The Subjective Experiences of Disagreeing with One's Diagnosis of Schizophrenia– a Phenomenological Study

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Tell me about despair, yours, and I will tell you mine.

Meanwhile the world goes on.

Mary Oliver—Wild Geese

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Abstract

This research focuses not on the diagnosis, aetiology and psychopharmacology of schizophrenia, but on the experiences of receiving an unwanted diagnosis of schizophrenia. Six participants were studied using semi-structured interviews focusing on their experiences of disagreeing with a schizophrenia diagnosis. The material was analysed using Interpretative Phenomenological Analysis (IPA). Three superordinate themes were identified: (I) A self, independent of psychiatric labels, (II) Stigma and being part of society, and (III) Moving away from "mental illness". Superordinate theme (I) centres around making sense of one's experiences and creating a coherent self-narrative that can be held as true. Superordinate theme (II) centres around the participants' experiences of themselves in relation to society. It is about stigma, fitting in, and the cost of social acceptance. Finally, superordinate theme (III) is centred around participants' strivings towards a better life, fuelled by an underlying sense of hope. Literature around a lack of insight into schizophrenia, illness identity, and acceptance and impact of a psychiatric diagnosis was used to shed light on the findings of the current study. Existential literature was also used, onto which a philosophical understanding of the emergent themes could be built. The clinical significance of this study included a recommendation for mental health professionals to assist people within this population to create a meaningful narrative for their life story, incorporating a positive self-image while practising tolerance towards an individual's own ways of meaning making. Further qualitative research on the experiences of disagreeing with one's diagnosis of schizophrenia is certainly called for and recommendations for future research include making clearer distinctions between different ways of disagreeing with one's diagnosis.

Keywords

Insight, lack of insight into schizophrenia, illness identity, critical psychopathology, subjective experiences of schizophrenia, Interpretative phenomenological analysis, IPA.

Statement of authorship

This dissertation is written by Moa Lundström and has ethical clearance from the New School of Psychotherapy and Counselling and the Psychology Department of Middlesex University. It is submitted in partial fulfilment of the requirements of the New School of Psychotherapy and Counselling and the Psychology Department of Middlesex University for the Degree of Doctor of Existential Counselling Psychology and Psychotherapy. The author reports no conflicts of interest and is alone responsible for the content and writing of the dissertation.

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1. Introduction

This study aims to explore how people have engaged with a schizophrenia diagnosis that they do not think they should have. It explores how they have made sense of their experiences and identity. The focus is on their illness narrative and their hopes for the future.

The fundamental understanding of what schizophrenia is—its aetiology and the future prognosis of those who have been diagnosed—can differ greatly, depending on the perspective held by an individual. A traditional psychiatric perspective is that schizophrenia is a disabling and chronic brain disorder characterised by disturbance in thought, disorganised speech, hallucinations and delusions (Bentall, 2003). Individuals with a genetic predisposition are more at risk of developing schizophrenia, but social and personal stressors can be contributing factors to developing the disorder and many will need medication for life (Bentall, 2003). There is, however, a rising voice of individuals and groups (e.g., Davidson, 2003; Roberts, 2015; Hearing Voices Network) who take a different stance on the concept of schizophrenia and its bleak prognosis. There are psychologists who oppose the diagnosis altogether (e.g., Read, 2013; Lasalvia, 2018), even if they agree that people with this diagnosis experience "symptoms of schizophrenia" (e.g., hallucinations and delusions). Longden, Madill and Waterman, (2012) argue that "voice-hearing" (a preferred term over "auditory hallucinations") is better explained as a dissociative phenomenon than a psychotic one. They argue that dissociating or disowning parts of the self is a common response to traumatic or problematic life events. Romme and Escher (2012) have long advocated that hearing voices can be understood as a natural response to trauma and interpersonal stressors, that voice-hearing is on a spectrum—meaning that not only people with a psychiatric diagnosis experience voice-hearing—and that effective coping strategies can be adopted to help voice hearers. Perhaps the important point of disagreement that someone from this perspective has is that individuals who experience the symptoms of "schizophrenia" do not have a mental illness per se but, rather, are experiencing a natural response to stressful life events. As such, people with this view are opposed to the medical model of schizophrenia.

Religious leaders both within and outside the psychiatric field have also opposed the traditional way to view "mental illness" as a body/brain disorder. Christian C. H. Cook (2020) argues that spirituality and the notion that God speaks to one, should be reintegrated with our psychosomatic experience of ourselves; not just in everyday life but also within the context of mental illness. Here voices are viewed through a spiritual, supernatural or religious lens, making a "schizophrenia diagnosis" a label deprived of any subjectively meaningful understanding. Individuals who explain their unusual experiences as supernatural or religious may be deemed by psychiatrists to have a lack of insight into their illness, which is a symptom of schizophrenia, in and of itself (APA, 2013). This can leave those on the receiving end of the diagnosis in a position where they feel discouraged or unable to voice their thoughts around their diagnosis, fearing they will be dismissed—or worse, that their perspective will be seen as a sign of illness (David, 2006).

There are also people with a schizophrenia diagnosis who believe that there is such a disorder (as defined by psychiatry) but that the diagnosis does not apply to them. Once an individual has been diagnosed with schizophrenia by a psychiatrist, perceived diagnostic dissent is typically interpreted as the individual lacking insight into their illness, or having an unawareness of illness (Amador, 2012; Forgione, 2019).

The different perspectives held by academics, user movement groups and those with a schizophrenia diagnosis make a single conceptualisation of "disagreeing with one's diagnosis of schizophrenia” problematic. Instead, a wider and more in-depth perspective of those disagreeing with their diagnosis has been sought.

Nearly sixty percent of individuals with a schizophrenia diagnosis are deemed to have a lack of insight into their illness (Amador, 2012). The participants in this study all disagreed with their diagnosis, and which can be construed to fall into the category of lacking insight into their illness. As such, literature around the concept of lack of insight has formed an important part of the literature review. The boundaries between having or lacking insight into one’s illness are not straightforward: there are several clinical measurements for assessing insight (discussed in chapter 2), focusing on cognitive aspects, compliance-related aspects, symptom-specific aspects, temporal aspects, and through self-reports (Amador and David, 2006; Osatuke *et al*., 2008). However, the definition of insight still varies significantly and, ultimately, reveals underlying epistemological, philosophical and conceptual differences. These different perceptions of what constitutes insight make impartial and unbiased judgements difficult. For instance, people from ethnic minorities are more likely to be assessed as lacking insight (Johnson and Orrell, 1996) and current clinical measurements have been accused of applying Western ideas of what insight is composed of (Jacob, 2010), making them unfit for global use, and insufficient in a multicultural society.

In an attempt to step away from starting the current investigation from a biased angle and, instead, move towards remaining impartial, this study did not use clinical measures of insight when recruiting participants. A broad definition of “disagreeing with one’s diagnosis of schizophrenia” was used by recruiting individuals who “have a diagnosis of schizophrenia but disagree with it”. The aim was to start with the participants’ own understandings in focus and not to be held back by more labels but, rather, to produce rich and in-depth ideographic data. This approach exposed the research to a potentially wide variation in the ways in which participants disagreed with their diagnosis. As I went on to examine their experiences, however, I found many commonalities as well as unique experiences.

While there is a vast amount of research into schizophrenia, lack of insight into schizophrenia (Amador, 2012) and subjective accounts of schizophrenia (Logden, 2013; Mizock and Russinova, 2016), there is to date only one piece of research (to the best of my knowledge) that has examined personal accounts of people who disagree with their schizophrenia diagnosis (Forgione, 2019). Forgione (2019) did a qualitative review of the narratives of three individuals with psychosis spectrum disorder, who did not believe they should have their diagnosis. This study was limited due to sample size and heteronomy across the psychosis spectrum disorder (not all had been diagnosed with schizophrenia), but it paves way for future research to examine the experiences of individuals with perceived misdiagnosis.

The current research is an attempt to shed light on the participants' experiences of engaging with a diagnosis that they do not think is appropriate. It explores how this diagnosis has impacted their sense of self and their outlook on their life and future.

The study will commence with a review of the literature on schizophrenia as a debated concept and "lack of insight" into schizophrenia. It considers qualitative research on experiences of schizophrenia, the impact this diagnosis may have on one's identity and self-narrative, and alternative perspectives on mental illness and schizophrenia. Although this research was not intended to be about recovering from schizophrenia, I found a strong undercurrent of hope for the future in the participants' narratives and have, therefore, included literature around recovery. Following this review, the methodology and methods used in this study will be outlined. I begin with my epistemological positioning and move on to a review of and rationale for the research methodology used (namely IPA). Following this, the results chapter offers the reader detailed interpretative accounts of the participants' narratives. In this chapter, three superordinate themes and their subthemes are presented. In the discussion chapter, the results will be considered in light of the literature review. Existential ideas and concepts will also be used to explore the results from a philosophical perspective. The discussion leads to the conclusion of this study, which includes clinical implications, limitations of the current work and suggestions for future research.

2. Literature review

To organise the literature review, it is necessary to point out some critical conceptual differences that come with the use of varying terminology. I recruited participants who had a diagnosis of schizophrenia with which they disagreed. From a medical perspective, it could be claimed that they were lacking insight into their illness. I, however, did not proceed from this position, but simply met with them to record their experiences of disagreeing with their diagnosis. In the following section, I will nevertheless use clinical terms relating to lack of insight into schizophrenia, as this is largely how this population is described in clinical settings and is the terminology used by much of the reviewed literature. Personal accounts (and qualitative studies) of schizophrenia mainly focus on the following categories: narrative accounts of illness in schizophrenia, subjective experiences of schizophrenia, self, identity and narrative, awareness of illness and psychological well-being, and recovery. To the best of my knowledge, there is currently no significant body of research looking closely at the subjective experience of disagreeing with a diagnosis of schizophrenia. However, the substantial clinical literature on lack of insight into schizophrenia and qualitative research into subjective accounts of experiences relating to schizophrenia form a crucial foundation of this study.

I began the literature review by searching “disagree with one’s schizophrenia diagnosis” in 2013 on Google, ScienceDirect, Mendeley and Google Scholar which yielded no results. I then searched “lack of insight into schizophrenia” on the same databases and found Xavier Amador and Anthony Davis to be two of the leading academic researchers in the area. I purchased *Insight and Psychosis* (2006) by Amador and Davis and began reading the substantial material they have reviewed, using their bibliography to access further sources and journals. Similarly, Richard Bentall’s *Madness Explained, psychosis and the human nature* (2003) formed a base from which I found and read more material. Initially when searching the databases, I included research published at any time, not limiting the date ranges. I found that lack of insight as a topic of investigation (including the development of clinical measurements to quantify it) began in 1990, so continuing, I excluded research published before 1990. Further into the literature search I narrowed the date ranges from 2012 to 2022 to ensure more up to date research formed the arguments made based on statistics such as the correlation between socioeconomic background, adverse childhood experiences, and receiving a schizophrenia diagnosis. Based on the title, I scanned the seemingly relevant articles, and if appropriate, I saved or printed them to read thoroughly.

I searched “insight in psychosis”, “anosognosia in schizophrenia”, “lack of insight into schizophrenia” and “awareness of illness in schizophrenia” on ScienceDirect, Mendeley and Google Scholar, including only research articles and review articles the fields of psychology, psychiatry, social sciences, and neuroscience. Throughout undertaking this research, between 2013 and 2021, I also frequently searched for “disagreeing with one’s schizophrenia diagnosis” to see whether someone had conducted a similar study to mine, not finding any results until late in the research (Forgione’s 2019 study of diagnostic dissent). I did not include research into disagreeing with other types of medical diagnoses because the receiving person’s sanity is not questioned in the same way if they disagree with e.g. their cancer diagnosis, or their diagnosis of borderline personality disorder.

The engagement with each piece of research material (including reviewing the bibliography) led me to find further research in which similar methods were applied: I searched the above-mentioned online sources for “assessment of insight in schizophrenia” and let each journal take me to new similar journals, which I read and saved those that felt most relevant and that I wanted to discuss in the current research.

The search terms used for the qualitative studies reviewed were “subjective experiences of schizophrenia”, “identity in schizophrenia”, “narrative accounts of schizophrenia” and “recovery from schizophrenia”.

2.1. What is schizophrenia and why is the concept debated?

Schizophrenia was first identified by physician Emil Kraepelin (1899) in the late nineteenth century and was originally termed *dementia praecox*. He grouped the “insanities” into two large categories; dementia praecox and manic-depressive illness; the so-called Kraepelinian dichotomy (Craddock and Owen, 2010). Kraepelin used the term dementia praecox to refer to a diverse cluster of cognitive and behavioural symptoms that he thought were primarily intellectual functioning disorders as opposed to the manic-depressive illnesses that were seen primarily as disorders of affect or mood. According to Kraepelin, dementia praecox had a deteriorating course and poor prognosis, whereas the course of manic-depressive illness was acute exacerbation followed by complete remission (1899). Swiss psychiatrist Eugene Bleuler (1908) did not consider that the term *dementia praecox* accurately reflected the symptoms of the disorder, because the condition did not always begin in adolescence (praecox) nor did all patients show signs of intellectual dullness (dementia). Instead, he coined the term *schizophrenia*, literally meaning “split mind”, thus emphasising the mental confusion and fragmented thinking he saw as characteristic in patients with this illness. He described schizophrenia as a group of disorders, rather than just one illness and defined the fundamental symptoms of the disease as “the four A’s”: alogia, ambivalence, autism and affect blunting, which are today known as negative symptoms. The *accessory* *symptoms* of the illness, e.g. hallucinations, delusions, along with accessory memory disturbances, somatic and catatonic symptoms, *acute syndromes* (e.g. melancholia, manic conditions, stupor and deliria) were named so due to being episodic, and not static, in the course of the illness (1950). Bleuler and Kraepelin both recognised that the symptoms of schizophrenia tended to cluster into distinct categories. Bleuler's subgroups of schizophrenia were 1) the paranoid group, 2) catatonia (e.g. immobility, mutism, withdrawal), 3) hebephrenia (shallow or inappropriate emotional response) and 4) schizophrenia simplex (an absence of will, impoverished thinking and flattening of affect) (Bleuler, 1950). The typology Kraepelin and Bleuler created for schizophrenia and its subtypes continues to frame much of the psychiatric discourse on schizophrenia today (Bentall, 2003).

Schizophrenia is today defined by the DSM-V as "a severe, chronic mental disorder characterized by disturbances in thought, perception and behavior" (APA, 2013). Key symptoms are 1) delusions, 2) hallucinations, 3) disorganised speech, 4) disorganised or catatonic behaviour, and 5) negative symptoms (i.e. lack of motivation and interest in the world, social withdrawal, anhedonia, inability to act spontaneously, decreased sense of purpose, etc). To receive a diagnosis of schizophrenia, one must have displayed two or more of these symptoms for a minimum period of six months, where one of the symptoms must be one of the first three (delusions, hallucinations, disorganized speech) (APA, 2013). The ICD-10, mostly used in Europe, states: "The schizophrenic disorders are characterized in general by fundamental and characteristic distortions of thinking and perception, and affects that are inappropriate or blunted. Clear consciousness and intellectual capacity are usually maintained although certain cognitive deficits may evolve in the course of time" (WHO, 2014). It lists 9 subtypes with descriptions rather than clear diagnostical criteria. The ICD-10 continues: "The most important psychopathological phenomena include thought echo; thought insertion or withdrawal; thought broadcasting; delusional perception and delusions of control; influence or passivity; hallucinatory voices commenting or discussing the patient in the third person; thought disorders and negative symptoms" (WHO, 2014). Although described as the most important psychopathological phenomenon, diagnosis can be made without displaying any of these signs but the last mentioned. A person with 'simple schizophrenia' will show "oddities of conduct, inability to meet the demands of society" (WHO, 2014). Similarly, 'catatonic schizophrenia' leaves out any positive symptoms in its description, making it markedly different from the DSM-V which requires display of delusions, hallucinations, or disorganised speech to warrant a diagnosis (APA, 2013).

Schizophrenia is typically diagnosed between late adolescence and early thirties with an earlier tendency in males than in females (Bentall, 2003). According to WHO (2014), 20 million people worldwide have schizophrenia. The National Institute of Mental Health (NIMH) suggests that between 0.26 per cent and 0.64 per cent of the US population have schizophrenia and related psychotic disorders, and 0.33 per cent to 0.75 per cent worldwide (NIMH, 2021). Similar estimates were found by Bhugra (2005), who undertook a systematic review of just under 200 studies across 46 nations where results indicated that 0.4 per cent of the world population has a lifetime occurrence of schizophrenia.

Schizophrenia has been accused of being a concept so diffused in semantics and meaning it cannot be a valid scientific construct and should, therefore, not be investigated as such (Read, Mosher and Bentall, 2013). Beginning with the criteria required to diagnose schizophrenia: using the DSM-V definition of schizophrenia means that two individuals who display symptoms from categories 1 and 2, respectively 3 and 4, have now been firmly grouped into the same category, without showing any specific shared symptoms. There are 12 ways in which two people can meet the criteria without having any symptoms in common, when using the same diagnostical manual. The ICD-10 uses a longer list of symptoms and a more loosely defined criteria for diagnosis, warranting a diagnosis by any of the symptoms in themselves. Logically, the disjunctive categories here are too primitive to be deemed scientific at all (Read, 2013). Psychiatrist Howard James (1996) states that schizophrenia is an unprovable nosological construct. If researchers do not agree on which patients have schizophrenia, then the conclusions from these studies are drawn about a group of people who have no symptoms or behaviour in common. For example, if people who have been diagnosed with 'simple schizophrenia' with the use of the ICD-10 are grouped with individuals diagnosed with the use of the DSM-V, some will be showing signs of hallucinations, delusions, or incoherent speech, whereas others may display odd behaviour but no signs of psychotic behaviour. Implications made for all individuals with "schizophrenia" based on such a sample cannot be reliable. As Read (2013) and Bentall (2003) explain: without asserting reliability, investigating validity is meaningless.

The American National Institute of Mental Health (NIMH) called the years between 1980 and 1990 "the Decade of the Brain", which brought attention to the considerable research and progress relating to the neurobiology of schizophrenia (Davidson, 2003). Thus, our understanding of the disorder has primarily been from a neuropathological perspective. As a result, the dominant perspective and narrative of schizophrenia are of a "broken brain".

Studies that support a biological model of schizophrenia have found hereditary factors to be contributory to a predisposed tendency towards schizophrenia (Bharath, Gangadhar and Janakiramaiah, 2000). Genetics appears to play a role in developing schizophrenia (Tosato, Dazzan and Collier, 2005) but despite scientists competing to find the gene responsible, no specific gene has been found to be directly linked to schizophrenia (Gilmore *et al.*, 2012; Deacon, 2013).

The origin of the biomedical model of schizophrenia can be traced back to the mid-twentieth century when French surgeon Laboret experimented with the drug chlorpromazine to help his patients with post-operative shock. He noted the sedative effect of the drug and wondered if it could help patients with mental disorders. He found that regular tranquilisers simply subdued psychotic patients, but chlorpromazine seemed to reduce or fully remove positive symptoms while keeping cognition relatively intact (Kunz, 2014). From here, studies into how chlorpromazine (and similar drugs affecting dopamine uptake in the brain) work on patients' brains have led researchers to draw the conclusion that dopamine plays a significant role in schizophrenia; thus, the dopamine theory for schizophrenia was developed. This theory has been the dominant perspective for over three decades and is still a widely accepted theory (Brish *et al*., 2014), although studies have found no evidence to support the dopamine theory (Fusar-Poli and Meyer-Lindenberg, 2013). Moreover, a third of patients do not respond to dopamine-altering medication (so-called “treatment-resistant schizophrenia”) (Potkin *et al*., 2020). Potkin *et al*. (2020) put forward that the reason many patients do not respond to antipsychotic medication is likely due to underlying biological differences—again, demonstrating that patients that have been grouped together as sharing this disorder, not only at times have no symptoms in common, as argued by Read (2013), but are also biologically different to the extent that what is widely considered to be the treatment for the disorder does not work on one-third of affected patients.

It has been the assumption that antipsychotic medication (or neuroleptics) work by altering the effect of some neurotransmitters in the brain and, therefore, schizophrenia must be the outcome of an imbalance of neurotransmitters in the first place, which can be corrected with this substance. However, there is no reliable evidence that schizophrenia is caused by chemical imbalances (Deacon, 2013) and the impact of the drugs reaches far beyond the type of "correction" they were intended for. Joanna Moncrief of UCL (2009) calls for a drug-centred model to be used, rather than a disease-centred one, to explain how psychiatric drugs work. The presumption is that the latter corrects an abnormal brain state, whereas the former recognises that drugs create an abnormal brain state. Moncrief gives the example of insulin working for diabetes because a diabetic person's pancreas cannot produce enough insulin (leaving the body deficient) and an insulin injection corrects this natural deficiency. As such, this is adequately explained through the disease-centred model. Alcohol, on the other hand, works as an effective reduction in the symptoms of social anxiety because it lowers inhibition. No one suggests that alcohol works because it corrects an underlying biochemical imbalance or an insufficiency of alcohol in the blood. Rather, it alters the normal anxious state of the brain through the superimposed effect of the alcohol. The drug-centred model stresses that taking a drug creates an abnormal biological state (Moncrieff, 2009). Moncrieff argues that neuroleptics do exactly that to the schizophrenic patient—the drugs "work" by overthrowing the natural state via the superimposed effect of the drug, rather than "correcting" anything in the patient's brain, thus challenging the basis for a biochemical aetiology for schizophrenia. Since the body tries to counteract the effects of the drugs, long-term drug therapy often has many side effects on the person taking them—sometimes severe, which can be explained through her suggested model. When a person challenges their schizophrenia diagnosis, the drug-centred model to psychiatric drugs does not directly support the argument that they should not have received the label, but it does support the argument that they are not unwell because of a chemical imbalance in their brain which can be corrected with medication. Their mental state is not comparable to diabetes or another physical disease – they are not pathologically ill. Whether someone has schizophrenia or not would be straight forward if that was the case, but it is not. Instead, the strong link with trauma (Outcalt and Lysaker, 2012) implies that the suffering of those who receive a schizophrenia diagnosis is often rooted in lived experiences, and the experiences of those who receive the diagnosis should therefore not be overlooked.

Although some researchers and clinicians take an almost entirely biomedical stance on the aetiology of schizophrenia, the main narrative today acknowledges that social stressors and trauma play a significant part in the onset of schizophrenia (Deacon, 2013). Children who grow up in poverty in Britain are eight times more likely to be diagnosed with schizophrenia than children from non-deprived backgrounds (Harrison *et al*., 2001). Even when there was no family history of psychosis, deprived children were seven times more likely to develop the disorder. A meta-analysis of self-reported childhood abuse in psychotic patients found that the prevalence of self-reported child sexual abuse, child physical abuse and child emotional abuse was 26 per cent, 39 per cent and 34 per cent respectively (Bonoldi *et al*., 2013). Outcalt and Lysaker (2012) found that 74 per cent of women and 36 per cent of men diagnosed with schizophrenia spectrum disorders had been subjects of child sexual abuse. Read, van Os, Morrison and Ross (2005) found the relationship between childhood abuse and schizophrenia to be a causal relationship and that the more severe abuse, the more severe symptoms. Bebbington (2009) confirmed in a review that there is substantial evidence of the association between child sexual abuse and psychosis. Although trauma can influence gene expression, reviews such as these can, therefore, partly be explained through a biomedical perspective: the substantial amount of evidence of psychological and social factors cannot be overlooked (Deacon, 2013; Bonoldi *et al*., 2013; Read, van Os, Morrison and Ross, 2005; Bebbington, 2009).

Kraepelin’s idea that schizophrenia was a degenerative brain disease influenced clinicians to take a pessimistic view of the prognosis of the illness for generations to come (Read, 2013). Despite Kraepelin's strongly biased hospital sample (in terms of severity), he reported that eight to 13 per cent of cases of long-term recovery and 17 per cent of marked long-term improvements (Kraepelin, 1903), but he noted some clinicians argued that these cases must not have had dementia praecox to begin with (Kraepelin, 1899). This is an argument that can still be heard today; which means that an accurate diagnosis cannot be determined until many years or even decades after it's been given (Ciompi, Harding and Lethinen, 2010). Research at the turn of the century (Harrison *et al*., 2001) followed up on patients with schizophrenia across 18 cities who had been part of a study by the International Study of Schizophrenia (ISoS), coordinated by the WHO. They found an average recovery rate after 15 or 25 years of 47 per cent. Despite such findings, schizophrenia continues to be referred to as a "chronic disorder" with a "chronic course" (Patel *et al*., 2014, p.638): arguably, in statements such as this, data from recovery is wholly ignored in favour of siding with the tradition of an overly pessimistic narrative. Ciompi, Harding and Lethinen (2010) argue that such scepticism is due to a heritage of ideological pessimism within the branch of psychiatry and the viewing of schizophrenia through the biomedical lens. Many decades ago, in 1950, Bleuler acknowledged that it was impossible to determine the course the illness would have on individual cases (Bleuler, 1950). Read (2013) points towards three characteristics in the outcome of long-term studies into recovery in schizophrenia; 1) there are large variations in outcome, 2) many people labelled "schizophrenic" recover, and 3) the best predictors are psychosocial factors. He argues that the course of schizophrenia resembles the course of any life that is open to all kinds of influences, including social support, social and economic skills, anxiety and other personal attributes, and substance abuse, among others.

Consider for a moment this hypothetical revision of schizophrenia's history: from the outset, the medical and scientific community identified the link between genetics, trauma, negative environments and the likelihood thereafter of the onset of schizophrenia. For decades, patients and their families could have been given the hope of recovery and built a clear understanding within families or communities of the part that stressors and trauma play in developing mental illnesses, thus encouraging communities to adapt their ways of life to avoid repetition of the cycle through the generations.

The heterogeneity across the prognosis of schizophrenia, as well as the conceptualisation itself, has led a growing number of researchers and practitioners to place the patient's own perspective in the spotlight: this is important as treatment does not necessarily mean the same thing for the patient as it does for the doctor. Rather than a reduction of the positive symptoms in schizophrenia, recent literature on patients' ideas of what recovery represents and their experiences of recovering show that it can often have different meanings. For example, it may mean a continuation of hearing voices, but with the ability to make sense of them, accept them as part of oneself and be able to function socially (Romme and Escher, 2012; Davison, 2003). The formation of a coherent self-narrative has also been found to be an important aspect of the recovery journey (Roe and Davidson, 2005). Roe and Davidson (2005) argue that the re-authoring of one's life story is not merely a by-product of recovery but also an essential component of the recovery process in schizophrenia. Studies like this show promising accounts of how people with what could be in some circumstances a devastating diagnosis can work through and find meaning in their experiences.

User movement groups continue to challenge the concept of schizophrenia and its gloomy prognosis (Corstens *et al*., 2014). These types of groups often focus on putting the individual back in the spotlight and emphasise personal meaning making as opposed to pathology; in other words, a focus on life, rather than illness. The growing interest in furthering our understanding of schizophrenia from within—not somatically, but through personal accounts—is making way for more qualitative research into schizophrenia. However, understanding psychosis from a subjective perspective is not a new endeavour; Karl Jaspers' *General Psychopathology* (1913), Ludwig Binswanger's *Grundformen und Erkenntnis menschlichen Daseins* (Basic Forms and the Realization of Human "Being-in-the-World") (1942), Carl Jung's *Psychology of the Unconscious* (1912), R.D. Laing's *The Divided Self* (1960) and Minkowski's *La schizophrénie: Psychopathologie des schizoïdes et des schizophrènes* (1927) are but a few historical psychiatric works in which the author has tried to understand the personal meaning behind delusions and hallucinations, rather than seeing them as nonsensical symptoms of a disease. However, empirical studies conducted from the patient's perspective have only recently begun to appear in the academic literature (Mollerhoj *et al*., 2019; Skodlar and Henriksen, 2019; Mote and Fulford, 2020).

These studies recruit participants who have a schizophrenia diagnosis but the research does not directly deal with the questions of whether participants feel wrongly diagnosed or think they should not have the diagnosis in the first place. This is the void in the literature that the current research paper hopes to shed light on personal accounts and experiences of those who explicitly do not accept or agree with their schizophrenia diagnosis.

