EDCD’ also seem to challenge the notion of ‘conscious mind’, and whether the idea of the ‘conscious mind’ as predominating is actually the case.

Daniel describes how being conscious whilst not being able to communicate (apart from a “grunt”), or being unable to prevent the behaviour of his body from playing out, gives him the feeling that he should be able to change what is happening by the fact that he is consciously aware. This seems to leave him feeling as though conscious awareness creates the impression that it is central when this is not actually the case, as he could not carry out what he had previously assumed he should be able to. There is also the sense that he feels isolated from others and from his experience of self, whereby he feels powerless to do much aside from small communications.



*“When I’m actually having a seizure I remain conscious and I can control, if somebody’s talking to me I can sometimes grunt or make noises. I don’t lose consciousness and because my consciousness is there, there’s a sense of, wherever our consciousness is, is where we should have control. To think your way out of it, but I can’t think away.” (Daniel: lines 3-21, p 6)*

Flick describes how his inability to exercise control over his body means that he has to compensate by focusing on developing his ‘non-physical’, mental side. He seems to be trying to compensate for what he cannot control by building on his ‘conscious mind’, which he seems to experience as holding control and of offering the potential for him to move into a stronger or more controllable position in his life.

*“If I’m having issues with the physical side of things then what I need to do is, I need to channel my energy into something which isn’t physical. So, for us to kind of, I’m trying to you know, learn new skills, to be able to you know, to be able to do that, to be able to take control of that.” (Flick: lines 13-20, p 21)*

Bryon seems to view the ‘conscious mind’ as holding the only possibility of power to prevent him from “slipping away”. Interestingly, although he describes his body and mind in a way that implies that they are separate, his mention of “slipping away” suggests that on another level he sees them as connected. This mention of “slipping away” suggests that he may feel as though he can consciously control his body to some extent, but that he also fears that his experience of self will ‘slip away’ with the loss of physical capacity. Thus, his focus on the conscious mind seems to arise in relation to the

feared consequence that losing control over the conscious mind could potentially lead to a loss of oneself.

*“So I’m trying to maintain a control to the rest of my body as much as I can so I can, you know like, you, I don’t feel like I’m slipping away but, I feel that if it progresses even worse then I need to be as sharp as possible try stave it off as long as possible. I don’t want my, I don’t want problems with my with my with my brain as well.”* (Byron, lines 13-16, p.20)

In contrast, Cecil appears to ‘let go’ of the ‘conscious mind’ in the sense that ‘losing oneself’ may lead to the ‘finding’ of oneself, and one’s sense of control, via the support of others. This can be seen by the way he describes himself as having been “lucky” that he had been so bad and of how getting worse may have opened up the possibility that, rather than ‘losing himself’, he might be ‘found’ and helped by another person.

*“I’ve been lucky, because of how bad I was, like a barrel down the hill, it just progresses and can possibly get worse, and being ignored by the doctor, and being told that there’s nothing really wrong, is just going to increase and make you worse.”* (Cecil: lines 11-1, p 1-2)

Overall, the participants seem to hold a paradoxical position where they experience both being in and out of control in relation to their conscious minds. When they do not experience ‘EDCD’ they describe feeling as though they are fully in control of their conscious experience, but when the ‘EDCD’ arise they seem to experience their ‘conscious mind’ as trapped or disconnected.

#### 9.3.1.4 Subordinate theme 4: 'Being experienced by others'

This subordinate theme explores how the participants seem to encounter 'distant' others in a way whereby they feel stigmatised, embarrassed, anxious, angry, depressed, humiliated and shamed. The reference to 'distant' others is in terms of non-personal relationships and social stereotypes.

Harry describes feeling irritated at being treated in a way where he seems to feel as though he is perceived as weak and powerless. The use of the word "hate" could suggest that he has an underlying anger about being judged unfairly by others, and of being treated in a way that leaves him feeling disempowered. The way that Harry expresses this frustration suggests a sense of empowerment in the active sense of communicating to others advertently or inadvertently "don't be sympathetic". He seems to be communicating that his experience with 'EDCD' is not something that holds him back, and that he does not need to be treated as though it does.

*"The first thing I hate, don't be sympathetic, I'm irritated by it, I'm not a little puppy."*

(Harry: lines 7-18, p 9)

In contrast, Aston takes a different approach to Harry, as he describes his experience with 'EDCD' in a way where he feels "shame" and needs to keep "it" hidden from others. He seems to feel disempowered, humiliated and stigmatised by his experience to the extent that the experience appears to have the quality of being an object or "it" that is separate to him.

*“More from shame than anything else. It’s bad enough that I’ve had my family see it. I don’t need my friends to see it.” (Aston: lines 5-6, p 20)*

Byron seems to experience people in a way whereby he almost feels as though they can engulf him. He seems to feel as though other people can control him to the extent that his body “trips” over. His thoughts of “what are they thinking” may involve the fear that his limbs will fall out from under him and that he will be judged as a result. This suggests that his thoughts about what others think may cause the outcome of his body collapsing. There is a sense of alienation and powerlessness in this.

*“But people staring at me as well. I end up tripping over because I know people are looking at me. I’m thinking: “what are they thinking?”” (Byron: lines 12-22, p 13)*

Overall, the participants seem to feel a lessening of control in relation to other people, which seems to lead to the need to exercise more control in their lives and relationships in order to cope with this.

#### 9.3.1.5 Subordinate theme 5: ‘Potentiality woven in time’

This subordinate theme explores how the participants had, at beginning of the ‘EDCD’, held hope that something could be clarified or offered by the medical profession that might enable them to understand and manage the ‘EDCD’. However, the passing of time seems to have left them feeling less and less hopeful. Time also seems to relate to their experience of ‘EDCD’ as they all spoke about being controlled by the ‘EDCD’ for periods of time.

Ethan's description seems to be communicating how he feels as though he has been deteriorating over time, but that he has had to wait to receive the support that he feels he deserves. There is the sense of him feeling unimportant and uncared for by those who have the tools to help him, to the extent that he seems to feel as though they are deliberately hurting him. It appears as though he may be blaming those whom he deems to hold the power over his ability to get better, as being responsible for his demise. There appears to be a disempowerment and a handing over of responsibility to the other person. Byron and Cecil also experience a progressive worsening of the 'EDCD' in relation to the lack of support that they have received from others.

*"I'm still waiting to see who else I'll be referred to. It's a possibly progressive for some people, for me it's proved very progressive. If they told me about distraction therapies, if they told me about freezing when you're walking and not having to worry about it, if they told me to expect non-epileptic seizures, I might have known at half past midnight when I was having one and thinking my world was ending, I might have known and had a bit more control over it." (Ethan: lines 1-19, p 10)*

Aston, Daniel, Flick, Gavin and Harry describe the 'EDCD' as controlling their ability to act in time whereby the 'EDCD' determines what they can and cannot do. This seems to happen to the extent that they experience 'living' as only happening around the times when they do not have 'EDCD'. For Cecil, this meant that he only had a period of two hours where he could be Cecil again. Flick and Harry seem to experience powerlessness and isolation in relation to others, and in their ability to act within the world.

*“I got into this mind-set of between 11 and 1 was the safe period to have a shower because between that point I wasn’t having any.”* (Cecil: lines 23-4, p 5-6)

*“Crushed, mid-section, hours and hours, or last for days.”* (Flick: lines 11-14, p 9)

*“In a week, 2 weeks, a month, however long it takes, I’ll get up again.”* (Harry: line 11, p9)

Overall, the participants seem to experience being rendered powerless in relation to time. For all of the participants this is in terms of the ‘EDCD’, but for a few, this is also in terms of the support provided by others.

### **9.3.2 Superordinate theme 2: Living within a dualistic framework**

The analysis of the eight interview transcripts seems to reveal that participants hold a dualistic approach to understanding themselves and the world around them. This dual perspective involves the areas of mind, body, identity and existence. The following four subordinate themes are discussed: ‘identities in conflict’, ‘mind-body duality’, ‘something becoming and nothing unbecoming’, and ‘conscious-unconscious separation’.

#### **9.3.2.1 Subordinate theme 1: “Identities in conflict”**

This subordinate theme explores how some of the participants seem to experience having separate identities that they cannot relate to, whereas others seem to not be able to relate to the expression of different aspects of themselves. Receiving a ‘non-

diagnosis', where they are informed that they cannot be explained 'medically', seems to shift participants' sense of identity. They seem to feel as though they have been told that they are not actually experiencing their own experience and/or that they are being deceptive.

Gavin describes feeling as though he is two different people and of how other people confirm this to him. He seems to be referring to two identities that are separated in time, as he describes looking identical to his deceased grandfather when experiencing 'EDCD'. Perhaps his experience of having two separate identities relates to life and death. When he experiences 'EDCD' and experiences himself as looking the same as his deceased grandfather, this may represent the duality of life and death whereby he may feel trapped between living and feeling as though he may die at any moment. There is also the paradox of him taking on the identity of someone who is dead when he himself is still alive, as well as having his living identity die and bring to life one that has already died.

*"She describes me as two different people. My face has changed and looks very old. My granddad passed away a few years back. When I look older in my face I really look like him. It spooked me out." & "You're two different people and you're trapped in between them." (Gavin: lines 16-12, p 32-33 & line 10, p 34)*

Aston describes having an identity that he has never encountered and only knows about through what he has been told by others. Not only does he perceive himself as completely vanishing for extended periods of time, but he also seems to isolate and alienate this other identity as "evil". He uses the word "twin", which implies that the

identity that he relates to is a part of him whilst also being entirely separate and individual like a twin. His use of the phrase “I wasn’t me” is interesting as it implies that he can relate to this twin as being ‘him’, but of also not being ‘him’ at the same time. Thus, these identities appear to be in conflict for him.

*“I was literally gone. I was somewhere else. For about a month and a half I was someone else. I wasn’t me. I wasn’t the man my wife married. I was the evil twin” (Aston: lines 19-20, p 16)*

Daniel describes having a separate identity that had been formed and forced upon him by family members. When he came to realise that this identity was not his true identity, he was then able to reject this identity and to allow his natural identity to emerge. His use of the word “paradigm” suggests that he has had to move aside from an entirely different and ‘other-created’ identity, and to step into his “genuine self” identity that had been repressed in the background. His use of the word “fractured” suggests that these two identities had been integrated to a certain extent, albeit in a potentially crooked or forced way, and that the separation of this is what led to the experience of fracturing. Although he describes his ‘genuine self’ as having been isolated and pushed aside by the ‘forced self’, his ability to move into his “genuine self” suggests that he has managed to win the battle between the two identities in a way where the “genuine self” dominates. This shows a disconnection and isolation in relation to his sense of self, as well as power and strength in being able to achieve this.

*“I need to step away from the paradigm they’d created. I fractured, because there was a complete and utter breakdown between my genuine self and who I sort of was naturally*



*progressing to be and this very structured self that I was sort of forced into.*" (Daniel: lines 19-23, p 9)

For Cecil, the duality of identity differs from the descriptions of Aston, Daniel and Gavin, as he describes being unable to relate to his own expression of anger. He is able to recognise and accept that it is he who is responding in an angry manner, but he does not seem to be able to view this behaviour as belonging to his 'personality' or sense of self. The use of "It's not me" shows that he may not relate to being "snappy" or acting out in anger. However, his description of having "moments that piss me off, but I don't snap" suggests that anger has always been there, but in a way that he has previously been able to control.

*"It's not me." "I'm not a snappy person. I have moments that piss me off, but I don't snap."*  
(Cecil: lines 4-9, p 39)

Overall, the participants show a duality of identity that involves a conflict whereby the 'main' identity struggles to dominate.

#### 9.3.2.2 Subordinate theme 2: "Mind-body dualism"

This subordinate theme explores how the participants seem to experience a mind-body duality, whereby the body is perceived as being physical and under the control of the non-physical mind. However, their experience of 'EDCD' seems to have disrupted this view, as they seem to experience the body as having the ability to take control of the mind.

Gavin's description implies a disconnection between his mind and body. He seems to experience his body in a way that positions him as an external observer. He also appears to observe his physical behaviour in an alienating way and as residing outside of his conscious control. Gavin then questions himself as to whether it is his mind that is alienating him from himself with "is that me, doing that or is it something else doing it?". He shows much uncertainty and powerlessness in relation to these experiences.

*"Flickering on your face, your arm shakes, having a fit. It's very strange. But then you're thinking "is that me, doing that or is it something else doing it?"*" (Gavin: lines 7-11, p 36)

Byron provides a rich description of the separation that he experiences between mind and body. He describes his mind as being separate from his body, whereby he experiences only having access to the upper half of his body in terms of controlling movement. He uses his mind to indirectly exert control over the bottom half of his body by using the control that he has over his upper limbs to control the lower half of his body. On the one hand, he may experience disconnection and alienation in relation to his body and. On the other hand, he also seems to be able to establish an indirect connection, as he is able to use his upper body to support his lower body. There is the sense that he views his body as being a 'vehicle' that is operated by the mind. This 'body as vehicle' can also be seen in the descriptions of Harry and Flick, who describe having a vigilant mental focus and control over the body.

*"I think the mind is one thing. My mind wants to move the legs but it can't. My mind can move my arms no problem. But it can't, it seems to be like, you know like, how can I say*

*like. A barrier. It's almost like there's a barrier you know, between like you know, my tummy and my legs, and the cord is thick, from your head down to your spine, you know, and it like gets very thin, when it gets to your legs so, when you try and lift them, there's not enough power you know, in that cable."* (Byron: lines 9-22, p 33)

*"If I'm in an area where there's a lot of stimuli, I'll constantly keep my arms crossed and just check the temperature. Once that picks up or goes down I know "okay, this is now time to step out"."* (Harry: lines 9-11, p 7)

Cecil describes a separation between his mind and body to the extent that he seems to feel completely trapped within his body and unable to communicate to anyone around him. There is a strong sense of powerlessness in relation to his ability to act and to communicate with others. He also seems to feel isolated, alienated and frustrated as, not only do his 'screams' for help go unheard, but he also seems to feel as though other people perceive him as deliberately choosing to withhold movements that he experiences a lack of control over.

*"I was trying to scream out in my head that "someone can you please help me?". The nurse was telling me "bend your legs" and I couldn't tell them "I can't bend my legs, I'm completely stiff"."* (Cecil: lines 6-13, p. 20)

Overall, the participants seem to experience the 'EDCD' as belonging to their physical bodies. Their inability to exert conscious control over the 'EDCD' seems to be viewed as supporting the idea that the cause of the experience is physically related. Although some are able to consider that this might not be the case, there is still an underlying

conceptualisation of a divide between mind and body, which is withstanding in the medical context that they are situated within.

### 9.3.2.3 Subordinate theme 3: 'Something becoming and nothing unbecoming'

This subordinate theme explores how the participants seem to experience the communication of a diagnosis as 'medically unexplained' in a way where they are left with the sense that their experience is self-created and no longer the responsibility of the medical profession. It seems that being 'medically unexplained' leaves them feeling as though their experience of 'EDCD' does not exist, which in turn may bring about uncertainty around their sense of self.

Flick describes feeling as though he has been treated like a machine by the medical profession, as he has been scrutinised in a way where the sole focus has been to find something objectively wrong with him. However, his communication of his intuitive feeling that the different phenomena that were being investigated could be related went by unacknowledged. He describes the process of having different conditions ruled out by the medical professionals as leaving him feeling as though he has become the sum total of every test that could be carried out. The elimination of each test seemed to lead to the elimination of an aspect of his sense of self- with the end result of emptiness, 'nothingness' and 'unbecoming'.

*"Going to the GP. You're kind of feeling as though they kind of are almost linked together. But they just deal with one thing at a time. It's been kind of compartmentalised. There's obviously a procedure. Same as any kind of mechanics of engineering, like when you have*

*a fault with something, there's a procedure." & "They're trying to rule out any kind of solid thing which they can see, but then it kind of leaves you feeling a little bit empty. You've got this and you've got that, which are mechanical material, you know, matter things. But it's not explaining. It's leaving you kind of, just open really."* (Flick: lines 1-15, p 3 & lines 10-19, p 5)

Daniel describes a particular experience had been alluded to in a stigmatising way by a medical professional, whereby the 'EDCD' had been described as not being real. Being given the term 'non' or 'not real' seemed to have left him feeling as though his experience had been devaluated. There is a sense that the other person has the power to tell someone what it is that they are experiencing, and what this means. The description positions him as powerless beneath medical professionals, who have the social status of holding a higher level of medical knowledge in comparison to those in other fields. He also seems to feel as though the medial professionals have the power to dehumanise him when they discuss him as though he is not there.