This group of individuals is often referred to in clinical settings as having a lack of insight into their illness or an unawareness of illness (Amador, 2012). This phenomenon can be observed in nearly 60 per cent of patients diagnosed with schizophrenia and has consistently been shown to be negatively correlated to treatment outcomes (Amador, 2012). People who do not believe themselves to be ill are less compliant with treatment and more likely to refuse medication. They stay longer in hospital and have more frequent hospital visits (Amador, 2012). Research is looking at ways to understand the phenomenon of lack of insight in order to help this population, e.g. by helping them form more insight so that they do not reject treatment (Lally, 1989; David 1990; Amador, Strauss and Gorman, 1991; Raffard *et al*., 2008; Gilleen, Greenwood and David, 2011; Osatuke *et al*., 2008; Mintz, Dobsin and Romney, 2003). The problem with these types of studies is that the concept of insight here constitutes agreeing to the perspective of the doctor and, subsequently, with the medical model of schizophrenia. As previously discussed, there is a growing number of service users and clinicians who are making sense of what are typically relayed as psychotic symptoms through different narratives and frames of reference than the medical model can offer (e.g., Davidson, 2003, Lysaker and Lysaker, 2008, Romme and Escher, 2012). According to Lysaker, Roe and Yanos (2007) the concept of lack of insight into schizophrenia leaves little to no room for the patients to form their own understanding of their disorder. However, as this is largely still how this population is perceived by the people in charge of their treatment and care (Amador, 2012), it has been important to include research on lack of insight to understand the phenomenon that so many with a schizophrenia diagnosis have been categorised to have. It is not enough to discuss the concept of schizophrenia and the experiences of those who have been diagnosed with the label when so many of those who disagree that they should have been given it in the first place are deemed to lack insight into their own illness (Amador, 2012). Thus, literature on lack of insight into schizophrenia, along with narrative accounts of schizophrenia and existential philosophy, have formed an important basis to this research and will be reviewed below.

2.2. Insight measurements and conceptual bases

Over the last twenty years, several clinical measures of insight have been developed to examine insight in patients with different kinds of mental illnesses (David, 1990; Amador, 2012; Lally, 1989; Beck *et al*., 2004). As will be seen, these different instruments reveal how lack of insight can be viewed in different ways, conceptually, and that this ultimately reveals underlying epistemological assumptions about the nature of reality: assumptions that are not shared within the academic field, let alone among the people deemed to be represented in the studies.

Beginning with the research on lack of insight into schizophrenia, it is evident that researchers take different perspectives on what constitutes insight, its aetiology and prognosis (Lysaker *et al*., Stanghellini, 2008; O'Connor *et al*.,2013; Gilleen, Greenwood and David, 2011; David, 1990), where some view a lack of insight as a neurological deficit (Amador, 2012) and others as a form of psychological defence mechanism (Lally, 1989). However, in the way the DSM-5 addresses the topic of insight into schizophrenia, one can see a preference for the neurological model of lack of insight over a psychological one:

> Some individuals with psychosis may lack insight or awareness of their disorder (i.e. anosognosia). This lack of insight includes unawareness of symptoms of schizophrenia and may be present throughout the entire course of the illness. Unawareness of illness is typically a symptom of schizophrenia itself rather than a coping strategy. It is comparable to the lack of awareness of neurological deficits following brain damage, termed *anosognosia.* This symptom is the most common predictor of non-adherence to treatment, and it predicts higher relapse rates, increased number of involuntary treatments, poorer psychosocial functioning, aggression, and poorer course of illness. (APA, 2013, p.101)

As research shows that insight is not a dichotomous factor that one either has or does not have but it is, rather, a factor on multiple dimensions ranging from complete denial to recognising one has an illness, understanding the consequences and recognising the need for treatment (Gilleen, Greenwood and David, 2011). The terms *illness* and *treatment* are directly linked to a medical perspective and insight, therefore, essentially means agreement with this perspective. This westernised perspective is being challenged by researchers calling for a change in the way that insight is currently measured universally across cultures, in a “one fits all” model (Jacob, 2010).

Furthermore, insight among people with schizophrenia has been shown to follow a U-shaped curve, as it is worse in the first episode, increases over time and decreases with old age (Gerretsen *et al*., 2014). Gerretsen, Plitman, Rajji and Graff-Guerrero point towards a fluctuation of insight in each episode due to the severity of positive symptoms and a stabilisation of cognitive ability in relation to insight impairment over time. Thus, insight appears to follow somewhat of a lifespan trajectory that must be accounted for both when researching insight among people with schizophrenia and when working with patients.

It has been argued that early assessment of insight was unsystematic and typically comprised of classifying patients’ insight as a global factor, for patients to have “poor” or “good” insight (Amador and David, 2006). Attempts to standardise the measurements of insight and measure insight on multiple dimensions have been made for around 30 years, beginning with the Schedule for the Assessment of Insight (SAI) developed by Anthony David in 1990. David’s SAI was developed as an improvement to the previous view of insight as a unitary phenomenon, where the SAI assesses insight on multiple psychological dimensions (David, 1990). The SAI proposes that insight comprises three distinct and overlapping schemes; namely, the patient’s recognition of having a mental illness, compliance with treatment and the ability to label unusual events (e.g. hallucinations) as pathological. What this measure does not do, however, is distinguish insight on different signs and symptoms; nor does it consider how insight may have evolved from historical to current levels of insight.

The multidimensional view of insight was further advanced by Amador and Strauss (1990) when they developed a measurement called The Scale to assess Unawareness of Mental Disorder (SUMD), which distinguishes two key components to insight: awareness of illness and attribution regarding illness. For instance, a patient with flat affect who does not recognise their lack of emotional expression demonstrates an unawareness of flat affect. However, if they recognise that they have flattened emotional expression but attribute it to a recent course of antibiotics, they demonstrate awareness but incorrect attribution regarding this sign of illness. Advancing on the SAI, this measurement differentiates between current and retrospective awareness of having a disorder. In addition to measuring the awareness of having an illness, it also measures the patient's awareness of the effects of medication, their awareness of the consequences of their mental disorder and awareness of specific signs and symptoms. As such, this is a superior measurement over a simpler instrument that focuses on whether the patient accepts a diagnostic label or whether they benefit from treatment. As a superior and, therefore, more thorough measurement, the SUMD comprises 74 items (compared to the SAI of three dimensions). In practice, it is a measurement often used in clinical trials but, due to its length, is rarely used in clinical settings (Michel *et al*., 2013). Instead, Michel *et al*. (2013) developed a shorter version of the same measurement to encourage the tool to be used in clinical practice. With rising pressure on the mental health services, it is not surprising that "long" assessments are avoided and there is a wish for short and quick diagnostical tools. The abbreviated version of the SUMD is not a problem in itself but it does represent a worrying trend within the field of mental health: the lack of time spent with patients. The human element of listening to someone's problems to try to find a solution is increasingly exchanged with a brief consultation with abbreviated clinical measurements. It is not surprising, therefore, that patients report feelings of not being heard within the mental health system (Kapur *et al*., 2013) and that there is a wish to be recognised as a whole person by professionals (Eldal *et al*., 2019).

Inherent in the SAI and the SUMD is the requirement for the patient to acknowledge that they have a disorder. The main critique of the SAI and SUMD is that insight is only conceptualised within a medical nosology. As such, there is little scope for patient viewpoints on their experiences to be considered unless it is through the medical lens. While this is a philosophical critique of a functional, clinical assessment model, the challenge appears highly relevant to the population given a diagnosis of schizophrenia.

Jacob (2010) argues that insight must be considered alongside the culture and subculture within which the individual exists. Jacob reviewed Indian studies of patients with schizophrenia and other disorders and examined explanatory models for illness among patients, their families, health workers and the general population. He found five themes: 1) the subjects often provide non-medical causes to illness (e.g. karma, evil spirits, punishment by god), 2) many hold multiple beliefs simultaneously which are often contradictory (e.g. medical, non-medical, supernatural, religious and black magic), 3) many simultaneously seek biomedical and non-biomedical interventions, 4) insight scores and severity of psychopathology are not significantly correlated. Jacob argues that assessment of insight should evaluate awareness, attribution and action. For example, people with schizophrenia who are able to re-label their psychotic experiences in a way that corresponds to local cultural explanation to illness, offer explanations to the changes in themselves that are shared within their culture or subculture (e.g. spiritual beliefs) and seek available help (not necessarily psychiatric help) should be deemed to possess insight. Jacob concludes that universal criteria to measure insight become invalid on individual levels if local beliefs and subcultures are not considered (Jacob, 2010). Common beliefs found among ethnic minorities in the UK should, therefore, not be overlooked when assessing insight in people with schizophrenia, and nor should less common beliefs found in subcultures across the UK (such as the viewing of experiences as spiritual phenomena).

There has not been much research into cultural [mis]conceptions and bias when assessing insight in patients with schizophrenia. However, there is data to support the argument of Jacob (2010). Johnson and Orrell (1996) investigated the notion that cultural bias can be present when judging insight. They compared demographics from the case records of 357 psychiatric inpatients and found that people from ethnic minorities were much more likely to be rated by clinicians as lacking insight (70 per cent of ethnic minorities were rated as having little or no insight, compared to 47 per cent of Caucasian British patients). Ethnicity was found to be the most determining independent factor when all demographics were accounted for. Possible explanations of this finding include that ethnic minorities hold more stigma towards mental health problems (Knifton, 2012) and consequently are more likely to deny having difficulties. They may also not be admitted to hospital until they are more severely ill, compared to Caucasian British patients. That 23 per cent increase in chance of being assessed as lacking insight for patients from ethnic minorities, however, is possibly explained by sociocultural bias in the judgement of patients' insight, as Johnson and Orrell (1996) note.

Considering the difficulty of conceptualising insight and multidimensional quality, it appears that professionals may have biased perspectives when it comes to making personal judgements on such a complex concept. These findings have important implications for people with a schizophrenia diagnosis and more research is necessary into the possible sociocultural bias that accompanies assessment of insight. These findings also invite the reader to consider insight in a philosophical light and to reflect on insight as a value-laden concept based on standardised norms and beliefs.

Saravanan, Jacob, Prince, Bhugra and David (2004) continued this discussion, questioning whether insight should be considered a concept based on values and social norms. If so, is it, therefore, likely to change alongside changeable medical concepts of illness and our changing public attitudes towards them? This is an important point to reflect upon when considering how insight might be viewed differently across cultures, especially by those different to our own. The authors go on to discuss how the notion that a patient's experience of reality is incorrectly constructed (i.e. that they lack insight) can be challenged. They suggest such experiences can be re-interpreted as divergent perspectives, with particular relevance to the patient's local world of meaning.

However, there is currently one instrument available that can be used to measure insight without the patient needing to agree with a nosological classification to their experience: the self-rated Insight Scale, developed by Markova and Berrios (1992). This measurement comprises 32 statements, including, "I feel different from my normal self" and "I want to know why I am feeling like this", to which patients give an answer of "yes", "no" or "I do not know". It was designed to provide insight into the patient's experience of themselves—rather than merely focusing on the patient agreeing that they have a mental disorder—and measures insight on a continuum of overall self-knowledge, not only on whether they believe they have an illness. As such, the concept of insight can be developed from a strictly pathological perspective and can be viewed as involving self-knowledge as present on a continuum. This stance on insight has encouraged further research to explore how complicated the experience of self is for individuals with psychotic disorders (Amador and David, 2006). Although no clinical measurement has been used in the current study, the phenomenological quality of the data collected does indeed shine a spotlight on the complexity of self-experience.

In summary, the development of standardised measurements of insight has been important in facilitating empirical studies in this area and, hence, in furthering the understanding of the phenomenon of insight itself. Researchers examine insight in multiple aspects (e.g. cognitive, compliance-related, symptom-specific, temporal), where the definition of insight still varies significantly. While more unity and focus on specificity are called for by some researchers (Osatuke *et al*., 2008), there are strong arguments to broaden the concept of insight and be sensitive to cultural and subcultural beliefs (Jacob, 2010). Individuals' disagreement with their schizophrenia diagnosis should not fall on deaf ears and be dismissed as being part of their illness, instead individual experiences and subcultural beliefs about their unusual experiences should be brought to light and examined. This research hopes to examine just that and broaden the perspective and conversation around patient's own understanding around their experiences.

2.2.1. Who lacks insight and what's the implication?

Theories on the aetiology of patients' lack of insight fall broadly into two categories: neurological deficits (Amador *et al*., 1991; Amador, 2012; Van Der Meer *et al*., 2012) and psychological defence mechanisms. This second category concerns the preservation of a sense of self-identity, the rejection of stigmatised social roles and the need to keep a positive self-image (Lally, 1989). Often, studies suggest that there can be degrees of both types of lack of insight, depending on which aspects of the disorder are being denied. For instance, insight into symptoms (e.g. delusional thinking) has been shown to be poor, while insight into cognitive deficits (e.g. memory and attention) remains relatively intact (Gilleen, Greenwood and David, 2011).

Osatuke, Ciesla, Kaslow, Zisook and Mohamed (2008) reviewed aetiological models of insight into schizophrenia and found that researchers identified the following dimensions: (1) cognitive aspects (awareness of having a disorder, of being labelled ill and of social consequences); (2) compliance-related aspects (perceived need for treatment, acknowledgement of its effects and benefits, cooperation); (3) symptom-specific aspects (awareness of particular symptoms and attribution of them to the disorder); (4) temporal aspects (insight into having the disorder, needing treatment and of benefits of treatment to include the present time, the past and the future course of illness).

Their review suggests that researchers' theories about the causes of poor insight fall broadly into the categories of neurological deficits and psychological defence mechanisms. There is support for each of these, and investigators agree that there is often a mix between different types of unawareness of illness and their underlying aetiology presented in patients. Therefore, drawing more certain conclusions regarding insight remains difficult and complicates the establishment of practice guidelines. The authors call for using more rigorous methodologies, articulating falsifiable hypotheses that test specific aetiological theories using richer data, such as that generated by qualitative studies. While unity and verifiable treatment methods are sound scientific aims, the current impossibility of a "one size fits all" model highlights the need for phenomenological, idiographic research.

The inconsistency of results across research was investigated by Mintz, Dobsin and Romney (2003). They explored the conceptualisation and assessment of insight and its relation to compliance, neuropsychological impairment and severity of psychopathology. This meta-analysis of 40 studies into insight and symptom domains in schizophrenia reported two interesting observations, suggesting, firstly, that there is a small negative relationship between insight and global symptoms and, secondly, that there is a small positive relationship between insight and depressive symptoms. The authors concluded that the more insight a person has, the less severe their overall schizophrenic symptoms tend to be—but that they are also more likely to be depressed. Although the relationships were statistically significant and the results supported previous findings, the authors noted that the relationships were weak and should be further studied if conclusions and clinical implications were to be drawn. Furthermore, they found that only three to seven per cent of the variance in insight was accounted for by the severity of symptoms, indicating that other factors might be involved. These, they suggested, might include previous experience of mental health professionals, perception of mental illness, knowledge of mental health and treatment, and level of distress as a result of the disorder. The authors concluded that lack of insight as a psychological defence mechanism cannot be wholly ruled out. If patients are trying to defend themselves against what the label schizophrenia comes with, is it time to reassess the value such a label brings?

The link between insight and depression was further investigated recently (Amore *et al*., 2020). Narrowing down on depressive symptoms, the authors of the 2020 study found that better insight was associated with greater self-depreciation, pathological guilt, morning depression and suicidal ideation. There was no difference in socioeconomic status, service engagement or illness severity and it was concluded that the relationship was causal, i.e. that greater levels of insight directly lead to higher levels of depression and suicidal ideation. The definition of insight (insight as acceptance of the medical model to illness), together with stigma towards people with mental illness—particularly schizophrenia (Huggett *et al*., 2018)—it is not surprising that levels of depression rise. The biomedical prognosis of schizophrenia is bleak and does not inspire much hope of recovery, let alone a bright future. Holding onto a different explanation of one’s experiences than is offered by the medical model appears to be a stronger strategy to preserve the possibility of a brighter future. As such, lack of insight as a psychological defence mechanism appears to be a rational strategy for survival or recovery.

Given that insight is linked to better treatment outcomes (Amador *et al*., 1991; Amador, 2012; O'Connor *et al*., 2013), while at the same time increases the risk for depression and suicidal ideation (Amore *et al*., 2020), further research should be undertaken to investigate how the two come together and what can be done to help patients gain insight in a way that is not destructive. Dantas and Banzato (2007) found that patients who had received previous psychotherapeutic intervention had better global insight, more awareness of being ill and a higher ability to re-label symptoms in a less negative way. With the possibility of insight impairment being part of a psychological defence constructed by the patient, the authors advocated psychotherapy as a possible means to reduce denial and thereby improve insight. Clinicians must, however, practice caution in any attempt to help patients develop insight so as not to cause further harm. Psychotherapists could focus on forming a positive self-image while working on gaining insight (Yanos, Roe and Lysaker, 2010). There is a case to make for patient-led insight, whereby forming a coherent self-narrative is the base for that insight and treatment. This will be discussed further in the qualitative section.

To conclude: insight should not focus on attempting to make patients conform to a medical perspective of mental health and illness. Rather, it should focus on awareness of the existence of issues and contradictions in one’s narrative. In other words, ‘insight in schizophrenia’ is more useful if the focus is on insight and gaining insight, rather than the lack thereof.

2.3. What are the experiences of people with a schizophrenia diagnosis?

Moving from the quantitative research on insight into schizophrenia, the review of qualitative studies on insight into schizophrenia and experiences of schizophrenia now follow. Greenfeld, Strauss, Bowers and Mandelkern (1989) interviewed 21 psychotic patients in recovery, asking participants to describe the experiences that led to them being admitted to hospital and their understanding and views of this experience. They were asked, for example, about how they viewed their illness with regards to symptoms, classification, origin, prognosis and relevance of treatment approaches. The patients' views fell into five broad categories: 1) views about symptoms, 2) views about the existence of an illness, 3) speculations about aetiology, 4) views about vulnerability to recurrence, and 5) opinions about the value of treatment. The accounts did not suggest clear global categories; rather, patients expressed an amazingly broad range of views on their psychosis. Greenfeld, Strauss, Bowers and Mandelkern (1989) found that all participants appeared to be struggling with understanding and adjusting to the fact that they were now patients in a psychiatric hospital. Although some patients could describe their symptoms accurately (e.g. hearing voices), they denied that there was anything wrong with them. Interestingly, results showed that patients who were in hospital for the first time described their symptoms (category 1) at length and were the most unwilling to say they were unwell. Patients who had been admitted to hospital several times gave fewer descriptions of their symptoms but were more willing to say they were unwell and indicating situational reasons for having been admitted to hospital, such as family problems and conflict. Greenfeld, Strauss, Bowers and Mandelkern (1989) did not speculate as to why this was the case, but it appears to be in line with the finding from Gerretsen, Plitman, Rajji and Graff-Guerrero (2014), that insight follows a U shaped curve—where more hospitalisations (in correlation with age) gives the patient time to acclimatise to their condition; they obsess less over symptoms and learn to consider triggers (e.g. stressful conflict) as a contributing factor to their having been admitted to hospital. Insight, here, appears to increase with lived experience, i.e. learning about themselves in regard to their unusual experiences.

A phenomenological investigation of self-experience of people with a diagnosis of schizophrenia benefits from considering how accepting or rejecting mental illness will form a central part of their perception of themselves—their self-identity. There is research on accepting physical disability and its relations to self-identity (Mizock and Russinova, 2016; Wright, 1983). Models on the acceptance of physical illness and its impact on self-identity indicate that a person's identity evolves to accommodate the losses initially experienced with a disability. This will form the foundation of a new identity. Acceptance of a psychical disability involves the need to keep one's previous self-value while taking on the new—but often stigmatised—identity, which can be a process to which it takes time to adjust. Mizock and Russinova (2016) argue that this model can be compared with the acceptance of a mental disability (mental illness) and may bring light to what accepting mental illness encompasses—namely, re-shaping one's identity in accordance with one's new circumstances while not diminishing one's value.

Yanos, Roe and Lysaker (2010) outlined a model for the impact of illness identity on recovery from severe mental illness. Illness identity was defined as the set of roles and attitudes that a person develops about themself in relation to their understanding of mental illness. This way of conceptualising illness identity allows for consideration of unconventional ways in which the patient may make sense of having a mental illness, which might include the development of empowered or survival identities or identities with which mental illness is irrelevant. This model outlines how the meaning the patient attributes to having a mental illness affects their self-esteem and hopes for the future. The model also describes illness identity as something that may further impact the risk of suicide, coping ability, social interaction, vocational functioning or symptom severity. If, for instance, mental illness means incompetence and inadequacy to the patient, these areas will be negatively impacted. If, on the other hand, a patient forms a more positive illness identity, their path to recovery will be enhanced. Morgades-Bamba, Fuster-Ruizdeapodaca and Molero (2019) investigated the effect of internalised stigma on well-being in people with schizophrenia. Internalised stigma had a negative effect on well-being and, consequently, had a deteriorative impact on patients' concept of self. This, in turn, led to worsening symptoms of schizophrenia, lower recovery and higher risk of suicide. Thus, illness identity (Yanos, Roe and Lysaker, 2010) appears to be intertwined with internalised stigma (Morgades-Bamba, Fuster-Ruizdeapodaca and Molero (2019)—if the patient has internalised negative stereotypes of "schizophrenia", then their illness identity will be negative and will hinder a path to recovery.

Yanos, Roe and Lysaker (2010) propose that treatment for people with severe mental illness should, therefore, be focused on illness identity and on helping people to form a more positive self-identity, which would lead patients to benefit more from other services (e.g. vocational rehabilitation). The authors draw attention to the importance of creating a meaningful self-narrative, suggesting this is something that people with mental illness often struggle with (Lysaker *et al.*, 2003). As self-esteem mediated the effect of internalised stigma (Morgades-Bamba, Fuster-Ruizdeapodaca and Molero, 2019), the forming of a positive self-identity should involve increasing self-esteem—which, in turn, helps to keep stigma at bay—and a positive illness identity will be more easily formed. Psychotherapy could help these individuals in narrating a life story that emphasises personal strength and ability to overcome adversity, diminishing any self-stigma they may have.

Roe, Hasson-Ohayon, Kravetz, Yanos and Lysaker (2008) performed a qualitative study of insight in psychosis with regards to the acceptance of a diagnostic label and compared the findings against scores on the most widely used insight measurement: the SUMD. Roe *et al.* interviewed 65 individuals with schizophrenia spectrum disorders and identified four clusters of varying degrees of acceptance of diagnosis. Individuals in cluster (1) "acceptance of illness/rejection of label" accepted experiencing mental difficulties but rejected traditional ways of describing them. People in cluster (2) "reject[ed] illness/searches for name"—they rejected being "ill" but were searching for ways to describe their experiences. In cluster (3) ("passive insight of the illness and label"), people passively repeated information they had heard about their diagnosis but did not display any real interest or understanding of it or of how it affected their lives. Finally, people in cluster (4) ("integrative insight") were actively working to understand their diagnosis. Participants in cluster (3) received significantly lower scores on the SUMD than participants in other clusters (where there were no differences across groups). Roe, Hasson-Ohayon, Kravetz, Yanos and Lysaker (2008) propose that the "narrative insight" should be considered when assessing insight in patients with schizophrenia. These clusters, they suggest, are indicative of specific outcomes (e.g. social functioning and engagement with services) and, as such, useful for clinicians to consider alongside the SUMD—which is not designed to detect individuals' search for a label or explanation to the illness. Not surprisingly, passivity and disinterest (cluster 3) scored the lowest rates of insight. Although the results did not indicate a causal relationship, it is not unreasonable to say that active engagement leads to insight; indeed, that is the base premise of psychotherapy—getting to know how our minds work (Siegel, 2010). Although poor insight in psychosis is found in the same brain region as anosognosia in other neurological disorders (Tordesillas-Gutierrez *et al.*, 2018) and psychologists argue this terminology should be used to signal the inability of psychotic patients to give informed consent regarding their treatment (Little and Bell, 2020), current understandings of neuroplasticity indicate that, although poor insight can be found on brain scans, it does not mean that it is a static state: efforts should still be made to move patients from lower levels of insight to more narrative integration and higher levels of insight. Being an active participant in your life-narrative is correlated with positivity and feelings of well-being (Siegel, 2010). The results of the Roe *et al*. (2008) study indicate that insight can be cultivated if there is interest from the patient. There is, therefore, an argument for alighting this interest in patients with schizophrenia, so that they can do the work themselves (arguably, by showing interest in their unusual experiences). Future research should investigate whether therapeutic intervention could help individuals move from one cluster to another. These four clusters form a good starting point both for further research into acceptance of and/or insight into a diagnosis and are a good starting point for therapists working with someone struggling to make sense of their diagnosis, helping them form a meaningful and useful understanding.

A qualitative study from 2014 examining service user experiences of receiving a diagnosis of schizophrenia gives excellent insight into the personal experiences of individuals with this diagnosis, in relation to their feelings about their diagnosis. Howe, Tickle and Brown (2014) interviewed seven men and women who had been diagnosed with schizophrenia between six and 17 years beforehand. The aim was to explore their experiences of receiving a diagnosis of schizophrenia and of the stigma associated with that label. Using interpretive phenomenological analysis, they found five interconnected superordinate themes: (1) Avoidance of the diagnosis of schizophrenia, (2) Stigma and diagnostic labels, (3) Lack of understanding of schizophrenia, (4) Managing stigma to maintain normality, and (5) Being ‘schizophrenic’. The authors found that participants seemed to be in constant avoidance of schizophrenia while simultaneously trying to understand it, managing stigma around it, and become it (schizophrenic). There were, indeed, beneficial and detrimental consequences relating to being diagnosed with schizophrenia. Receiving the diagnosis provided a means of access to treatment while simultaneously being a source of stigma and social exclusion. Participants also expressed negative feelings resulting from believing they were perceived as dangerous and incompetent. Howe, Tickle and Brown (2014) found that there was a clear lack of self-stigma but that participants did expect stigmatising views from others. They reported that this finding contradicts previous research, which states that self-stigma is woven into the self-image of the mentally ill. However, more recent research indicates that less than a third (31.3 per cent) of patients with serious mental health issues have higher levels of self-stigma (Dubreucq, Plasse and Franck, 2021), supporting Howe, Tickle and Brown’s finding that self-stigma is not as common as previously believed. Howe, Tickle and Brown (2014) draw attention to a particular difficulty that people with these types of psychiatric labels face; they must attempt to balance making the label a coherent part of their self-image with making sense of the stigma already attached to the label. To some, this meant losing self-esteem, whereas others were energised by the stigma and attempted to resist or denounce it. Participants felt that professionals withheld information about the diagnosis, which contributed to the anticipation of negative reactions from others. This enhanced participants’ secrecy about their diagnosis and decreased the quality of their social relationships. An important finding was that avoidance preceded diagnosis. This means that participants hid their true experiences in an attempt to avoid being diagnosed with schizophrenia and avoid the stigma attached to the diagnosis. As such, people in distress may avoid seeking help as a means by which to protect themselves from being labelled “schizophrenic” and the perceived stigma and negative consequences the label comes with. Findings such as these give sustenance to the argument of those who call to stop using the term “schizophrenia” entirely (Lasalvia, 2018). Avoiding the label could cause further harm, however, if it means avoiding mental health services altogether.

Furthermore, this study shines a light on the apparent struggle to form a coherent identity that incorporates the “old self” and the new “schizophrenic self” into a self that makes sense to the individual and can be “owned”. What is not directly represented in this study, however, is the rather large population of people who receive a diagnosis of schizophrenia but who do not agree with it. Arguably, such individuals will not try on the new identity of the “schizophrenic self”, but will work against professional advice. What effect does this have on the formation of a coherent self-image?

Forgione (2019) comes close to answering this question in her investigation of the subjective experiences of diagnostic dissent in people with psychotic spectrum disorders. As part of a larger study investigating experiential and cultural heterogeneity in persons diagnosed with schizophrenia spectrum disorders, three interviews were selected for qualitative investigation by Forgione to examine the research question “how do individuals with psychotic spectrum disorders experience perceived misdiagnosis?”. The larger study comprised three parts, with the first a narrative task in which participants were asked to freely and in their own words talk about their life story to date, including significant events, and were then given three questionnaires. The questionnaires were entitled: “The Examination of anomalous self experience” (EASE) (Parnas *et al.*, 2005), “The Examination of anomalous world experience” (EAWE) (Sass *et al.*, 2016), and “The Positive and Negative Syndrome Scale” (PANSS) (Kay, Opler and Fiszbein, 2006). Only the latter was used for the qualitative interview data, although the qualitative score was not. The first participant had been diagnosed with schizophrenia, the second with schizoaffective disorder and the third had a previous diagnosis of drug-induced psychosis. The data was analysed using the descriptive phenomenological method outlined by Georgi (2009) and one general psychological structure was found: “diagnostic dissent as an assertion of agency in response to perceived invalidation”. This structure comprised three parts: “the clinician’s loss of legitimacy”, “privileging self-experience” and “psychosocial consequences of diagnostic labelling and stigma”. The structure also had distinct “before” and “after” temporal variations, i.e. variations before and after diagnostic dissent. The experiential variations of the “before” category were “expectations of adequate professional intervention”, “expectations of misdiagnosis and improper treatment” and “no expectations of professional intervention”. The variations of the “after” category were “forgiving the invalidating other(s)” and “not forgiving the invalidating other(s)”.

Forgione (2019) explains that “diagnostic dissent” was both an experience and an act—it was a response to an invalidating other’s (often a clinician) attempt to redefine the subjects’ self-experience with a stigmatising label. This experience is different to “perceived misdiagnosis”, which does not involve perceived invalidation from another. The view offered by the clinician was incongruent with the self-understanding of the subject, who expected to be judged by the clinician as incompetent, unable to understand their condition and diagnosis, and unable to make decisions about their treatment. As such, the act of refusing the diagnosis means validating their own self-experience and autonomy, retaining sovereignty of their selfhood and affirming their personal agency. Similar to Howe, Tickle and Brown’s (2014) notion that individuals sought to protect themselves from the stigma and negative consequences they perceived to come with the label, dissenting their diagnosis also appeared to have a self-protective quality. Forgione (2019) does not discuss a coherent self-image as a possible reason for dissenting a diagnosis, but it can be argued that validating one’s self-experience as one understands it is parallel to retaining the coherent self-narrative one has for one's experiences. An imposed label to explain one's experiences shatters the coherence and invalidates one's own understanding of one's situation.

Forgione's (2019) sample is too small to make any noteworthy observations; some of the highlighted variations come from only one participant. Furthermore, there were significant differences in participants' diagnoses. Although both are on the psychotic disorder spectrum, drug-induced psychosis differs in many ways from schizophrenia. One can expect a chronic schizophrenia label to have a different impact to drug-induced psychosis, which is by definition temporary and triggered by an outside force, rather than stemming from the individual—although preexisting vulnerability for psychosis may be present in either case (Bramness *et al*., 2012). Forgione (2019) does not claim to generalize her findings, but the value of this research lies in opening the area of diagnostic dissent and exploring the experiences of people who do not think they should have the diagnosis they have been given. The present study explores the same area but within a sample of people who have all been given the same diagnosis (schizophrenia) and with a larger sample.

2.4. Schizophrenia spectrum disorders from an existential-phenomenological lens

Existential philosophy and phenomenology applied in psychiatry has helped in moving the narrative on schizophrenia further from psychopathology and closer to humanism. It has helped in bringing out the 'person' from the 'patient'. These ideas and perspectives have been important to user-movement groups and the development of patient-led care (Bentall, 2003) and have been the foundation upon which the current qualitative study has been built. As such, a brief outline on the history and development of some of the more influential existential-phenomenological ideas will be discussed below, giving the reader a better understanding of the literature that has helped move subjectivity and patients' rights into today's narrative on mental health care.

Karl Jaspers is widely considered to have started the phenomenological movement in psychiatry. Jaspers wrote *General Psychopathology* in 1913, after feeling that, while there were many theories on mental illness, none benefitted the patients themselves. He saw psychiatry as empirically based but lacking any underlying systematic framework of knowledge. Questioning the diagnostic criteria and method of psychiatry, Jaspers felt that it was a person's life-biography that told one who they were and their subjectivity, and that it needed to be understood. The patient's psychopathological manifestation was understood on the horizon of the totality of their existence. In other words, he took a social, psychological and existential stance on a patient's presentations. Jaspers studied the patient in detail, keeping notes about how they felt about their symptoms and noting his own biographical outline of the patient. The main focus for Jaspers was the patients themselves—including their symptoms—and he distanced himself from viewing patients in terms of their anatomical, physiological or genetic qualities, or brain structures and functions (1913/1963). Jaspers explained psychopathology as a patient's attempt to describe themselves or express their own experiences. His method of accessing these subjective experiences or states of consciousness was through phenomenological enquiry, influenced by Husserl (1999), and thus beginning the phenomenological movement in psychiatry. In his investigation of the patient, Jaspers used the phenomenological concepts of appearance, representation, and form and content. When making diagnostic assessments, a doctor should be concerned with the form rather than the content of symptoms, i.e. they should note how the patient experiences visual hallucinations but not pay too much attention to what it was that they saw (1913/1963). Jaspers described how delusions should be considered different to normal beliefs because they were “ununderstandable”. Today, delusions are often discussed in the context of existing on a continuum of normal beliefs (Jones, Delespaul and van Os, 2003). The continuum model of beliefs underpins modern cognitive therapy for psychosis. However, studies show that CBT for psychosis only helps about half of patients undergoing treatment (Turkington and MacKenna, 2003) and researchers argue that this supports Jaspers’ note on delusions as “ununderstandable” (Jones, Delespaul and van Os, 2003). If they were the same as “normal” beliefs, should they not be malleable under CBT treatment? Whether beliefs are “normal” or “abnormal” within the range of human experience continues to be a philosophical question, which is, therefore, clearly pliable to conceptual and value-based notions of cultures and researchers. While research in this area continues, this point needs to be continually raised to avoid dogmatic perspectives on what is fundamentally a philosophical issue. Furthermore, the assessment that delusions are “ununderstandable” has been criticised by Kinderman and Bentall (2007) for having negative therapeutic implications. Such an approach, they suggest, might get in the way of empathising with the patient and helping them to make sense of their experiences:

> If delusions are ununderstandable and do not emerge from the kinds of psychological processes involved in normal beliefs and attitudes, it follows that the ordinary technologies of belief manipulation (discussion, debate and psychotherapeutic interventions) are likely to be ineffective with deluded patients and that engaging with them in mature discussion about their beliefs will be a pointless exercise. (Kindermann and Bentall, 2007 p. 275)

Indeed, empathy and having one’s self-identity recognised and supported is a theme among inpatients (Eldal *et al.*, 2019) and, as we have seen, dismissing schizophrenia patients’ unusual experiences as “symptoms of their disease” has a detrimental effect on their recovery.

Jaspers distinguished between understanding and explaining when considering mental disorders. He believed that understanding came about through empathetically transferring oneself onto the patient’s mind and consciousness. Describing symptoms objectively (explaining), on the other hand, would not lead to an understanding of the patient’s experience, consequently dismissing its subjective relevance to the patient himself (1913/1963). This point is of great relevance to the population of people who disagree with their schizophrenia diagnosis. Explaining symptoms objectively does not help patients to form an understanding of their situation (Lasalvia, 2018); nor does it lead to an empathetic connection with the doctor (which is both desired by patients and helpful for treatment (Eldal *et al*., 2019)), or invite the patient to learn about their situation and thereby cultivate higher levels of insight (Howe, Tickle and Brown, 2014). Jaspers considered only psychological disorders accompanied by cerebral pathology to be true disease entities: an idea welcomed by many in the anti-psychiatry movement (Read, 2013).

Similarly to Jaspers, Ludwig Binswanger also sought a philosophical understanding of his patients’ mental states. He, too, was dissatisfied with traditional psychiatry’s reductionist approach to understanding human existence and experience (1942). Binswanger believed that one could not understand psychopathology if one could not first understand normal psychology. He found Heidegger’s *Being and Time* (1927) to hold many answers for the human condition: Heidegger offered a theory beyond the Cartesian mind-body problem, which Binswanger felt was a problematic issue in psychiatry. In particular, he found the concept of *being-in-the-world* useful in understanding normal—and, therefore, also abnormal—psychology.

Heidegger expressed his conception of the human being, or *Being*, as *Dasein* (literally meaning *being there* in German) (Heidegger, 1927). He described how the person always exists within the context of their environment, living immersed in a world of other things and people. *Dasein* asserts something about itself as it exists, such as certain capabilities. It comes into existence precisely because it is out there in the world, “being” there. Mental illness can, therefore, be construed as a disturbance in the individual’s existential structure (Schmid, 2018). Schmid (2018) argues that, for the psychotic individual, the *Dasein* concept fails to assert itself in an environment of shared meaning. The impossibility to experience oneself in a shared world with others and thus being closed to normativity marks the experience of mental illness and explains why others describe actions and thoughts of people with psychosis as “unintelligible”. Qualitative research on the experiences of people with psychosis, therefore, could be considered attempts to broaden the shared world of meaning and interpretations.

Heidegger used phenomenology as the method by which to reveal the truth about a given phenomenon. Phenomenology brings us back to the things themselves: the phenomenon being revealed is *Being* (Heidegger, 1927). Binswanger applied this approach to the study of *Being* and developed *Daseinanalysis*, outlined in his 1942 book *Grundformen und Erkenntnis menschlichen Daseins* (“Basic Forms and the Realization of Human Being-in-the-World"). By expanding on Husserl’s (1936/1990) *Lebenswelt,* Binswanger specified three modes of existence: *Umwelt* (around world), *Mitwelt* (with world) and *Eigenwelt* (own world). He suggested that these tenets were essential to explore with the patient when trying to understand their experiences; empathising the subjective experience of individuals and how their experience of the world is interconnected with the immediate environment in which they live.

To Binswanger (1958), mental illness was understood as a reshaping of the patient's own world, including changes in the fundamental structures of the *Eigenwelt* and its structural links to the *Mitwelt* and *Umwelt*, and altering the lived experience of time, space, body sense and social relationships. Abnormal existential structures—or ways of *being-in-the-world* (caused by either biological or psychological reasons)—are a foundation for mental illness and its symptoms. It is the practitioner's task to expose these existential structures with the patient in an anthropological manner in order to gain understanding of the patient's way of being, as expressed in their mental illness. In the famous case of Ellen West, Binswanger's interpretation was that the patient had, in her childhood, withdrawn into her *Eigenwelt* and was not relating well within her *Mitwelt* (with others) or *Umwelt* (the world around her). After some failed romantic relationships, her interest in her *Mitwelt* and *Umwelt* shrunk and she became more and more cut off from them, which left her feeling alienated and profoundly disconnected from "real life" (Binswanger, 1958). While the anthropological exposing of the patient's existential structures is, arguably, not completely different to the type of insight integration with which modern psychotherapy is concerned (Perera, 2021), Binswanger's case study of Ellen West has been widely criticised for misdiagnosing Ellen who, in fact, had bulimia (Bray, 2001). Binswanger has also been accused of aiding Ellen's suicide after consulting with German psychiatrist Alfred Hoche, who was a driving force behind the eugenics movement and renowned for advocating euthanasia for those who were "mentally dead" and did not contribute to society; a category in which he placed people with schizophrenia (Di Nicola and Stoyanov, 2021). This attempt to see the person behind the "madness" was a step in the right direction—and a step away from the earlier days of mental asylums, such as "Bedlam", in which people with mental illnesses were imprisoned and, by today's standards, abused (Whitaker, 2002). However, the main criticism of Binswanger's

Daseinanalysis is that, although the doctor was trying to understand the patient, the authoritarian position of the doctor was undoubtedly robust. Ellen’s attempts to express herself were understood through the imposed model of *Daseinanalysis*, which not only led to a misdiagnosis of the patient but to more suffering and, ultimately, the patient's death. One can ask oneself how Ellen would describe her understanding of her situation and experience of the treatment she was receiving. The status quo of psychiatry is bound to change over time, as it becomes influenced by new voices in the field and as new research emerges. Contemporary thoughts and sentiments about healthcare have changed and will change again (Foucault, 1964). *Daseinanalysis,* for Binswanger, is the biomedical model for some psychiatrists today. Parallels can be drawn between how Ellen West was viewed and, therefore, treated and how someone diagnosed with schizophrenia today is deemed to lack insight: there is a lens through which they are viewed and they are on the other side of that lens being observed by those with the knowledge. Here, the power lies with the doctor, who determines what constitutes illness and what constitutes treatment. Foucault’s (1964) concept of power/knowledge is that the knowledgeable have power and that the powerful ones decide what is “knowledge”. Unveiling the relationship between doctor and patient, or researcher and subject, is crucial to avoid a totalitarian model towards treatment of individuals with mental health issues. Subjective perspectives from patients are, therefore, vital to best help this population. It is through hearing, empathising and learning what works for patients—on a group and individual basis—that effective care can be modelled.

The traditional doctor/patient relationship and the power dynamics that come with it were also challenged by British psychiatrist, Ronald D. Laing, who wanted to break down the conventional power relationship between patient and doctor and relate to patients as fellow human beings. Laing defied the predominant clinical perspective—that unusual ideas, paranoia, delusions and hallucinations are signs of “madness” expressed irrationally—as nonsensical and disputed orthodox psychiatry as being the best way to help patients (1960). He revolutionised psychiatry through his insistence on helping people by first understanding them. Medication was seen as something standing in the way of understanding patients, i.e. you cannot understand someone if you cannot talk to them and tranquilisers make it impossible to connect to and help patients (on top of the cruelty these methods impose on them). Laing viewed the feelings and unusual experiences of the patients as valid expressions of their sufferings and past experiences; importantly, not as symptoms of disease. This way of thinking appealed to many people with mental illness, as well as their families, and mental health practitioners. Laing’s work paved the way for a new way of looking at the experience of psychosis, which was a deeply humanistic and empathetic way of relating to the patient. Such perspectives continue to form an important basis for both clinical work with people with schizophrenia and research into subjective experiences of schizophrenia.

In *The Divided Self* (1960), Laing explores how “madness” can be a journey the patient must undertake in order to heal a damaged self. It may also be a strategy the psyche implements to protect itself and its own identity. Schizophrenic symptoms are presented as understandable within the context of the patient’s environment. Here, family relationships are seen as the root of the child’s development of schizoid personality (grown out of ontological insecurity), leading to schizophrenia in adolescence. Laing describes how the child's self fails to integrate into the person, instead developing in a way that is isolated from others and begins to relate to itself:

> The totality of [the individual’s] experience is split in two main ways: in the first place, there is a rent in his [sic] relation with his world and, in the second, there is a disruption of his relation with himself. Such a person is not able to experience himself

> [sic] 'together with' others or 'at home in' the world, but, on the contrary, he [sic] experiences himself [sic] in despairing aloneness and isolation; moreover, he [sic] does not experience himself [sic] as a complete person but rather as 'split' in various ways, perhaps as a mind more or less tenuously linked to a body, as two or more selves. (1960, p.17)

This is understood as a strategy for the self as a means to maintain its identity and protect itself from external danger. The self may begin to relate only to its "false" self—a self that complies emptily with the world and eventually ceases to exist at all. Laing has been criticised for laying too much blame on the mother and family of the patient. He also does not seem to have entertained the idea that a family could offer support (Crichton, 2007). Neither does Laing attempt to offer scientific evidence to support his theory of what schizophrenia is and how it develops (Kirsner, 2015). However, the real value of *The Divided Self* lies in its search for the meaning behind what was previously seen as erratic and incomprehensible speech and behaviour, and the impact the book had on the general public; inspiring hope to individuals to re-claim power over their own lives, not just as "patients" but as individuals. He offers the reader a perspective less commonly seen; one that is closer to the patient's own and an opportunity to step away from our potentially biased worldview and begin to consider "madness" from a different perspective. It is a perspective, perhaps, with less judgement and more empathy. The respect Laing showed his patients is a great model for any practitioner beginning therapeutic work—the starting point is an empathetic understanding, which Laing seems to have mastered. Laing's philosophy of patients right to autonomy, respect and empathy are echoed in the expressed desires of patients with schizophrenia (Eldal *et al.*, 2019; Davidson, 2003), and have underpinned my own engagement with the participants in the current research.

2.5. Rationale for the current investigation

The literature review has highlighted several problems with schizophrenia as a concept, as well as the concept of lack of insight into schizophrenia, and the implications for the individuals who receive the label and are deemed to have a lack of insight into their illness. The conceptualisation of schizophrenia has not changed much since the term was first coined, over a century ago (Bleuler, 1908) and, although there is vast research into schizophrenia, there has been little progress in treatment (Bentall, 2003): psychiatrists are still not able to say to their patients with clarity why they receive the label, how drug treatment works and the expected prognosis (Read, 2013). There is a dire need to hear what the individuals who receive this diagnosis have to say about what they make of their unusual experiences, their experiences with mental healthcare treatment, and what they need in order to progress with a meaningful life. Qualitative studies investigating these types of questions are increasing in number and the mental health profession is beginning to listen to the voices of the people under its care (Cheung, Fulford and Graham, 2007). However, much more needs to be done for the care, treatment and de-stigmatisation of individuals with a schizophrenia diagnosis. Adding to the perceived loss of self-identity that can follow having been given a schizophrenia diagnosis (Howe, Tickle and Brown, 2014), patients who share their own interpretations of what is going on for them are at risk of being deemed to lack insight into their own illness, which is a symptom of the illness itself. Thus, denying one has schizophrenia can be construed as confirming it. This leaves patients in a difficult situation, whereby they may feel afraid to share their experiences with mental health professionals: but, by not sharing, they are making it more difficult to get access to the help they need. Once a patient has been judged to lack insight, everything else they express may in addition be dismissed as nonsensical symptoms of schizophrenia, enhancing the problem of patients feeling unheard (Eldal *et al*., 2019). While lack of insight has been researched as a clinical construct for over thirty years, there is little or no research at all on lack of insight from a subjective perspective; the same can be said for the concept of disagreeing with one's schizophrenia diagnosis. This is the gap this research seeks to explore.

This present study aims to shed light on the unexplored area of people who disagree with their schizophrenia diagnosis. The aim is to obtain a deep understanding of the participants' experiences of engaging with a diagnosis that they do not think is appropriate. It explores how this diagnosis has impacted their senses of self and their outlooks on their lives and futures. This type of qualitative understanding of the current population has several clinical implications. Firstly, as this area is largely unexplored, the present research paves the way for later studies looking into the experiences of people who disagree with their diagnosis—it helps to categorise the experiences (or themes) for new research to further specify and, thus, potentially gain more homogenous findings and conclusion. Secondly—and importantly—this research has aimed to produce practical implications and recommendations for mental health professionals working with the current population. It is the hope that this study will comprise a drop in a growing river of change and hope within the field of counselling psychology; a work among others that helps narrow the gap between "us" and "them".

3. Methodology and method

To do justice to the participants and the research itself, it has been necessary to inquire into methodology—the philosophy behind the method. This has helped me to choose a means of investigation that suits the aims of my study (gaining insight into a small number of peoples' personal experiences of disagreeing with their diagnosis of schizophrenia). I have investigated which method is suitable for the research in regard to its epistemological and ontological underpinnings (outlined below) and have also outlined my own, personal view on the philosophy of what the world and knowledge are like.

3.1. My ontological and epistemological position

My perspective on what the world is like and what knowledge is has developed as I have had more experiences of the world and of people. Influenced by my undergraduate degree in psychology, I started viewing knowledge and, indeed, the world through more critical eyes, questioning what was considered objectively "true".

More recently, my perception has broadened by considering ideas about which we may think we know and why, which views are accepted as "truths" and why that might be (influenced by Heidegger (1962), Merleau-Ponty (1964) and Foucalt (1964)). Growing up, I had a much more positivistic outlook on the world than I have today. Either it was one way or it was the other: there was little scope for a grey middle ground. I believe this stayed with me as an attitude towards the world and informed my way of engaging with it. I would not have disagreed with a constructionist point of view if the discussion had been raised but I had not given much consideration of what concepts such as truth and knowledge meant. I had adopted a rather positivistic stance toward understanding.

With age, perhaps—but certainly through engaging with philosophy and having had personal therapy—my view of what the world is like and what knowledge is has become far more expansive and flexible. Before, I might have attempted to abandon a paradoxical position in order to come to a neat and solid conclusion. Today, I comfortably hold paradoxical viewpoints as equally true. I can often feel myself swaying between trying to understand something as objectively and scientifically true and accepting a much more fluid type of knowledge, which may be true for a specific person at a specific place in time.

Throughout my training, I have learnt to question theories, research and people. I have learnt to ask myself who said what and what their personal circumstances might be. I have learnt to consider how someone's particular environment might have shaped their view. This line of questioning might reveal a tendency towards a constructionist positioning, although I would not like to categorise myself as firmly as that (and bearing in mind that with these viewpoints come biases).

However, this rather interpretative epistemology feels more true to me within the concept of psychology and, certainly, counselling psychology, than it may do in other disciplines such as physics and biology. This is important when considering that schizophrenia is (rightly or wrongly) often viewed from a medical and biological perspective.

3.2. Epistemology

Building on the above, my constructivist ontological positioning leads me towards an interpretivist epistemology. This standpoint perceives that social phenomena are created from perceptions and interpretations of the world that are always culturally and historically situated. Interpretivism rejects the objectivist view that meaning resides within the world independently of consciousness. Interpretivism is often linked to the work of Max Weber, who argued for the distinction between understanding (*Verstehen*) and explaining (*Erklären*). He argued that social science is concerned with the former and that the latter is found in the natural sciences, which are principally concerned with causality (Crotty, 1998). Within the context of research, it is assumed that any access to a given phenomenon is through social constructs such as language, consciousness and shared meanings. The study of experience (phenomenology), the theory of interpretations (hermeneutics) and the study of the particular (idiography) are three key concepts that have major significance to the philosophical underpinnings of the chosen method in this study. These will be briefly outlined below.

3.2.1. Phenomenology

Phenomenology as a philosophical study began with Edmund Husserl (1859-1938), who famously said that we should "go back to the things themselves". It is the study of how things appear to our conscious awareness and, ultimately, how the world appears to us in terms of our subjective experience.

Husserl argued that if we could put aside our pre-existing views and ideas of what a phenomenon is like (our *natural attitude*), bracket these assumptions and adopt a *phenomenological attitude*, then we could arrive at the phenomenon for what it is really like—we can get to the essence of the phenomenon (Smith, Flowers and Larkin, 2009). Husserl's transcendental phenomenology claims that, once this essence of the phenomenon has been found, it holds true in a universal sense.

Phenomenology as a discipline was developed from the purer transcendental form—initially by Martin Heidegger (1889-1976) and later by Merleau-Ponty (1908-1961) and Sartre (1905-1980) (among other philosophers)—to a form of phenomenology that can be referred to as existential phenomenology. This branch of phenomenology disputes the possibility of the existence of any knowledge outside an interpretative stance. Anything that is known to a human being is known through consciousness, which is continuously shaped by the life-world, language, culture and relationships. Meaning is, therefore, an essential component of existential phenomenology, as individuals can make sense of their world only through themselves subjectively.

3.2.2. Hermeneutics

Hermeneutics is the theory of interpretation. It was initially developed as a method of interpreting biblical texts. Later, it developed as a philosophical approach for interpreting a wider range of texts (Smith, Flowers and Larkin, 2009). Hermeneutics is an activity and a branch of philosophy: it is a way to understand not only texts but life as a whole.

Every act of perceiving requires the perceiver to put together the world in a certain way. Perception will be dependent on one's personal history and cultural circumstances. Therefore, the interpreter's task is to understand not only the text but also the writer or speaker. They try to understand the meaning a person has of the topic discussed in the text (e.g. what the words and language being used mean to that person). In this sense, the interpreter can analyse a text one step beyond merely what is being said.

Hermeneutics recognises that the understanding of something comes from integrating the unfamiliar into a familiar context (our pre-existing context) and doing so changes a person because it broadens that person's perspective. This is true for both the writer/speaker of the text and the text's interpreter, hence the importance of reflexivity.

Gadamer (1975/2004) says that it is nearly impossible to say something about another's experience because of how much of our selves are involved in our perception of what is presented to us. We are always interconnected with our description of others. Gadamer's concept of *horizon* means that which is visible to us is always perceived from our particular vantage point. Understanding a text hermeneutically means that there is a cyclical understanding: the whole is understood by reference to the particular and the particular is understood in the context of the whole.

3.2.3. Idiography

Idiography is the study of the specific. It describes an effort towards understanding the meaning of particular, individual phenomena. This is in contrast to a nomothetic approach to research, which is concerned with making claims that can be generalised to larger populations. Descriptive detail and depth of analysis are hugely important when conducting idiographic research. As can be seen, there are overlaps between the concepts of idiography, hermeneutics and phenomenology. These are concepts used for adopting a certain attitude when conducting a certain action: Van Manen (1990) says that any real understanding of hermeneutic phenomenology can only be accomplished by actively doing it.

Although idiography reflects a commitment to the specific, it does not reject making some small, more general claims based on the observations, but does so with caution and reference to the particular (Smith, Flowers and Larkin, 2009). Idiographic research is of particular value for counselling psychology because, in an attempt to fully understand another human being, we need to step far closer to a person than a nomothetic understanding of individual distress can achieve (even if understanding begins at that level). To reframe Husserl's famous words, we need to "go back to the *persons* themselves".

3.3. Interpretative Phenomenological Analysis

Phenomenology, hermeneutics and idiography are the main building blocks for Interpretative Phenomenological Analysis (IPA) (Smith, Flowers and Larkin, 2009). IPA is a method used to examine the human lived experience in detail and depth. IPA suggests that engaging with data involves a double hermeneutic. This means that there is a focus on meaning making, where the researcher is trying to make sense of the participant trying to make sense of their world (Smith, Flowers and Larkin, 2009). The term double hermeneutic also refers to the way researchers position themselves in relation to their participants' accounts: a double hermeneutic of empathy and suspicion is often referred to. An empathetic approach is used to get as close to the original experience as possible and suspicion involves engaging as an outsider and viewing phenomena with a critical eye. The researcher is also aware of their perception of the world and how this may shape their interpretations. They have a critical eye on themselves and are aware that a biased perspective is impossible to completely step away from.

IPA does not make claims of being able to generalise its findings: it is not a method for constructing theory. Rather, IPA refers to what has been found among its particular sample. The findings of a study will be dependent on the researcher themselves (on their life-world and perceptions) and it is, therefore, of utmost importance to adopt a reflexive attitude throughout the research and to make this clear and transparent to the reader.

The concept of validity in qualitative research is somewhat disputed. For instance, if a researcher rejects the assumptions of positivism (that there is a truth out there independent of our perception of it), it does not make sense to attempt to falsify the findings of a specific study. The concepts of validity and reliability cannot be addressed in the same way across quantitative and qualitative research. Therefore, qualitative researchers have developed different ways of approaching these issues. Denzin and Lincoln (1994) used different terminology for the criteria used to judge qualitative research in order to distance themselves from the positivistic paradigm. Traditional criteria for judging quantitative research are internal validity; external validity; reliability; objectivity. These can be exchanged to credibility; transferability; dependability; confirmability when ensuring the soundness of a qualitative study.

Simply by using different words when thinking of the trustworthiness of qualitative in comparison with quantitative research, we get a different sense of what qualitative research offers, revealing its underlying ontological assumptions. Thoroughness, effort and detail are essential aspects of producing quality research.

Hefferon and Gil-Rodriguez (2011) expressed concern for the rising popularity of IPA, saying it has become the “go-to” method for qualitative research and that it is often used without a thorough understanding of the method or its underlying philosophy. They describe projects conducted without embracing the interpretative aspect of the method, which produce broadly descriptive results lacking depth and any real insight.

As the authors suggest, this may be due to a lack of understanding of the philosophical background and application of IPA, as well as a lack of confidence to make interpretations about deeper or contextual factors. A lack of trust in one’s ability as a researcher may lead to “playing it safe” and sticking to the descriptive text too closely in an attempt to ground the findings in the explicitly expressed and not venture too far from the participants’ expressed experiences.