*"Initially it was just no non-epileptic and there was this sense of 'not real'. A nurse stood over me and said to the technician "is it a real one?" and there was this sense of it not being real and not being valid."* (Daniel: lines 24-8, p 2-3)

Harry describes how the communication delivered by the medical professional impacts on his sense of self and sense of control. Harry views the medical professional as holding a certain level of power and being entrusted with the responsibility of care. He receives the communication of there being "nothing physically wrong" as having so much power that he then feels as though he is "mad". There is the sense that reality is

created in relation to the trust, power, responsibility, and belief that is given to another, which in this case is the medical professional. When he eventually receives a communication and engagement that gives him meaning and does not 'un-define' him, his previous experience of feeling "mad" changes. Thus, being given a meaningful answer and being related to in an empathic way seems to reconfirm his existence.

*"The neurologist, his answer was "it's psychosomatic". You actually go into a state where "am I mad?" because the neurologists don't go further into this and actually explain. It breaks you into pieces. GP's, the same thing, they tell you "well, we don't know, we can't help you". I actually ended up in in the hospital where I was in the psych ward and I met these doctors of mine and they just said: "well, we need to find out what's wrong". This is what he said: "there's something wrong in my brain. Understand that you have an illness but it's not something that you can see". And from then I decided that I need to make a decision for myself to actually stand up for my own rights." (Harry: lines 4-17, p 19-20)*

Overall, the participants all describe having had the experience of being told that there is 'nothing' wrong when they all feel as though there 'is' something wrong. The communication that there is nothing wrong seems to leave them all feeling as though they almost are 'nothing', and as though they have been fabricating the 'EDCD'.

#### 9.3.2.4 Subordinate theme 4: 'Conscious-unconscious separation'

This subordinate theme explores how the participants seem to show a strong duality between the concepts of conscious and unconscious 'mind'. Their experience of 'EDCD' seems to shift unconscious aspects into a different frame, whereby these areas seem to

have a 'mind or identity' that can enable the same access to the physical body that only the conscious mind has previously been assumed to possess.

Aston seems to describe what appears to be the 'unconscious process' or 'mind' as developing in the background of his immediate conscious experience. His description seems to show two separate 'identities', whereby the 'unconscious' identity is able to consume the conscious identity that is usually in play. There seems to be a substantial loss of control, both in relation to the loss of the ordinary identity, and in the ability of the 'unconscious' identity to exercise control over the 'shared' body. There is the sense that the body is what these two identities have in common, and that both identities alternate between 'conscious' and 'unconscious' positions. Powerlessness, abandonment, loss and alienation, all seem to come out of this.

*"It just sat there in the back of my brain just boiling up and boiling up and boiling up until it said "ah it's enough – lets go". And I was gone. I was literally gone. I was somewhere else. For about a month and a half I was someone else, that couldn't control its body. I could walk about four steps and my legs would just give out under me. I fell down about 10 flights of stairs in a month." (Aston: lines 15-23, p 16)*

Ethan describes how it seems to be important for the conscious mind to exert control by focusing on being conscious in order to prevent what could arise from unconscious areas. He goes on to talk about the experience in a way where he uses the word 'it'. He seems to be referring to the 'unconscious' part that continues to act out even whilst he sleeps, for example, he experiences seizures whilst asleep.

*"You have to be conscious. It just doesn't give in."* (Ethan: lines 16 & 22, p. 19)

Gavin describes the separation between 'conscious' and 'unconscious' in a way whereby the 'EDCD' seem to arise in relation to the 'unconscious' or 'other' that takes control of his body. He also refers to control in relation to imaginative images with form and substance, which possibly suggests that his unconscious experience has been given conscious form. He may be alienating his experience in order to feel a greater sense of control.

*"You know you see these films and there's like little people controlling stuff. It's like the little people. "I'm going to play with him today". They pull out these levers you know. Certain parts of your body stop working for a while."* (Gavin: lines 5-10, p.31)

Overall, the participants seem to experience their immediate conscious experience as needing to predominate. To the same extent they seem to also be aware that potential unconscious processes that they do not have control over may operate in the background.

### **9.3.3 Superordinate theme 3: Disconnection from self and others**

This superordinate theme reveals how the participants experience feeling disconnected from people in their lives and disconnected from aspects of themselves.

#### **9.3.3.1 Subordinate theme 1: 'Body as distorting perception'**



This subordinate theme explores how the participants seem to feel alienated from their bodies. This is in the sense that they experience the 'EDCD' as an inability to exert conscious control over their bodies, as they have previously been able to do. The participants also seem to find the 'EDCD' confusing, as they have not consciously chosen to behave in such a way and cannot understand what is happening and why.

Ethan describes what seems to be a sense of alienation in relation to his future direction, as he feels as though he does not have any control over his body and the 'EDCD'. There is a sense that he feels that the 'EDCD' have taken control and are trying to take his life away from him. He seems to be battling to not lose his life as opposed to battling to regain the life that he used to have, which implies loss and isolation.

*"Before this happened I was training to do round the mountain runs. That's never going to happen. I'm destined for a wheelchair within the next six months if this continues at this rate but I'm so much fighting against it."* (Ethan: lines 3-7, p 18)

Gavin seems to feel alienated from his body. He appears to perceive his body as something that is separate to his self-identity, and as behaving in a manner that should not be possible. There is a disconnection and powerlessness that seems to arise in relation to the behaviour of his body, whereby he seems to be stuck in the position of having to passively watch the 'EDCD' unfold.

*"It's really strange, your body's doing something you just can't control. It's very strange, very strange, because you're aware that it's happening, but you can't do anything about it."* (Gavin: lines 12-14, p 5)

Aston describes how his experience has led to him feeling alienated by others to the extent that he feels as though other people perceive him as a “psycho”. He also seems to experience much shame, sadness, isolation and alienation, in relation to other people.

*“I had to beg and plead to keep my driving license, but my gun license. I understand the reasoning behind it, because I could turn into a psycho.” (Aston: 12-15, p 25)*

Byron seems to view the diagnostic label as being involved in his sense of alienation, as it is a label that describes every physical symptom that would ordinarily be thought to describe a numerous array of different neurological conditions. Perhaps he feels that, if the medical profession is not clear, then why should they expect him to be. The diagnosis seems to leave him feeling as though he has been ‘dumped’ into an unexplained and alienating area, where responsibility is subjugated.

*“It’s an FND. And he explained to me, like it’s like an umbrella term sort of thing, of illnesses. They can’t actually figure out basically, to be clear, they don’t, they don’t, know what the cause of it is really.” (Byron: lines 3-5, p 7)*

Overall, the participants seem to feel as though their bodies alienate them from their ‘embodied’ or physical relationship with themselves, as well as in relation to the people around them.

#### 9.3.3.2 Subordinate theme 2: “I’ isolate, ‘you’ isolate, ‘we’ isolate’

This subordinate theme explores how the participants seem to feel isolated from their bodies, whereby they have an awareness that they are behaving in an undesired manner but they are not able to intervene in this process.

Daniel describes being conscious with the 'EDCD' but being unable to communicate (with the exception of small grunting sounds). He seems to feel isolated from his body in a way whereby his conscious experience lies in the background. His conscious awareness, "I am there", appears to have been disconnected to the extent that he cannot interact and engage with both his body other people.

*"I may be able to vocalize to a small extent or I may, I may not be able to speak at all. I may not be able to respond at all. It's almost like saying, the worse the seizure is the less control I have. I don't lose consciousness, I am, I am there, and it's very frustrating to have that sense of: "I can hear you, I know what's going on, but I can't respond"."* (Daniel: lines 7-12, p 6)

Byron describes feeling isolated by other people to the extent that he chooses to isolate himself. He seems to feel rejected and abandoned as a result of having been told that there is "nothing wrong". He also seems to isolate himself so as to prevent other people from doing this to him, as well as to potentially enact his experience in other people.

*"I only went out at like, probably once a week, went to the shops, didn't talk to anybody, came back home and that was it. So I sort of like isolated myself. I was just sick and tired of telling people me there's nothing wrong with me, there's nothing wrong with me, and them not believing me."* (Byron: lines 11-15, p. 32)

Ethan seems to feel a sense of isolation in relation to the medical profession, and potentially other people, to the extent that he seems to be losing hope and feeling as though he will remain in isolation because of how others do not appear to connect with him or offer support.

*“You wonder why sometimes you bother. You’re left on your own.”* (Ethan: lines 17-18, p. 12)

Overall, the participants seem to feel isolated and abandoned by those whom they had believed would offer them help. The participants seem to struggle with carrying out ‘normal’ activities and are not in employment (with the exception of Aston who mainly works from home). This, in combination with the substantial amount of time that is spent at home alone, may feed into the isolation and disconnection that they experience in relation to other people.

### 9.3.3.3 Subordinate theme 3: ‘Trust in mistrust’

This subordinate theme explores how the participants seem to feel a lack of trust in relation to their bodies, as they cannot prevent or absolutely predict when they will experience having their conscious control overridden by ‘EDCD’. They also seem to mistrust how others will respond to them, and whether or not others will believe their experience.

Flick seems to feel mistrust in the sense that he describes his experience of 'EDCD' in a way where he almost attributes a succession of difficult experiences as being purposefully placed upon him by 'something' separate to himself. He seems to mistrust what might happen to him in the future as well as with his life in general. He also seems to feel as though society is not constructed in a way that encourages others to have the ability to empathise with his experience. This seems to leave him 'trusting' in mistrust whereby he views members of society as being un-empathetic and/or un-supportive.

*"Everything's been kind of, it's been, it's not in your favour. So as things have kind of progressed, you start wondering whether things are put in place on purpose, to kind of hinder you, like against you. And I don't know whether that's a kind of paranoia thing, difficulty with your health, just the way kind of society is based."* (Flick: lines 4-12, p. 24)

Harry describes how, as he cannot trust how his body might respond in various situations, he uses this mistrust to carefully plan and prevent his body from potentially expressing 'EDCD'. He seems to trust in his state of mind to look after his body, as he constantly prepares himself for the possibility that anything may affect his body in the environment. His description of "overstimulation of senses" with "a lot of people" suggests that his experience of being around many people evokes mistrust. The more people that he has around him, the more he seems to feel as though he cannot predict their behaviour and control his own. This could be a threatening experience for him.

*"I have to recondition my body for everything. I'm going away and I need to plan beforehand what my possibilities are. I need to get my mind ready for if there might be a*

*lot of people. If I get overstimulation of senses I need to then back off.”* (Harry: lines 7-11, p 4)

Daniel seems to have experienced a great deal of mistrust in his life to the extent that it has become safer to trust in mistrust. His experience of life seems to have always involved uncertainty and anxiety. Although he seems to feel as though there is uncertainty in trusting, he is also able to trust in himself to trust that he will be able to cope with this uncertainty. This suggests that he might feel a much greater sense of power and control in relation to his past.

*“I’ve had to release control and allow myself to stand, because I don’t need to hold myself tight anymore, because the ground isn’t moving underneath me. Trusting that. That I’m not going to be hurt. I’m so used to having, you know, to keep myself afloat in a turbulent world.”* (Daniel: lines 2-13, p 36)

Overall, the participants seem to experience mistrust in relation to the ‘outside’ world. At the same time they also seem to be able to hold a deep trust towards those who are close to them. Although there seems to be a sense of safety in mistrusting other people and in mistrusting their bodies, there also appears to be some form of recognition that this might not be serving them well.

#### 9.3.3.4 Subordinate theme 4: *‘This body of mine is not ‘me’ in authenticity’*

Authenticity is integral to our human existence and our engagement with the world around us, and it is a way of engaging that emerges from a deeply true position in

contrast to superficial interactions that can often take place between people (van Deurzen, 2010).

This subordinate theme explores how participants seem to show inauthenticity in the way that they do not seem to identify with, or want to accept, that their bodily behaviour belongs to them. They also show inauthenticity in relation to accepting other sides to themselves as being a part of them.

Aston describes being aware of another side to him and of how he is determined to not allow it to be a part of him. This might show an inauthentic relationship with himself, as he does not seem to want to accept aspects of himself that he does not like, or cannot relate to. This seems to put him in a difficult position whereby he constantly attempts to deny himself a 'full' existence for fear that this part might take over how he identifies with his sense of self.

*"There's definitely a side of me I don't like and that's it. I'm fighting an uphill battle trying to control it. Today I'm winning."* (Aston: lines 10-14, p 22)

Gavin describes inauthenticity in relation to denying the behaviour of his body as being his own. Despite the fact that he recognises that it is his own body that is behaving in such a way, he seems to refuse to accept this to the point whereby he convinces himself consciously that the behaviour rather belongs to someone else. This shows a denial of his own experience and an inauthentic approach to engaging with himself. The experience of his body seems to feel so alienating and isolating to him that he has to disconnect the 'EDCD' from how he perceives himself to be.

*“Is that me doing that or is it someone else doing it? It’s not. It’s not me, because I don’t do that normally. And that’s what you’ve got to keep saying to yourself. This is just, this is someone else doing it.”* (Gavin: lines 10-14, p 36)

Daniel vividly describes what he perceives to be the ‘genuine’ self and the ‘unnatural’ self, the latter of which has been forced upon him. He seems to experience a complete separation of these two selves to the extent that he feels as though they cannot exist together, for example: “cookie cutter, cutting me down the middle”. His description of being ‘cut down the middle’ brings a strong physical image to mind of his body having been cut in two. It is interesting to note how he talks about being fractured between these two selves but to the same extent the use of “I” suggests that there is also something whole about his experience. Although he seems to feel as though his “genuine self” is authentic, it could also be the case that he is actually being inauthentic in denying a part of himself that he finds undesirable.

*“Utter break down between my genuine self and who I sort of was naturally progressing to be and this very structured self that I was sort of forced into. Cookie cutter, cutting me down the middle where I would be fractured between two selves.”* (Daniel: lines 21-3, p 9-10)

Overall, the participants show inauthenticity in relation to accepting parts of themselves. For some participants there seems to be a desire to develop a more authentic relationship with themselves and with other people (Daniel, Ethan, Flick,



Harry), whereas for the other participants there seems to be resistance towards engaging with aspects of themselves (Aston, Byron, Cecil, Gavin).

#### 9.3.3.5 Subordinate theme 5: 'Dissevering anger'

This subordinate theme explores how participants seem to experience anger as an emotion that they feel disconnected from, or that they otherwise struggle to identify with to varying extents.

Cecil describes himself in a way where he can recognise that he has been feeling angry but cannot relate to this or express it. In this case, it appears as though his anger may be prevented from being released, as his body seems to immobilise him and contain the anger so as to potentially prevent it from being expressed to others.

*"I can't describe it, it was just, "I'm really angry", but I couldn't show it because I couldn't speak." (Cecil: lines 12-13, p 16)*

Byron seems to express anger when he fabricates the truth of 'EDCD' when conversing with other people who have asked about the 'EDCD', for example, "a woman run me over with a car". He also describes how he is not an angry person but then goes on to say that he may actually be angry. This suggests a denial of, and disconnection from, anger. There also seems to be awareness that he may experience an emotion that he does not want to relate to. There seems to be an indirect, inauthentic, alienating and isolating type of communication that takes place in terms of how he relates to himself and others.

*"If someone out the blue asks me "what's wrong", if like a stranger asks me, I say well "a woman run me over with a car"" & "I'm not an angry person you know, but inside I get angry I think."* (Byron: lines 19-20, p 30 & lines 7-8, p 42)

Ethan describes how he has become angry with himself to the point that he has acted out aggressively towards his body. This may show that he has a relationship with himself that is in opposition, whereby there is a part of himself that he is angry with and would like to destroy.