This takes me to a point stressed both by Larkin and Thompson (2012) and Smith, Flowers and Larkin (2009), who all encourage the researcher to be creative in the research process. By attempting to apply stricter methodological guidelines to ensure validity, the essence of a study can be compromised. A researcher who wants to conclude what feels true to the researcher themselves can keep in mind Kierkegaard's (1846/1980) description of subjective truth and engage with the research with passion and commitment.

IPA has clear and well-established strategies of how to analyse data but allows researchers a freedom in analysis, interpretation and expression—freedoms that many see as essential components of the method. Larkin and Thompson (2012) outlined a number of quality indicators that good research practice will likely demonstrate:

- Collecting appropriate data from appropriately selected informants.
- Some degree of idiographic focus (attention to the particular), balanced against “what is shared” within a sample.
- An analysis that transcends the structure of the data collection method (e.g. the schedule for a semi-structured interview).
- A focus on “how things are understood”, rather than on “what happened”.
- Incorporating and balancing phenomenological detail (where appropriate) and interpretative work (where appropriate) to develop a psychologically relevant account of the participants’ engagement-in-the-world.
- Appropriate use of triangulation (e.g. via methods, perspectives, data, analysts, fieldwork) or audit and/or credibility-checking (e.g. via respondents, supervisors, peers, parallel sample) to achieve trustworthiness.
- Appropriate use of extracts and commentary to achieve transparency (claims should usually be referenced to data, data should not usually be left to “speak for themselves”, and there should be substantive engagement with and commentary on some longer extracts of data).
- Appropriate levels of contextual detail for the extracts, participants, researchers, and study.

- Attention to process, including both analytic and reflexive components.
- Appropriate pitch and engagement with theory (in making sense of the analysis).

(Larkin and Thompson, 2012, p112)

Yardley's (2000) four principles of validity are often used to evaluate and demonstrate validity when using IPA and I have used these as guidelines to ensure my own research sits deeply within these principles.

- *Sensitivity to context*: A process of familiarising myself with the method of IPA, practising, studying textbooks and revisiting my own work, has given me a firm foundation upon which to build my research. I thoroughly understand the philosophy behind the method and have given much attention to my personal positioning within these philosophical principles. I have also paid close attention to socio-cultural settings, for each participant and for the study itself (e.g. current politics and trends within the broader field of mental health). Interactions and relationships have been taken into account, both during meetings with participants and during the analysis of transcripts.
- *Commitment and rigour*: The commitment to this research has been naturally fuelled by a deep interest and curiosity in the topic and a strong desire to do justice to the important project I have undertaken. This underlying attitude has assisted me in collecting broad and in-depth data, which has been analysed with dedication and rigour following Smith, Flowers and Larkin (2009) and Larkin and Thompson's (2012) principles.
- *Transparency and coherence*: I intend to show complete transparency and coherence throughout my research, from the research question and theoretical approach to

method, analysis and results. I hope the reader will find the presentation of my findings clear and easy to understand. There will, without doubt, be contradictions in the collected data (these are often where the richest aspects of data can be found). However, the analysis of the contradictions should not be contradictory.

- *Impact and importance*: It is hoped that the research will have some impact on the community concerned with insight, schizophrenia and the applications of care within these circles. Because of the lack of comparable studies looking into the personal experiences of disagreeing with one's diagnosis of schizophrenia, this study has the potential for real significance in bringing attention to this area. I intend to disseminate my study to these circles and seek to be published in recognised academic journals.

3.4. Alternate methods

There were other qualitative methods taken into consideration before deciding on IPA. I was interested in Grounded Theory (GT) (Tween and Charmaz, 2012), which is a method that can also be used to gain in-depth perspectives on people's experiences. GT holds a more positivistic notion of objectivity and has a pragmatic stance towards data analysis, focused on action, language and meaning (Tween and Charmaz, 2012).

The part of me attracted to drawing neat and solid conclusions was attracted to GT. This part of me tries to get to the bottom of what is going on for people with schizophrenia and will naturally theorise about the data (my personal experiences and observations of people with schizophrenia) that is put in front of me. GT can be found on a continuum from positivistic forms to post-positivistic to constructivist forms, where the aim is to produce a theory based on the observations of the researcher. This is not consistent with my epistemology. My view of my findings and conclusions is that they are very much interpretations and certainly dependent on me (my life-world and perceptions). I do not suggest that they can be generalised into a theory of what is going on for people who disagree with their diagnosis of schizophrenia. Given the research population and the limited number of people interviewed in this study, it is not appropriate to form a theory to be applied to all individuals who disagree with their diagnosis of schizophrenia. Instead, the themes found within the current population can be used to inform future studies using a much larger sample, for which GT may be an option.

I also considered Narrative Analysis (NA) as a possible method of investigation. It is one that aims to understand how people create meanings in their lives as narratives (Murray and Sargeant, 2012). The impact of social structures is highly relevant in NA, which is something I believe to be important to examine within the area of institutionalised mental health and, hence, for my area of research. It is also particularly interesting to understand the self through the stories we tell ourselves (self-narrative). This is relevant to my participants, who have been identified in a certain way (schizophrenic) against their will and how this impacts their self-identity. However, this aspect of identity and narrative can be looked at equally as well with the use of IPA, which I believe gives a broader and deeper understanding in response to my research question.

The emphasis on personal meaning making that hermeneutic phenomenology offers might be undermined with the use of NA and its more social constructionist epistemology. NA would, in that sense, give a very interesting point of view to my research question, although I believe it would be limiting compared to using IPA. The men and women in my research population certainly had a clear narrative around their experiences, but the essence of this research doesn’t lie in how their stories are told and unfold but, rather, in how their common experiences are felt and interpreted by the participants themselves. The complexity of this understanding can be portrayed in more depth with the use of IPA over NA.

Finally, Thematic Analysis (TA) (Braun and Clarke, 2022; Joffe, 2012) could possibly have been a fitting approach when entering a largely unexplored area. The purpose of TA is to develop patterns of meaning (themes) across a dataset that address the research question (Braun and Clarke, 2022). Theoretically, one of the advantages of TA is that it can be flexible and thus can be used to address many different types of research questions, including peoples' experiences, views and perceptions (Braun and Clarke, 2022). Because of its highly systematic and transparent method, it could provide good clarity and foundations upon which future research could build (Joffe, 2012). However, I feel that the double hermeneutic interpretative engagement that IPA offers over TA is very important for the more complex understanding of my participants' experiences that I want to gain. Furthermore, TA would not take into account each individual's meaning making as fully as it does the whole. A focus in individual meaning making is essential to my study in order to fairly give voice to each participant's unique perspective.

3.5. Reflexivity

Reflexivity is of great importance when conducting qualitative research because the researcher is using themselves and their own perspective in the analysis of the data. To get as close to the participants' experiences as possible, my own bias should be reduced. However, one cannot detach one's work entirely apart from oneself and, therefore, my personal experience of the topic will doubtless have an impact. Reflecting on my own values and opinions and how they impact my research at every step is, therefore, of utmost importance.

Following the discussion, there is a long reflexivity section in which my thoughts and internal processes can be followed throughout my involvement with this topic.

My experience with this topic comes from outside of me, in that I am seeing, hearing and reading about schizophrenia and the experience of disagreeing with a diagnosis, rather than having those experiences myself. I have never had a psychiatric diagnosis and I cannot say that there is any particular category that has been applied to me with which I have disagreed. In this sense, I have no personal or emotional conviction fuelling my interest or leading my perception. The interest that has fuelled this research—and my interest specifically in people with schizophrenia—can be traced to two significant sources. Firstly, *Madness and Civilization* (1961) by Michel Foucault made a huge impact on me when I initially started to see "madness" in the context of a historical spectrum: how society has seen and treated it in the past and how we view and treat people considered "mad" today. How will future generations see how we treat people within the mental health system today? The issue of "treatment" against someone's will should be discussed in our society, especially among people within the field of psychology and, more widely, mental health. We need to understand what the experiences are of those diagnosed and treated in a way that they themselves don't agree with. Secondly, during my first year at the Dpsych programme I was volunteering as a befriender for Mind where I met a woman (that we shall call Dr Mary) on a weekly basis. She had been given a schizophrenia diagnosis which she believed to be inaccurate, and the impact of it had ended her career as a doctor and had wholly negatively affected her life. Her story had a huge effect on me, and I felt very sympathetic to her situation. Dr Mary seemed to be the human form of the philosophical problem represented within the critical work of Foucault and Szasz. Schizophrenia is widely regarded as the ultimate form of mental illness: those who were "mad" in Foucault's text have "schizophrenia" today. This was the reason behind choosing to study people with a schizophrenia diagnosis. Furthermore, "schizophrenia" is a definable term and, therefore, much more suitable for research over a loosely defined term such as "madness" or "mental illness".

All my current experience with this topic under discussion in this research comes from a place of curiosity. Rather than trying to prove or disprove anything with my research, I am driven by curiosity and a wish to better understand the topic at hand. This attitude has been useful in approaching my participants' stories with an open mind: it has increased my ability to move as close as I can to participants' individual experiences. I had no particular expectations when meeting my participants—indeed, my experiences had taught me that personal experiences (and truths) are as individual as fingerprints, in that they can look remarkably similar at first glance but no two are ever exactly alike.

Nevertheless, I cannot entirely separate my findings from myself. My own philosophy and epistemology (as outlined above) are that we see the world through our own unique lens. However, what I can do is guard against allowing my biases and assumptions to come in the way of the research process.

I have reflected intensively on my own position in relation to the topic throughout the research, and continue to do so. It is important for me to know where I stand, which I haven't known in the past and have consequently thought about obsessively since I became engaged with this topic over six years ago. I kept a journal throughout this time to assist me in keeping track of and clarifying my thoughts and—because I am subsequently more aware of my assumptions—this has helped me to bracket them. I took this stance both when engaging with participants and during the analysis of their transcripts. I actively sought to put myself to the side and work with what is in front of me (a narrative and, later, a transcript).

When engaging with participants, I asked them for descriptions of the phenomena, in order to get as many details from their perspective as possible. I attempted to get closer to the phenomena and did assume that I knew what participants were saying: I frequently verified my understanding with them, reflecting back what I have heard them say, which often led to receiving further descriptions. My four-year training at the Existential Academy laid a solid foundation for developing the attitude of not knowing, which is very useful in protecting against bias, as well as I could.

3.6. Method

3.6.1 Participants

I recruited six men and women between the ages of 27 and 52 who had a diagnosis of schizophrenia but who did not agree with the diagnosis. The rationale for the chosen age group was that schizophrenia generally has an onset in late adolescence for men and somewhat later on in women and, therefore, anyone younger would be an exception to general schizophrenic development (APA, 2013).

Table 1: Participant demographics

	Age	Gender	Ethnicity	Length of diagnosis	Participant source	Location of interview
Rose	44	Female	White British	24 years	MIND	MIND Day Centre, Croydon
Bill	52	Male	White British	32 years	Facebook	Garnet Hill Centre, Glasgow
Stu	37	Male	White Irish	14 years	Facebook	Donegal County Library, Donegal, Northern Ireland
Ryan	42	Male	White British	22 years	Metro ad	Highbury Counselling Centre, London
Sarah	27	Female	White Irish	10 years	Facebook	Cork Counselling, Cork
Greg	36	Male	White Irish	17 years	Facebook	Malmaison, Belfast

The participant criteria for recruitment were that participants should be considered in remission and that they should not have been admitted to hospital within the last six months. Remission could have been achieved with or without the help of medication. A person who agreed with their diagnosis of schizophrenia was considered to be someone who did so verbally and/or behaviourally (i.e. complied with treatment) or simply did not verbally express disagreement with their diagnosis. A person who disagreed with their diagnosis was considered to be someone who verbally expressed this, even if they behaved in an accepting way (e.g. took their medication). Participants should have had schizophrenia as their most recent diagnosis.

Ethical considerations meant that potential participants should only be allowed to participate in the understanding that participation was of no direct benefit to them, other than possibly enjoying sharing their experiences and contributing to research in an area that affects them. They should not receive financial or other benefits. One person who contacted me was hoping that I could help them to challenge their diagnosis or, even better, help remove the label of "schizophrenia", which they did not think they should have. Due to ethical boundaries laid by Middlesex University, I did not interview that person.

3.6.2. Recruitment

I considered several options when recruiting participants. I wanted to reach a non-specific audience: this meant not recruiting specifically and only from the Hearing Voices network, for example, due to the clear connection the network has with anti-establishment ideas. I did not want my research to become a platform for certain pre-held ideas to be reflected. I advertised my study in the Metro newspaper, at MIND day centre sites across London, asked MIND staff to distribute my recruiting flyers, and advertised my research on Facebook.

3.6.3. Method

The goal of this study was to get as close as possible to the personal experiences of my participants. Therefore, a phenomenological enquiry was suitable because of how well-grounded phenomenology is in its explicit attention to human subjectivity. Specifically, I used the method of IPA because it focuses on individuals' lived experiences. This allowed me to focus on what is it like to be diagnosed with schizophrenia when you do not believe yourself to be mentally ill. With the use of IPA, I would be best able to study the meanings my participants derived from these experiences and how they made sense of them.

I did not aim to produce general "facts" through my research. Instead, through my own interpretation, I gained access to my participants' specific experiences and produced much more ideographic results. IPA also recognised my role as a researcher, whereby my own perspective and experiences might impact how I made sense of participants' experiences.

I conducted semi-structured interviews with my participants, beginning with the question "what is it like to have been diagnosed with schizophrenia when you feel you don't have this diagnosis?". My training in phenomenological enquiry was then applied to extract data that was as rich as possible.

3.6.4. Interviewing

The interviews were conducted using a semi-structured interviewing method. I wanted the interviews to be very open so that participants could speak about what came to their mind when reflecting on disagreeing with their diagnosis. However, I had prepared a sheet with questions and areas that I would potentially like to cover with the participant, as follows:

Can you start by telling me a bit about yourself and your situation?

You have a diagnosis of schizophrenia, but you disagree with your diagnosis. Can you tell me about your experiences?

Can you describe what you disagree with/ how you disagree?

What are your experiences of the mental health system?

Are you taking medication/ have you taken medication? What are your experiences of that? How does that impact how you experience yourself and the world around you?

How have you experienced doctors? Nurses? Have you had therapy? How was that experience?

Has your disagreement with your diagnosis been consistent? Always rejected it? Have there been moments in the past when you have agreed with it? Has it been confusing?

How do you view yourself/ your life?

How do you view schizophrenia?

Have you met other people who have been diagnosed with schizophrenia? How was your perception of them?

Have you experienced stigma?

How do you view mental illness/ mental health?

Do you feel the schizophrenia label has affected you? How?

Do you feel you can have open/ honest conversations with people involved in your care?

Do you feel listened to? Your opinion valued?

Areas: Label, stigma Self and others mental health system

(Appendix IV)

It is important to note that, a lot of the time, these questions were not asked as directly as they are written on the paper but, rather, arose naturally during the conversation. Not all questions were covered with each participant. I did not want to fall into a "question and answer" style of interviewing, which I feel direct questions often lead to. This way of interviewing can be rather restricting; an open and non-directive interviewing style gives much richer idiographic data.

3.7. Method of analysis

I began by transcribing the interviews. I listened to the recordings carefully while typing out the content, including pauses and sounds (e.g. laughs). This gave me the opportunity to further familiarise myself with the transcripts. Once transcribed, I read and re-read the transcripts and wrote down comments in the right-hand margins. The comments were initially descriptive and close to what the participant said, paraphrasing and/or clarifying what they had said. As I went through the transcript again, the comments tended to become more interpretive and I would write down thoughts and ideas I had about the text. This included use of language that stood out if, for instance, the participant had used unusual and/or descriptive language, metaphors or sayings. Finally, I went through the transcript looking for meaning beyond the words. I identified emergent themes (which, at that point, resembled ideas more than labels) and wrote these down in the left-hand margins. Below is an example of my initial notations and associated emergent themes for a section of transcript.

Table 2: Transcript excerpt: Rose "p11", p.2.

Emergent theme	Verbatim	Descriptive	Interpretive	Researcher's reflections
Illnesses as words-images that can be related to Reasoning with self of the "reality" of experiences	And now I might be moving on or I might not be. Erm…, they said that I had like an "emotionally unstable personality disorder" as well so I thought "yeah that's probably a part of my diagnosis". But when they said, wrote down, that I had paranoid schizophrenia I was really stressed and angry and I don't think I have. I mean I've had these, from 2000, 2000 and 2001, I've been hearing these, these voices, through my ears, like me and you talking. And I... I can hear them saying paedophile and prostitute and They are not nice voices. But I don't have them in my brain.	Emotionally unstable personality disorder is accepted as probably part of her diagnosis. Paranoid schizophrenia rejected and being connected with these made her feel stressed and angry. Connects paranoid schizophrenia with hearing voices and negative experiences (not nice voices). Hears voices through ears, not inside her brain.	Emotionally unstable personality disorder are "normal" (not crazy) words (can hear and understand what it is) and can therefore be related to and accepted. Rejecting paranoid schizophrenia pushes away stress and anger? Unusual experiences connected to being unwell Rejection of label, acceptance of experiences	Rejection of stigma What does being "stressed" mean?

Table 3: Transcript excerpt 2: Steve “p3”, p.2.

Emergent theme	Verbatim	Descriptive	Interpretative	Researcher’s reflections
Inner “knowing” is the strongest force of guidance	Part of me thinks that is might be right, but the other part of me thinks that it isn’t, in that... just to be brutal about it... my sensual... I’m not sure you would call it a belief cause it’s sort of real, is that I’m evil, and that my aim is to sort of help the ending of the world. And to me that’s more real than the diagnosis of schizophrenia.	Questions intellectually whether the diagnosis is right, but the felt experience is that he is evil, which is more real to him.	There is an openness to the diagnosis but the felt sense trumps logic – felt sense as “truth”/reality Need/wish to be authentic/ true to himself	Difficulty expressing this – aware of how it may sound
	The people who treat me have spent loads of time sort of talking about the symptoms of schizophrenia, and we spent in my last CPN we spent a couple of days going through all my notes, all my hospital notes and she would say, look this is when you stopped taking medication, this is when you went into hospital, this is when you started taking medication and this is when you were at home. And for about a day I said “yes, you’re right, what I do really have is schizophrenia, it’s completely true” and then somehow, I turn around and	Willing to go through notes to look at the relationship between hospitalisation and medication, initially being convinced	Open to information about a contradicting view of one’s self – a self that is unwell, and to be convinced of diagnosis	

Schizophrenia as having illness (not being schizophrenic) Being true to self	say, “it’s not right, what I really am is this evil person”. And I think I’m different from a lot of people who disagree with their diagnosis of schizophrenia in that if I could believe I had it, I would be delighted. Because it would mean that I could stop thinking I was evil, or at least question it better, because I’d much prefer to think that I’m not someone who pollutes all the people that he loves, just than someone who’s got an illness, that would be lovely, just to have an illness, and I’d take my medication and everything. But a lot of me thinks that it’s just not true and I shouldn’t take my medication, I should just be what I really am. The problem with that is when I know what I really am, is that I try to kill myself.	When shown notes he can believe he has schizophrenia for a short time, but comes back to believe what is right, that he is evil Would be happy to have an illness over what he believes is true (being evil) Sees himself as polluting the people he loves He should be what he really is, which is achieved by not taking medication, but results in suicidal ideation	No choice in listening to reason when one’s being is telling a different truth Self-hatred over his “true” self Has a need to be true to what he is Medication blocks his way to be true to himself, but he doesn’t want to kill himself	Having vs. being.

				Paradox in “willingness” to die to be himself (authenticity over life), but doesn’t want to die Implications of “the truth”

After noting down all emergent themes in the transcript, I printed them out on paper and began to form them into clusters. Some themes were dropped if they began to feel weak or irrelevant and others were brought together to form a clearer or stronger theme. I kept a reflective journal throughout the interpretive process and kept a critical eye on myself while engaging in the process, keeping aware of bias as much as possible and trying to stay close to the transcript while allowing my interpretations to arise. An average of 96 initial themes emerged from each transcript. These were then arranged into clusters.

I wrote down the headlines of the clustered themes and continued to engage with the themes through a process of noting down my thoughts and ideas about each headline/theme. Each transcript produced between 13 and 28 clusters. The mean number of clustered themes was 21.5. I assigned a different font to each participant so that, when I printed the clustered themes, I could easily see which theme originated from which participant, as I began to further organise them into new clusters. This was very much a bottom-up process, although some of the original themes were strong and carried straight through up to the final themes and superordinate themes, while others were less strong or recurrent across the transcripts but appeared important. This process resulted in 12 themes, 8 subthemes and 3 superordinate themes.

3.8. Ethics

In accordance with the British Psychological Society, an important concern when conducting qualitative research is to cause participants as little harm as possible and practice respect for their autonomy and dignity (2012). Middlesex University ethical guidelines were also considered, requiring complete transparency by the researcher, as well as openness and clarity of purpose and procedures of the project (Research Handbook, 2013).

It was important to create a safe and non-judgemental atmosphere when interviewing participants—both for their well-being and for the quality of the research (i.e. what is being shared).

Before interviewing, I considered the possibility that participants might find the interview stressful and ostracising, having claimed previously that they are not mentally ill. Professionals may have dismissed this view as part of their illness and, therefore, I approached participants with care and empathy.

I considered the likelihood that participants had felt and continued to feel misunderstood and that their opinion did not matter to professionals and other people in their lives. Being interviewed by me may have felt like an opportunity to be fully heard and that their story was being taken seriously. Because of this, it was very important that my participants fully understood that, by taking part in this study, they were helping me and that this would not have any influence on their healthcare. Telling me about their experiences did not mean that their case would be re-evaluated by a psychiatric professional and would not bring amount the opportunity to rid themselves of the label. I took measures to ensure this was fully understood by clearly stating this in the recruitment letter and repeating it verbally when they signed the consent form.

Because I expected personal and sensitive material to be discussed during the interviews, I used my therapeutic skills to keep participants contained in our meeting and made sure they were stable and in a good frame of mind when leaving the interview. In case participants wanted to discuss anything that came up further, I had typed up a list of professionals they could contact for counselling or support in their local areas, such as GPs, the Samaritans and counselling charities.

As I was to be interviewing people with a schizophrenia diagnosis, there was a potential risk that they might be actively psychotic during the interview. I was, therefore, prepared for the possibility that they could have a psychotic episode during the interview, which I would feel unable to handle. Were this to happen, I planned to terminate the interview and I made sure there were other staff at the interview premises location.

I took measures to ensure participants' anonymity, changing names and identifying details and saving this information as an encrypted file. I transcribed the recorded interviews myself and plan to delete the recordings and transcripts once the dissertation has been marked.

I have given participants my contact details in case they wish to withdraw from the study for any reason, in which circumstance, their data would be destroyed. Should anyone contact me wishing to talk further, I plan to direct them to other supporting services.

3.8.1. Informed consent and debrief

It was important that the participants had a clear understanding of the aim of the research and what participation entailed. Therefore, I emailed the information sheet (appendix iii) to them several days before the arranged meetings, giving them time to read and, in their own private time, once again fully consider their participation. I also brought the information sheet with me prior to the interview and went through it with them before they gave their written consent.

After the interview, I asked the participants about their experience of having taken part in the interview and was prepared in case they felt the need to further discuss their experiences with a counsellor, having printed out a sheet with organisations in their areas they could contact for support, e.g. the Samaritans and local counselling centres. I also gave them a debriefing sheet, which I went through with them; it gave further information about the topic, the research and my contact details as well as my supervisors'.

4. Results

I was surprised by the significant variation of experiences each participant had in relation to disagreeing with their schizophrenia diagnosis. The themes that surfaced reflect this difference. The participants did share some experiences while having very different narratives. The results will show both themes that were shared by all participants and experiences unique to individual participants.

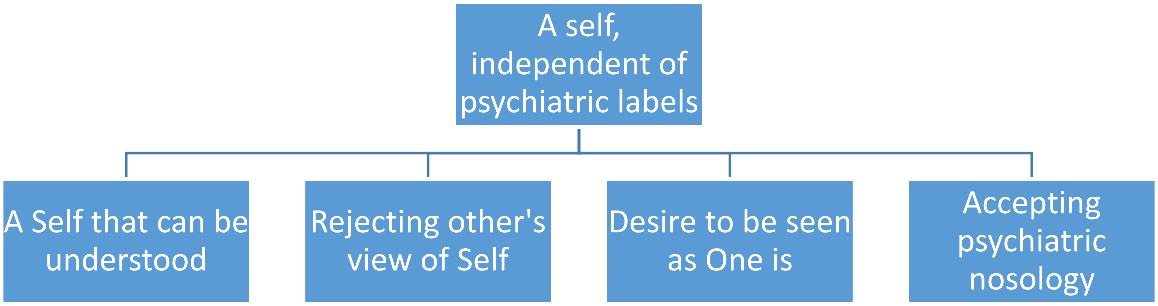
As a general rule in the results, I have identified themes that are rather broad and then go into detail about how these broader themes were experienced differently by different participants. For instance, in the case of the stigma theme, some participants struggled with self-esteem and held a lot of stigma towards themselves. Others were plainly angry about being treated in particular ways due to their label. Some had a greater understanding than others of the difficult social relationships that came with mental health problems, i.e. experiencing stigma but not blaming others for it and feeling victimised because of it. The results section will showcase experiences such as these, which were often complex and so required detailed and in-depth analysis.

Using Interpretative Phenomenological Analysis, three superordinate themes were identified:

I. A self, independent of psychiatric labels.
II. Stigma and being part of society.
III. Moving away from “mental illness”.

4.1. Superordinate theme I: A self, independent of psychiatric labels

Figure 1: Superordinate theme I: A self, independent of psychiatric labels



There was a strong sense of wanting to get to a place of authenticity—to be one's true self and not be identified by a psychiatric label. This was shared by all participants and meant attempting to have a secure sense of who one is and to be able to live with this image of who one is, through a process of making sense of one's experiences, incorporating old and new self-images and a strong need to listen to one's inner knowing (inner truth/inner felt-sense truth). There was a need to reject other people's views of oneself in order to protect the image one has or wishes to have of one's self.

All participants had a desire to be seen by others in the same way in which they saw themselves: they expressed a desire for their true selves to be expressed and accepted. There was an acceptance of psychiatric nosology (and of schizophrenia as a psychiatric illness); however, this was not applied to their own self. Having the label schizophrenia put upon participants (without them agreeing with it) was a struggle for five of the participants; it often meant conscious or unconscious avoidance of the label, rejection and confusion, and was associated with negative feelings.

4.1.1. A self that can be understood

Attempting to get to the point of having a self that can be understood was a broad theme comprising making sense of and applying meaning to one's [unusual] experiences and having a narrative about the circumstances of one's situation. This was shared by all participants. These ways of trying to understand what is going on were at times straightforward and clear to the participant:

> I believe there are three main approaches [to psychosis]: biological, psychological and spiritual and all three should be looked at. I do believe there is an intelligence behind it. I don't believe it's just voices in my head. I talk to them and they talk back to me and it's very oversimplified to say it's all in your head. (Greg, lines 13-17)

There was a tendency to think back to when their unusual experiences or the cause of their suffering had begun. This resulted in attempts to work out why it had started, thus revealing having invested some time and thought into creating a coherent self-narrative. Greg described the first time he heard a voice:

> I had depression, but never got treated for it. I perhaps should have got treated for it. I heard a voice come out of the wall saying 'you play guitar really well'. It was a guy sitting across from where the voice came from in the room. I thought it was telepathy. (Greg, 18-21)

At times, participants' ways of making sense of their experiences were more subtle. This was particularly true for those who were still in the process of trying to come to a conclusion that they could hold as true. Rose described an instance in which she applied logic to make sense of an otherwise illogical situation.

> Rose: [my care coordinator] says ‘Rose, it’s not real’ and I say ‘yes, it is real’, because if... I don’t know, if [they use] CS gas spray or, but I can never see them.
>
> Researcher: Sorry what’s CS gas spray?
>
> Rose: Some sort... you spray and they can spray in your eyes and you cannot see them. (Rose, 141-143)

In this instance, she could not see her perpetrators but, listening to her felt-senses, she knew that they were there and believed they were spraying something in her eyes, rendering her unable to see them.