*"One experience where I have, I've failed to win that battle. Breaking a glass, cutting myself."* (Ethan: lines 15-16, p 18)

Overall, the participants seem to experience anger in a way that divides up their sense of self and alienates them from other people. Although they seem to feel angry that other people alienate them, they do not seem to identify anger as a natural emotion that they acknowledge as belonging to them.

#### **9.3.4 Superordinate theme 4: Engaged in a battle or fight**

This superordinate theme reveals how the participants seem to experience being engaged in a battle or fight in such a way that the mind, body and other people, are involved.

##### **9.3.4.1 Subordinate theme 1: "Fighting to not lose oneself"**

This subordinate theme explores how the participants appear to engage in a battle, whereby defeat represents the loss of some way of relating to their sense of self.

Ethan's description of a fight with his body turning into a fight with his mind is interesting. This is because it connects mind and body in a way that the participants tend to disconnect. He seems to experience much mental and physical pain, whereby the alleviation of pain may reveal a victory over the behaviour of his body. He may also view his 'body' as the opponent that is trying to take his "destination" away from him. He seems to hold both an understanding that body and mind are connected, whilst simultaneously rejecting this. He also seems to feel out of control in relation to his body and appears to blame his body for his suffering. He further appears to view emotion as needing to be hidden from others and suppressed. Perhaps he feels as though expressing emotions means that he is losing the battle, which suggests that the battle may be one against overwhelming feelings. For Flick it seems as though the 'EDCD' possess the power to take away his life, whereby he has to fight to prevent this from happening.

*"I'm so much fighting against it. My destination would be to at least keep walking. I'm content with whatever I end up getting. But I've no control over it. It turns into a battle with the mind, cutting myself. I'd sometimes get teary when I'm walking, on my own, I won't do it in front of anyone else. But it just, the emotions that come out when it's struck you so hard and it really hurts."* (Ethan: lines 7-13, p 18)

Byron seems to describe the 'EDCD' in terms of a disease that he needs to utilise his conscious mind to prevent from getting worse. He perhaps feels as though he needs to exercise his mind to be able to notice the potential spread of the 'EDCD', as he seems to feel as though it could potentially take over his brain whereby he may start "slipping away". The battle seems to be about not losing himself altogether.

*"So I'm trying to maintain a control to the rest of my body as much as I can. So ,I so I can, you know, like you, I don't feel like I'm slipping away. But I feel that if it progresses even worse then I need to be as sharp as possible try stave it off as long as possible. I don't want my, I don't want problems with my brain as well."* (Byron: lines 13-16, p. 20)

Overall, for some participants the consequence of losing the battle with the 'EDCD' is that they could lose themselves altogether (Byron, Ethan, Flick, Harry), whereas for others the fear seems to be about losing a part of themselves that they identify most with (Aston, Cecil, Daniel, Gavin).

#### 9.3.4.2 Subordinate theme 2: "Stuck in frustration"

This subordinate theme explores how the participants seem to all experience frustration in a way where there appears to be a tension and the sense of feeling stuck.

Byron shows frustration in relation to how he feels others have treated him, both in terms of the medical system and by those on a larger social scale. His frustration seems to involve feeling as though he is perceived as being unimportant, as he feels that he has

not been given the respect or support from those who should provide this, for example, the medical staff.

*"It's frustrating I think, you know, I think, you know, some doctors, they just haven't done their job properly, or somebody hasn't done their job properly or they, and you know, like I've been fobbed off."* (Byron: lines 5-7, p 42)

Gavin seems to feel a sense of frustration in being stuck between two different experiences of self. It seems that this may leave him feeling as though he cannot fully be one or the other, whereby the frustration is in feeling "trapped". This could suggest that, although he previously spoke about the 'EDCD' as not belonging to him, to the same extent he also seems to see a relation as "you're two different people" implies that he sees himself as two people rather than one who has nothing to do with the 'EDCD'. The frustration in this case may be about not knowing how or what to do about this. Cecil also describes feeling frustrated by being trapped within his own body.

*"It's just frustrating. You're two different people and you're trapped in-between them both.."* (Gavin: lines 3-10, p 34)

Aston seems to experience frustration in relation to feeling as though he has control over the 'EDCD' for much of the time, but not all of the time. This suggests that he lives in a state of uncertainty, whereby he feels as though he needs to be fully attentive in order to control his experience, whilst also feeling powerless to do so.

*"I think the only frustration is that I've got a white ball and then I get more frustrated because then you can't find it." (Aston: lines 13-14, p.19)*

Overall, participants seem to experience frustration in relation to feeling powerless to direct their lives and to control their experiences. They also seem to feel frustration at the uncertainty of life and over the difficulty in being able to trust in this uncertainty. For some, communication is direct, whereas for others, communication is trapped or escapes from them unwillingly.

#### *9.3.4.3 Subordinate theme 3: "Battling undesired aspects of self"*

This subordinate theme explores how the participants seem to describe the 'EDCD' in a way where they use words such as 'it' and allude to being somewhat 'possessed'.

Flick describes how he is sometimes his own worst enemy. This implies that there are times where he makes things harder, or more of a struggle, for himself. He describes being aware that he pushes himself, whilst also recognising that he has to then "pay" for this. There might be an element of him inflicting the 'EDCD' on himself if he is aware of this. To the same extent, he may also be fighting for his independence and challenging the 'EDCD' in the hope that he may regain his life back.

*"I keep on pretending that there's nothing wrong. I know I do it because I'm sometimes, I'm my own worst enemy. I knew I was getting into it, I thought, you know, I might struggle. I do push myself. You pay for it you know." (Flick: lines 21, p 14)*

Cecil describes being in a losing battle with himself. This suggests that he sees himself as two parts, whereby one part could potentially be beaten and release the side that he identifies with. It is interesting to note that self is singular and a battle involves two sides. Fighting against oneself automatically means that there cannot ultimately be a victor, as both sides are the same person.

*“I was fighting against myself constantly to stay in control, but I was losing.”* (Cecil: lines 13-17, p 13)

In contrast to the other participants, Harry seems to have discovered a way to work with himself and his experience of ‘EDCD’. He seems to have a better understanding of himself and he also appears to be able to develop meaningful relationships with other people through his ability to explain his experience to them. Rather than viewing the ‘EDCD’ as an opponent, he seems to have drawn meaning from this whereby he has developed a more fulfilling life as a result.

*“And I just decided, well, it isn’t going to change my life. I’ll just change whatever I’m doing. It’s given me a chance now, to help others. I’ve lost my ability to do my own work, but I’ve now just changed my passion over.”* (Harry: lines 20-4, p 24-25)

Overall, the participants describe the ‘EDCD’ in a way whereby there appears to be an overarching desire to win a fight and to no longer have ‘EDCD’. However, although they could all identify that it was ‘they’ who were experiencing the ‘EDCD’, and that they were in a battle with themselves, none of the participants (with the exception of Harry)

seemed to be able to identify other ways of working with themselves that might prove to be less hurtful.

### **9.3.5 Superordinate theme 5: Meaning and reality as dependent on other people**

This superordinate theme reveals how the participants seem to experience other people as holding the position of power, responsibility, and knowledge. In terms of the medical system, the participants all seem to view doctors as holding this position. The doctors seem to be viewed as having the ability to enable the participants to understand their own experience, which may then offer them the potential of being able to feel understood and accepted by all.

#### *9.3.5.1 Subordinate theme 1: "Expecting one's power to be provided by another"*

This subordinate theme explores how the participants seem to desire a medical diagnosis that will help others understand them as well as to help them understand themselves. They seem to desire the medical professional to be responsible for providing them with a sense of power in relation to their bodies and lives. However, receiving a diagnosis that is a non-diagnosis seems to leave them feeling powerless.

Cecil describes how, when the neurologist told him that there was nothing that they could do for him, he became progressively worse. This might show a relation between his experience of self and his experience of interacting with another, whereby the withdrawal of support is like the withdrawal of his own sense of power and self (which



eventually progressed to the point where he had no memory and was in an unconscious state for an extended period of time).

*“The neurologist said “well, go on holiday, you’ll be alright in two weeks” and we were like “are you kidding me?”. I couldn’t walk out, I couldn’t do anything and, once I got home, my mum phoned the doctor. The doctor was shocked in the way they sent me home because she called out a crisis team. I’d gone from being able to walk down the stairs and normally, to five days later having to go on my backside with someone in the front of me, someone at the back of me.” (Cecil: lines 21-20, p. 9-10)*

Ethan also seems to place the responsibility and power regarding his care in the hands of the medical professional. It seems that ‘treatment’ for him is about relationships, whereby he sees the medical professional as predominantly responsible for the delivery of this care and support. He seems to place the power in the hands of the medical professional where he expects their duty to be that of empowering him. However, when he is given a ‘medically unexplained’ diagnosis that cannot be treated in a conventional medical way, and which lies outside of the capabilities of the medical professional responsible for his care, he then seems to realise that feeling powerless involves feeling a lack of empathy and compassion from those around him.

*“I’m still waiting to see a neurologist. I am eventually going to see someone who cares. I’m looking forward to meeting someone in the health service who cares. My neurosurgeon is the same, he doesn’t go and cut skulls open because he doesn’t care. But that is what I am looking for.” (Ethan: lines 1-15, p 5)*

Overall, the participants seem to experience confusion around receiving a diagnosis that they do not understand, and that the medical professional who delivered this also does not seem to understand. This seems to have engendered a sense of powerlessness for all of the participants when initially diagnosed, as they had expected to be given a solution from the medical system. The participants who then moved away from looking towards the medical system to provide their sense of empowerment in favour of finding it for themselves were: Aston, Daniel, Flick and Harry.

#### 9.3.5.2 Subordinate theme 2: "Knowledge being the door to acceptance"

This subordinate theme explores how the participants seem to desire a particular kind of knowledge to be delivered to them about the 'EDCD'. The start of each interview involved a question concerning what had drawn the participant towards participating. In every case, the answer involved the following: 1) developing a better understanding of their own condition, 2) facilitating the potential that others might receive help earlier than they had, and 3) contributing towards the knowledge in the area so that other people 'like them' could understand and feel supported through the account of their own experience.

Flick seems to expect the medical system to have more knowledge about his experience than he does. It seems as though he has given himself over to the medical system and, when it cannot deliver, he then feels uncertainty within himself about what is going on and what this means in relation to his experience of self. There is almost the sense that knowledge can put him back together, take him apart again, and make him whole or empty.

*“There’s not a great deal of information. All the information, which I seem to kind of come across, is all, kind of not solid if you know what I mean. It’s not something, which has, which seems to have been researched to say ‘this is definitely how things are’. Trying to get answers. Why you don’t feel very well and why you have certain symptoms. Trying to understand why. You don’t get a lot of kind of help.” & “It kind of leaves you feeling a bit empty.” (Flick: lines 9-25, p 2 & lines: 12-13, p.5)*

Harry describes how important the way that knowledge is communicated is for him. He seems to experience rejection when the communication is that his experience is “psychosomatic”. In contrast, when he is told that there is something wrong with him that cannot be ‘seen’ in the objective measurement sense, he then seems to feel accepted and in control again.

*“I went to the neurologist. His answer was “its’ psychosomatic”. Now you, that tells me that there’s something in my brain, that, there’s something wrong in my mind. It’s, there’s nothing physically wrong with me. You actually go into a state where “am I mad”?” & “I met these doctors of mine and they just said, “well, we need to find out what’s wrong”. He explained to me “understand that you have an illness but it’s not something that you can see”. I made the decision for myself to actually stand up for my own rights.” (Harry: lines 3-9, p.19 & lines 6-17, p.20)*

Byron describes the knowledge that he has previously received as explaining that there is a breakdown in communication within his body. This description could lead to him feeling as though there has been a breakdown in communication between himself and

others, as well as in other aspects of his life. As he has had the diagnosis for the longest period of time and maintains that he has been “fobbed off” by the medical professionals, this could be a possibility. There is the sense that he may be seeking to have this ‘broken down’ communication re-established and re-connected.

*“Been described is, a breakdown in communication in between the brain and muscles. Like an electric cable that is sort of like threaded, sort of like come away sort of thing, so it’s not as strong as it should be.” & “...“Someone hasn’t done their job properly. I feel fobbed off.” & “My mind wants to move my legs but it can’t.” (Byron: lines 21-1, p 4-5 & lines: 22-2, p.24-25 & lines: 9-13, p.33)*

Overall, the majority of participants seem to want to understand the diagnosis to a greater extent. There also seems to be the notion that there is a better explanation that can be attained (Aston, Byron, Cecil, Ethan, Flick, Harry). The participants seem to express that a better understanding of the ‘EDCD’ could help them to: 1) manage the ‘EDCD’, 2) enable them to accept their experience of this to a greater extent, and 3) leave them feeling as though other people also accept this. Those participants who have a better understanding of the diagnosis seem to be able to communicate this to others in a way that enables others to fully comprehend and relate to the ‘EDCD’ themselves (Daniel and Harry). There was also the sense that knowledge may enable the participants to feel as though their existence is more ‘solid’ in relation to themselves, and in relation to how others perceive them.

#### 9.3.5.3 Subordinate theme 3: “Responsibility as residing outside of oneself”

This subordinate theme explores how the participants seem to view responsibility as belonging to the medical profession. As they initially sought medical support for something they viewed to be physically wrong with their bodies, it could be assumed that they may have expected a physical explanation and a physical treatment for this.

Ethan's description seems to suggest that he has felt in the dark and unaware of how to work with the 'EDCD'. He seems to feel as though this knowledge is held within the medical profession on the one hand, but on the other hand he also seems to be aware that he may be more responsible for his experience than he admits to himself.

*"If they told me about distraction therapies, if they told me about freezing, I might have known and had a bit more control over it." & "Making it better yourself. Just the little. Like when I'm stroking my thumb, that's making my thumb a lot better and I'm dealing with it."*

(Ethan: lines 15-19, p.10 & lines 10-13, p.20)

Cecil describes potentially positioning the responsibility in the hands of the medical profession to the extent that he may have allowed himself to get worse in order for the medical profession to take responsibility for his care. This is interesting, as there seems to be a sense of trust in the power of the medical system to help him and to potentially rescue him.

*"I've been lucky because of how bad I was. I got the help I needed but I know people."*

(Cecil: lines 11-12, p.1)

Overall, when the participants initially described being diagnosed with 'CD/FND', there was a sense that the doctors communicated the diagnosis in a way that handed the responsibility back to the participant who sought help. This reveals an implicit expectation in the physician's role as well as a denial of responsibility on the part of the medical professional. As the participants had all sought help for their symptoms, they seem to have initially felt shut out by the explanation of 'CD/FND'.

#### 9.3.5.4 Subordinate theme 4: *'The underlying desire for cohesion'*

This subordinate theme explores how the participants seem to have alluded to, in various ways, ideas that can be described by concepts including: 'holistic', 'wholeness', 'unity', 'cohesion', 'cycle' and 'full circle'. For some, this involved looking for deeper meaning, whereas for others, there was the sense of losing 'oneself' and of attempting to regain this.

Flick seems to feel that the medical system treated him as though he was an object, as information was fed back to him about his body in an objectified way. He does not seem to feel as though he has been treated as an individual, whom is neither solely an objective body nor a subjective mind (as he talks about "automate system" and "organic based within the health service" rather than "holistic"). He seems to view the medical system as dividing the person up as opposed to treating them as a whole, which seems to obstruct cohesion.

*"You know the neurologist and like stuff, automate system. Where it's, you just get process, you know and there's just, there's not a like, you just see, you used that, holistic kind of, it*

*seems so far away and you know the holistic side of things and the spiritual kind of side of things. You know, who you are, why you're here and you know and, there doesn't seem to be a lot. Everything's very kind of organic based within the health service."* (Flick: lines 20-2, p 24-25)

Byron seems to be describing how, although he has gone through all of the medical tests, the 'EDCD' have become progressively worse to the point that he feels as though he may be "slipping away". He seems to want to start again so that he can prevent this process from playing out, and to keep himself from "slipping away". Thus, it could be that every negative medical test represents an undoing of his sense of self and that positive tests are desired to reverse this. Again, the power and responsibility seems to be positioned with the medical system to provide this or to take this away.