Greg attempted to make sense of what he was experiencing by generating theories that could fit with what was happening to him:

> You get in a bad way and the brain is like a computer, and computers get viruses in them. Maybe that’s what it is, I don’t know, but it was too full on and I believe what happens. Continuing the computer analogy: computers can get hacked into, then can humans be hacked into? (Greg, 79-82)

Here, he revealed how his inner belief comes first: the theory is generated afterwards to fit in with what he already believes to be true. He still questioned his theory and appeared open to it being amended until it could become firmer.

There was a need to be able to fit the personal theory into their experiences in a way that felt right and described what was going on for them so that they could have a sense of ownership over it and it would make sense in a way that was personally meaningful to them.

> I recently came to see it like with epilepsy or what do they call it? Temporal epilepsy when they can have like the seizure sort of thing. I would just say, if I was explaining to someone I would go... like I went to this swimming pool and they were playing this really loud dance music and it was really crushing on my head, so I would say […] 'listen, I've got a brain seizure, you know the music is really hurting me. Can you turn it down?' But the last thing I would say to people is oh you know like, 'I have schizophrenia'. (Stu, 130-137)

In this way, the label "schizophrenia" did not attribute any meaningful understanding to what participants were actually experiencing. Rather, Stu demonstrated here an anticipation of how this label would distance others from an empathetic understanding of his experiences. His description is one of anticipating stigma.

The need to make sense of one's self and situation meant there was a wish for engaging in talking therapies:

> I wanted to explore why I was feeling the way I was feeling, why my life was the way it was and make sense of it. (Bill, 443-444)

To the participants, the engagement with therapy was not about curing themselves, but about making sense of what was going on for them—self-affirmation rather than correction.

The theme A self that can be understood comprised having a personal understanding and narrative around why it is that one is having the experiences one is—a personal aetiology.

Sarah made the direct link of trauma as the root of her voices, which she applied as a general theory to the mind:

> I'm a person who went through unbelievably traumatic events. Do you know, from day one, I've experienced child sexual abuse, emotional and physical abuse. […] Of course, when you traumatise, you split, you go into these kind of shattered selves and they appear as voices, they appear as visions, they just appear as whatever. (Sarah, 36-46)

Here, she revealed a certainty about her beliefs, both personally (i.e. what is going on for her) and about a universal understanding of hearing voices.

> You're wrong, you're wrong, you're wrong. You're saying I'm diseased? I'm not diseased, never was. I've been traumatised. This is the reason I'm in here and you're not listening. (Sarah, 167-170)

The strength of Sarah's conviction here assisted her in being able to put herself on the path she needed for recovery (which was not the same path as professionals had in mind for her).

Having a self that can be understood involved considering their position and beliefs so that these beliefs became clearer to them – they strove to became convinced by their beliefs and could express them with conviction. Participants seemed to be striving to get to a place of certainty in their beliefs (or conviction of their beliefs) so that their image of themselves could be understood and make sense to them. What they could already feel was going on for them led them to draw conclusions and find evidence to back these beliefs. What they could feel was real came before identifying themselves by a psychiatric label, even if they were able to consider it:

> Part of me thinks that [the schizophrenia diagnosis] might be right, but the other part of me thinks that it isn't. Just to be brutal about it, my central... I'm not sure whether you would call it belief because it's sort of real, is that, is that, I'm evil and I sort of may be taken over by a devil. My, my aim is to help the ending of the world. And erm.. that to me is more real than the diagnosis of schizophrenia. (Bill, 25-29)

Arriving at a place of belief conviction involved a process of participants reasoning with themselves. Although stating with certainty that she did not have schizophrenia and was certain about what was happening to her, Rose expressed uncertainty about how to make sense of her experiences.

> But I hear them through my ears so I think to myself it's for real and then, it is for real when I'm being touched. [...] I cannot even see the scars that they've done. I can really feel it, but I cannot see it. (Rose, 184-188)

The need for certainty was not only demonstrated in terms of attempting to reach a position where one's understanding could be held as true but also involved a desire to receive a level of certainty from professionals. There was a perceived lack of clear communication in mental health settings, which participants found to be frustrating and discouraging.

> I was given a diagnosis in hospital […] I think it was severe depression, they change it all the time, it's very vague. (Stu, 22-25)

Participants wanted to know about medication and schizophrenia but experienced not being given sufficient answers:

> I just think psychiatry is, I don't know how they work or whatever […]. Like my old prescription, I don't know if they do a lot. Everything's anecdotal

> is what I’m saying so I can steer it any way I wanted potentially. (Stu, 155-157)

Not knowing professionals' intentions was experienced negatively and had the effect of the participants distancing themselves from professionals.

> I don’t know what he was trying to achieve […] and it would feel awful. So I stopped going to see him. (Bill, 378-380)

In contrast, certainty and control were experienced as positive:

> He was very warm and very... he took control to a certain extent, which was nice because I didn’t have any control. I felt held and looked after. (Bill, 387-388)

Contradicting this, when professionals expressed certainty about a participant’s mental state (insisting on saying they had schizophrenia and that their experiences were not real/were only in their head), this led to negative feelings—feelings of not being understood—and led to participants distancing themselves from professionals.

Participants appeared to be seeking the type of information that appealed to them, in order to make their theories about themselves or their experiences stronger, to form a firmer positive self-image, which could be owned.

> I think that evidence has shown that the wider population base in general humans has... anyone can be prone to this. They are relating it a lot more to trauma and stuff like that. (Stu, p.6)

Here, trauma is something that can be experienced by anyone, removing the participant from a self-image of being ill or diseased—that there is something wrong with him.

There was an acceptance of having mental difficulties when these were described with more acceptable words and words that could be understood and related to. Being described in the more negative way as having "paranoid schizophrenia" elicited stress and anger. The extract below shows such an instance of accepting more neutral words and rejecting negative ones.

> They said that I had like an Emotionally Unstable Personality Disorder as well, so I thought yeah that's probably part of my diagnosis but when they said, wrote down, that I had Paranoid Schizophrenia I was really stressed and angry. (Rose, 67-70)

Emotionally unstable personality disorder offered Rose a certain diagnosis where the words matched her lived experience – it could be held as true. Paranoid schizophrenia, although a certain diagnosis, did not match her experiences and could therefore not be held as true.

When asked how this emotionally unstable personality disorder affected her, she responded: "I don't know. I don't know much about the illness" (263), seemingly conveying a preference for the *words* of which this label consisted (and to which she could relate) over those of the paranoid schizophrenia diagnosis, rather than understanding the diagnosis at any great depth.

From this more neutral label, which highlights the emotional part of a disorder, a self-identity could be created around being emotionally unstable. The participant could tie this in with their past experiences and create a coherent self-narrative, having come from a background of abuse. In this sense, she had created her own personal aetiology that was distinctive from that of others around her (e.g. family and professionals). As such, she was creating a self-image that she could understand within the context of her experiences.

At times, arriving in a place of self-understanding involved the need to allow for living in contradiction. This excerpt demonstrates a conflict between listening to one aspect of Bill's self with which he identified (logic) and needing to listen to what his inner knowing told him is the truth. There is a willingness to comply with professionals' views, but it doesn't trump what he believes in his heart.

> Everyone not only thinks I have schizophrenia, but think I should take my medication, and if I sit down and listen to the logic and reason with which they speak, I can see that. But my heart doesn't want me to. (Bill, 115-117)

Although there was a strong need to make sense of one's self and experiences, there were times when logic and reason had to be released in favour of allowing what one 'just knows' to be expressed. Sometimes, participants demonstrated an avoidance when faced with the task of making sense of experiences that they 'just knew' were, right when logic was difficult to apply. Bill, however, demonstrated good self-knowledge of this process and reached a point in which he came to terms with living in contradiction:

> That's where it's so silly because, I don't know, I find it very hard, because I am usually quite logical. I think I'm an atheist who believes in devils. Or that I'm a devil anyway. Which I don't really understand. (Bill, p.8)

There was an attempt to form and keep a positive self-image that could be owned. However, negative feelings towards one's self interfered with the maintaining of a coherent positive self-image.

> It’s like you’re disgusting to people; I do suffer from voices and hallucinations and I get quite depressed, suffer from depression and various things, like a lot of people. These things are probably a bit more amplified in me. (Stu, 52; 82-84)

Stu demonstrated a struggle between being aware of his interpersonal difficulties and attempting to have self-compassion, neutralising his negative experiences. However, he demonstrated insight into his experiences/condition without much defensiveness, appearing to have formed a self-image that he understood and made sense to him.

4.1.2. Rejecting other’s view of oneself

There was a rejection of other people’s views of oneself, which was shared by all participants. They felt that the label schizophrenia came with many negative images and presumptions with which they did not identify. In connection to the term schizophrenia, Stu describes feeling like an outsider:

> Those terms (schizophrenia), I don’t think they help. […] it’s like being Frankenstein, something like that. That’s what it’s like for me in my community in a small town. (Stu, 86-88)

There was a rejection of ‘being mad’, with which the label schizophrenia was perceived to be synonymous:

> They are saying ‘you’ve got schizophrenia and you hear voices; you’re mad, you’re mental’. Inside, I don’t agree with that. I say ‘no, I’m not mental’. (Ryan, 78-80)

As previously mentioned, participants strived towards being able to hold on to a positive self-image. This involved rejecting others' (negative) views of oneself as an attempt to strengthen one's self-image. Below, Stu described how he had not been evidenced as pathologically diseased and how he confirmed his own self-knowledge as the most important, attempting to turn his back on people who hold the view that he is diseased.

> If people wanna come to me and start pathologising me or whatever you just say 'go ahead, pathologise me if you want, I don't care, I know who I am'. If I know who I am myself and I know more about myself and see things a bit more… I mean there is no test for any of this stuff you know. It's not like any other condition where there is mostly evidence. (Stu, 364-368)

It was, perhaps, particularly difficult for participants to reject professionals' images of themselves because of the authority that trained doctors are perceived to have. Sarah described the need to listen to her inner knowing, to strengthen this by finding proof elsewhere and to reject professionals' opinions of her:

> I knew they were wrong, but I had to prove, even though… do you know when your intuition tells you something, but because you're dealing with medical doctors who all have degrees and whatever, where they are literally trained in this idea, do you know? I had to look elsewhere. (Sarah, 210-213)

Rejecting others' views of them was fundamental for participants to have any chance of survival—of being able to have a life—as the label schizophrenia comes with some dire predictions.

> It's insulting to a person like me because the minute you're given [the label schizophrenia], it's like you know, 'congratulations—you're

> schizophrenic'. So welcome to poverty, welcome to social isolation, do you know? There is no hope. It's immediately a stamp and it's like a big black cloud over you. (Sarah, 177-183)

Accepting being a chronic schizophrenic implied the need for medication and services for life, which Sarah did not want for herself:

> I sat with [the psychiatrist] for 10 minutes and I was 17 and when I got my medical notes he'd labelled me 'chronic schizophrenic' at 17. And on those notes it usually says 'I'm in the view that this woman has chronic schizophrenia, she will need medication for the rest of her life' and basically no chance of recovery, 'she will need services for life'. (Sarah, 415-421)

There was a strong sense of not being understood by others, not connected to others and, therefore, not receiving an empathetic response in relation to the difficulties one was experiencing. Participants expressed strong negative feelings in association with being disbelieved when sharing experiences with others, including annoyance, anger, sadness, isolation and loneliness. This often led to participants distancing themselves from the people expressing disbelief, which was experienced as a lack of support. The extract below shows such an instance:

> I get annoyed when people like say like 'oh it's your imagination' or you know... [I feel] quite angry about it. I have to walk away from the person I speak to sometimes. Sometimes I feel like crying. (Rose, 236-241)

Not being understood was experienced as isolating and leading to feelings of despair. To Rose, these feelings were so strong that she attempted suicide:

> I took that overdose when I was in that hostel, because it just felt like on one believed me and no one understood what I was going through. (Rose, 713-715)

Stu struggled with feelings of alienation and disconnectedness from others. The term schizophrenia did not invoke any meaningful understanding of his experiences—neither to himself nor from others—but was, rather, a term avoided because common associations with the term were synonymous with the negative term, “psycho”. Stu had, instead, learnt to use explanations with which most people could empathise. In that sense, he had learnt to take responsibility for making himself understood.

> [Saying] I’m feeling anxious’ or whatever, and ‘I want to relax for a while and step back’. I mean it’s kind of hard, saying those things. It is difficult and I always found it difficult to express myself, to be understood, you know. It’s always different but you have to. There is always more that you have to do it for yourself, ‘I feel a bit down’ or whatever. That’s a normal thing as well you know, people understand depression terms a lot more. (Stu, 484-489)

Not feeling understood by a person meant that participants often distanced themselves from that person:

> If you say to a doctor [that you disagree with your diagnosis of schizophrenia] they give you a cursory look and say ‘well as long as you’re taking your medication’, ‘you really don’t believe it, do you?’, ‘it’s just a cry for help’ you wouldn’t’… it’s none of their business. They don’t see what’s going on so I don’t include them in that. (Greg, 442-445)

To Greg, the closed-mindedness of the mental health workers meant that he saw no point in trying to tell them what was going on for him because they would only see his experiences through the medical lens: that he was schizophrenic. He revealed how speaking his truth was met with either a shutting down or worse, condescending comments, making Greg defensive and excluding himself from the person in question [doctor].

4.1.3. Desire to be seen as one is

Participants experienced a desire to be seen by others as they themselves felt they were—a desire to express their true self: “I have a thing that says I should be true to what I am” (Bill, 139). This proved difficult at times, as not only did others not understand or believe the participants’ realities, but participants often anticipated struggles in having their true selves accepted. This was shared by all participants.

By using logic, Bill tried to accept that he did, indeed, have schizophrenia, which was preferable than to what he believed was really happening (the he was evil). However, the need to listen to what his inner knowing or true self was saying and to express it was very strong, irrespective of the consequences (killing himself).

> For about a day I said ‘yes you’re right, I do have schizophrenia, it’s completely true’ and then somehow I turn around and say ‘it’s not right, what I really am is this evil person’. […] But a lot of me thinks that it’s just not true [that I have schizophrenia] and I shouldn’t take my medication, I should just be what I really am. The problem with that is when I know what I really am I try to kill myself. (Bill, 37-47)

The need to be seen as one is also took the form of self-expression—to be able to openly express or share one's experiences. Greg enjoyed talking to his voices and connecting with what he called his other reality. He expressed disappointment with his parents for not having shown any interest in this other part of him and just wanting him to take medication (thereby suppressing it):

> My parents would never show any interest into what my voices exactly said or who they were. They just put me on medication. I'd like to tell them about the voices and the ones I've met. (Greg, 164-166)

In hospital, there was a freedom to express his other reality and he was left alone to talk to his voices, which he found very positive:

> I had actually said to the doctor 'I don't want to live with my parents anymore' because I was living with the voices and they were ruining it […]. In hospital I went to get medication and I had a good time I was talking to all these different voices and people. (Greg, 43-48)

The desire to be seen as one is also involved a wish to have a certain extent of control over how one was viewed (and judged) by other people. Being identified as schizophrenic removed this control of one's self-image to a large degree. Below, Rose describes how, even if she managed to separate her own understanding of herself from the schizophrenia label, it would still not be entirely under her control, because other people could also label her this way, which she does not like.

> Rose: My ex support worker said to me it's only a label, don't worry about it
>
> Researcher: And how do you feel about that?

> Rose: I just don't want it printed on me, you know.
>
> (Rose, 507-512)

There was a wish not to be judged or categorised:

> I was like looking at people in the bus today, thinking, like, 'never judge a book by its cover'. Well that's true isn't it? Because you could see someone, they look well but they might not be well, or the other way around. (Rose, 664-670)

Being categorised as schizophrenic had an impact on how other people viewed participants, which, in turn, influenced their views of themselves. Bill described how his life took a different turn when he came out of hospital with a schizophrenia diagnosis. He was seen differently and began to identify as a different person to the one who went into the hospital:

> I think in a way it was quite a huge shock [being categorised as schizophrenic]. Because I had quite a privileged upbringing, I went to a private school and all that sort of stuff, and I was now a different person, or seen as a different person. (Bill, 356-358)

Once labelled with schizophrenia, there was a sense of a diminished self from the perspective of other people, as though participants' personal stories didn't matter when schizophrenia took the foreground:

> When you get labelled schizophrenic, it's like you no longer exist as an individual person. There are like millions of people diagnosed with schizophrenia now at this stage and you're all put into that one bracket. All those millions of people are not just one thing, like they all have stories,

> they've all their own life experiences, they've all their own ways of dealing, hoping, everything, but the word 'schizophrenia' just clumps you into one thing. (Sarah, 379-384)

Becoming identified by aspects other than just being a patient was experienced as healing:

> I just don't want to think about it and try to get on, things are pretty good at the moment, trying to get a job of security with the health services. All these things take a lot of time but things are pretty good, there is things happening, like there is stuff getting us involved which is pretty good, it makes a difference compared to just being seen as a patient. (Stu, 407-411)

Here, Stu explained how experiencing other roles gave him value as a person and implied a detachment from the image of being a patient.

4.1.4. Accepting psychiatric nosology

There was an acceptance of psychiatric nosology by three participants. Two rejected the label schizophrenia when applying it to themselves, whereas one told his doctor he had schizophrenia because he knew that's what outside society would call what he was going through, believing the label to be a "blanket term for that reality" (Greg, 216)—but one that is limiting and not understood spiritually (hence accepting psychiatric nosology, albeit not believing in the medical model for mental illness). Bill came from a position of knowledge about schizophrenia as a psychiatric disorder but rejected having it based on his inner beliefs:

> I think I'm different from a lot of people who disagree with their diagnosis of schizophrenia in that if I could believe I had it, I would be delighted because it would mean that I could stop thinking that I'm evil, or at least

> question it better, because I would much prefer to think that I'm not someone who pollutes all the people he loves, than just someone who's got an illness. It would be lovely just to have an illness, and I'd take my medication and everything. (Bill, 39-44)

It was necessary for participants to have a view on psychiatric illnesses because it was with one of those illnesses that they had been categorised: it seemed important to them to have a self-narrative that could be compared and contrasted with this view. For Rose, schizophrenia was viewed as hearing voices in her head, coupled with delusional thinking, and was equated to 'being crazy':

> [Schizophrenia means] voices, thinking you could be the Queen or whatever (laughs) I don't know, but I haven't got it. (Rose, 274-275)

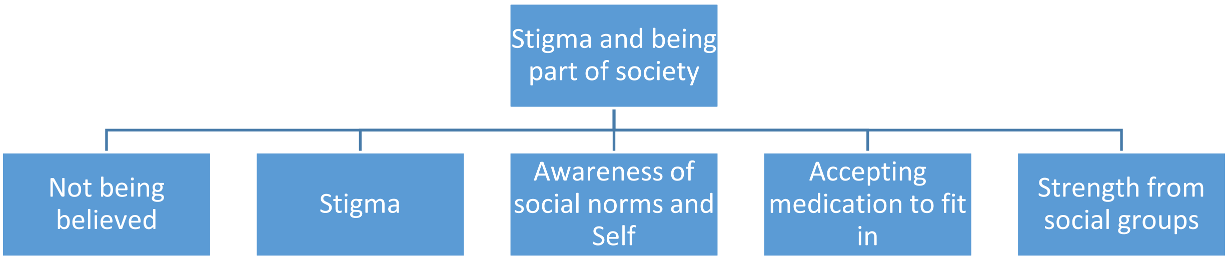
Here, she revealed holding a certain stigma towards the label herself, laughing at the delusional thinking of the hypothetical person with schizophrenia. She also revealed a rejection of the label based not on careful thinking but, rather, on impulse feeling:

> I actually saw on a piece of paper that I had paranoid schizophrenia at X Hospital, and I didn't believe it then and I still don't believe it to this day. But like I had Borderline Personality Disorder. (Rose, 33-36)

Rose seemed to perceive other psychiatric illnesses as more acceptable than schizophrenia. She laughed at schizophrenia seen in the way she described above—voice-hearing and delusional thinking—which didn't match her experiences. Rose didn't reveal how much factual knowledge she had of borderline personality disorder (BPD), but accepted it as a mental health disorder and was able to accept the label of that disorder. An important distinction here is that, by accepting the label BPD, it could form part of her identity but was not a depending factor. She could still be Rose, with all her imperfections, whereas schizophrenia appeared to hold so much potency that it overtook all other defining factors. Paranoid schizophrenia imposed a new identity that could not be held alongside the identity of ‘regular Rose’: it was a new identity that she rejected.

4.2. Superordinate theme II: Stigma and being part of society

Figure 2: Superordinate theme II: Stigma and being part of society



The superordinate theme Stigma and being part of society was based on participants’ feelings about themselves in regard to where they fit in or did not fit in societally. It was about social inclusion and exclusion, and stigma and the cost of social acceptance.

4.2.1. Not being believed

There was a sense of not being believed by other people; of having participants' realities doubted. This was shared by all participants. To Sarah, it was not about having the voices she heard believed by other people but, rather, about having her stories and personal narrative about her distress heard, instead of being seen only through the lens of being diseased:

> They don't listen to your stories, they don't take it into consideration. First of all, they don't have time, you get about five or ten minutes with a psychiatrist and then it's all medication. It's all medical based. Everything you do is under some bracket of disease. (Sarah, 171-174; 190)

Sarah experienced how the reasons behind the suffering—the humanness of distress—had been removed and replaced by an objectional disease for which medication was the answer. Her subjective experiences were not of significance to the psychiatrists and she believed that that was wrong.

All participants expressed many negative emotions in relation to not being believed (and not being taken seriously) by others—such as sadness, anger, frustration and humiliation—which often led them to distance themselves from the people expressing disbelief:

> In hospital it's awful […] every day you see a psychiatrist and they will be assessing you and every day they and the nurses will say 'we understand this is something you believe and it's your reality but for us it's not true'. And it just gets like a trite, boring, humiliating phrase. You have to tell them what you believe and then they have to say they don't believe it in such a way that it's inoffensive, but it is offensive. And it's also humiliating having to say

> stuff you know people just think confirms how ill you are in their eyes. I really hate it in hospitals when they do that. (Bill, 682-690)

Participants felt that their experiences were dismissed by others as madness and were not taken seriously, because of their label of schizophrenia. Ryan expressed how his diagnosis meant people might not listen to him because they saw him as mad:

> When you get diagnosed with schizophrenia you never get believed. You might be mad, they might not agree to talk to you. (Ryan 114-115)

The sense of not being believed was true both in regard to dealing with professionals and when talking to people not related to their care (such as myself), as shown in the following two extracts:

> I get very sad [when doctors tell me I have schizophrenia], very low. I know there is nothing wrong with me. (Ryan, 31)

> If I say I was tortured by police officers, would you believe it? Police tried to kill me: would you believe it? It's like being raped: would you believe it? Honestly, it's all true, but if you're somebody who, like yourself, doesn't know me it's gonna be really hard to know. You're gonna think: is it true, or isn't it, 'cause you don't know. (Ryan, 608-613)

The wish to be believed was strong. Rose described asking a person to do a post-mortem on her if she died:

> It's not me who's trying to kill myself. I said to someone, I can't remember exactly, but I said, 'look, do a... post-mortem, do a post-mortem on me, if I did ever die, 'cause it's not me, it's them'. (Rose, 466-468)

Here, she is looking for the truth of her experiences to finally come out into the open after her death, demonstrating that it was not all in her mind and proving the reality of the terrible things she felt were happening to her.

4.2.2. Stigma

Stigma was a background theme for all participants and it seeped into many of their other experiences: feeling different or overlooked and wishing for acceptance were all woven into the experience of being met by and/or anticipating stigma.

Sarah felt that schizophrenia was viewed by others as an illness one has and as something one is, for life; she wished this perception would change:

> The way society views schizophrenia is that it is a tag for life. It's not. It's not anything. Schizophrenia is nothing. (Sarah, 433-435)

To Sarah, who was well-read on the topic, the label schizophrenia was a term so loosely defined and poorly applied that it really meant nothing to her. She wished that others would also see it this way.

The data analysis revealed how complicated the construct of stigma is. There is the reality of the experiences that participants had about other people's behaviour and reactions to themselves:

> I felt very stigmatised by [the label schizophrenia] for a long time and very much so by the community and everything, like people chasing you down the street and shouting at you and things like that. Basically abused for over 10 years. (Stu, 60-63)

Negative experiences of how other people treated participants were often attributed to the label of schizophrenia:

> I complained about [the label] that I had problems with it, like it hurt me a lot. It made me very agitated and angry and all that. I suffered a lot and it hurt me a lot I would say. It's probably taken years out of my life. (Stu, 330-332)

However, Stu had insight into his interpersonal difficulties (communicating with other people) and expressed annoyance, frustration and a reluctance to engage with others. These experiences would still be true, whether or not the other person knew he had a diagnosis of schizophrenia. In many ways, his experiences of stigma were intertwined with his low self-esteem and were partly an expression of the frustration he felt and the unfairness of that, which was rooted in the difficulties caused by his mental health problems but were attributed to stigma:

> You don't have to feel inadequate or less than somebody else. (Stu, 290)

Bill was aware of the self-stigma he carried, which he believed to originate from other people rather than himself. He detached his behaviour from stigma in such a way as to be able to view the results of his actions independently from the excuse of mental illness:

> I think I probably have what you might call self-stigma, but in many ways, I think it's just prejudice directed against you from other people. I think some people assume that the shame I feel for what I've put people through is a form of stigma because I should feel no shame for having what people see as a mental illness, but I feel ashamed whether it was willingly or not, many people suffer incredibly. (Bill, 552-557)

He demonstrated real insight into the complexity of stigma and did not feel unfairly treated because of a label, but felt that the reality of his experiences was fundamental to his experiences of stigma:

> Now to say that [my wife] was stigmatising me because she would sometimes lose her temper and maybe call me a ‘schizo’ or ‘psycho’, or she would say ‘Bill, I’ve spent my life with you and you don’t know how to love me because you’re schizophrenic’ is true to stigma, but it’s also built on the agony that we put each other through. And that probably is because of what that schizophrenia thing is, but it’s also a real experience. To say that the experience is anything than horrific is really silly. So stigma becomes clouded with the reality of impairment and illness. (Bill, 568-575)

For all participants, it was necessary to have some acceptance of being connected to the group of schizophrenics (unwillingly put in that category) for stigma to arise as a perceived issue and to be aware that other people might see them as schizophrenic. Rose was largely unattached to the label and did not identify herself (even unwillingly) as a person with schizophrenia. She did not experience stigma; instead, her narrative revealed how she held stigmatising views towards people with schizophrenia:

> [Schizophrenia means] hearing voices. Thinking [one] could be the queen or whatever (laughs). (Rose, 274); I’m not one of these people who think Oh it’s the TV, I’m talking to the TV and the TV is talking to me (laughs). (Rose, 88-90)

Rose seemed to believe that people with schizophrenia were perceived as crazy and she did not experience other people as viewing her in that light.

Media was experienced as a strong contributor to the perceived negative image of schizophrenia, both the news and fictional media:

> Detective programmes with ritual killings and stuff, it doesn’t give you a very good image, you don’t feel too good about yourself!. (Bill, 589-590)

There was a desire for change in society, which was related to the stigma all participants felt was projected on them from society in general. There was a wish for understanding and acceptance.

Greg did not see his voices as a symptom of a disease but felt that he had special access to a different reality, one which was not accepted in our society. There was a wish to be able to live freely with his other reality out in the open, without feeling the need to hide it and comply with society’s rules in order to be accepted:

> Different societies have different ways, like the aboriginals they bring it out in the open and they do something about it, but that’s absolutely impossible in our society. (Greg, 175-177)

Greg showed a preference for how he believed aboriginal culture handled schizophrenia. It was unclear how much knowledge he had on the topic, but it seemed he would like our culture to focus less on medicine and illness. Instead, he wanted to be able to live with schizophrenia openly within a culture that could view schizophrenia through a spiritual lens, much like himself. The wish to be more open about his experiences also implied that, in his ideal societal circumstances, there would be much less stigma around these unusual experiences. Stigma, the fear of being judged or worse (e.g. ridiculed, beaten) was holding him back from being fully open:

> In like southern America and Africa or something they think it's a gift. They would go on to be shamans or witch doctors. They think people can learn a lot from people who have undergone psychosis, especially with regards to things like compassion and stuff. You've got to be compassionate to these voices all the time, otherwise they'll start accusing you of things, and you have to be relaxed and be at peace and things like that. (Greg, 359-362)

Greg also pointed out the value that can be found in psychosis and the life-lessons that can be taken away from it, which is not part of our society's narrative about mental health. He described how learning about compassion and being at peace with oneself have been essential components in being able to live with his experiences, and that this could be a gift from which others in society could learn.