*"I don't feel like I'm slipping away but I feel that if it progresses even worse then I need to be as sharp as possible to stave it off." & "I'd just like to run through all the tests again. It was fifteen years ago that I had all these tests done."* (Byron: lines 14-15, p 20 & lines 12-14, p 40)

Harry seems to have shifted his approach to 'EDCD' in a way where he is able to draw on this experience to connect with other people. He seems to experience cohesion and connection as a result. He is the only participant who has learned how to derive greater meaning and empowerment in his life through experiencing 'EDCD'.

*"You know, giving it back to human kind it's, I think that's the biggest change that I've had in my life now, not just taking but actually giving some back."* (Harry: lines 9-13, p 44)

Overall, although the participants seem to ultimately desire deep and meaningful relationships with other people, their cautious approach to this seems to make this difficult to achieve.

## 10 DISCUSSION

### 10.1 Study aims

The aim of this study has been to gain an in-depth understanding of the lived experience of *agency* for males who identify with the diagnosis of 'CD/FND'. An Interpretative Phenomenological Analysis (IPA) approach was used, with semi-structured interview schedules. As previous studies have not focused on the lived experience of males within this context, the hope is that this project will contribute towards existing knowledge in this area, which has predominantly been based on findings from quantitative research. The research question is:

**How do males who have experiences described as 'conversion disorder/functional neurological disorder' experience the phenomenon of *agency*?**

The main findings from the analysis are considered in relation to this question and are discussed in the context of existing theory. The significance of the study, clinical



implications, evaluation of methodology, and suggestions for future research, are then explored.

The findings have shown that all of the participants seem to experience agency in a paradoxical way, whereby they reported to be both lacking and not lacking in control, and in relation to feeling as though they were the agents of their lives across the domains of mind, body, and society, for example, superordinate theme: 'paradox of control'. Dualistic notions permeated the findings, for example, superordinate theme: 'living within a dualistic framework'. The themes that involved the participants' relationship to themselves and others also came across strongly, for example, superordinate themes: 'disconnection from self and others', 'engaged in a battle or fight' and 'meaning and reality as dependent on other people'. These areas shall next be explored in relation to existing literature and future directions.

### **10.1.1 Paradox of control**

The first superordinate theme contains the following subordinate themes: 're-conceptualising control', 'body disconnected', 'centrality of conscious mind', 'being experienced by others' and 'potentiality woven in time'.

The data seems to suggest that participants have undergone a revision of what it means to be in control of their bodies, minds, and capacity to act within the world, which comes under the subordinate theme 're-conceptualising control'. This notion seemed to lead to the view that it was even more important, in the context of experiencing phenomena identified as 'CD/FND', to be in control and to maintain this (Aston, Byron,

Ethan, Flick, Gavin, Harry). To the same extent, it was held by every participant that control was not something that could be guaranteed. This can be seen from the subordinate theme 'body disconnected', whereby all of the participants experienced a lack of control over their bodies when the 'EDCD' arose. As a result, there seemed to be overcompensation in the areas that appeared to be under the participants' control, almost as though to counterbalance those experiences that arose from outside of their control. This involved an emphasis on the control residing in conscious, rational thought processes, for example, the theme 'centrality of conscious mind'. The participants thus showed a constant monitoring of internal states (Aston, Byron, Daniel, Gavin, Harry) and control over the extent to which they engaged with their environment and other people (Aston, Byron, Cecil, Daniel, Gavin, Harry). Some participants even described how other people were able to remove the control that they should have over their bodies (Byron, Cecil, Daniel, Ethan) and future (Aston, Byron, Cecil, Ethan, Flick), which can be seen from the subordinate theme 'being experienced by others'.

In terms of implicit and explicit agency, which was mentioned previously (where implicit agency involves bodily movements and explicit agency refers to beliefs and perceptions in relation to acting within the world), both of these seem to be strongly involved in the findings (Gallagher, 2005; Kranick et al., 2013; Voon et al., 2010). All of the participants seemed to experience a lack of implicit agency when their bodies behaved in an involuntarily ('EDCD') fashion, as well as a lack of explicit agency in the sense that previous life options and possibilities had shifted into those essential for long-term survival (Byron, Cecil, Ethan, Gavin, Harry). The subordinate theme 'potentiality woven in time' links to the long-term survival mentioned above, as some participants who described having had the 'EDCD' for a long period of time showed a

gradual worsening of the 'EDCD', whereby the focus became survival orientated (Byron, Ethan).

As described earlier, four elements have been described to be involved in agency: "intentionality (for example, actively making and carrying out plans), forethought (for example, projecting into the future about what can be done and what needs to be carried out to achieve this), self-reactiveness (for example, adapting one's behaviour to bring about plans), and self-reflectiveness (for example, the ability to reflect on one's behavioural consequences in order to appropriately adapt and achieve objectives)" (Bandura, 1989, 2006). In terms of intentionality, the participants all demonstrated this aspect of agency in the sense that they had all intentionally approached a medical doctor and intentionally adhered to the medical referral process. This intentionality was in the context of the participants' observation that their bodies had at times behaved in a way that they had not intended. However, the participants then had the contrary experience of intentionality when they were informed that there was nothing that could be done for them (Aston, Byron, Cecil, Ethan).

For 'forethought', the participants had all begun by observing their bodies as behaving in an unintentional way, after which they intentionally sought medical support in order to better understand the nature of their experience. This suggests the use of 'forethought', as it assumes that the participants had been seeking a way to continue moving in an intentional manner in their lives via the acquisition of a medical explanation. However, the information that the participants received seemed to remove 'forethought', as the knowledge that they could not be medically explained or medically

treated (Aston, Byron, Cecil, Daniel, Ethan, Flick, Gavin) seemed to leave them lacking in regards to the information available to use 'forethought' on.

In terms of 'self-reactiveness', this aspect of agency differed for the participants that were interviewed. For some, this adaptation took place (Cecil, Daniel and Harry), but for others (Aston, Byron, Ethan, Flick and Gavin), it did not. For Aston and Flick there was a sense that they had been attempting to adapt, but that the adaptation was actually another way of going about their lives in the same way. For those that adapted, there seemed to be a 'facing up to' the 'EDCD' and finding a new way to relate to, and live with, this (Cecil, Daniel and Harry). This contrasted with the latter group who all seemed to attempt to isolate the 'EDCD' and to function as they had always done (Aston, Byron, Ethan, Flick and Gavin). Although the latter group believed that they were exercising agency by not allowing the 'EDCD' to take over their lives, in actuality it rather seemed as though they felt that the 'EDCD' had significant control over their lives. As the former group did not seem to feel as though the 'EDCD' were controlling them to the extent found in the latter group, they spoke in a way that appeared to be more directed towards the future.

'Self-reflectiveness' seemed to play out in an interesting way for the participants. Expectations and emotional need seemed to influence decision-making and subsequent behaviour in a way that often seemed to make the 'EDCD' and social encounters harder to bear. For example, Byron would ask to be tested and re-tested in hope that the diagnosis would change and, even though it did not, he seemed to refuse to alter his course of action because he felt as though he had been overlooked and not examined properly by medical staff. All of the participants with the exception of Cecil, Daniel, Flick

and Harry behaved as such. These four participants differed in that they showed self-reflectivity, and a much greater sense of agency in their lives, as a result of this.

Interestingly, these four participants (Cecil, Daniel, Flick, Harry) who showed greater agency had also all received psychological therapy in contrast to the other four who held onto the view that the doctor did not have the tools to adequately treat them (Aston, Byron, Ethan, Gavin).

People can be said to be agents in the sense that they act within the world as embodied beings where action is viewed as bringing about desired outcomes, as agency involves the belief that one has the power to change one's actions (Bandura, 2006; Merleau-Ponty, 2002; Vasterling, 2003). In terms of how the participants described their experience of agency, there appeared to be an interpersonal and intrapersonal breakdown of communication. The 'EDCD' may not have necessarily reduced their sense of agency but rather, it might have been the way that the 'EDCD' was responded to that reinforced this breakdown of communication, as the social exchange had not been that of clarification, knowledge, and help with their experience (Aston, Byron, Cecil, Ethan, Flick, Harry). In response to the medical feedback that described 'EDCD' as 'medically unexplained', some participants became more determined to obtain what they had initially set out to find, whereas others altered their plans. Those who adapted reconceptualised agency so as to feel as though they were still agents (Cecil, Daniel, Flick, Harry), whereas those who do not adjust seemed to experience a lack of agency (Aston, Byron, Ethan, Gavin). In both cases, agency was reconceptualised in the sense that the participants questioned what it meant in a way that they had not done before. A different way of understanding and functioning as an agent occurred, whereby some

participants felt less of an agent and others regained their sense of agency to a certain extent.

### **10.1.2 Living within a dualistic framework**

The second superordinate theme contains the following subordinate themes: 'identities in conflict', 'mind-body duality', 'something becoming and nothing unbecoming', and 'conscious-unconscious separation'.

Throughout this research there has been a Cartesian duality (Descartes, 1961) whereby all of the participants have implied a separation between 'mind and body', 'conscious and unconscious' experience of mind, and 'self and other'. Each of the eight participants that were interviewed had initially expected to receive a physical explanation for how and why their bodies could behave in an involuntary way (which comes under the subordinate theme 'mind-body duality'). However, when the participants received an explanation that did not fit with their own expectation, or with the expectation that may be assumed within the medical system, this left some feeling lost and confused (Aston, Cecil, Flick, Gavin, Harry). Others seemed to feel rejected by those whom they had thought would offer clarity to their experience (Byron, Daniel, Ethan). Such experiences fit with the subordinate theme 'something becoming and nothing unbecoming'. This is because those participants that felt lost and confused seemed to feel as though the lack of a tangible diagnosis meant that they too lacked in substance or existed to a lesser degree. Some of the participants also seemed to identify less with the term 'FND' (Byron, Ethan, Flick) as they seemed to view it as covering a broad area that made it difficult to relate their experience to. In contrast, those who identified with 'CD' (Aston, Cecil, Harry) seemed to find a greater clarity in being able to understand that there was

a conversion of emotion and a build-up of stress that manifest physically in 'EDCD'. Both of these terms support the subordinate theme 'mind-body duality' and 'something becoming and nothing unbecoming', as the term 'CD' seemed to provide a more concrete way of conceptualising the 'EDCD' in contrast to 'FND', which was referred to as an umbrella term.

These findings support the notion that there is a 'mind-body' dualistic way of understanding the world that permeates western culture (Bullington, 2013). Again, this duality is at the heart of what has been described in the background of this work, whereby duality arises out of the history and terminology of 'CD/FND' (Crommelinck, 2014; Edwards, 2009; Tasca et al., 2012). This is still evident in the use of the term 'FND', which is a term that supports a neurological explanation by describing symptoms as irregular brain 'functioning'. This repositions symptoms back into the neurological context. The term 'CD' differs in the sense that it has arisen from the work of Freud and Breuer, where repressed psychological trauma was described as 'converted' into physical phenomena (Owens & Dein, 2006). In considering both of these terms, researchers have criticised 'CD' as showing a mind-body duality as well as being a term that 'patients' struggle to identify with (Stone, LaFrance, et al., 2010). The findings that led to these criticisms were used to move the diagnosis away from 'CD' towards 'FNDs', as can be seen in the DSM-5 (APA, 2013b; Stone, LaFrance, et al., 2010). However, as mentioned in the findings section of this research, the clearer conceptualisation of 'CD' may have led to the participants feeling as though there was something that was the matter with them that they could grasp. The label 'FND' could be seen to situate the person 'inside' their brain in a neurological sense, whereby the person is under the discretion of a neurologist who may not necessarily fully understand the diagnosis.

Byron, Ethan, and Flick experienced this. The term 'FND' also seems to exclude a psychological component for participants (Ethan, Flick), whereby it came across as though they found it difficult to relate to the 'EDCD' in any way that did not fit with a neurological explanation. In contrast to this, the label 'CD' seems to provide more clarity and a simple understanding of something emotional being converted into physical, where this has the potential to be altered or overcome (Aston, Cecil, Harry). Although the reasoning behind the shift towards 'FND' was about de-stigmatising such individuals and removing the association of something being converted (Stone et al., 2014; Stone, LaFrance, et al., 2010), the participants that were interviewed did not feel this way. Also, the mind-body divide that comes up with 'CD' also comes up with 'FND', as 'FND' separates out the mind and focuses solely on the body whereby the explanation is in relation to the *physical brain* that is both structural and functional. Although there has been a movement away from this, as a recent article has proposed that CD/FND be placed into both categories of the ICD-11 where it falls under both neurology and psychiatry (Stone et al., 2014), this still raises the subordinate theme 'mind-body duality' as being upheld in relation to the medical model.

The participant interviews also brought out the subordinate themes of 'identities in conflict' and 'conscious-unconscious separation'. A couple of participants described experiencing themselves as separate people. They said that other people had also described them in this same way (Aston, Gavin). Others referred to a pre 'EDCD' and post 'EDCD' identity (Byron, Cecil, Ethan, Flick). One participant had specifically changed their gender identity (Daniel) whilst another had re-established his pre 'EDCD' identity (Harry). This division of identity was striking in all of the participants. For Aston and Gavin in particular, the subordinate theme 'conscious-unconscious



separation' came out, as both participants referred to another identity that was unconscious in relation to their own conscious experience but accessible to the observation of others. For others, there was an acknowledgement of an unconscious element involved in 'EDCD' (Cecil, Daniel, Ethan, Flick, Harry) that other people could not observe.

The participants that were interviewed all described feeling alienated from others, whereby their sense of identity seemed to be separated. This could be linked to the idea of the 'false self' and 'real self', whereby a child will respond in a way that fulfils the mothers image of himself/herself to the extent that the 'real self' becomes separated from the body, and the inauthentic 'false self' remains and is expressed via the body (Laing, 1960). As the participants described feeling as though their bodies were separate when they experienced 'EDCD', it could be the case that the denial of the behaviour of their body as belonging to them, and the desire to receive a medical explanation that could potentially enable them to feel explained, may describe the "false self". This can be linked the subordinate themes 'identities in conflict' and 'conscious-unconscious separation'. The description of the body and subsequent 'false self' as compulsively compliant to the will of others where it is felt as alien, unreal, and meaningless (Laing, 1960) could, for example, be seen by the account given by Bryon who described falling over when people looked at him. The participants could also be said to show a "fear of engulfment", "fear of implosion", and "fear of petrification" (Laing, 1960). This is in the sense of that the diagnosis and the process of elimination of other medical causes may have left them feeling empty and as though the medical setting de-humanised them (Aston, Byron, Cecil, Ethan, Flick). In particular, this can be seen by the subordinate themes: 'identities in conflict', 'something becoming and

nothing unbecoming', and also in the subordinate theme 'disconnection from self and others'.

### **10.1.3 Disconnection from self and others**

The third superordinate theme that is addressed contains the following subordinate themes: 'body as distorting perception', 'I isolate, 'you' isolate, 'we' isolate', 'trust in mistrust, 'this body of mine is not me in authenticity' and 'dissevering anger'.

Some of the participants referred to the 'EDCD' in a way where they seemed to experience their bodies as behaving in an alienating way that they could not relate to, and where they almost denied the behaviour of own bodies (Aston, Byron, Cecil, Ethan, Flick, Gavin). This can be seen by the theme 'this body of mine is not me in authenticity'. Some of the participants seemed to feel alienated from other people (Aston, Byron, Cecil, Gavin) as well as in relation to unconscious aspects of self (Aston, Cecil, Daniel, Gavin). This can be seen in the subordinate theme 'body distorting perception', whereby the participants described feeling alienated from the behaviour of their bodies and those around them. This in turn impacted on how participants engaged with people and how they experienced others as engaging with them, which can be seen in the theme 'I isolate, 'you' isolate, 'we' isolate'. Some participants actively distanced themselves from all except for those who were immediately close to them (Aston, Byron, Daniel, Flick, Gavin). This impacted on trust to the extent that some participants were extremely mistrustful of the medical profession (Byron, Cecil, Ethan, Flick) as well as social stereotypes (Aston, Bryon, Daniel, Flick, Gavin). Some participants dealt with the

mistrust that they held towards others by remaining in a safe home environment (Aston, Byron, Daniel, Harry).

As there is a strong historical basis that arises from the psychoanalytic work of Freud and Janet (Freud & Breuer, 1895; Freud, 1963; Janet, 1907; van der Kolk & van der Hart, 1989; Verhaeghe & Masson, 1992), the research findings are explored in relation to this. As mentioned earlier, psychoanalytic findings involving “pseudoseizures” have shown that “mirroring, idealization and twinship transference” are processes that appear to come out in individuals who experience ‘pseudoseizures’ (Kalogjera-Sackellares, 2004; Kohut, 1971). These processes can be viewed as having arisen in the context whereby the participants had sought out support and understanding from the medical profession. However, when the needs of the participants were not met, this may have led to anger and isolation in regards to the medical profession (Byron, Cecil, Ethan) as well as instability of self (Aston, Cecil, Flick, Gavin). This can be seen in the theme “‘I’ isolate, ‘you’ isolate, ‘we’ isolate’ and ‘dissevering anger’, which suggests that the anger felt by some participants was experienced as cutting them off from whomever they were confronted with, to the level that they could not express the anger (Aston, Byron, Cecil).

The themes ‘this body of mine is not me in authenticity’ and ‘dissevering anger’ can be looked at in relation to the dissociation theory presented by Janet (1907). The experience of the body as acting out beyond the participant’s control may show that emotions may have been dissociated to the extent that they emerge via the body rather than conscious ‘mental’ awareness. Anger is also described by some of the participants as something that does not belong to them (Aston, Byron, Cecil). Concern is also

expressed by some of the participants around the consequence of anger arising unchecked (Aston, Byron, Cecil, Gavin). This may suggest that the anger has been dissociated or 'separated' for the participants (van Der Hart & Horst, 1989; van der Kolk & van der Hart, 1989).

Support can also be provided for previous research that has outlined emotional dysregulation, whereby individuals with symptoms of 'CD/FND' have been shown to have either an exacerbated or inhibited response to threat (Uliaszek et al., 2012). For example, Cecil described feeling so angry that he became frozen and progressively more trapped. However, to the same extent, Cecil could not relate to feelings of anger. This in turn could be looked at in relation to the research on dissociation described previously, whereby the participants descriptions seem to support both 'compartmentalisation' and 'detachment' (Holmes, 2001), as they all spoke about feeling an altered sense of consciousness as well as a disconnecting from certain emotions.

#### **10.1.4 Engaged in a battle or fight**

The fourth superordinate theme contains the following subordinate themes: 'fighting to not lose oneself', 'stuck in frustration' and 'battling undesired aspects of self'.

Some participants spoke about being involved in a battle to not lose their sense of self, identity, or mind (Aston, Byron, Ethan, Gavin). This can be seen in the theme 'fighting to not lose oneself'. Two participants described having lost this battle to the extent that they had to rebuild their sense of self, and lives, following this (Cecil, Harry). In contrast, Aston described losing his sense of self to the level where he then remained in perpetual

fear that this could happen again in the future. He also became concerned that he could potentially lose his identity altogether. Others described the theme 'fighting to not lose oneself' in terms of a fight to prevent the exacerbation of the 'EDCD' (Byron, Ethan, Flick, Gavin). The theme 'battling undesired aspects of self' can be seen by the rejection or denial that participants exhibited in relation to their anger (Aston, Byron, Cecil, Ethan, Gavin,), whereby some seemed to have to actively hold anger at bay (Aston, Cecil, Gavin). All participants, apart from Harry, seemed to feel frustrated at being stuck in a position of experiencing 'EDCD' and of feeling limited by what they could do in their lives. Harry differed in this sense because he seems to have adjusted his mind-set to derive a sense of purpose and fulfilment from the 'EDCD'.

In relation to this, Freud (1917) spoke about the process of "internalization", which involves the individual internalising a traumatic experience where the aggressor or person involved in this experience cannot be confronted directly and opposed (Kalogjera-Sackellares, 2004; Strachey, Freud, Strachey, & Tyson, 1956). Rather, the person internalises the relationship with the other person, who is the aggressor or source of pain, so that they can engage in a battle or fight internally, as they cannot do this directly (Kalogjera-Sackellares, 2004; Strachey et al., 1956). This serves to provide a sense of control and safety, as the person is confronting the "aggressor" within their own self. However, it does not lead to resolution and can result in frustration whereby one is constantly fighting oneself (Kalogjera-Sackellares, 2004). This frustration and being in a fight/battle with oneself was mentioned frequently in the interviews that were carried out, whereby the medical profession seemed to be viewed as the aggressor to internalise (or otherwise society at large). Thus, the participants may have looked towards the medical field in a paternal way, whereby they had sought out the processes

of “mirroring, idealization and twinship transference” (Kalogjera-Sackellares, 2004; Kohut, 1971; Siegel, 1996) to be met. This may have arisen in the context of not having had these processes fulfilled in their early upbringing. However, the nature of the ‘EDCD’ can be viewed as a communication that reinforces this disconnection and way of relating to others, so that experience of not having had these processes met is reinforced (as the ‘EDCD’ does not fit in the medical model way of understanding the world). The ‘EDCD’ can be viewed as communicating suffering and isolation as well as the desire to merge and repair this. However, this may unfortunately result in the potential reinforcement of pre-existing rejection and anger.

As mentioned in the literature earlier, both trauma and dissociation have been associated with ‘CD/FND’. The findings of this study seem to link with this, as all of the participants mentioned having experienced either the death or harm of someone that they had cared about via violence or ill health. This can be said to relate to the theme ‘fighting to not lose oneself’ whereby some participants seemed to worry that they could lose themselves entirely (Aston, Byron, Ethan, Flick, Gavin). Only one participant discussed sexual abuse, which is interestingly in the context of this participant being the only one who is transgender. This relates to previous research where symptoms of ‘CD/FND’ in males have been linked to trauma involving death and/or violence (Dworetzky et al., 2005; van Merode et al., 1997) as opposed to females, where a higher level of trauma involving sexual abuse has been shown (Asadi-Pooya et al., 2013; van Merode et al., 1997).

#### **10.1.5 Meaning and reality as dependent on other people**

The fifth superordinate theme contains the following subordinate themes: 'expecting one's power to be provided by another', 'knowledge being the door to acceptance', 'responsibility as residing outside oneself', and 'the underlying desire for cohesion'.

The first time that all of the participants approached the medical profession there seemed to be an expectation that they would receive some kind of knowledge that would allow them to make sense of their experience, and to feel as though they were no longer powerless. This can be seen by the subordinate themes: 'expecting one's power to be provided by another', 'knowledge being the door to acceptance' and 'responsibility as residing outside oneself'. However, the way that the participants reacted to receiving a medically unexplained diagnosis differed between them. For some, there was a sense of being accused of fabricating the 'EDCD' or of it being 'in their head' (Byron, Cecil, Daniel, Harry), whereas others seemed to feel empty and confused from having a diagnosis that could not be explained (Aston, Byron, Ethan, Flick, Gavin, Harry). This can be seen by the theme 'knowledge being the door to acceptance'. After the initial diagnosis, some participants seemed to attempt to draw on inner resources in a way that seemed to be a response to feeling as though they had been denied support (Aston, Daniel, Flick, Gavin). In contrast, other participants directed their focus towards seeking further help and clarification from the medical profession, although they often times showed frustration and occasional anger at having to do so (Byron, Cecil, Ethan, Harry). In this sense, the latter group can be seen to fit the subordinate themes: 'expecting one's power to be provided by another' and 'responsibility as residing outside oneself'.

As mentioned in the literature review, early attachment experiences have been shown to influence how people understand and relate to the world around them (Dallos, 2006).

Bowlby's (1988) theory of attachment discussed how early relationships lead to children developing either secure or insecure attachment styles. This in turn impacts on how they engage with those around them as adults (Dallos, 2006). It may be the case that the participants have been demonstrating insecurely attached ways of relating to others and in particular, the medical system and wider society. In this way, the medical system could be seen as the parental figure that represents support, care, nurture, and authority. The response of each participant could be that of their individual attachment style, for example, the anxious-ambivalent attachment style is when the child's response to the main provider of care (who in the case of participants could represent the medical system) is either that of anger or helplessness (Bowlby, 1988; Dallos, 2006; Kinniburgh & Blaustein, 2010). Thus, the subordinate themes of 'expecting one's power to be provided by another', 'knowledge being the door to acceptance' and 'responsibility as residing outside oneself', appear in relation to the notion that the medical system may represent the parent, whereby the participant had expected these aspects to be fulfilled as one would expect a parent to do so. Also, in relation to the dynamic-maturational model involving attachment, the "freeze response" and "appeasement defense behaviour" (Kozłowska, 2007) can be supported in terms of the phenomena of 'CD/FND', as both paralysed states ('freeze') and excitable states of seizures ('appeasement defence') were described.

Merleau-Ponty's (1962) work 'Phenomenology of Perception' can also be drawn upon to interpret the way that the participants approached the medical setting. This is in terms of the response they had expected and the response that they received. Merleau-Ponty spoke about the body that speaks, which contrasts with the assumption commonly held that speech is something that is not of the body but rather the communication of



thoughts that have no physical basis (Merleau-Ponty, 1962; Vasterling, 2003). In adopting the approach of Merleau-Ponty, each word could be viewed as an act of communication whereby the lungs, body, mouth, and tongue, are engaging so as to bring into being an experience of thought. This understanding of language reveals it as embodied and as representing physical engagement with oneself and others, whereby engaging with the world involves intentionality. In addition to this, Merleau-Ponty has also been said to talk about the body as being expressive and intentional, whereby there is a dynamic of creativity and sedimentation constantly at play (Bernard, 2004; Vasterling, 2003).

In terms of Merleau-Ponty's views, the physical phenomena experienced by participants could be seen as embodied communication and expression. It could be said that the participants' bodies may be physically communicating distress, alienation and isolation, in relation to themselves and those around them. The participants did not seem to feel as though they had agency over 'EDCD'. However, they did exercise agency when they asked the medical professional to provide them with an understanding of their experience, which can be seen by the themes: 'expecting one's power to be provided by another' and 'responsibility as residing outside oneself'. As an onlooker, such physical expressions of 'EDCD' could automatically be viewed as distressing and as indicating that something was amiss with the person. In terms of the ideas of Merleau-Ponty, their bodies could be viewed as communicating in a way that is important and informative. In terms of 'speaking and spoken speech', it might be the case that the person does not have any sedimented 'spoken speech' that can be used to communicate this distress to themselves or to others, which may then lead to this being expressed via the body (Vasterling, 2003). This physical communication could be said to show a form of

'speaking speech', whereby the body is communicating the person's internal state even if the person does not recognise this.

Another way of looking at how the participants may place the responsibility and power in the hands of the medical profession is to draw on the work of philosopher Jean Paul Sartre's (1943) work 'Being and Nothingness'. As mentioned in the background literature, Sartre discussed how a person's experience will alter when another person enters their field of experience (Gallagher, 2010, p.13). In 'Being and Nothingness' (1943) there is a part called "the look", where Sartre challenges how it is possible for one person to experience another person as a subject, for example, someone peeps through a keyhole at another who is the object for them, but when they become aware that they too are being observed, then they become an object in the eyes of the other person (Sartre, 1943). The difficulty lies in: 1) solipsism comes about through defining another as the reflection of oneself, 2) the other becomes objectified if one defines them in relation to oneself, and 3) to define the other person as a subject through being an extension of one's experience makes one the source through which others are rendered subjective (Sartre & Barnes, 1992; Sartre, 1943). There is a constant oscillation between subject and object whereby both are always aware of being re-objectivised through the look of the other, which Sartre describes as "being-for-others" (Sartre & Barnes, 1992; Sartre, 1943).

The participants in this research seem to experience being rendered the object by the look of the other. This can be seen in the way the participants approach the medical profession, as they are not encountered as individuals in need of support, but rather as objects or bodies that present in a peculiar way that cannot be helped. However, rather

than looking back at the other and reclaiming their subjectivity by engaging the medical representative in an authentic dialogue of their subjective experience and feelings, they remain fixed as an object by allowing an unexplained diagnosis to be placed upon them. In terms of 'the look', they are made into an object by the look of the other (for example, doctor) but then fail to look back at the other and reclaim their subjectivity, as they seem to desire for the other to give it to them. They may also hold themselves in objectivity by isolating themselves from others. The subordinate themes 'expecting one's power to be provided by another' and 'responsibility as residing outside oneself' can also be seen to relate to this. However, there is also the sense that anger is used to maintain this objectivity, as it creates distance between themselves and others, and thus reinforces the isolation they experience in relation to other people (Aston, Byron, Cecil, Ethan, Gavin).

The final subordinate theme, 'the underlying desire for cohesion', comes across in the way that some of the participants seem to feel as though they have been unravelling and need to be put back together in a clearer and more meaningful way (Byron, Cecil, Daniel, Ethan, Flick). Some participants emphasise deep and meaningful relationships with significant others as being fundamental, whereby they seem to experience a strong sense of cohesion with these people (Aston, Byron, Daniel, Ethan, Flick, Gavin, Harry). This can be linked to the work of Martin Buber (1937) who described two attitudes from where we can relate to anyone or anything. These are the 'I-It' or 'I-Thou' attitudes. 'I-It' involves distancing and objectifying in time and space, whereas 'I-Thou' involves a sense of being part of a whole and not separate (Buber & Smith, 1937; Hess, 1987). As relation occurs in any event or situation, Buber describes how we can only grow and develop once we have learned to live in relation to others, as well as to

recognise the possibilities of the space between us (Buber & Smith, 1937; Hess, 1987). The fundamental means of achieving this is through dialogue, and encounter is what happens when two I's come into relation at the same time (Buber & Smith, 1937; Hess, 1987). The participants all seemed to approach the medical professional so as to establish an I-Thou relationship, but instead they seemed to enter into an I-It one.

## **10.2 Significance of study**

This study has contributed towards the understanding of how males who encounter phenomena that they identify under the medical label of 'CD/FND' experience agency in their lives. Research involving symptoms of 'CD/FND' has not previously addressed the lived experience of *agency* in males. This study has contributed towards qualitative research in this area as a whole, which is a very small proportion given that the majority of research is quantitative. As the people that this research relates to seek medical support, the idiographic nature of IPA, which enables the participants to have a voice, could be very helpful in this field of research as well as in terms of support available at the medical level.

## **10.3 Clinical implications**

### **10.3.1 Clinical implication for the field of Counselling Psychology**

As this area of research and patient/individual support is heavily situated in a medical setting, where the lived experience of 'patients' can often times be interpreted within a different conceptual framework, qualitative studies such as this are particularly

relevant. The patient's sense of agency in the medical context is shown to be extremely important and as potentially providing insight for all involved in this study. Also, as the four participants who showed a greater sense of agency were also the only participants who had received psychological support, this could potentially highlight the importance of involving the field of Counselling Psychology in supporting individuals in this area.

Counselling Psychology is a field that is positioned so as to fully engage with what is communicated by the individual from a humanistic and phenomenological perspective. Thus, research exploring lived experience is particularly relevant to this field. As the area of 'CD/FND' is strongly situated within the medical model, this provides Counselling Psychologists with the opportunity to mediate and communicate the 'patient's' voice to the medical professionals involved, as they are more likely to view the 'patient' in relation to existing medical knowledge. As individuals with 'EDCD' do not fit in with the standard medical model, learning more about their experience is something that could potentially extend the way that health is approached so that it can move beyond the singular model approach of 'mind-body' duality.

In particular, this research raises the misconception of mind and body as existing separately. As the researcher is in the field of Counselling Psychology, it is easier to recognise the dual perspective as entrenched in the medical model of health and illness, and of how the area of 'CD/FND' highlights the problem of this duality. As the philosophy underlying the field of Counselling Psychology means that it is not situated in this duality, this may give the field a role in educating those who continue to adopt this. As the area of 'CD/FND' is situated in the crux of the fallacy of this duality, it is

prevalent that Counselling Psychologists adequately communicate this in the hope that this may begin to initiate the dissolution of this age-old paradigm.