4.2.3. Awareness of social norms and self

There was an awareness of which behaviours were perceived as normal and which were perceived as mad in society, even if such "madness" was, in fact, perceived to be true by the participant. Often in social settings, this perceived unacceptable behaviour was hidden in order to protect participants from ridicule and social exclusion. This feeling was shared by four participants.

Although Greg rejected having schizophrenia on the basis that his experiences were real and not symptoms of a disease, he was aware of how his experiences were viewed in society at large and explained through the medical lens of schizophrenia:

> Before I went to see a doctor, I knew that outside society would call what I have schizophrenia so when I went to the doctor, I said I have schizophrenia

> because I knew that's society's term of what I was going through. (Greg, 218-221)

There was an understanding of social norms and a desire to apply to these:

> [If you're not careful] you're gonna ridicule yourself, people are gonna laugh at you. (Greg, 200)

> I sometimes talk to myself just a little louder than most people probably talk to themselves, but I'm trying to manage it. (Stu, 174-175)

Here, Stu reveals how he is attempting to normalise his experiences by comparing talking to himself (to his voices) with most people talking to themselves: an attempt to put this behaviour on a spectrum. He shows awareness of himself in these situations and attempts to manage them so that he does not appear too out of the ordinary.

Ryan described himself as being in a close relationship with Prince Harry (while simultaneously knowing that this was not real) and that telling himself so gave him a sense of security:

> It really annoys me [when people say] 'Prince Harry is not your friend'. I know, in my eyes—and I'm not doing any harm, he is my friend. I don't bother him. It makes me feel safe. I know that's not real, right, but I know it makes me feel safe. I know the difference between a real thing and not a real thing. (Ryan, 57-65)

He was aware that talking about Prince Harry as his boyfriend made people distrust his grip on reality and that this was connected to his diagnosis of schizophrenia:

> Say I imagine Prince Harry is my boyfriend, cause I'm gay yeah. So he's my boyfriend. I know that isn't real, right. But when they say I've got schizophrenia, I know that stuff is not real. That's what I believe. I know the difference, I know that stuff is not real. (Ryan, 71-74)

Bill spoke to me as though we both perceived him to have an illness. There was an assumption that what he believed to be true, I would view as symptoms of his schizophrenia. There was a sense of him keeping his dignity by talking about himself on the presumption of illness when, actually, he did confess that he believed he was the devil and possessed by evil:

> I thought that my blood was… erm, filled with devils and that all the reflections in the lights and all the sparkles that you see were devils speaking to me and altering my thoughts. (Bill, 58-60)

He spoke about these experiences in that past tense, implying that he no longer believed them to be true; however, there was a hesitancy to share what he knew would be perceived by society at large as mad.

4.2.4. Accepting medication to fit in

Because of the awareness that one's beliefs and/or behaviour might lead to social exclusion, participants' desire to fit into society came at the cost of suppressing their true selves. This was shared by three participants. This was most easily achieved with the help of medication, which was experienced as disconnecting them from their other reality:

> I wouldn't come off medication 'cause I've got it all set up. The thing is I don't want to ruin it by going to hospital again or acting strange in front of people, 'cause you do that. You don't think they are looking at you and you'd

> be having this shifting conversation with your voices and they are like ‘that guy’s weird’. (Greg, 249-253)

Greg had prepared lies that he could tell people so that they would not question him or be suspicious of how he spends his time and how he gained an income:

> You just have to be careful so you don’t spill the beans. You have to be careful so you’re not barred; if someone asks you what you do you have to be careful. You say ‘I’m a student’, or ‘my parents are rich and I live off them’. (Greg, 194-197)

Having a social life and friends was valued highly by participants, even if it meant letting go of their other reality:

> There are always people [voices] around me, I talk to them from time to time still, getting my best out there, but… erm, I don’t know. You’ve got to have friends and things are ok. (Greg, 266-268)

Similarly, Bill had a very nice life that he did not want to give up; it was a difficult dilemma for him, however, as he felt very strongly that he should just be who he really was. This would have meant not taking medication, which would probably result in him killing himself:

> I feel in many ways that I’m not real, by taking medication, which stops me from being who I am. It doesn’t give me many side effects, but it stops my identity, it masks the real me. (Bill, 146-151)

There was a need to suppress the reality they felt was not accepted in society by taking medication. This meant living in mainstream society at the cost of being true to other aspects of themselves. Social acceptance was, therefore, very important and an aspect of having a good quality of life. There was, however, a wish or longing to be able to live openly with what others might see as delusions or hallucinations.

4.2.5. Strength from social groups

Three participants described receiving strength from different social groups in which they participated. The importance of social groups was experienced as problematic when they were excluded from certain groups (mainstream society) and put into others with which they did not identify (schizophrenics). Support groups were a source of strength, often due to feelings of acceptance and being able to share aspects of themselves and their experiences openly without feeling judged, as they often felt outside these groups.

When discussing his diagnosis and how that was experienced, Stu used language that revealed how he relied on the strength of the group, rather than merely himself. For example, he expressed himself by saying “we would say”, rather than “I would say”:

> [Schizophrenia] is a very vague sort of thing, you know, that’s why we would say you know best yourselves, you’d be the expert on the experience. (Stu, 25-26)

Analysis of the data revealed many instances where Stu’s views or opinions were backed up by what the group would say in a similar fashion. “I” was exchanged to “we”, indicating identification with the group and receiving strength from it.

Greg described his supported housing setup as positive and described his regular attendance at the voices group as supportive:

> I live in supported housing, the people are there 9 to 5 during the week, and take you out for coffee once a week. There are old people in the place there, so the voices group is a support, talking to the voices group. (Greg, 398-400)

Reflecting on his past experiences, Bill explained how he felt valued and that he belonged in the anti-psychiatry movement. He expressed that the victimhood of that group can be attractive, but how he ultimately has come to see it as a negative and polarising practice:

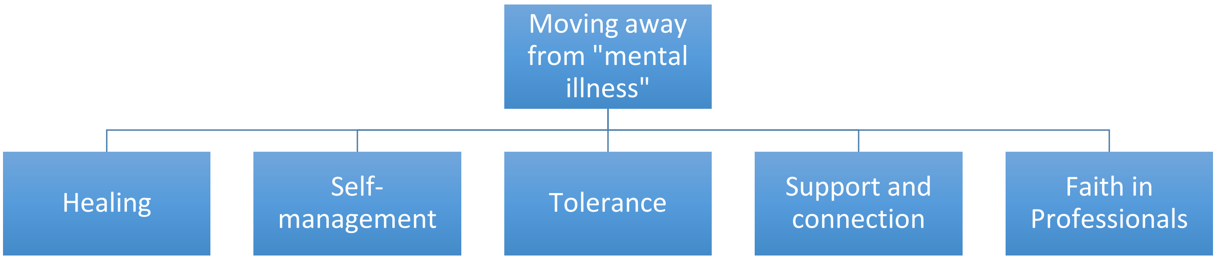
> I was working as a volunteer and I was part, in those days, in the kind of anti-psychiatry movement. And the various relatively radical social workers and community development workers were very keen, in my opinion, to use people like us to sort of becoming a growing voice to take on their ideas. And it was very attractive, it feels very attractive to think that 'I am an oppressed person who has been wounded by the state and by the system and by paternalistic psychiatry'. It's a very attractive thing, if you're feeling the need to blame something and to feel a comfort in almost that victimhood, it's a very comforting world to go into, and you can look at the world through those lenses and say 'look at each thing that the psychiatrist does, or the CPN does or whoever' and use that as another example of your oppression and you're not listening to me and you can become so focused on looking at all the mistakes instead of looking at each of those humans that it becomes a polarised world where you live more in theory than in reality.
>
> The more times I've been in hospital, the more I've picked up on the reality of it. I think too many people get caught on, what should be ideals and models and victimhood. Generally, when I'm in hospital I meet lots of lovely people, and there are some very damaged patients who are hard to be with, but you can understand why they are damaged, but they can also be lovely. And there are some damaged and exhausted nurses and the same with the psychiatrists. And there are some lovely ones who give as much as they

> possibly can, and to turn in all into a symbol of anti-psychiatry or critical psychiatry or oppression is such a meaningless, pointless thing to do. (Bill, 521-540)

Bill gives nuanced and perceptive accounts of his time in hospitals and how the group offered him something to blame his problems on; how it can be experienced as very comforting to be the victim of somebody else's oppression. He describes how he was moving within the anti-psychiatry movement but felt used by various mental health workers (used as a voice for their ideas). The inherent power dynamics between professionals and patients were present, even though they held similar ideas about mental health. As a result, he experienced an ideological push, ultimately feeling exploited by mental health workers to voice their ideas of an oppressed role and victimisation by the system. With time, however, he came to see the polarisation and victimhood that that particular group advocated as negative and de-humanising itself, which the anti-psychiatry movement wants to move away from. He demonstrates real compassion for both patients and mental health workers here. Paradoxically, by viewing everyone as unique and imperfect individuals, there is a group identification here: being human.

4.3. Superordinate theme III: Moving away from mental illness

Figure 3: Superordinate theme III: Moving away from mental illness



The superordinate theme Moving away from mental illness revolved around the participants’ striving towards a better existence and was shared by all participants. It was centred around hopes for the future and taking action towards positivity and growth. The superordinate themes comprised five subthemes: healing, self-management, tolerance, reaching out for support and faith in professionals.

4.3.1. Healing

Healing was a broad theme that was not discussed as an expressed aim or goal for all participants, but a theme that was a constant in the background in the sense that there was hope and an attempt to move in the direction of a better existence.

A sense of healing was experienced differently by different people and appeared to be tied in to their personal projects (e.g. education, self-expression) or aspects of themselves that the participant benefitted from developing (e.g. sense of self-worth, compassion).

Often, other previously discussed themes are tied into the theme of healing (and moving away from mental illness); for instance, trying to make sense of one's self (a self that can be understood) is a path towards healing—creating a sense of coherence where previously there was chaos.

Sarah, who had a strong sense of self, also had a firm belief in what was necessary for healing. She viewed her voices as shattered parts of herself and saw healing as integrating these parts, which she thought could be done with the help of talking therapies and understanding one's self, rather than through the way patients are treated in the system today. Talking about how a traumatic childhood can break a person like a shattered mirror, she said:

> All those mirrors are little pieces of you and you have to try to integrate yourself. What psychiatry does and schizophrenia does - it doesn't help you integrate those parts of you and make you understand why They are there and show them compassion. They don't show you compassion, it's more a power play. […] This is the thing about the system, they make it so complicated, all these meds, when all that is simply needed is someone to talk to, to help you understand, to show compassion back to yourself. (Sarah, 360-369)

Sarah viewed insight into oneself was as healing:

> I think to help is to show a person, to help them develop that insight, you know? […] And how do you develop that insight? You talk to them. (Sarah, 680-689)

Sarah wished mental health services would help service users to develop insight by talking to them and helping them understand themselves and what they are going through. She did not view healing as symptom-reduction; rather, as something experienced by participants as living well with what one has got:

> It's not about fixing a person either, it's about showing a person compassion and trying to help them live and have a good life. (Sarah, 825-827)

To Bill, who had spent decades trying to make sense of and understand his experiences, living well was about letting go of making sense—allowing for paradoxes and focusing on getting on with everyday aspects of life. Speaking of how one health professional had been particularly helpful, Bill said:

> She described it in a way that it was just part of life, like you don't have to spend your every waking moment thinking about good and evil and medication and sectioning and schizophrenia or whatever you want to call it, or depression or anxiety. You can just say 'this is part of my life, it affects my life, I get on with life, there is a whole lot to actually really enjoy. There is my friends, there is my writing, there is music, there is cooking, there is work, and actually those are important things and I found a lot of comfort in that. (Bill, p.486-492)

As healing involved seeing one's self and situation with more clarity, it also involved taking responsibility for aspects of one's self that were experienced as problematic. Stu was aware that he had difficulty expressing himself and made a conscious effort to make himself better understood by others, which resulted in improving social relationships and connections:

> [Being understood] is also two ways, learning to be clever with the words you use. (Stu, 443-444)

Openness and dialogue were experienced as healing. Stu had recently begun seeking groups, education and connection with others—acts that were experienced as healing—and he showed insight into his past denial:

> I kind of had denial for a long time, a lot of denial for about three years and there was no one to talk to, but this is like an opening up and kind of coming out and having a dialogue with certain people who understand it, like whether health professionals or carers or families, it's improved since people have started talking about these things. (Stu, 228-232)

Healing was associated with coming back to oneself as opposed to managing oneself, which was more about being able to function:

> I can get why they think [suppression with medication] is a good idea, but the problem is you become numb not only to bad memories but to everything good as well. You usually can't feel your own pain and that's not human, we should all be encouraged to feel our feelings, do you know? It's nothing wrong with that. (Sarah, 518-522)

Medication was seen as a way of assisting functionality, while integration and sensation were associated with healing. There was a wish to be allowed to be human, to feel all feelings (good and bad) in order to be able to be fully alive in the world. That was Sarah's idea of healing and living well: not suppressing but experiencing the full range of feelings.

4.3.2. Self-management

As part of moving away from mental illness, some participants had learnt ways to manage their difficulties in order to function better in different situations. Self-management was built on a foundation of self-awareness, e.g. insight into what type of situations might be difficult in different aspects and ways to handle those difficulties (e.g. by taking medication or avoiding certain places). This was shared by four participants.

Greg was aware of environments that were particularly stressful to him, for which he sometimes prepared himself by taking Valium:

> There are certain bad areas, like I know I'm gonna have a bad time at an airport. I know I'm gonna have a bad time at a rock concert, pop quiz. I don't have a bad time at a pop quiz if I take the Valium. (Greg, 306-308)

Similarly, Stu expressed how self-insight has improved his self-control over time and he has learnt to better manage his voices and feelings:

> I've learnt to manage it (the voices) and deal with it a lot better now, and stuff like anxiety all that kind of stuff you gonna manage, like going on an aeroplane or whatever, like I'm getting more self-control. (Stu, 193-196)

In other cases, participants had learnt to manage their voices rather than their environments. In the following extract, Sarah describes how she has learnt to talk back to her voices in a constructive way and that she has come to understand that self-compassion is often the best way forward:

> Sometimes I get very aggressive [voices], certainly at night time. And I literally have to—like I almost went to a person in the pub saying, 'shut up

> I’m not in the mood for you today’, and the voice will go away. Or sometimes, if a voice is being aggressive and I’m being aggressive back, that doesn’t work. It’s like anybody, if you show that voice compassion and... say, like, I’m hearing aggression, then I’m almost like, ‘maybe something is hurting me’, you know? (Sarah, 768-776)

The voices, although aggressive at times, contained a message for her, if she only stopped and listened to them—they made her pay attention to her well-being. Above, she showed how she needed to establish boundaries with somebody. In learning to show compassion towards her voices, she ultimately showed herself compassion.

4.3.3. Tolerance

There was a wish for tolerance, which was experienced positively by all participants. Much of the time, participants were aware of how their perception would be perceived by others—including that there would be a disagreement of perception or opinion—and there was a wish to not have their perception challenged. As I have attempted to illustrate, participants had their own ways of making sense of their experiences and rejected an outside perspective and explanation of their unusual experiences. Therefore, it was important for participants to have their beliefs tolerated (if not respected). Analysis of the narratives also showed a large degree of tolerance for other people’s explanations for their unusual experiences, even if participants disagreed with them.

Bill explained how other people’s views of psychosis—as a spiritual awakening—was working for them. He rejected that explanation for himself, but displayed a real tolerance for others’ perspectives:

> While I'm convinced I'm going to a really negative place (hell) and I find it hard to bear that, so I tend to reject it and say that's valid for them and it gives them a great deal of comfort and a real, lovely way of seeing themselves and their lives and approaching other people, but I don't know how to relate that to myself. But I think there is a lot of validity in those ways of seeing life. (Bill, 760-764)

Tolerance and not being challenged or pushed regarding one's perception were experienced as positive:

> Everybody is up their own belief about their voices. You don't push what you think on other people. (Greg, 108-109)

This was partly why support groups were experienced as positive spaces; there was a respect of perception and, therefore, safety in sharing.

Speaking about the positive ways of relating to his community psychiatric nurse, where they were discussing everyday things and not focusing on the errors of his ways and worldviews, Bill said:

> We'll probably talk about what we did with [my girlfriend] on Mother's Day and I'll probably talk about central station where I keep wanting to throw myself in front of a train. She'll say, 'there is no need to' and I'll say, 'of course there is no need to', and we'll talk about people looking at me and I'll say, 'yes, [my girlfriend] is very good at making me think it's quite funny' and that will be good because that's actually all we need to do. I don't need to immerse myself in either her or me challenging each other's perception of what I am. I just do normal stuff. (Bill, 692-698)

While participants themselves exhibited a large degree of tolerance towards others, mental health services were experienced as showing very little tolerance for other ways of thinking and making sense of experiences:

> The problem with the system is it doesn't see beyond its own idea of something they still don't understand. (Sarah, 399-400)

To Sarah, this was a continued source of frustration and anger. She perceived a lack of tolerance from them that ultimately led her to have a lack of faith in the mental health services.

4.3.4. Support and connection

Because the participants experienced themselves as being in distress in different ways, there was a sense of reaching out for support and connection. This was shared by all participants. To some, this meant contacting professional services. To others, it revolved around finding safety and comfort wherever they could.

Sarah described how she first got involved with the mental health system; it began with her wanting someone to talk to about the trauma she had gone through:

> When I was 17, I just became so distressed by my voices, by how I was […] I actually didn't want to go near psychiatry, I just needed a psychotherapist and someone to talk to. (Sarah, 42-48)

Rose stated how she had told lots of professional (and non-professional) people about her experiences while expressing a sense of anger and frustration for not being believed:

> I've told my doctor about it, I've told the police about it, I've told [the hospital] about it, I've told my support worker, my, I've told my care

> coordinator but she says this, she says 'Rose, it's just symptoms. It's not real' and I said 'yes, it is real'. (Rose, 139-142)

Bill describes contradicting forces. He explains that he wanted to kill himself but also, unconsciously, had made sure that people would look after him and keep him alive. He was reaching out for help without, at the time, being aware of having done so:

> I wanted to burn myself and become a spirit, because I thought I was no good as a human… and I did two things, one was I wrote a letter to my best friend and I alluded to something which she picked up on. And I also phoned my CPN up to say I had realised that I had never been ill, and I wanted to wish her well and say thank you for all the support she had given me. […] I don't know if it was conscious or not but certainly those were ways in which I got help. (Bill, 710-715)

> But I think what I done in the initial bit was ensured that people looked after me and stopped me from doing what I wanted to do. And I find that a funny contradiction. I think part of me wanted to be kept alive and wants people to stop me killing myself, and part of me wants the opposite of that. (Bill, 723-726)

Ryan did not seek support from mental health services but found support in making himself connected to important people who were there for him in a supportive capacity (the army and the Royal family). He spoke of Prince Harry as his boyfriend but pointed out that he knew it was not real and that this was a way of giving himself a sense of safety:

> It's having a friend. I love [Prince Harry] as a friend, as well; it's having somebody to turn to. How I might turn to him is a bit different than to

> everyone else, I turn to him in a voices way or I turn to him and write a letter to him. I wouldn't go to the army, I could turn up to them, but I wouldn't, that's how it is with the army, isn't it, that's how my connection is with the army. Basically, it's somebody I will turn to, somebody I will always love, even though people don't believe it, it doesn't bother me. It's one of those things where it keeps me steady, but if I didn't have anybody, I'd be packing up by now. (Ryan, 425-432)

When it came to moving away from mental illness and reaching out for support, the connections participants made with others were important. Support groups were experienced as positive spaces in which participants felt accepted and where they were helping each other:

> I am friendly with all the people with schizophrenia anyway but I guess [the group] is good that there is other people who empathise with it as well, we try this, we try that… you know, helping each other out. (Greg, 405-407)

Social networking sites were also experienced as supportive and positive:

> [Being more open] is definitely helping, like the Facebook page is, I mean there is a lot of fucking mad, crazy stuff, what I would consider crazy stuff, but there is some good stuff you know, it's a good network to have. (Stu, 258-260)

Sometimes, the smallest signs of connection and care from others had a significant impact on participants. Ryan shared a seemingly fleeting exchange with a member of staff in a bank, which had had the impact of him not killing himself:

> The person in Metrobank said to me 'Hi Ryan, have a nice day', 'cause there was somebody who actually cared and I knew they cared and it stopped

> me killing myself one night. I do care what people, other people’s opinions […] Imagine, little things like that can have an effect on your life in the future. (Ryan, 457-461)

In this paragraph, Ryan explained how, at that time in his life, there was no one there for him—nobody who cared, except ta person in the bank who wished him a nice day. That earlier human connection in the bank and show of compassion—which, to Ryan meant that they cared about him—was the thing that stopped him from killing himself. This clearly shows the positive impact of experiencing connection and support from others.

4.3.5. Faith in professionals

There was a need for having faith in professionals and mental health services. This was shared by four participants. Although faith and respect were not always there (there were often mixed feelings towards professionals), there was a desire to know there were people out there who could help.

Rose mostly had a positive attitude towards professionals. Although she did not feel understood by them, she expressed having faith in them and the care they provided. This was the case even if she was not entirely aware of (or did not agree with) why they made certain suggestions. Here, she explains a way that staff were helpful to her during her eating disorder and how she came to be in connection with schizophrenia (through Clozapine):

> …I was in a YMCA and I had an eating disorder, and it was like they helped me along, they really helped me, but when they kept saying like ‘would you like to go on Clozapine? Would you like to? Would you like to?’. In the end I gave up and said, ‘alright, I’ll have Clozapine’. (Rose, 41-46)

Bill did not accept a psychiatric explanation for his experiences. He knew the psychiatry professionals’ perspective and explanation for his experiences (i.e. delusional thinking, symptoms of an illness (schizophrenia)). However, he needed to rely on professionals to be islands of sanity and wellness; he needed to know that he could count on them to be grounded in reality—even if Bill himself did not believe that that reality was true—because losing himself in what he believed to be true was a negative and all-consuming experience that he believed would result in him killing himself.

> I was talking about the evilness and I was talking about my first admission and [the psychotherapist] said it may be that I was very receptive of the terribly disturbed souls who had been in the hospital, and it was literally true that I had been possessed by the souls of possessed people in the old hospital and that was why I was like I was now. And at that time, I was desperately trying not to believe things like that and so I really didn’t want to hear that. I lost a bit of faith in him then and I moved away after that. (Bill, 456-462)

Stu expressed a wish for having faith in mental health services but had had negative experiences that made it difficult to keep faith in medicine:

> If they can help me, I don’t know. I suppose it destroys your faith in medicine which is the only thing, but you know, you would like to have some faith in… there are a lot of good people in medicine as well. (Stu, 146-149)

Here, he shows how he has felt let down in the past but, nonetheless, remains willing to be open and have trust and faith in professionals again. Despite his bad experiences, he seeks positivity.

5. Discussion

In this section, the themes will be discussed, covering the ways in which they are interconnected. Themes will not be discussed in chronological order but, rather, by their relationships. I believe that, as this is an overview of the results and their implications, this will best facilitate an understanding of what was found. The results are discussed in the light of previous research and existential literature and conclusions are drawn regarding implications for mental health services.

Most prevalent in this study was the idea of making sense of one's self and world (a self independent of psychiatric labels). All participants continuously engaged in creating a coherent self-narrative that was consistent with their experiences. This seemed to be important in order for their story to feel true for them and to reach a place of certainty and conviction about their beliefs.

Although none of the participants agreed that they had schizophrenia, they were aware of having experiences that other people did not have. They felt that they were suffering (to different degrees) from "mental health problems". I use quotation marks as four participants would say that they were suffering from problems in life such as having had an abusive upbringing or experiences of bullying or social exclusion, which were the cause of their "mental health problems". All participants' interpretations of their experiences were more consistent with a social/psychological approach to the aetiology of mental distress rather than with a physiological/psychological one.

Using the term mental health problem seemed to imply to the participants that their problems originated from within themselves. This was not something that they accepted. However, there was ambiguity about the root of their problems: the effect different events have on one’s life trajectory and on mental life is incredibly complex. People are not tabula rasas (Siegel, 2010), able to single out the effect one interaction or problem has because they are continuously changing and affected by numerous stimuli every day. Possible biological pre-dispositions also contribute to this complexity (Bentall, 2003). Stu, for instance, talked about having anxiety and depression and understood these issues as mental health problems originating from himself. However, these problems made his life more difficult, which resulted in more anxiety and depression. From another angle, the reason a person might be experiencing anxiety and depression could be understood to be the result of social exclusion, poor relationships or abuse (Bentall, 2003). It is hard in this situation to say which problem existed first and which is the cause of the other; nevertheless, this was something that participants continuously attempted to understand and solve (to feel certain in their beliefs and views about themselves).

There was a fundamental concern identified in all participants’ accounts whereby, in one way or another, they were striving to move away from “mental illness” and move towards positivity and a better life for themselves. This was fuelled by an underlying sense of hope. The idea of a better life meant different things to different participants, e.g. learning to deal with anxiety more competently, getting work and establishing a valued role in society or dealing with so-called perpetrators. What appeared to be a fundamental building block to this non-verbal end-goal (non-verbal in the sense that there was a general attitude of striving to move away from “mental illness”—to a better place in life—rather than an expressed ambition) was having that participants had a good understanding of themselves and situations: it seemed essential to be able to be themselves fully and feel comfortable with where they fit into society—they were concerned with stigma and being part of society.

Having a good understanding of oneself and reflecting on one's position in society can be conceptualised slightly differently and be informed by literature around self-narrative and identity. Indeed, research on narrative and perception of the self (in schizophrenia) forms a good base from which to look into and understand these themes.

Roe and Davidson (2005) argue that being diagnosed with schizophrenia introduces a disruption and discontinuation of a person's social and personal narratives. They argue that, after the initial impact of receiving such a devastating label, the person is engaged in trying to overcome these narrative disruptions and reconstruct a sense of self. They attempt to regain agency over their life story and create a coherent self-narrative. Research has found this phenomenon to be associated with recovery (Jacobson, 2001; Ridgway, 2001) and both Jacobsen and Ridgway suggest that this engagement is a component of recovery in itself and not simply a product of it. They emphasise the importance of creating a coherent self-narrative in the recovery process of those determined to be severely mentally ill. The findings in the current study also support the authors' argument that creating and maintaining a coherent self-narrative is part of the recovery process (and not only a result of it). The formation of a coherent self-narrative – to be able to make sense of one's experiences and hold them as true served the function of building a stronger foundation for oneself. Having conviction of one's beliefs, especially when back up by others, e.g. support groups, created stability for all participants which had a positive effect on their well-being.

Similarly, Yanos, Roe and Lysaker's (2010) study highlights the importance of creating a meaningful self-narrative in the recovery process of people with mental illness. The model they presented of the impact of illness identity on recovery from severe mental ill-health suggests that the views and attitudes that the patient have about themselves regarding their illness will influence their self-esteem and hopes for the future. This then further provokes an array of personal and vocational outcomes, such as an increased risk of suicide, a reduction in coping ability, difficulties with social interactions, reduced vocational functioning and increased symptom severity. They found the relationship to be causal; the more positive type of illness identity the individual had, the better their recovery was. The model Yanos, Roe and Lysaker (2010) presented can be linked with the current findings; the narratives participants were engaged in creating for themselves formed a basis for their evolving identity. They attempted to create a more positive self-narrative and identity with the aim of moving in the direction of a better future, away from mental illness (i.e. towards recovery). As Yanos, Roe and Lysaker (2010) suggest, it appears crucial to assist this population in forming a more positive self-identity and overall self-narrative; however, particular focus should be on the identity and narrative concerning their mental health difficulties. Finding meaning in their experiences of mental health problems is of particular significance, whether or not the individual agrees that they have "schizophrenia", i.e. individuals who have received a schizophrenia diagnosis do not need to incorporate a new positive "schizophrenic self", but instead need to find their own unique way of finding positivity and meaning in their present situation, to which their diagnosis— while rejected—has led them.