The clinical implication of this is that the approach to health may become more of a dialogue, whereby both sides exchange knowledge and views that can potentially lead to an enhanced learning and understanding for all involved. Counselling Psychologists could also devise training initiatives to facilitate such dialogue between 'patients' and medical professionals in the future, for example, in relation to neurologists and neuro-psychiatrists. As the participants all described problems around the way that neurologists explained the diagnosis, the dissemination of this research involving a focus on the field of neurology may be particularly important. This is because the voice of the participant has been given a position of importance and attention that may not always be possible to uncover in neurological consultations with patients. Along these lines, the researcher has been in contact with neurologist Dr Mark Edwards about taking these results forward. Also, the results that have been uncovered in this research can potentially be used alongside the research that has arisen from the CODES trial, whereby the researcher's personal observation has been that the CODES participants have shown an increased sense of agency as a result of having adequate interventions from the neurologists involved in their care.

### **10.3.2 Clinical implication for practice**

The results of this research show that agency and social relationships are key areas in working with the diagnosis of 'CD/FND'. A formulation driven therapeutic approach is something that the researcher uses in practice and has found very beneficial. This is

because it is an approach that a) enhances the agency of the individual, b) evens out the power dynamic between the therapist and client, c) facilitates connection in the relationship, and d) positions responsibility as something that is shared between client and therapist in different ways, for example, the client takes responsibility for their bodies and mind, and the therapist takes responsibility for the struggle of the medical system in communicating and clarifying 'CD/FND'. This sharing of responsibility means that the individual can begin to recognise that the bodily movements that appear to be involuntary may be functioning to enable the individual to cope with areas of their experience that they find distressing. This may enable them to see that, if this is understood and accepted, agency can be exercised to confront and deal with such difficult areas of their experience so that the involuntary behaviours are no longer needed. This takes courage and trust on both parts. The process of this is that the relationship that develops between the client and therapist can serve to repair the disconnection, isolation, alienation, agency, and duality, which have been shown in these results.

#### **10.4 Evaluation of methodology**

The main strength of the methodology was that it enabled a rich, detailed exploration into the experience of the participants. In order to achieve rigour and to derive the most in-depth detail about the experience of the participants, the interviews were all analysed as precisely as possible. The text was also engaged with to the extent that everything that could possibly be drawn out by the researcher was. The sample size of eight was another strength, as it adhered to the ideographic nature of IPA where the

light was shone on individual experience as opposed to a generalised quantitative view (Smith et al., 2009).

A criticism of this study was that all of the participants were recruited via the social media site *Facebook*, which is a limited sampling pool as it only draws from those individuals who subscribe to particular groups. To the same extent, the advantage of this was that this made the recruitment process quicker and easier, as there were numerous groups to request permission from. Another criticism was the sole use of Skype interviews. Although the advantage of Skype interviews was that the interviews could be conducted at the convenience of researcher and participant, as well as there being a certain level of 'safety and security in distance', the qualitative nature of this research made this a disadvantage. As IPA interviews are intended to gain deep and rich qualitative data, the lack of additional information that comes from face-to-face interviews may have undermined this (Iacono, Symonds, & Brown, 2016).

This reveals that a limitation of this research was in the non-verbal cues that were absent due to the use of Skype as the medium of communication. As the use of Skype interviews also means that the participant is located in their own home, the potential for distraction could potentially increase. In some interviews, participants were noticeably distracted by a sound in their environment and sometimes they would leave the interview position to clarify this. This meant that the researcher had to pay extra attention in order to maintain the flow and to engage the participant to the deepest level possible. Part of this was achieved by asking questions that required full attention. The main way that this was achieved was via the researcher's ability to establish a good



rapport with each participant. This was supported by comments at the end of the interview such as: “I think I might have learnt something about myself today”.

Another limitation of the study was the focus on recruiting male participants in the context of unisex *Facebook* groups. The female members of the groups at times expressed disappointment at not being allowed to participate. Although part of the reason why a male sample had been chosen was to do with the historical exclusion of men, the focus on men in this instance was achieving this in reverse, which served to discriminate against the female group members. A better approach would have been to advertise in a way where the advertisement would have only been offered to men.

In terms of evaluating the quality of this work, it is important to recognise that qualitative research is still a new area in contrast to quantitative research (Yardley, 2000). As a result, it is crucial that stringent criteria that are relevant to qualitative research are applied in order to achieve the necessary quality (Yardley, 2000). Some of these criteria are: “sensitivity to context”, “commitment and rigour”, “transparency and coherence”, and “impact and importance” (Yardley, 2000). ‘Sensitivity to context’ was achieved by ensuring that all relevant literature was included in the study and that any potential ethical issues were addressed prior to the start of the recruitment process. ‘Commitment and rigour’ was achieved through a detailed and thorough engagement with the literature and data analysis, as well as with the methodological process. ‘Transparency and coherence’ was achieved through providing a clear and detailed delivery of the data and methodology, as well as through showing reflexivity throughout. Finally, ‘impact and importance’ was achieved through linking the

relevance of the findings to the beneficial impact that this could have for the profession of Counselling Psychology and wider medical field.

### **10.5 Future directions**

Future research could look at a sample of women who identify with CD/FND in order to explore how they experience *agency* in their lives. The social constraints and mechanisms would vary between men and women, and research looking into this for this particular area could prove informative.

Another future direction could be to further extend research involving this particular male population in a way whereby the focus is more on their social environment rather than the medical profession. Although this was discussed in the interview, it was not the focus. However, this may have been due to the provision of background information that the researcher provided about working in the NHS.

One of the findings was that for all of the participants, with the exception of the one transgender participant, there were self-reports of distressing life experiences (that could be termed trauma), which had involved some kind of loss of life or violence (in contrast to the transgender participant who discussed sexual abuse). Previous research has also implicated this form of trauma for males who show symptoms of CD/FND (Dworetzky et al., 2005), whereas research involving women implicates sexual trauma (Barsky et al., 2001; Tasca et al., 2012). Future research could explore this further.

## 11 CONCLUSION

The main aim of this research has been to derive an in-depth understanding of the lived experience of *agency* for males who identify with the diagnostic label 'CD/FND'. The sense of *agency* was investigated in relation to the participants' physical body, psychological state of mind or 'conscious mind/mental processes', and social relationships. This detailed, idiographic exploration into the participants' experience of *agency* was achieved through the use of Interpretative Phenomenological Analysis, where the analysis of the data led to five superordinate themes. The first superordinate theme, 'the paradox of control', related to the participants experience of having discovered that their pre-existing notions of control were not as they had originally assumed. The second superordinate theme, 'living within a dualistic framework', discussed how the participants seemed to experience a division between mind and body, personal identity, and in relation to others. The third superordinate theme, 'disconnection from self and others', involved experiences of alienation and isolation, and the fourth theme, 'engaged in a battle or fight', brought out internal struggles. Finally, the fifth theme, 'meaning and reality as dependent on other people', engaged with the participants relationships and the meaning that this held for them.

The results highlight what could be described as a disconnection or difficulty in communication between the participants and other people, as well as in relation to their own experience of self. Their sense of *agency* might represent or express the extent to which they experience connection or disconnection in relation to self and other.

Overall, the aim of this research has been to give an idiographic and in-depth approach that can shed light on how males experience *agency* in the context of the diagnostic label 'CD/FND'. As there are few qualitative studies in this area, the hope is that this study will contribute something unique to the existing literature.

## 12 REFLEXIVITY

As mentioned earlier, my inspiration for embarking on this area of research arose in the context of my work as a trainee Counselling Psychologist, where I worked with the diagnosis of 'conversion disorder' and 'non-epileptic attack disorder' in the Sussex Foundation NHS trust. The fact that I worked with 'CD' for the entire time that I carried out my research meant that I became particularly familiar and intimate with this area. I was able to derive a level of depth and exploration that I do not feel I would have otherwise. I am thus especially grateful that I was further able to develop the placement into an employed position and to sustain this throughout my own research.

At the beginning of the research process I had intended on recruiting participants from the NHS. I was strongly advised against this due to the difficulties that would arise in obtaining the ethical approval from the NHS. I was disappointed, as I had wanted to recruit a sample that had been in the medical context that I was situated within. On reflection, I can see that my initial interest had arisen from the pathological presentation of 'CD' in the context of the medical system that I was a part of. In a way, I had assumed that recruitment from a medical setting meant that the data would be more robust and valid. I can now see that I had been adopting a line of thought whereby

I had placed more relevance on the medical model, which was the exact model that seemed to be failing individuals with the 'CD' diagnosis. This is particularly relevant as one of the main areas of learning throughout the research process has been the recognition of how embedded I had been with the dualist medical model approach, and of how difficult it can be to see and understand this. I am now aware that my research interests arose on the basis of the assumption that there is a mind-body separation (Descartes, 1961), as I had been fascinated with how the mental seemed to be converted into the physical. However, if I had been asked if this had been my assumption at the time, I would have argued adamantly against this. This shows how ingrained this view has been for me and how long it has taken me to realise the extent to which it had been a part of my understanding and approach. This research has facilitated my own developmental process and knowledge by way of my recognition that this mind-body separation perspective can be an underlying system of thought.

Although I mentioned earlier that the fact that I worked and researched in the area of "CD/FND" in parallel served to enhance my research, I believe that it also added a level of bias. The reason for this is that my therapeutic experience and accumulative knowledge influenced my literature interest, questionnaire design, and overall structure and frame of my research. The process of research has also proved challenging as my training has taken place in an institution that develops philosophical, non-dualistic ways of thought. At certain times I have felt torn between different models of thought whilst at other times these have synergised beautifully. This dynamic has played out at every stage whereby I have moved to and fro in this tension. The most challenging part has been in recognising my multiple, overlapping roles/identities as researcher, therapist, student, mother, wife, friend, child, and how they have all

influenced each other. I have had to pay constant attention towards how to stand back enough from these for the purposes of research and clarity. In particular, I have battled with having worked as a therapist in this area throughout the process of research as, on the one hand it provided me with an invaluable depth of understanding, but on the other hand, it positioned me too close to the research. Thus, there have been many occasions where I have felt extremely lost and I have had to refocus. I believe that this experience is one that is not dissimilar to the participants that I researched, as well as in relation to the individuals that I have worked with in this area. On reflection, although I specifically arranged to have a supervision session so as to refocus and 'bracket' my therapist bias, I perhaps could have done this earlier on.

Prior to interviewing the participants, I had intended on obtaining as many face-to-face interviews as possible. However, in the end, I only conducted Skype interviews. I believe that there are a number of factors that I had not recognised at the time that were involved in this. I think that because I had only been able to recruit Skype interviews at the start, I had then become accustomed to this. I also think that the fact that I had struggled to separate my role as a researcher from that of therapist with the initial interviews meant that I had felt an underlying desire to avoid meeting face-to-face, as this would have been even closer to my therapeutic experience. Finally, as I had been able to use my therapeutic skills to obtain rich data despite not having all the non-verbal cues, I did not feel that it would have been necessary in the end. Perhaps I should have persisted in the recruitment process and waited until I had eventually found a participant willing to be interviewed in person. This might have provided me with more tangible information to support my view that I had been able to obtain the same level of depth via Skype as I might have in person.

In terms of other biases, I recognise that I am starting from the position of assuming that males who identify with 'CD/FND' feel less agency when they experience such phenomena. I am aware that I am basing notions of agency on my therapeutic experience, which is of course biased. The way that I attempted to refrain from imposing my own views and experience involved the recognition that I have had a very particular experience in a particular NHS setting, and of how this could impact on my interaction and meaning making with the participants. Also, the fact that I chose to work in a setting such as this is important, as it would relate to my own beliefs, values and ideas, which would in turn have shaped the nature of communication between myself and the participant being interviewed.

In analysing the data and writing up the results I discovered that one of my participants proved problematic. I had decided to accept a participant who was transgender, as I felt that, because my exploration involved gender and not sex, this would not be a problem. However, I struggled with how to present this participant and with not wanting to discriminate by over-reporting or under-reporting. On reflection, I feel that having included this participant may have brought in other factors that I did not have the capacity to blend into my research, as well as making the study less homogenous. This is something that perhaps I would have done differently. Again I could have waited longer until another participant responded to my advert. However, as the percentage of men is much lower, I think that I had feared that this might have never happened.

Overall, I found the process of research incredibly challenging and also rewarding. I devoted a huge amount of time and effort into completing this and I feel excited by the

results. Despite having worked and researched this area for some time, I do not feel exhausted by this, but rather doubly inspired and excited to bring my results into publication.

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# *Appendices*

## **APPENDIX A:**

### **RESEARCH STUDY INFORMATION SHEET**



Information about research project:

*Exploring how males who experience phenomena they identify as 'Conversion Disorder'/'Functional Neurological Disorder' experience agency in their lives*

being carried out by:

Danielle Phoenix

as a requirement for a DCPsych in Counselling Psychology and Psychotherapy  
from NSPC and Middlesex University

NSPC Ltd

Existential Academy

61-63 Fortune Green Road

London NW6 1DR

Middlesex University

The Burroughs

London NW4 4BT

Dated:

You are being invited to take part in a research study. Before you decide to participate, it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following information carefully, and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish to take part.

What is the purpose of the research?

This study is being carried out as part of my studies at NSPC Ltd and Middlesex University. 'Conversion disorder' is a term used to describe specific types of bodily and sensory experiences, for example, seizures, disturbed balance, stuttering of speech, double vision, etc. Such experiences can involve feeling a lack of control over what is happening whereby one may feel as though they are no longer the agent of their own actions. The further exploration of how agency is experienced in a wider social and psychological context may serve to increase the understanding for both individuals and medical professionals. My study is designed to see how agency is experienced for individuals who have experiences described as 'conversion disorder'. You are being asked to participate because you have replied to my advertisement for i) males who speak fluent English, ii) are 18 years old and above, iii) experience phenomena that have been described as 'conversion disorder', and iv) are able to read and understand



the consent form as well as to participate in in-depth interviews. If however, you are i) a child, ii) an adult with a learning disability or dementia, iii) are currently self-harming and/or are suicidal, iv) have experienced a recent bereavement, or v) are intoxicated by a substance, you will be asked to refrain from participating in this research.

#### What will happen to me if I take part?

I would like to initially have a brief conversation with you to see if this research is something that you may be interested in participating in and if so, then we could proceed to make an arrangement to meet so that you can undergo a single interview at a location that is convenient for us both, for example, a library or therapy room that has been hired out. The interview will last approximately one hour and will be audio-recorded. Should the interview take place over Skype it will be agreed beforehand that this take place in a suitable setting where confidentiality cannot be breached and no disturbances will take place. A qualitative research method approach called 'interpretative phenomenological analysis' will be used whereby your data will be analysed alongside other participants in order to discover how you experience agency and what it means for you to experience phenomena of 'conversion disorder'.

#### What will you do with the information that I provide?

I will personally transcribe the audio recording and use a pseudo-name in place of your real name in order to ensure anonymity. I will transfer the files from the digital recorder to an encrypted computer and delete the files from the recorder. Any information that you provide me will be identified only with a project code and stored either on an encrypted USB stick or in a locked filing cabinet. I will keep the key that links your details with the project code in a locked filing cabinet.

For Skype-based interviews, I will carry out the necessary precautions to ensure that my private location will remain private at all times. It is important that you make the same arrangement for your own private location so as to ensure your privacy and any interruptions in the interview.

The information will be kept at least until 6 months after I graduate, and will be treated as confidential. If my research is published, I will make sure that neither your name nor other identifying details are used.

Data will be stored according to the Data Protection Act and the Freedom of Information Act.

What are the possible disadvantages of taking part?

In the interview I will ask you about your experience of phenomena described as ‘conversion disorder’ and your experience of agency (which is the extent to which you feel as though you are the agent of/in control of your life/world) involving this and other areas your life. However, talking about personal experiences may be distressing. If so, please let me know, and if you wish, I will stop the interview. Although this is very unlikely, should you tell me something that is required by law to pass on to a third person, (for example, child abuse, terrorism, money laundering), I will have to do so. Otherwise whatever you tell me will be confidential.

What are the possible benefits of taking part?