The development of psychotherapeutic guidelines that encourage practitioners to engage patients in narrating more optimistic life-stories and self-identities must be considered a positive step forward in the care of those who disagree with their schizophrenia diagnosis. Emphasis on personal strength and ability to overcome adversity could potentially provide a highly differentiated and much needed alternative treatment model to the medical approach most prevalent in the UK today. A coherent self-narrative (Roe and Davidson, 2005)—meaning and positive illness narratives (Yanos, Roe and Lysaker, 2010)—could be direct therapeutic goals for people with a schizophrenia diagnosis. For individuals who disagree with their schizophrenia diagnosis, particular emphasis should be placed on creating a coherent and optimistic self-narrative, independent of traditional psychiatric labels.

A self independent of psychiatric labels involved a continuous engagement in making sense of one's self and one's world. It involved persistent work towards having a self that could be understood and owned as true. Making sense of one's self involved different ways of trying to understand one's situation. Participants who had experienced hallucinations were primarily concerned with making sense of their unusual experiences. There was a sense of 'just knowing', and speculations and theories were then built around this feeling. This just knowing something appeared as an inner conviction or inner truth that participants felt they had no choice but to accept. To be authentic to themselves, they had to listen to what they understood to be true and they could not be convinced by the narrative the psychiatric label offered. Even when the label was welcomed, as it was for Bill, it meant not being true to oneself: it meant self-deception. Authenticity is a central theme in existential philosophy, where it is seen as a cornerstone to a life well-lived (Kierkegaard, 1843/2012; Sartre, 1946/2007). To Kierkegaard, living authentically meant stepping aside from the pre-set norms of the environment in which an individual finds themselves (1843/2012). This is achieved by taking a leap of faith and going out on a limb to follow what one believes to be true, even if it is in contrast to what is laid out in front of one. From this perspective, the drive to authenticity can be seen as a healthy instinct within the participants; an attempt to live well and with meaning within one's constructed reality. Other people's (e.g. professionals or family members) views and interpretations of the participants' experiences were heard but not experienced as "true". Instead, when having their convictions challenged, all participants rejected others' views of themselves and distanced themselves from those doing the challenging. This was experienced negatively and reported with disappointment. In cases where challenges were made by a mental health practitioner, this led at times to the participant rejecting attempts to explore their experiences (reported by four participants). It was possible here that they might then miss out on opportunities to strengthen their personal narrative and increase understanding of themselves and their experiences. Therefore, it is important to approach therapeutic engagements phenomenologically in order to see how the participants themselves make sense of their experiences. It may very well be the case that when a practitioner approaches a client with the attitude of Jaspers' (1913/1963) form over content, the client may feel that their beliefs have been dismissed. Roe and Davidson's (2005) paper on the importance of a positive self-narrative for people with a schizophrenia diagnosis draws attention to the paradoxical nature of the concept of lack of insight. If the patient agrees that they have schizophrenia, they have confirmed having a diagnosis that calls all of their other beliefs and opinions about themselves and the world into question. If, on the other hand, they disagree with the diagnosis, this so-called lack of insight could be viewed as part of the illness and their beliefs and opinions are equally questioned or dismissed. The authors conclude that "either way, the person is viewed as lacking the essential prerequisites for being a narrator of her own experience: awareness and insight" (2003, p.91). This was, indeed, something that all participants in the present research struggled with. Bill described feeling humiliated when he was required by professionals to describe his own understanding of his experiences, knowing how this was perceived by them. Greg described not seeing the point in discussing his perception of his experiences with professionals at all. If patients distance themselves from professionals (as was found among the participants), what is already a difficult situation for patients becomes an even more isolating experience.

Kinderman and Bentall (2007) point out that strong beliefs (whether delusional or not) are often accompanied by strong emotions. Efforts to change beliefs (religious, political or “delusional”) typically evoke discomfort and are also often met with resistance and/or anger. Kinderman and Bentall (2007) reported that most delusional beliefs were grandiose and persecutory and involved notions of guilt. This led the authors to conclude that these beliefs reflected an intense preoccupation with the person’s position in the social sphere and that these beliefs were, therefore, intimately related to the process of self-evaluation. The content of participants’ unusual beliefs was not the focus of the present study, but superordinate theme II (stigma and being part of society) showed that all participants were, indeed, concerned about their position in the social sphere, especially where stigma (both perceived and anticipated) was experienced as pushing one towards the edge of society, where an accepted and valued role is difficult to find.

All participants in this study made speculations and theorised about the factors possibly underlying what they believed regarding their unusual experiences. This appeared to help them develop an understanding of what had previously been only a conviction based on intuition. There was an attempt to understand what were, in some cases, very confusing situations (e.g. being touched without being able to see who was doing it). Because all participants had been categorised as schizophrenics, they used the knowledge they had of schizophrenia and other psychiatric diagnoses to get a better sense of who they were. Here, schizophrenia was often seen through the lens of “madness”, which they did not apply to themselves and, thereby, rejected others’ views of their selves. Thus, the label schizophrenic was seen as something someone might ‘be’, rather than representing an explanation for the experiences one might have—a label that strongly imposed an identity.

Kraus (2003) discussed how phenomenology could be used as a fundamental basis for diagnosis. A phenomenological-anthropological approach—as opposed to a symptomatological-anthropological approach—is concerned with exploring the individual's subjective world, their experiences of what is disturbing to them and their existential relationships with themselves and others. On the other hand, a symptomatological-anthropological way of diagnosing focuses on reducing experiences to some definable criteria and does not necessarily relate to subjective meanings. A phenomenological-anthropological approach is concerned with being rather than having and may, therefore, be more beneficial to the person receiving the diagnosis. Subjects may reject being schizophrenic, but the focus is still on their being, which implies embodiment and ownership over the dismissive "having schizophrenia" (or any other illness affecting the self). Furthermore, all participants were, indeed, more concerned about their experiences from the angle of a self-narrative and understanding. They were already engaged in a phenomenological-anthropological exploration of their experiences. They reported that the label schizophrenia did not contribute any meaningful understanding to their experiences: instead, they felt that the label of schizophrenia dismissed their real experiences, discounting their true nature by attributing it to symptoms of an illness. Importantly, the experiences are understood to be real for the person having them, even if they do not derive from physical stimuli—feeling touched is the same as being touched on an experiential basis.

For the participants, having a self that can be understood was a way of owning their experiences. To understand their own life story, it appeared to be important to have some form of explanation as to why they were experiencing such difficulties. Looking back at life and connecting the dots was not always straightforward and was easier for some than others. The three participants who came from a background of abuse clearly recognised the negative effects of their past and attributed their current negative experiences to it, at least in part. Seeking an understanding of one's experiences outside of one's personal history (e.g. from the literature on critical psychiatry and from user movements), three participants were able to shape recognised theories about mental health and "schizophrenia" (other people who had received this label) around their personal experiences. In this way, their beliefs and understandings of themselves were strengthened.

Taking Sarah's case as an example: there is a lot of literature relating to childhood trauma as a strong predictor of mental illness (Bonoldi, et al., 2013; Schäfer and Fisher, 2011). In particular, theories (previously discussed in the literature review) often point to the notion of the schizoid personality as having split off repressed parts of itself. These ideas fitted well with Sarah's own understandings of her experiences and were, therefore, easily adopted and held as true. She firmly believed the abuse she received in childhood had caused her to psychologically split off the trauma her mind could not handle and that the repressed—or split—sides of her later began to appear to her in the form of voices. This understanding, as it was supported by established theories of how the mind works, made it easier to move towards a position of certainty in her beliefs.

Having conviction of one's personal aetiology appeared more difficult when one's own experiences did not match with some of the more accepted user movement theories. For example, the view of mental distress as generated by trauma was not helpful when the participant had enjoyed a happy childhood. There was a sense of all participants seeking explanations (or theories) for their unusual experiences or causes of distress that appealed to them—in other words, having a biased embracement of what is adopted as true. Even if a background of abuse did not fit their own experiences (e.g. for Stu), it was a cause of mental distress that was preferred over being schizophrenic (and therefore "diseased"). When personal experiences did not fit in with accepted or preferred theories of mental health, it was more difficult to move towards a place of certainty of their beliefs.

Although it has been argued here that having a coherent self-narrative was experienced as positive and something the participants were striving to achieve, there is a case to be made for accepting a more fluid concept of self. Having several identities has been found to lead to psychological well-being if the identities are in harmony as opposed to in conflict with each other if the identities are highly important to the individual (Amara, Garcia and Fleming, 2008). If the different identities an individual has are not important, the conflicting nature of the identities is not a source of psychological distress (Amara, Garcia and Fleming, 2008). Bill found great comfort in accepting that he would not be able to fully understand the contradictory nature of his experiences and beliefs. To him, living well included letting go of sense-making and moving towards appreciating the many aspects of his life. Here, a fluid identity allowed emphasis on acceptance.

5.1. Meanings attached to labels

Language and wording appeared to play an important part in the way all participants made sense of their experiences. As mentioned, the word schizophrenia did not offer the participants any meaningful understanding of their experiences: not only did it appear difficult to relate to but the associations all participants made with the word were particularly negative.

There was some acceptance of other psychiatric labels (e.g. BPD/emotionally unstable personality disorder (EUPD)), which I believe were partly accepted because of the ability to relate to the words that made up the diagnosis (e.g. emotionally unstable linked with Rose’s experience of herself whereas paranoid schizophrenia did not). Perhaps it is appropriate to question how useful the label of schizophrenia actually is: if a label is unclear and a barrier to treatment outcomes, why not change the composition of the label? A person’s past experiences could then be tied in coherently with the self-narrative of, for instance, being emotionally unstable—one’s self-identity could match the diagnosis. Anxiety and depression were also words which three participants used to describe themselves; they were more neutral words to which they could relate. In the case of the all participants in this study, “schizophrenia” as a diagnostic label did not offer the opportunity to make meaningful connections with their experiences.

Howe, Tickle and Brown (2014) argued that service users who had received a diagnosis of schizophrenia avoided the label partly due to a lack of understanding of the diagnosis but also as a way to avoid the stigma attached to it. In their exploration of peoples’ experiences of receiving a diagnosis of schizophrenia and the stigma associated with the label, they presented five superordinate themes: (1) Avoidance of the diagnosis of schizophrenia, (2) Stigma and diagnostic labels, (3) Lack of understanding of schizophrenia, (4) Managing stigma to maintain normality, and (5) Being ‘schizophrenic’. While the conclusions the authors derive from the findings (namely that professionals need to be conscious of how they deliver a diagnosis of schizophrenia to a patient and explain what it means as a way to facilitate understanding and reduce stigma), the study also suggests implications for notions of self-identity and self-image within this population. The authors argue that incorporating the new self-image of being schizophrenic may be a part of the recovery process. It appears the meaning that individuals attach to their diagnosis influences how they then relate to and engage with that diagnosis (e.g. avoiding it, managing it and/or learning how to apply it to themselves). The words and meanings attached to psychiatric labels evidently influence the way patients view themselves. Therefore, it appears important that psychologists working with this population explore what these meanings represent to the individual receiving them. Self-stigma can be seen as occurring when a person accepts the general population's negative image of a "schizophrenic" (Howe, Tickle and Brown, 2014). This happens when a person has not formed their own understanding or conviction of their experiences and has instead applied "the others'" explanation of their condition to themselves, which is rarely positive in the case of "schizophrenia". The real value of working through such a diagnosis with a professional may be that, in finding their own explanations and understandings of their experiences, individuals with a schizophrenia diagnosis become the experts on their own conditions and thus gain a sense of empowerment. It appears such understanding and empowerment are helpful to their mental well-being and quality of life. This type of re-authoring of one's life story is an important component of recovery for people with a schizophrenia diagnosis (Roe and Davidson, 2005). Furthermore, when a label is offensive to the person receiving it, it may influence their view of the person who attributed it to them (Forgione, 2019). When that person is in the position of caregiver, this may negatively impact what should be a therapeutic relationship.

The implication of receiving and rejecting such a negative label was apparent in Forgione's (2019) investigation into diagnostic dissent from individuals with psychosis. She argues that not only is rejection of the label an experience but it is also an act of self-validation and assertion of agency. Receiving the label was experienced as the attempt of an other (a clinician) at invalidating and redefining one's own experiences with a stigmatising label. The individuals in the study felt they were now no longer seen as being able to make decisions about themselves or their treatment and as lacking the self-insight to do so; both of which came with the label. The act of dismissal was an act to re-affirm personal agency. It was an act of self-empowerment. These findings were echoed in the present study. The rejection of others' views of themselves was necessary to be able to hold their own more positive views of themselves, contrary to the views and stigma that came with the schizophrenia label. It was an attempt to strengthen their own self-image. The label was described by Sarah as "big black cloud" and it was a label that meant mediation and services for life. Rejection of the label was thus an act of rejecting a life of illness, medication and services; of instilling some hope in what was otherwise a wholly negative path ahead.

Internalised stigma is negatively correlated to well-being (Morgades-Bamba, Fuster-Ruizdeapodaca and Molero, 2019), thus rejecting it appears to be a good strategy for preserving a positive self-image. It has been argued that strengthening one's own narrative and forming a positive illness narrative (Yanos, Roe and Lysaker, 2010) are important aspects of healing. The empowerment that can come with asserting one's own understanding of one's experiences should be encouraged. As David (2006) reminds us, "lack of insight is, in my view, not a matter of pressurizing people with psychotic disorders in some totalitarian way […] it is more about insight than lack of insight" (David, 2006, p.370). Rather than viewing people with a schizophrenia diagnosis as lacking insight into their own experiences and conceptualising insight as agreement with the biomedical model of mental illness (Lysaker, Roe and Yanos, 2007), the affirmation of personal agency and individual's own insights into what is going on for them should be viewed as positive: if rejecting the label means rejecting the stigma.

5.2. The value of psychotherapy

All participants described that the act of initially reaching out for support with their difficult experiences was an act of seeking someone to talk to, to help them make sense of what was going on. There was an expressed desire to feel listened to and to be able to openly share their experiences. The core of this research is that the participants had been given a label that did not offer them congruence with their own understanding of their situation; rather, it offered stigma, social exclusion and illness for life. Participants were engaged in making sense of their experiences but were left to do so on their own, as the professionals and givers of the label had already defined participants' experiences as symptoms of "schizophrenia". Above, we have seen the arguments of why self-assertion (Forgione, 2019), positive illness narrative (Yanos, Roe and Lysaker, 2010), rejection of stigma (Morgades-Bamba, Fuster-Ruizdeapodaca and Molero, 2019) and the re-authoring of one's life story (Roe and Davidson, 2005) are all positive and components of recovery. It is apparent that psychotherapy can help people who disagree with their diagnosis to form more positive self-images and re-narrate their life-stories and thus life-trajectories.

The cornerstone of psychotherapy is to gain insight into one's psyche, behaviour and holistically; into one's life. Existential-phenomenological psychotherapy is, arguably, more suitable than a reductionist approach such as CBT. Meaning-making was an important aspect of all participants' experiences of disagreeing with their diagnosis of schizophrenia. They needed to come to an understanding of their experiences in a way that was personally meaningful to them. Eldal et al. (2019) reported that there is a wish among individuals in mental healthcare to have one's self-identity recognised and supported and to be seen as a whole person. These findings were reflected in the sub-theme Desire to be seen as one is. There was a wish by all participants to be seen as an individual, not just as a person with a mental illness - to be understood as they understood themselves. Considering that it is common for people in mental healthcare to feel unheard (Kapur, et al., 2013), which was reported by three participants in the present study, a trusting relationship with a psychotherapist whereby the individual can freely share how they make sense of their experiences appears to be, at least in part, a remedy to the complaints of feeling unheard and offers the individual a space in which they feel safe to share their whole self and be seen for who they are. As psychotherapy has been found to help individuals gain awareness and re-label symptoms in a less negative way (Dantas and Banzato, 2007), there is support for psychotherapeutic care for people who reject their schizophrenia diagnosis.

In making a case for psychotherapeutic care, it is not the intention of this study to condemn the medical and pharmacological treatments provided to alleviate suffering. Instead, it is suggested that both approaches can provide benefits to the patient community by increasing understanding, providing models for engagement with experiences and generating foundations for improved treatment outcomes, but that the individual receiving the care is an active participant in their own trajectory towards health and well-being.

5.3. Moving away from “mental illness”

What shone through all of the participants’ narratives was a strong engagement with sense-making and attempting to move towards a sense of clarity and positivity. It appeared they instinctively strove towards a better place in life and away from “mental illness”, fuelled by an underlying sense of hope.

Although the word ‘healing’ was not verbalised in any interviews, I have used the term healing to capture the theme of a self in less distress—more secure and more positive. The terminology of “treatment” is rooted in the medical model and implies treatment for illness. As there was a striving to distance oneself from “mental illness”, ‘healing’ appears to be a more appropriate term than ‘treatment’. Being seen as a person rather than a patient, this theme was in the background of all participants’ narratives—they were not speaking of healing themselves but were certainly concerned about the quality of their lives and moving forward in a positive direction. Davidson (2003) points out that treatment is understood to be the removal of something negative, such as symptoms of an illness. The process of recovery will look different for different individuals, but often encompasses the following areas: redefining self and accepting illness (not necessarily by medical terms but an acknowledgement of one's suffering), overcoming stigma, renewing senses of hope and commitment, resuming control over and responsibility for one's life, exercising one's citizenship (the entitlement to not be discriminated against, have the same rights and responsibilities as other members of the public), managing symptoms, being supported by others, being involved in meaningful activities, and expanded social roles. As can be seen, the components of recovery outlined by Davidson (2003) are reflected in the themes found in the present study. The participants were all attempting to improve the quality of their lives; healing and moving away from "mental illness"—which were interlinked with making sense of self and experiences (a self, independent of psychiatric labels)—strengthening oneself through forming a coherent self-image and self-narrative, social connections and support, managing stigma and tolerance.

Attempts to move away from "mental illness" were reflected in all participants' efforts to create a positive self-image. Rejecting other peoples' negative views of them, therefore, appeared to be an important aspect of this process. Of course, there was an element of disagreeing with other peoples' views; however, there was also a sense of needing to protect oneself from the highly negative perceptions and lifetime predictions often associated with the diagnosis of schizophrenia. As argued by Mizock and Russinova (2016), when making sense of one's new circumstances and re-shaping one's identity, it is important that healing takes place when one's own value as an individual is not diminished.

For the participants in the current study, accepting a diagnosis of schizophrenia meant accepting the prospect of an illness for life. It meant accepting that they might need medication and the input of services for life. It suggested a life with little prospect of finding work or a valued role in society. Therefore, accepting a diagnosis of schizophrenia gave very little hope of a better future, hope which according to much of the literature cited, is necessary to heal and move towards a better future.

The diagnosis of schizophrenia and what that meant seemed to eclipse much of the meaning-making processes in which all participants had been engaged. While experiencing an array of complex difficulties, schizophrenia as a label reduced all understanding to "you have a mental illness that is the cause of your suffering". In addition, it meant accepting that their perceptions and own self-knowledge were seriously doubted.

The accounts from all participants in the present study suggested that the label schizophrenia removed their other identifying aspects, overriding what made them individual people with unique life stories and problems. They felt as though they were taken less seriously because of their diagnosis, and neither listened to nor heard. All participants tended to distance themselves from people who expressed disbelief regarding their experiences. However, in contrast to this, there was also a need to be able to rely on professionals to have a firm foot in reality and know what to expect from them in periods of illness and confusion. This presents professionals with a somewhat challenging situation. People who disagree may reject candid interactions because they feel they are being disbelieved and thus not share what is going on for them. At the same time, they may need professionals to remain firmly rational and not show collusion with their beliefs. The therapeutic relationship, however, depends on some degree of empathetic understanding, which is difficult to achieve without the therapist allowing themselves to enter the client's own world. Balance may be reached by engaging with this population with curiosity, openness, and empathy. An empathetic connection that communicates understanding can arguably be made without sharing beliefs. Such an approach may help with the problems of this population's negative feelings of not being believed.

5.4. Tolerance towards others

One theme that came up that might be helpful when approaching the above-mentioned dilemma was tolerance. Four participants exhibited a large degree of tolerance towards other peoples' beliefs about their unusual experiences, even when these appeared hard to believe to the participants themselves. For example, Bill could appreciate the value of viewing voices in a spiritual sense and could see why a person understanding their experiences in such a way might benefit them, even if he did not believe this was objectively true. The four participants who reported this could appreciate the peace of mind and positive outlook on life such perspectives could give, even if they themselves did not believe such ideas applied to their own experiences or, indeed, were valid outside of the person expressing them.

Furthermore, tolerance was one of the most valued qualities that three participants experienced in various support groups. They reported appreciating the freedom to express their beliefs without feeling judged or challenged, with Greg describing his feelings thus: "everybody is up their own beliefs about their voices. You don't push your beliefs on to other people". All participants reported often feeling strongly that various mental health professionals, and the mental health system more broadly, pushed their own ideas onto them and this was experienced as being highly negative.

Psychiatry was experienced as narrow-minded and limiting, as Sarah explained: "The problem with the system is it doesn't see beyond its own idea of something they still don't understand”. Sarah explained that, in her experience, psychiatry has fixed ideas regarding experiences “they still don’t understand”, which she described as problematic. This also means that, when being engaged with creating a coherent self-narrative, psychiatry’s explanation of schizophrenia does not offer a thorough understanding because of the lack of firm evidence in the current theories. Patients with this view, therefore, must cope with a lot of uncertainty by accepting a medical label they feel lacks coherence and taking medication of which the doctors are not able to explain fully explain the function.

It has been argued before that mental illness can be construed as individuals not conforming to social norms (Szazs, 1972). This situates conceptualisations of mental illness in a political sphere. It asks: “Who is having the problem: is it the individual who behaves or sees things differently or those who experience anxiety because of having the comfort of social expectancy compromised?”. Within the profession of mental health, showing compassion towards clients/patients and being empathetic are often discussed (LaPera, 2021; Siegel, 2010). These are certainly good aims, but I would argue that, even before these qualities, we need to show tolerance for patients’ own views and their understanding of their experiences. The tolerance the participants experienced in support groups was experienced as positive and the part of the reason they felt safe and open to share their experiences. Intolerance in the other hand, unsurprisingly had the opposite effect. Tolerance was not a concept I came across in the literature related to the current subject, so there is room for much more research into this dynamic. There is a distinction to which practitioners should be sensitive; namely, showing tolerance towards others’ beliefs and encouraging the normalising of certain experiences and phenomena that are either irrational or fantastical.

5.5. Stigma and being part of society

All participants were concerned about their place in society. There was a desire for social connections and not to feel like outcasts. The relationship between social inclusion and recovery is well established (Bentall, 2003) and this was consistent with the findings of this study. Five participants were aware of what was considered to be “normal”. Four participants also acknowledged that their own behaviour might, at times, not fit into such categories. The desire to fit into the norm and not be seen as—or feel like—an outsider was very strong.

Stigma was experienced by five participants, but the wish to be seen as a whole person and not to be judged was expressed by all. Stigma was manifested and expressed subtly in the relationship the participants had with others. Davidson (2003) points out that it is not only stigma itself that is important, but “the space the person is left to occupy as a result of the effects of stigma” (Davidson, 2003, p.165). The participants needed to be part of society, not as a “patient” or “service user” but as a human being with value. Having social support in the form of family and friends is beneficial to the well-being of people diagnosed with schizophrenia (Bentall, 2003) but cannot be “prescribed” by professional mental health workers. However, taking part in meaningful activities such as work and support groups are ways that can be arranged by healthcare teams and are offered to individuals with a schizophrenia diagnosis. These have been found to significantly correlate to well-being (Guedes de Pinho, de Sousa Pereira and Balula Chaves, 2018) and, therefore, are recommended to form part of the overall care for this population.

All participants described a wish to be themselves and express themselves freely. However, despite this strong desire, three participants would deny aspects of themselves when they felt it would aid social inclusion. This was most easily achieved with the help of medication, which was experienced as a “blurring up” of their “other selves”, experienced as creating a disconnection from a part of themselves that felt true and authentic to them. At times, they would simply avoid facing what they knew to really be the truth, in order to live more at ease in connection with others. Indeed, being part of society and connection with others were large components of what moving away from “mental illness” was about: it was both a path towards a better existence and an end goal of a better existence.

5.6. The existential dimensions

There have been existential elements and references in the discussion so far but, when looking at the themes from an existential platform, it is useful to also consider the results of this study across van Deurzen-Smith’s (1988) four worlds or the four dimensions of human existence. This provides the reader with an overview of the participants experiences over these for dimensions which all individuals share; dimensions which form the basis for our day-to-day experience, irrespective of mental illness or not. By presenting the themes across these dimensions it is hoped that the reader recognise the participants’ struggles as part of the existential struggles we all face as part of the human condition, thus narrowing the us and them gap. Van Deurzen-Smith added Heidegger’s Überwelt (“over-world” or “world beyond”) to Binswanger’s Umwelt, Mitwelt and Eigenwelt (discussed in chapter 2). Van Deurzen-Smith refers to these as the Physical Dimension (Umwelt), Social Dimension (Mitwelt), Psychological Dimension (Eigenwelt) and Spiritual Dimension (Überwelt). The spiritual dimension is the one in which our experiences are put into context: it is where we find our values, assumptions and beliefs, where we make sense of our life and where we look to find the purpose and meaning to our existence.

All participants were concerned with considering the impact of their diagnosis on these four dimensions. To give a full analysis, each participant’s interview would have to be presented as a case study, since the way each participant was engaging with each of these dimensions varies significantly and is an expression of their own being-in-the-world, which cannot be unified. Nevertheless, there are elements of the results as a whole that are useful to consider across these dimensions.

For the participants, engaging with a diagnosis they did not believe they should have revealed existential struggles in these four dimensions, which were all intertwined with and affected by one another. Receiving a schizophrenia diagnosis forced participants to consider who they were (Personal Dimension; Eigenwelt), whether or not they had been inclined to do so before.

Heidegger (1927/1961) describes how people are inclined to fall into a state of forgetfulness whereby they exist without giving much reflection on who they are and their identity and role in life, merely existing with a passive acceptance of what their role expects of them. To break away from this forgetfulness, a person must face the anxiety of deciding for themselves who they are and choosing and setting their own path in life, thus entering into a state of authentic existence. In many ways, receiving a schizophrenia diagnosis forced participants to face the question of who they were (to reflect on their being) and, ultimately, who they would become and how their life journey would proceed. Could participants allow themselves to surrender their futures to the influences of this devastating illness?

When participants rejected their diagnosis, they had first 'tried it on’ (whether for a shorter or longer time) and, ultimately, rejected it as not fitting in with who they considered themselves to be. If they had been able to reject the diagnosis only once and not think about it again, they may have been able to stop engaging with thoughts about their being. However, with diagnosis came care or treatment, throughout which the participant’s own beliefs about who they are continued to be challenged and attempted to be (at least partly) exchanged for an identity as a person with schizophrenia. Their thoughts about themselves and their hopes for their lives had, in some ways, been hijacked by their diagnosis—and, even if they rejected the diagnosis, it stuck with them and continued to influence how they engaged with their sense of selves.

For participants, the personal dimension was illustrated in superordinate theme I: Being one's self. In this dimension, all participants were trying to reach a point of empowerment. It was difficult to be heard by others and their sense of self was weakened. Some struggled to find self-worth.

For all participants, the social dimension (Mitwelt) can clearly be seen in Superordinate theme II: Self in society. Overall, they felt they were different to others. They engaged in a continuous comparison of who they were, in contrast to who others were, and their place in the social sphere. To three participants, a sense of being different was clearly negative and there were suggestions of them trying to diminish this perceived difference and longing to become an accepted part of society. These were the people who most clearly rejected the term schizophrenia and more predominantly experienced themselves as marginalised, often as a result of others' words and actions.