Being interviewed about your experience of phenomena described as 'conversion disorder' and agency has no direct benefit, either, although some people may find it an opportunity to reflect and could find this in itself beneficial. Should the research findings enhance the understanding of individuals and professionals involved so as to enable better communication, support and overall quality of life; this would provide a possible benefit of taking part in the study.

### Consent

You will be given a copy of this information sheet for your personal records, and if you agree to take part, you will be asked to sign the attached consent form before the study begins.

Participation in this research is entirely voluntary. You do not have to take part if you do not want to. If you decide to take part you may withdraw at any time without giving a reason and your data will be immediately destroyed.

### Who is organising and funding the research?

The research is an entirely self-funded study.

### Who has reviewed the study?

All proposals for research using human participants are reviewed by an Ethics Committee before they can proceed. The NSPC research ethics sub-committee have approved this study

### Expenses

If there are travel expenses, these will be fully reimbursed.

Thank you for reading this information sheet.

If you have any further questions, you can contact me at:

NSPC Ltd

Existential Academy

61-63 Fortune Green Road

London NW6 1DR

[DP723@live.mdx.ac.uk](mailto:DP723@live.mdx.ac.uk) or

[rescd@gmail.com](mailto:rescd@gmail.com)

If you any concerns about the conduct of the study, you may contact my supervisor:

Dr Jacqui Farrants

[jacquifarrants@hotmail.com](mailto:jacquifarrants@hotmail.com)

Existential Academy

61-63 Fortune Green Road

London NW6 1DR

07850 082160

Or

The Principal

NSPC Ltd

Existential Academy

61-63 Fortune Green Road

London NW6 1DR

02074358067/0845 5577752

## APPENDIX B:

### RESEARCH PARTICIPATION CONSENT FORM:



Information about research project:

*Exploring how males who experience phenomena they identify as 'Conversion Disorder'/'Functional Neurological Disorder' experience agency in their lives*

being carried out by:

Danielle Phoenix

as a requirement for a DCPsych in Counselling Psychology and Psychotherapy  
from NSPC and Middlesex University

NSPC Ltd

Existential Academy

61-63 Fortune Green Road

London NW6 1DR

Middlesex University

The Burroughs

London NW4 4BT

### Written Informed Consent

Supervisor (*only for students*): \_\_\_\_\_

I have understood the details of the research as explained to me by the researcher, and confirm that I have consented to act as a participant.

I have been given contact details for the researcher in the information sheet.

I understand that my participation is entirely voluntary, the data collected during the research will not be identifiable, and I have the right to withdraw from the project at any time without any obligation to explain my reasons for doing so.

I further understand that the data I provide may be used for analysis and subsequent publication, and provide my consent that this might occur.

\_\_\_\_\_

Print name

\_\_\_\_\_

Sign Name

date: \_\_\_\_\_

**To the participants:** Data may be inspected by the Chair of the Psychology Ethics panel and the Chair of the School of Social Sciences Ethics committee of Middlesex University, if required by institutional audits about the correctness of procedures. Although this

would happen in strict confidentiality, please tick here if you do not wish your data to be included in audits: \_\_\_\_\_



## APPENDIX C:



Information about research project:

*Exploring how males who experience phenomena they identify as 'Conversion Disorder'/'Functional Neurological Disorder' experience agency in their lives*

being carried out by:

Danielle Phoenix

as a requirement for a DCPsych in Counselling Psychology and Psychotherapy  
from NSPC and Middlesex University

NSPC Ltd

Existential Academy

61-63 Fortune Green Road

London NW6 1DR

Middlesex University

The Burroughs

London NW4 4BT

## **Study Debriefing**

Thank you for taking the time to participate in this research and for contributing valuable information towards this study. Your data will be used alongside other participants in order to develop themes around the way that you experience agency (the extent to which you feel as though you are the agent or in control of aspects of yourself and life). This will cover agency in terms of 'conversion disorder' as well as the sense of agency that you have in your life as a whole. Such experiences can involve feeling a lack of control over what is happening whereby one may feel as though they are no longer the agent of their own actions. As the pathway that leads to terms such as 'conversion disorder' or 'functional neurological disorder' tends to involve a process whereby the individual at first is led to believe that their experience is neurological and then later discover that it is more likely to be psychological in nature, this may influence the individuals' sense of agency. Thus, it may be important to explore how agency is experienced in the way described above so as to increase the understanding for both individuals and medical professionals in a way that will lead to individuals feeling and being treated in a way where they feel more empowered in their lives.

As you may have discussed experiences of a distressing nature, it is important that you feel you have been supported during this process and that there is further support at hand once you leave. In order to ensure this, I have provided a list of sources that you may access should you require further support.

**Sources of support:**

**1) Local NHS mental health line or local mental health line for overseas location.**

**2) FND Hope**

Functional Neurological Disorder (FND) Hope promotes awareness and supports individuals to achieve a higher quality of life.

Website: <http://www.fndhope.org>

**3) Mind**

Mind promotes the views and needs of people with mental health problems.

Phone: 03001233393 (Mon-Fri, 9am-6pm)

Website: [www.mind.org.uk](http://www.mind.org.uk)

**4) The Samaritans**

The Samaritans offers confidential support for people experiencing feelings of distress and despair.

Phone: 08457909090 (24-hour helpline)

Website: [www.samaritans.org.uk](http://www.samaritans.org.uk)

## **APPENDIX D:**

### **RESEARCH QUESTIONNAIRE SHEET:**

#### PILOT INTERVIEW SCHEDULE:

##### Opening questions:

“Could you tell me a little about what drew you towards participating in my research?”

“There are two technical terms that are used here - ‘agency’ and ‘CD/FND’. Do you understand what these terms mean?”

“How do you experience agency or control?”

##### Prompt questions:

“Could you tell me more?”

“How do you experience this in relation to your body/environment/social life?”

“How would you relate this to agency or control?”

“How do you make sense of this?”

“What else comes up for you?”

“What is it like for you to feel this way?”

##### Ending question:

“How have you found the interview?”

#### DEVELOPING INTERVIEW SCHEDULE:

Further questions that were introduced over the course of interviews:

“How do you experience agency or control in terms of your physical body?”

“How do you experience agency or control in terms of bodily experiences or ‘symptoms’ that you describe with the term CD/FND?”

“How do you experience agency or control when you are not experiencing such ‘symptoms’?”

“Do you feel as though you are the agent or in control of your life?”

“How do you experience agency/control when it comes to other people?”

“How do you experience agency or control in terms of your relationships?”

“How do you experience agency or control in terms of society?”

“How do you experience agency or control in terms of social encounters involving ‘symptoms’ you identify with as CD/FND?”

“How do you experience agency or control in terms of how you feel that you can act within the world and what you can achieve?”

“In terms of your mind, how would you say you experience agency/control?”

“How about agency/control when it comes to emotions?”

“How do you experience agency or control in relation to your thoughts?”

Further added prompt questions:

“And how do you experience agency/control in relation to what you have just described?”

“What does that mean in terms of agency/control?”

“And how would that look if thought of it in terms of agency/control?”

## APPENDIX E:

### Transcription process:

#### 1) Stage 1: Initial transcription

- |    |                                                                                                                                                                                                                                                                                                    |
|----|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1  | P: yeah.                                                                                                                                                                                                                                                                                           |
| 2  | D: so are those the kind symptoms or experiences that you have are seizures and paralysis?                                                                                                                                                                                                         |
| 3  | P: Yup.                                                                                                                                                                                                                                                                                            |
| 4  | D: Okay.                                                                                                                                                                                                                                                                                           |
| 5  | P: And that's, they go hand in hand.                                                                                                                                                                                                                                                               |
| 6  | D: Okay. And how do you experience agency, or control in your life?                                                                                                                                                                                                                                |
| 7  | P: Okay that's, I have to recondition my body for everything I'm actually going to do um,                                                                                                                                                                                                          |
| 8  | D: okay                                                                                                                                                                                                                                                                                            |
| 9  | P: it's um I'm looking at going away for a weekend. I need to plan beforehand what my possibilities are. Um, I need to get my mind ready for if there might be a lot of people. So, if, I get overstimulation of senses I need to then back off um, so we, for instance shopping during the month. |
| 10 | D: mmm                                                                                                                                                                                                                                                                                             |
| 11 | P: I do it mid month because then there's not a lot of people in the shops.                                                                                                                                                                                                                        |
| 12 | D: okay                                                                                                                                                                                                                                                                                            |

2) Stage 2: Descriptive notes included

<p>He has a very neurological conceptualisation – how he talks about himself feels like an object.</p>	<p>1 P: yeah.</p> <p>2 D: so are those the the kind symptoms or experiences that you have are seizures and paralysis?</p> <p>3 P: Yup.</p> <p>4 D: Okay.</p> <p>5 P: And that's, they go hand in hand.</p> <p>6 D: Okay. And how do you experience agency, or control in your life?</p> <p>7 P: Okay that's, I have to recondition my body for everything I'm actually going to do um,</p> <p>8 D: okay</p> <p>9 P: it's um I'm looking at going away for a weekend. I need to plan beforehand what my possibilities are. Um, I need to get my mind ready for if there might be a lot of people. So, if, I get overstimulation of senses I need to then back off um, so we, for instance shopping during the month.</p> <p>10 D: mmm</p> <p>11 P: I do it mid month because then there's not a lot of people in the shops.</p>
--------------------------------------------------------------------------------------------------------	--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------



3) Stage 3: Descriptive notes on left and themes on right

<p>He has a very neurological conceptualisation – how he talks about himself feels like an object.</p>	<p>1 P: yeah.</p> <p>2 D: so are those the the kind symptoms or experiences that you have are seizures and paralysis?</p> <p>3 P: Yup.</p> <p>4 D: Okay.</p> <p>5 P: And that’s, they go hand in hand.</p> <p>6 D: Okay. And how do you experience agency, or control in your life?</p> <p>7 P: Okay that’s, I have to recondition my body for everything I’m actually going to do um,</p> <p>8 D: okay</p> <p>9 P: it’s um I’m looking at going away for a weekend. I need to plan beforehand what my possibilities are. Um, I need to get my mind ready for if there might be a lot of people. So, if, I get overstimulation of senses I need to then back off um, so we, for instance shopping during the month.</p> <p>10 D: mmm</p> <p>11 P: I do it mid month because then there’s not a lot of people in the shops.</p>	<p>Agency/control body.</p> <p>Agency/control environment.</p> <p>Time.</p> <p>Certainty.</p>
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# APPENDIX F:

## Middlesex University, Department of Psychology

### REQUEST FOR ETHICAL APPROVAL (STUDENT)

**Applicant (specify):** UG PG (Module: DCPsych.) PhD

*Date submitted: 05 March 2015*

<b>Research area (please circle)</b>				
Clinical	Cognition + Emotion	Developmental	Forensic	Health
Occupational	Psychophysiological	Social	Sport + Exercise	
Other: Counselling Psychology			<b>Sensitive Topic</b> <input type="checkbox"/>	
<b>Methodology:</b>				
Empirical/Experimental	Questionnaire-based	Qualitative <input type="checkbox"/>	Other _____	
<p><b>No study may proceed until this form has been signed by an authorised person indicating that ethical approval has been granted.</b> For collaborative research with another institution, ethical approval must be obtained from all institutions involved.</p> <p>This form should be accompanied by any other relevant materials (e.g. questionnaire to be employed, letters to participants/institutions, advertisements or recruiting materials, information and debriefing sheet for participants<sup>1</sup>, consent form<sup>2</sup>, including approval by collaborating institutions).</p>				
<ul style="list-style-type: none"> <li>• Is this the first submission of the proposed study? Yes</li> <li>• Is this an amended proposal (resubmission)? No <b>Psychology Office: If YES, please send this back to the original referee</b></li> <li>• Is this an urgent application? (<u>To be answered by Staff/Supervisor only</u>)<sup>1</sup> No</li> </ul> <p style="text-align: right;">Supervisor to initial here _____</p>				
<u>Name(s) of investigator:</u> Danielle Phoenix				
<u>Name of Supervisor (s):</u> Dr Jacqui Farrants, Dr Edith Steffen				

<sup>1</sup> See Guidelines on MyUnihub

Title of Study: Exploring how individuals who experience phenomena that have been described as 'Conversion Disorder' experience agency in their lives.

Results of Application:

***REVIEWER – please tick and provide comments in section 5:***

APPROVED	APPROVED SUBJECT TO AMENDMENTS	APPROVED SUBJECT TO RECEIPT OF LETTERS	NOT APPROVED
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**SECTION 1**

1. Please attach a brief description of the nature and purpose of the study, including details of the procedure to be employed. Identify the ethical issues involved, particularly in relation to the treatment/experiences of participants, session length, procedures, stimuli, responses, data collection, and the storage and reporting of data.

**SEE ATTACHED PROJECT PROPOSAL:**

- i) Page 2 - 'Abstract'**
- ii) Pages 13-15 - 'Gap in research and contribution to the field of counselling psychology'**
- iii) Page 15 - 'Research questions'**
- iv) Pages 25-28 - 'Methods and design' - 'Procedure'**
- v) Pages 29-35 - 'Ethical considerations'**
- vi) Pages 41-44 - 'Appendix A' - 'Research study information sheet'**
- vii) Pages 45-46 - 'Appendix B' - 'Research participation consent form'**

2. Could any of these procedures result in any adverse reactions? YES

If "yes", what precautionary steps are to be taken?

**SEE ATTACHED PROJECT PROPOSAL:**

- i) Pages 41-44 - 'Appendix A' - 'Research study information sheet'**
- ii) Pages 45-46 - 'Appendix B' - 'Research participation consent form'**
- iii) Pages 47-48 - 'Appendix C' - 'Study debriefing'**
- iv) Pages 29-35 - 'Ethical considerations'**

3. Will any form of deception be involved that raises ethical issues? NO

*(Most studies in psychology involve mild deception insofar as participants are unaware of the experimental hypotheses being tested. Deception becomes unethical if participants are likely to feel angry, humiliated or otherwise distressed when the deception is revealed to them).*

Note: if this work uses existing records/archives and does not require participation per se, tick here .....  
and go to question 10. (Ensure that your data handling complies with the Data Protection Act).

4. If participants other than Middlesex University students are to be involved, where do you intend to recruit them? (A full risk assessment must be conducted for any work undertaken off university premises)<sup>6,7</sup>

**SEE ATTACHED PROJECT PROPOSAL:  
Pages 22-25 - 'Recruitment of participants'**

5a. Does the study involve:

Clinical populations	NO
Children (under 16 years)	NO
Vulnerable adults such as individuals with mental or physical health problem, prisoners, vulnerable elderly, young offenders?	YES
Political, ethnic or religious groups/minorities?	NO
Sexually explicit material / issues relating to sexuality	NO

5b. If the study involves any of the above, the researcher may need CRB (police check) YES

Staff and PG students are expected to have CRB – please tick

UG students are advised that institutions may require them to have CRB  
please confirm that you are aware of this by ticking here \_\_\_\_\_

6. How, and from whom (e.g. from parents, from participants via signature) will informed consent be obtained? (See consent guidelines<sup>2</sup>; note special considerations for some questionnaire research)

**SEE ATTACHED PROJECT PROPOSAL:**

- i) Pages 41-44 - 'Appendix A' - 'Research study information sheet'**
- ii) Pages 45-46 - 'Appendix B' - 'Research participation consent form'**
- iii) Pages 21-22 - 'Selection of participants'**

7. Will you inform participants of their right to withdraw from the research time, without penalty? (see consent guidelines<sup>2</sup>) YES

8. Will you provide a full debriefing at the end of the data collection phase? YES

**SEE ATTACHED PROJECT PROPOSAL:  
Pages 47-48 - 'Appendix C' - 'Study debriefing'**

	<p>9. Will you be available to discuss the study with participants, if necessary: YES monitor any negative effects or misconceptions?</p> <p>If "no", how do you propose to deal with any potential problems?</p>
<p>10. Under the Data Protection Act, participant information is confidential unless otherwise agreed in advance. Will confidentiality be guaranteed? YES (see confidentiality guidelines<sup>5</sup>)</p> <p>If "yes" how will this be assured (see<sup>5</sup>)</p> <p><b>SEE ATTACHED PROJECT PROPOSAL:</b></p> <p><b>i) Appendix A - pages 41-44 - 'Research study information sheet' - 'What will you do with the information that I provide?'</b></p> <p><b>ii) Appendix B - pages 45-46 - 'Research participation consent form'.</b></p> <p>If "no", how will participants be warned? (see<sup>5</sup>)</p> <p><i>(NB: You are not at liberty to publish material taken from your work with individuals without the prior agreement of those individuals).</i></p>	<p>11. Are there any ethical issues that concern you about this particular piece of research, not covered elsewhere on this form? YES</p> <p>If "yes" please specify:</p> <p><b>SEE ATTACHED PROJECT PROPOSAL:</b></p> <p><b>For face-to-face interviews: i) for interviews taking place in the public domain see page 29-35 - Ethical considerations - 'Respect', 'Competence', 'Responsibility', 'Integrity', 'Safety', ii) Appendix A - pages 41-44 - Research study information sheet - 'What are the possible disadvantages of taking part?'</b></p> <p><b>For Skype interviews: i) for interviews taking place in the private domain via Skype see page 29-32, 33-34, 35 - Ethical considerations - 'Respect', 'Responsibility', 'Safety', 'Scientific value', ii) Appendix A - pages 41-44 - Research study information sheet - 'What are the possible disadvantages of taking part?'</b></p>

12. Is this research or part of it going to be conducted in a language other than English?	NO
If YES – Do you confirm that all documents and materials are enclosed here both in English and the other language, and that each one is an accurate translation of the other?	YES/NO

**(NB: If “yes” has been responded to any of questions 2, 3, 5, 11, 12 or “no” to any of questions 7-10, a full explanation of the reason should be provided – if necessary, on a separate sheet submitted with this form).**

**SECTION 2 (to be completed by all applicants – please tick as appropriate)**

	YES	NO
13. Some or all of this research is to be conducted away from Middlesex University	<input type="checkbox"/>	
If “yes” tick here to confirm that a Risk Assessment form has been submitted	<input type="checkbox"/>	
14. I am aware that any modifications to the design or method of this proposal will require me to submit a new application for ethical approval	<input type="checkbox"/>	
15. I am aware that I need to keep all the materials/documents relating to this study (e.g. consent forms, filled questionnaires, etc) until completion of my degree / publication (as advised)	<input type="checkbox"/>	
16. I have read the British Psychological Society’s <i>Ethical Principles for Conducting Research with Human participants</i> <sup>4</sup> and believe this proposal to conform with them.	<input type="checkbox"/>	

**SECTION 3 (to be completed by STUDENT applicants and supervisors)**

Researcher: (student signature) Danielle Phoenix  date 05/02/2015

**CHECKLIST FOR SUPERVISOR – please tick as appropriate**

	YES	NO
1. Is the UG/PG module specified?		
2. If it is a resubmission, has this been specified and the original form enclosed here?		
3. Is the name(s) of student/researcher(s) specified?		
4. Is the name(s) of supervisor specified?		
5. Is the consent form attached?		
6. Are debriefing procedures specified? If appropriate, debriefing sheet enclosed – appropriate style?		
7. Is an information sheet for participants enclosed? appropriate style?		
8. Does the information sheet contain contact details for the researcher and supervisor?		
9. Is the information sheet sufficiently informative about the study?		
10. Has Section 2 been completed by the researcher on the ethics form?		
11. Any parts of the study to be conducted outside the university? If so a Risk Assessment form must be attached – Is it?		

12. Any parts of the study to be conducted on another institution's premises? If so a letter of acceptance by the institution must be obtained - Letters of acceptance by all external institutions are attached.		
13. Letter(s) of acceptance from external institutions have been requested and will be submitted to the PSY office ASAP.		
14. Has the student signed the form? If physical or electronic signatures are not available, an email endorsing the application must be attached.		
15. Is the proposal sufficiently informative about the study?		

**Signatures of approval:**

**PSY OFFICE**  
**received**

Supervisor: \_\_\_\_\_ date: \_\_\_\_\_ date:.....

Ethics Panel: \_\_\_\_\_ date: \_\_\_\_\_ date:.....

(signed pending approval of Risk Assessment form)  
date:.....

If any of the following is required and not available when submitting this form, the Ethics Panel Reviewer will need to see them once they are received – please enclose with this form when they become available:

- letter of acceptance from other institution
- any other relevant document (e.g. ethical approval from other institution):

\_\_\_\_\_

**PSY OFFICE**  
**received**

Required documents seen by Ethics Panel: \_\_\_\_\_ date: \_\_\_\_\_ date:.....



**SECTION 4 (to be completed by the Psychology Ethics panel reviewers)**

		<b>Recommendations/comments</b>
1. Is UG/PG module specified?		
2. If it is a resubmission, has this been specified and the original form enclosed here?		
3. Is the name(s) of student/ researcher(s) specified? If physical or electronic signatures are not available, has an email endorsing the application been attached?		
4. Is the name(s) of supervisor specified? If physical or electronic signatures are not available, has an email endorsing the application been attached?		
5. Is the consent form attached?		
6. Are debriefing procedures specified? If appropriate, is the debriefing sheet attached? Is this sufficiently informative?		
7. Is an information sheet for participants attached?		
8. Does the information sheet contain contact details for the researcher?		
9. Is the information sheet sufficiently informative about the study? Appropriate style?		
10. Has Section 2 (points 12-15) been ticked by the researcher on the ethics form?		
11. Any parts of the study to be conducted outside the university? If so a fully completed Risk Assessment form must be attached – is it?		
12. If any parts of the study are conducted on another institution/s premises, a letter of agreement by the institution/s must be produced. Are letter/s of acceptance by all external institution/s attached?		
13. Letter/s of acceptance by external institution/s has/have been requested.		
14. Has the applicant signed? If physical or electronic signatures are not available, an email endorsing the application must be attached.		
15. Is the proposal sufficiently informative about the study? Any clarity issues?		
16. Is anyone likely to be disadvantaged or harmed?		
17. If deception, protracted testing or sensitive aspects are involved, do the benefits of the study outweigh these undesirable aspects?		
18. Is this research raising any conflict of interest concerns?		

## **APPENDIX G:**

Ethics approval letter:

Danielle Phoenix

Flat 3 51

Hermon Hill London

E11 2AR

17th April 2015

Dear Danielle Re: Ethics Approval

We held an Ethics Board on 18th March 2015 and the following decisions were made.

Ethics Approval Your application was approved with some recommendations.

Yours sincerely Prof Digby Tantam

Chair Ethics Committee NSPC

Recommendations: 1. Add an apostrophe to many people owning something, as in individuals' interpretation and participants' experience. 2. Include when a hyperlink was accessed in the bibliography. 3. Be mindful of possible differences in how experience is described in face-to-face interviews vs Skype, and if possible only do face-to-face interviews.

## APPENDIX H:

Ethics amendment and approval:

### **Approved ethics amendment:**

I would like to make one amendment to the exclusion criteria of the sample that I am in the process of recruiting.

Page 22 of the research proposal that I submitted to the Ethics board holds the exclusion criteria in section c) which states: “recent bereavement of eighteen months or less”.

There have been two screening interviews that I have carried out where participants have failed to meet this requirement and I have found myself disagreeing with this exclusion criterion. In both cases the participants gave ample descriptive evidence to show that they firmly believed that they would not be placed in a vulnerable position by a recent bereavement during an interview as they had emotionally processed their losses to a large extent (and had spent significant time dealing with the bereavement with a psychologist).

This made me realise that one person could have experienced a bereavement many years ago yet still remain in a vulnerable and distressed state of mind whereas another individual may have adequately confronted and dealt with their response to and feelings around a bereavement within a relatively short period.

Thus, I would like to use my own clinical judgement to determine an adequate period of time within which to exclude a potential participant. I intend on doing this by devoting extra time in the screening interview to ascertaining to what extent a potential participant has dealt with a bereavement and how they would feel about such issues arising during an interview.

# APPENDIX I:

## INDEPENDENT FIELD/LOCATION WORK RISK ASSESSMENT FRA1

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*This proforma is applicable to, and must be completed in advance for, the following field/location work situations:*

- 1. All field/location work undertaken independently by individual students, either in the UK or overseas, including in connection with proposition module or dissertations. Supervisor to complete with student(s).*
- 2. All field/location work undertaken by postgraduate students. Supervisors to complete with student(s).*
- 3. Field/location work undertaken by research students. Student to complete with supervisor.*
- 4. Field/location work/visits by research staff. Researcher to complete with Research Centre Head.*
- 5. Essential information for students travelling abroad can be found on [www.fco.gov.uk](http://www.fco.gov.uk)*

### FIELD/LOCATION WORK DETAILS

**Name** Danielle Phoenix

**Student No**  
**Research Centre (staff only)**

**Supervisor** Jacqui Farrants

**Degree course** DCPsych

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Telephone numbers and name of next of kin who may be contacted in the event of an accident

#### NEXT OF KIN

**Name:**

**Phone**

**Physical or psychological limitations to carrying out the proposed field/location work**

No .....

.....

.....

**Any health problems (full details)**

Which may be relevant to proposed field/location work activity in case of emergencies.

No .....

.....

**Locality (Country and Region)**

Around the UK and at home via Skype.

.....

.....

**Travel Arrangements**

Public transport.

.....  
.....

NB: Comprehensive travel and health insurance must always be obtained for independent overseas field/location work.

n/a.....  
.....

**Dates of Travel and Field/location work**

April 2015. ....  
.....

## PLEASE READ THE FOLLOWING INFORMATION VERY CAREFULLY

### Hazard Identification and Risk Assessment

List the localities to be visited or specify routes to be followed (**Col. 1**). For each locality, enter the potential hazards that may be identified beyond those accepted in everyday life. Add details giving cause for concern (**Col. 2**).

#### Examples of Potential Hazards :

Adverse weather: exposure (heat, sunburn, lightening, wind, hypothermia)

Terrain: rugged, unstable, fall, slip, trip, debris, and remoteness. Traffic: pollution.

Demolition/building sites, assault, getting lost, animals, disease.

Working on/near water: drowning, swept away, disease (weils disease, hepatitis, malaria, etc), parasites', flooding, tides and range.

Lone working: difficult to summon help, alone or in isolation, lone interviews.

Dealing with the public: personal attack, causing offence/intrusion, misinterpreted, political, ethnic, cultural, socio-economic differences/problems. Known or suspected criminal offenders.

Safety Standards (other work organisations, transport, hotels, etc), working at night, areas of high crime.

Ill health: personal considerations or vulnerabilities, pre-determined medical conditions (asthma, allergies, fitting) general fitness, disabilities, persons suited to task.

Articles and equipment: inappropriate type and/or use, failure of equipment, insufficient training for use and repair, injury.

Substances (chemicals, plants, bio- hazards, waste): ill health - poisoning, infection, irritation, burns, cuts, eye-damage.

Manual handling: lifting, carrying, moving large or heavy items, physical unsuitability for task

**If no hazard can be identified beyond those of everyday life, enter 'NONE'.**

1. LOCALITY/ROUTE	2. POTENTIAL HAZARDS
<b>Interviewing in public locations, for example, libraries and/or therapy rooms.</b>	<b>Lone interviewing and dealing with the public.</b>

***The University Field/location work code of Practice booklet provides practical advice that should be followed in planning and conducting field/location work.***

**Risk Minimisation/Control Measures  
CAREFULLY**

**PLEASE READ VERY**

For each hazard identified **(Col 2)**, list the precautions/control measures in place or that will be taken **(Col 3)** to "**reduce the risk to acceptable levels**", and the safety equipment **(Col 5)** that will be employed.

Assuming the safety precautions/control methods that will be adopted **(Col. 3)**, categorise the field/location work risk for each location/route as negligible, low, moderate or high **(Col. 4)**.

**Risk increases with both the increasing likelihood of an accident and the increasing severity of the consequences of an accident.**

**An acceptable level of risk is:** a risk which can be safely controlled by person taking part in the activity using the precautions and control measures noted including the necessary instructions, information and training relevant to that risk. The resultant risk should not be significantly higher than that encountered in everyday life.

**Examples of control measures/precautions:**

Providing adequate training, information & instructions on field/location work tasks and the safe and correct use of any equipment, substances and personal protective equipment. Inspection and safety check of any equipment prior to use. Assessing individuals fitness and suitability to environment and tasks involved. Appropriate clothing, environmental information consulted and advice followed (weather conditions, tide times etc.). Seek advice on harmful plants, animals & substances that may be encountered, including information and instruction on safe procedures for handling hazardous substances. First aid provisions, inoculations, individual medical requirements, logging of location, route and expected return times of lone workers. Establish emergency procedures (means of raising an alarm, back up arrangements). Working with colleagues (pairs). **Lone working is not permitted where the risk of physical or verbal violence is a realistic possibility.** Training in interview techniques and avoiding /defusing conflict, following advice from local organisations, wearing of clothing unlikely to cause offence or unwanted attention. Interviews in neutral locations. Checks on Health and Safety standards & welfare facilities of travel, accommodation and outside organisations. Seek information on social/cultural/political status of field/location work area.

**Examples of Safety Equipment:** Hardhats, goggles, gloves, harness, waders, whistles, boots, mobile phone, ear protectors, bright fluorescent clothing (for roadside work), dust mask, etc.

If a proposed locality has not been visited previously, give your authority for the risk assessment stated or indicate that your visit will be preceded by a thorough risk assessment.

3. PRECAUTIONS/CONTROL MEASURES	4. RISK ASSESSMENT (low, moderate, high)	5. SAFETY/EQUIPME
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<p>A therapy office or library room will be rented so that I am able to summon help easily and will not be isolated. I will keep a mobile phone on my person at all times. I phone someone prior to the interview and if I do not contact them within 2 hours post interview then they will contact the relevant source of help (for example, the library reception) to ensure my safety.</p>	<p>Low</p>	<p>Mobile phone.</p>
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**PLEASE READ THE FOLLOWING INFORMATION AND SIGN AS APPROPRIATE**

**DECLARATION:** The undersigned have assessed the activity and the associated risks and declare that there is no significant risk or that the risk will be controlled by the method(s) listed above/over. Those participating in the work have read the assessment and will put in place precautions/control measures identified.

NB: Risk should be constantly reassessed during the field/location work period and additional precautions taken or field/location work discontinued if the risk is seen to be unacceptable.

**Signature of Field/location worker (Student/Staff)**      Danielle Phoenix      **Date**      05/02/2015

**Signature of Student Supervisor**           **Date**      06/02/2015

**APPROVAL:** (ONE ONLY)

**Signature of Director of Programmes**      .....      **Date**      .....

(undergraduate students only)

**Signature of Research Degree Co-ordinator or Director of Programmes**      .....      **Date**      .....

(Postgraduate)

Signature of Research Centre  
Head (for staff field/location  
workers) .....

Date .....

### **FIELD/LOCATION WORK CHECK LIST**

1. Ensure that **all members** of the field party possess the following attributes (where relevant) at a level appropriate to the proposed activity and likely field conditions:
  - Safety knowledge and training?
  - Awareness of cultural, social and political differences?
  - Physical and psychological fitness and disease immunity, protection and awareness?
  - Personal clothing and safety equipment?
  - Suitability of field/location workers to proposed tasks?
2. Have all the necessary arrangements been made and information/instruction gained, and have the relevant authorities been consulted or informed with regard to:
  - Visa, permits?
  - Legal access to sites and/or persons?
  - Political or military sensitivity of the proposed topic, its method or location?
  - Weather conditions, tide times and ranges?
  - Vaccinations and other health precautions?
  - Civil unrest and terrorism?
  - Arrival times after journeys?
  - Safety equipment and protective clothing?
  - Financial and insurance implications?
  - Crime risk?
  - Health insurance arrangements?
  - Emergency procedures?
  - Transport use?
  - Travel and accommodation arrangements?

### **Important information for retaining evidence of completed risk assessments:**

Once the risk assessment is completed and approval gained the **supervisor** should retain this form and issue a copy of it to the field/location worker participating on the field course/work. In addition the **approver** must keep a copy of this risk assessment in an appropriate Health and Safety file.