Three participants did not necessarily regard their perceived difference as wholly negative. Self-stigma seemed to be partly determinant of this difference, but arguably more important was the sense of personal agency they experienced. The degree to which they were influenced by what they felt others thought and how strongly they were able to retain their own sense of self both had implications for how positively or negatively notions of difference were regarded. Those who bore more resentment and arguably suffered more were also the ones who felt victimised by the diagnostic label and by those involved in their care.

When one’s difference was by other people to one’s experiences rather than to symptoms of an illness, there appeared to be a sense of acceptance and, in turn, less suffering involved. In this sense, the self might be considered to be part of both the social and personal dimensions. Van Deruzen-Smith (1988) explains how activity and passivity is an important polarity on the personal dimension: finding one’s own answers to one’s situation (or: self-affirmation) was experienced as positive. Surrendering to the other’s explanation of one’s difficulties was experienced as negative and part of what all participants were trying to break away from.

The difference between those who felt a sense of agency and those who felt victimised is another call for psychotherapeutic intervention. The results suggest that if an individuals’ experiences are examined in detail and they feel they are being understood, this is responded to more positively than when it is felt that frameworks are imposed as an explanation for their experiences. Such understanding arguably needs to come from the bottom up—rather than from the top down—so that it may valuably reflect the experiences of the person involved. Helping an individual form such an understanding of themselves may help them move from a state of feeling that they are surrendering to others’ explanations and being victimised to a state of self-affirmation and personal resolution.

The physical dimension (Umwelt) was not a direct area on which the participants reflected, but it was implicated in their accounts. Most clear was the physical nature of some of the experiences with which participants struggled; for example, sensations of being touched without seeing who was touching them (e.g. for Rose) or hearing or seeing things that others were not able to (experienced by all participants). These physical experiences caused the participants to reflect on their nature and meaning, similar to the way receiving the diagnosis made them reflect on who they were. They were able to consider what was happening to them psychically and how this made them feel (scared, sad or special, for instance). They also considered how it might upset their social positioning in terms of being different or seen as mentally ill. For someone like Stu, where the physical discomfort he experienced impacted his day to day life (e.g. his anxiety and “brain seizures”), his physical existence became an important factor in how he experienced himself in the world.

The label of schizophrenia generated questions for all participants regarding who they were and how they identified themselves. The more they engaged in questioning the beliefs and values that were around them—particularly those that had been handed to them to absorb—the clearer they became as to which values and beliefs were theirs and which belonged to another person (a person with whom they did not agree).

Sarah had formed very strong opinions regarding the treatment of herself (and others) based on her own experiences and her knowledge of psychiatry. Her deeply held values around the mistreatment of herself and others gave her the will to stand up against what she felt were wrongdoings; this enriched her life with meaning. The spiritual dimension (Überwelt) lay as an undercurrent to participants’ narratives. Similarly to Superordinate theme III: moving away from “mental illness”, they engaged with the here and now with a stance to project themselves onto a more positive future. Through their engagement with their experiences, they were forming a narrative, or a life story, in which their values and beliefs could be understood.

5.7. Reflexivity

Any qualitative study requires transparency and reflexivity. I think it is most crucial to consider your own position within the study and how this may be inseparable from all its aspects. Deciding what literature to review and the evaluations of it, the way data are collected and analysed and what conclusions are drawn, can all be influenced by one’s own particular position. Although these issues have been alluded to in the literature review and other parts of the dissertation, I have reserved one section specifically for reflexivity. I think this will make the text a lot clearer to follow as I have had many moments of personal reflection along the way. I will now explore and discuss reflexivity with a tighter focus.

I am aware that I am influenced by my previous and ongoing experiences in many ways. My attitudes and beliefs have changed since I initially met the woman who I spent a year working with as a befriender for Mind and who gave me the inspiration for this study – Dr Mary who had been given a schizophrenia diagnosis which she did not believe she should have. My attitudes and beliefs have continued to change with my growing experience of working with and listening to people who have been given a diagnosis of schizophrenia and my ongoing involvement with the literature on this topic.

When I first met Dr Mary in 2011, I did not know much about schizophrenia (other than the Diagnostic and Statistical Manual of Mental Disorders (DSM) definitions). I was not aware that a lack of insight is very common among people who receive this diagnosis. This was likely a good thing, as this perspective of not knowing helped me to be able to listen to what was presented to me uninfluenced by previous judgements. Had I known then what I know now, I would certainly have viewed, and probably treated, Dr Mary differently; and herein lies the essence of my research. I have attempted to avoid such preconceptions and listen to the experiences of those who have received this diagnosis and to try and understand their communications from their own perspective.

Dr Mary was angry: she felt an enormous sense of injustice. To me, she appeared to be entirely stuck in the past, obsessing over details. She described constantly trying to get in touch with “the right people”, both from the past and the present, who could confirm her side of the story. She wanted the truth to finally come out.

I was deeply moved by what she told me and the way she conveyed it with such deep feelings attached. I started seeing her not too long after having completed the counselling foundation course at Regent’s College, where I had been significantly influenced by the literature surrounding the anti-psychiatry movement, and particularly by Thomasz Szasz. Already having a strong sense of patients’ rights and freedoms, Dr Mary’s intense feelings of injustice initially enhanced my previous convictions. However, seeing a steady deterioration in her mental health made me consider more and more that complexities were present both within her and within the mental health system. I began letting go of my firm convictions—at least, those that could be generalised to whole populations—and felt more and more that each person comes with their own unique circumstances: rarely are things straightforward.

Nevertheless, what stayed with me was the very real feeling of despair Dr Mary felt at having lost the life she felt she deserved due to this diagnosis, which she did not believe she should have. The sense of unfairness was enormous. This experience made me very interested in the complexities around what currently constitutes “madness” and “sanity” in society and how they might be approached differently.

On a broader level, I find the philosophy around this matter fascinating. I read Michel Foucault’s (1964) *Madness and Civilization* around the time that I was beginning to think about my research project. It was a book that stirred my fascination around the place of madness in our society throughout time and provoked thoughts of where it is today. Bringing this together with the patient’s freedom and right to decline treatment, I felt a strong sense of curiosity. I wanted to learn more about this. I did not know what to think or what my own position or opinion was: I simply wanted to learn more about what it was like for people who were perceived by others as crazy, insane or mentally ill, or had been labelled with a psychiatric diagnosis when they had a different perspective.

I have wanted to get away from considering a ‘right or wrong’ argument and focus on the truth of my participants’ experiences. At times, this has proven to be challenging for me. I am innately a black-or-white kind of person. I have an inclination to seek truth, to confirm one way as superior to the other—to choose right over wrong. Throughout my training as an existential psychotherapist, I have become much better at holding opposing viewpoints at the same time, with less desire to prove any one way better or truer than the other. Nevertheless, this black or white attitude recurred throughout my engagement with this project.

At times, I have felt that it is important for me to know where I stand regarding many of the issues raised, such as the nature of mental health, schizophrenia, treatment and movements to fight stigma. I have felt that, if I do not have a firm position, it may not be possible for me to conduct research that makes sense to others. At other times, I have thought that my position is immaterial: I am an observer and a researcher, whose job it is to simply present what I have observed and my interpretation of my observations.

Initially, it was the other side of “madness” that I wanted to study. Due to the difficulty of capturing such an abstract construct, I decided to interview people specifically with the diagnosis of schizophrenia. I hoped that this would help bring structure and clarity to the study. It has been a challenge to bring this clarity and structure to the project while keeping the door open for people’s own interpretations around the ways in which they disagree with their schizophrenia diagnosis. Similarly, it was often difficult to stay out of the conversation, as it was a conversation first and foremost around the politics of the mental health system.

I read the book *Learning from the voices in my head* by Eleanor Longden (2013) in 2014, by which time my research proposal had been approved and I was on the cusp of submitting my ethics application to the University. This book centred entirely on the author's experiences of learning to live (well) with her voices and it made the discussion around the meaning of madness come alive for me yet again. I felt, quite strongly at the time, that I had to change the title of the study once more as I felt it was misleading: that it conveyed a sense of having been misdiagnosed. Would people who identified as "disagreeing with one's diagnosis of schizophrenia" objectively agree that they experienced "auditory hallucinations" or other clear symptoms? Would they acknowledge experiencing what could be classified as schizophrenia, arguing that they were not ill and that there was nothing wrong with these experiences? The possible change of title was discussed with my supervisor. Would I align my research with established ideas by using terms such as "diagnosis" and "schizophrenia", hence continuing a language that people similar to the participants in my study were trying to fight? Would the terminology in the title play into power dynamics that were already possibly present for the population I intended to interview? By using the term "schizophrenia", would I validate the diagnosis and, therefore, undermine participants' perspectives before we had started the interview? I discussed these questions with my supervisor and it was decided that the title did not need to change. The participants had been categorised in a way that used this specific terminology with which they did not agree, whether that disagreement was with the categorisation, the terminology or both. The title reflects the understanding that it is for the participants to interpret in what ways they disagree with their diagnosis. As a researcher, I did not have to make the title void of any feelings participants may have towards the wording itself in order to validate the research. They had a "diagnosis of schizophrenia", no matter the term I used to refer to it and it was up to them to tell me how they disagreed with this. The title does not imply that I agree that they should have a “diagnosis of schizophrenia”.

The research title was the title used when recruiting, so all participants who contacted me had seen it and felt that it captured their experiences to the degree that they reached out to me. I did, however, try to capture the above questions in my interviews with the participants.

These types of questions about, what madness is and what agreeing or disagreeing means, have been with me from the beginning of this study and resurfaced when I engaged with different literature. I have kept a reflexive journal and thus have been able to consider my thoughts at each step. I often reminded myself to strive for an understanding of the way participants made sense of their experiences. Therefore, by attending to the more reactive and positivistic aspect of myself, I have been able to quieten its voice and return to the study with my learnt, reflective attitude and thinking.

Before conducting the first interview, I was feeling somewhat anxious about seeming to deceive participants. It has often been assumed by people who have been in touch with me regarding the research that I am something of an activist for the population classified as mentally ill by society at large. I think a part of me wanted to take this stance. Individuals have assumed that I may have also disagreed with their diagnosis as though both of us together thought that they had been misdiagnosed—one person even asked me to help her prove that her diagnosis had been a mistake and that she did not have schizophrenia. I explained that I would not be able to do that and excluded her from the sample for ethical reasons. Through the ethical approval process with Middlesex University, I learnt that it had to be clear to all potential participants that participating in the research should not be of any benefit to them, other than supporting research in an area that affects them and for the possible enjoyment of sharing their experiences. It would be unethical if a participant agreed to take part in the research under the hope that my interview would form a basis for having a schizophrenia diagnosis challenged or removed by psychiatric services.

The aim of the study was to give voice to this population and show their very real experiences. However, I'm unsure whether some of my participants would be pleased with the interpretations I have made from the transcript because, although I have tried to show their experiences as they showed them to me, I have also interpreted the transcript beyond what participants expressed verbally and have reframed some of their experiences in terms of symptoms and hallucinations, which may not be how they would like to be portrayed.

I have considered whether this means that I have taken the position of the "professional", talking about the "patient" when the aim of this study is to narrow the gap between these two. However, these are terms that I think accurately describe some of my participants' experiences (e.g. seeing people one foot tall walking across the room). I cannot describe that as "real" in the same way that the participant thought it was real, but I have tried to capture their experiences as real and tried to capture their suffering and their humanness—if not all of their beliefs—as "real". This is also the reason that respondent validation was not used in the analysis. I saw my role as researcher to interpret the narrative one step beyond what has merely been said and take into account the whole narrative around the participants, including social, environmental and historical factors. This type of double hermeneutics has been crucial in reaching the core of trying to answer the research question.

I have been very much aware of the tension between these two positions in each step of the transcript interpretations and write-up of the thesis. I believe this awareness has ensured that I have shown participants' experiences as closely as possible to how they experienced them.

To sum up my research journey, my starting point in this project was: “they think I’m crazy but I’m not”. I learnt about the concepts of lack of insight and anosognosia, which showed me the medical angle on the subject. While such ideas may tell us about the construct of schizophrenia, they reveal less about people’s own experiences. I began from a point of curiosity and I ended up at a place of empathy. My perspective now puts me somewhere completely different; perhaps much like my participants. This study has not been concerned with objective truth: rather, my interest has in been the experiences people have.

6. Conclusion and clinical implications

This study has investigated the experiences of those who disagree with their diagnosis of schizophrenia. As explored earlier, there is a fundamental difficulty—perhaps even a paradoxical dilemma—one encounters when attempting to capture a concept or experience relating to something that a person does not believe they have. Despite these inherent challenges, this study found that its participants were primarily concerned with making sense of themselves and their experiences. They appeared to be concerned with creating a coherent self-narrative and understanding, which would give them a sense of strength in themselves and enable them to move towards a better future.

The self-narrative of someone with a schizophrenia diagnosis often contains both personal aspects of their history and more ambiguous elements, which some may call, for instance, delusions. Together, these are woven into a narrative that strives to be coherent. Perhaps, at times, the non-truths of participants' narrative function as bridges of the things of which they cannot make sense—their individual coherent narrative—is them making sense of themselves. This study has found that to be important for healing and so, in a way, mental health professionals need to accept the non-truths—at least as part of their personal narrative; they should practice tolerance towards their patients' own interpretations.

I would argue that creating a coherent life story as a means by which to understand what happened and why is typical for anyone who has gone through a difficult situation or had experiences that have significantly shaped their lives. Not only are seeking meaning and making sense a part of human nature but they are also important aspects of surviving traumatic experiences.

People engage in meaning-making and making sense of experiences or situations that have altered their lives. Common explanations might be “it’s fate”, “god’s will” or “meant to learn a life lesson”. Participants’ experiences of disagreeing with their diagnosis of schizophrenia were, in one sense, similar to this—but arguably were experienced more strongly. As their diagnosis had a huge impact on each of their lives, and because their perceptions of the diagnosis were not necessarily agreed with, participants may have felt more defensive and sensitive about their own self-narrative. Professionals should help this population with their process of meaning-making by allowing a narrative to be told, to hear it and make connections.

Engagement and connection are often suggested to be important when treating people with psychosis. In this light, the results of this study indicate that it is crucial to interact with this population in such a way that does not undermine their attempts to make sense of their experiences. Rather, sense-making should be encouraged in order to help this population make sense of what is going on for them in a way that is right for them. This should be a focus of the care offered to this population.

This could take the form of focusing on the positive aspects of everyday life or assistance in other personal projects that this population feel would move them in a positive direction, such as finding meaningful activities in which to engage. This suggests that psychotherapy would be an excellent activity for this population as it could provide a space in which they could reflect on themselves and their lives in a supportive way. They could be helped to find out how they would, individually, like to move forward in life. Help and encouragement for this population in finding personal projects (e.g. work or a hobby) leading to a valued role in society (reintegration) would be a positive therapeutic goal.

Tolerance needs to be shown towards people's own opinions about what is going on for them. Insisting on pushing one's own view onto those who disagree with their schizophrenia diagnosis is simply not helpful; furthermore, it appears that this population are not convinced via this route. Conviction begins at a much deeper and more complex level than simply having a cognitive understanding: indeed, it appeared that conviction was a deep-felt sense of just knowing. Participants had not sought help with knowing differently: moving away from "mental illness" was not about being convinced of society's "reality" (that is to say, of society's perception of participants' experiences). Rather, it was about various personal projects, making sense of the self and, importantly, about creating a positive self-image and narrative.

In summary: psychotherapy appears to be an excellent way in which to help this population form stronger and more positive self-narrative and self-image; ones that make sense to the individual and are meaningful. Outside of psychotherapy sessions, mental health professionals should practice tolerance towards this populations' own views and ideas about their experiences and support them in their own attempts at meaning-making, and finding a valued role in society.

6.1. Limitations and future research

The general topic of the subjective experience of disagreeing with a diagnosis of schizophrenia is, to my knowledge, wholly unexplored in academic literature. The broad makeup of the participant sample gave the benefit of introducing the topic and themes found in a general sense, with the small sample size ensuring that the data gathered was rich and I was able to analyse it in great depth. However, far more can be done in this field, with a larger and wider array of data.

Future research could, then, dissect and explore each (and, potentially, new) themes that were identified and begin to make findings, recommendations and changes to the ways in which other patients who share the present participants' experiences are heard, listened to and, ultimately, cared for by the professionals involved. From the start, one of the main aims of this study was to narrow the gap between the "us and them" experience that many service users have and to let the current participants' narratives stand as valid accounts of their own experiences, rather than as symptoms of disease. The area of disagreeing with one's diagnosis of schizophrenia was approached rather openly and, although the experience of "us and them" was discussed by participants, it was not explored with any particular focus. This could be looked into in greater detail in future research.

There is little to no representation of participant experiences of disagreeing with their diagnosis of schizophrenia in journals or published literature. Therefore, in isolation, the sample size of this study presents limitations on any broad-ranging interpretations that could be drawn; however, there are bases upon which future research could develop themes and constructs through further research. What was apparent within the sample was that there were two different forms of disagreement. Schizophrenia could be rejected or accepted as a construct while rejecting the link between it and participants' experiences. Studies exploring this divide in greater detail would hopefully make a significant contribution to academic understanding, as well as offer nuance to engagement guidelines for care professionals.

Although the current study benefited from having a variety of reasons for disagreeing with a schizophrenia diagnosis (through the rich and diverse ways in which the participants interpreted the same phenomena), future research needs to develop a clearer distinction between the reasons participants have for disagreeing with their diagnoses. One way of separating these could be to recruit participants who have been labelled by a psychiatrist as lacking insight. However, in so doing, future researchers should be careful not to compartmentalise and label even further—something this study initially aimed to take a significant step away from. Such research would, nonetheless, add clarity and further understanding of this population's particular experiences.

On a practical level, the exploration and examination of these personal accounts clearly indicate that medical and care professionals may not be advancing care and treatment by pursuing agreement with diagnosis. Accepting a schizophrenia diagnosis could have more negative connotations than purely agreeing that symptoms equate to a diagnosis so, in seeking an agreed diagnosis, there is likely to be a disconnect between patient and practitioner. Further studies, including clinical psychology research, are needed in order to explore and curate specific guidance to negate this inherent issue in diagnosis acceptance, both for schizophrenia and other mental health disorders.

One key finding of this paper is the power of tolerance and this could well yield some valued advances in this field. Given that tolerance and meaning-making were found to be such important aspects of healing, future research should explore these themes further, particularly looking at the link between these themes and recovery in people diagnosed with schizophrenia but disagreeing with the diagnosis.

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8. Appendices

Appendix I – Ethical clearance

Middlesex University, Department of Psychology

REQUEST FOR ETHICAL APPROVAL (STUDENT)

Applicant (specify): *DCPsych* *Date submitted:11/8/2014*

Research area (please circle)

Clinical Cognition + Emotion Developmental Forensic Health

Occupational Psychophysiological Social Sport + Exercise

Other _____________**Counselling**________ **Sensitive Topic** ☐

Methodology:

Empirical/Experimental Questionnaire-based Qualitative **X** Other _______________

No study may proceed until this form has been signed by an authorised person indicating that ethical approval has been granted. For collaborative research with another institution, ethical approval must be obtained from all institutions involved.

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[1], consent form[2], including approval by collaborating institutions).

- Is this the first submission of the proposed study?
  Yes

- Is this an amended proposal (resubmission)?
  No

Psychology Office: If YES, please send this back to the original referee

- Is this an urgent application? (To be answered by Staff/Supervisor only)[1]
  No

Supervisor to initial here ___________________

Name(s) of investigator **Moa Lundstrom**

Name of Supervisor (s) **Niklas Serning, Alison McGourty**

Title of Study: **The Subjective Experiences of Disagreeing with one's Diagnosis of Schizophrenia – a Phenomenological Study**

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**

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

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

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

The participants will be informed of the possibility of becoming upset as a result of being interviewed about what is possibly sensitive material. I will use my therapeutic skills to contain the participants during interviews and make sure they leave feeling relatively stable and ok. Should they wish to further discuss anything that might have come up for them, I will have prepared a list of counselling services they can contact.

---

[1] **See Guidelines on MyUnihub**

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 premise*

I intend to recruit my participants through Hear Us in Croydon, where I have been invited to talk about my study at one of their monthly meetings which many service users (with schizophrenia) attend.

5a. Does the study involve:

Clinical populations	YES
Children (under 16 years)	NO
Vulnerable adults such as individuals with mental or physical health problems, 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 X

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

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

Informed consent will be obtained by the participants themselves at the time of the interview by signing the consent form.

7. Will you inform participants of their right to withdraw from the research at any tim YES without penalty? (*see consent guidelines[2])*

8. Will you provide a full debriefing at the end of the data collection phase? YES (*see debriefing guidelines[3]*)

9. Will you be available to discuss the study with participants, if necessary, to monit any negative effects or misconceptions? If "no", how do you propose to deal with any potential problems?	YES
10. Under the Data Protection Act, participant information is confidential unless otherwise agreed in advance. Will confidentiality be guaranteed? (*see confidentiality guidelines*[5]) If "yes" how will this be assured *(see*[5]*)* If “no”, how will participants be warned? *(see*[5]*)* Participants will be informed that confidentiality cannot be guaranteed but that the data will be anonymised. Participants will also be informed when I am required to break confidentiality (by law and in accordance to ethical guidelines). This will be orally explained as well as in writing. Participants will be made aware that their data may be requested for inspection in the course of institutional audits (hence their identity will be revealed to the auditors). The consent form will therefore include a small paragraph giving the participants the possibility to request specifically for their data not to be included in institutional audits. They will also be informed that the researcher is aiming to publish the result (or the finished paper) in an academic journal or elsewhere. (*NB: You are not at liberty to publish material taken from your work with individuals without the prior agreement of those individuals*).	NO
11. Are there any ethical issues that concern you about this particular piece of research, not covered elsewhere on this form? If “yes” please specify:	NO
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	**X**	
If "yes" tick here to confirm that a Risk Assessment form has been submitted	**X**	
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	**X**	
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)	**X**	
16. I have read the British Psychological Society's *Ethical Principles for Conducting Research with Human participants*[4] and believe this proposal to conform with them.	**X**	

SECTION 3 (to be completed by <u>STUDENT</u> applicants and supervisors)

Researcher: (student signature) ______Moa Lundstrom____________ date _____7/8/14________

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:…………...

Appendix II – Risk assessment

INDEPENDENT FIELD/LOCATION WORK RISK ASSESSMENT FRA1

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

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FIELD/LOCATION WORK DETAILS

Name ……Moa Lundstrom………

Student No

Research Centre (staff only)….M00415400……

Supervisor …Niklas Serning & Alison McGourty…

Degree course ………DCPsych…………………

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

NEXT OF KIN

Name ……Harry Thorne………………………………..

Phone ………07713928936……………………………..

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

……n/a……………….……………..……………………

Any health problems (full details) Which may be relevant to proposed field/location work activity in case of emergencies.	……n/a…………….……
Locality (Country and Region)	…London, UK, Highbury and Islington/ Croydon………
Travel Arrangements	………Cycle/train………………………………………
NB: Comprehensive travel and health insurance must always be obtained for independent overseas field/location work.	…………..…………..………….…………..………………… …………………….
Dates of Travel and Field/location work	……Dates unknown …………..…………..………………

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
Travel (cycle) Aldgate East – Highbury Islington	**Traffic, adverse weather, building sites**
Highbury Counselling Centre (place of interviewing)	**Lone interviews**

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 PLEASE READ VERY CAREFULLY

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/EQUIPMENT**
En route I will take care and being attentive around traffic. If cycling (as most possible) I will use a helmet and appropriate lights/reflexes.	Low	Helmet
Because I am conducting the interviews 1-2-1 in a closed space, I will make sure that the interviews	Low	Alarm button

will be held during office hours when the building is staffed. There are also alarms in the rooms should I need assistance. I will also be using my therapeutic skills that I have acquired through my training as a counselling psychologist to try to ensure that the situation will not escalate to that.		

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) ……….……Moa Lundstrom………..…………… **Date** …8/8/14……..…

Signature of Student Supervisor ……….……………..……….…… ……..…………… **Date** …….……………..…...

APPROVAL: (ONE ONLY)

Signature of Director of Programmes (undergraduate students only) ……….……………..……….…… ……..…………… **Date** ……….……………..…

Signature of Research Degree Co-ordinator or Director of Programmes (Postgraduate) ……….……………..……….…… ……..…………… **Date** ……….……………..…

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.

Appendix III – Participant information sheet

Information about a research project:

The Subjective experiences of Disagreeing with one's Diagnosis of Schizophrenia – a Phenomenological Study

being carried out by Moa Lundstrom as a requirement for a Doctorate in Counselling Psychology 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.

<u>What is the purpose of the research</u>?

This study is being carried out as part of my studies at NSPC Ltd and Middlesex University.

Some people who have been diagnosed with schizophrenia feel that there is nothing "wrong" with them, that they shouldn't have this diagnosis, which can be a very depowering situation to be in, where one's own side of the story isn't always being respected as a valid view.

There is currently not much research about this from a subjective point of view. This study aims to get a better insight into what these experiences are like, and so to give voice to the many people who have these experiences, which will hopefully contribute to providing better care for people with similar experiences in the future.

What will happen to me if I take part?

I would like to interview you for about an hour at a time that is convenient for you. Interviews will be held at a public but confidential space, e.g. a private room in a library or in a rented therapy room. In the interview you will be asked a few questions about your experiences of not agreeing with your diagnosis of schizophrenia. I am interested in your personal story, to understand what this has been like for you. I may encourage you to talk about what may have been difficult for you, but ultimately I am plainly interested to hear about what you have got to say about your personal experience of disagreeing with your diagnosis of schizophrenia.

What will you do with the information that I provide?

The interview will be recoded and later transcribed by myself. All the information will be anonymised so that anyone reading the material would not be able to identify you. The interview will be transferred to an encrypted USB stick for storage, and deleted from the recorder. Transcribed documents will be safely stored. This information will be kept at least until two years 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 British Psychological Society Data Protection Act and the Freedom of Information Act.

What are the possible disadvantages of taking part?

You may find that talking about your experiences of disagreeing with your diagnosis to be distressing. You might find yourself thinking of things you hadn’t considered before, and talking about personal, upsetting details. 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 I am required by law to pass on to a third party, I will have to do so. Otherwise whatever you tell me will be confidential.

What are the possible benefits of taking part?

There will be no direct benefit for you to take part in the study. However, as this is an area that does not currently receive a lot of attention, by taking part you will contribute to knowledge and hopefully, in the long run, to better patient care. Although being interviewed about your experiences has no direct benefit for you, some people may find it an opportunity to reflect on themselves and their lives, which could be beneficial.

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.

Who is organising and funding the research?

This research is entirely self-funded.

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 you do take part, I will cover travel expenses to reasonable limits.

Thank you for reading this information sheet.

If you have any further questions, you can contact me at:
NSPC Ltd
258 Belsize Road
London NW6 4BT
Lundstrom.research.mdx@gmail.com

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

Niklas Serning
NSPC Ltd
258 Belsize Road
London NW6 4BT
office@nspc.org.uk

Or

The Principal
NSPC Ltd. 254-6 Belsize Road
London NW6 4BT
Admin@nspc.org.uk
0044 (0) 20 7624 0471

Appendix IV – Interview questions

Interview questions

Can you start by telling me a bit about yourself and your situation?

You have a diagnosis of schizophrenia, but you disagree with your diagnosis. Can you tell me about your experiences?

Can you describe what you disagree with/ how you disagree?

What are your experiences of the mental health system?

Are you taking medication/ have you taken medication? What are your experiences of that? How does that impact how you experience yourself and the world around you?

How have you experienced doctors? Nurses? Have you had therapy? How was that experience?

Has your disagreement with your diagnosis been consistent? Always rejected it? Has there been moments in the past when you have agreed with it? Has it been confusing?

How do you view yourself/ your life?

How do you view schizophrenia?

Have you met other people who have been diagnosed with schizophrenia? How was your perception of them?

Have you experienced stigma?

How do you view mental illness/ mental health?

Do you feel the schizophrenia label has affected you? How?

Do you feel you can have open/ honest conversations with people revolving your care?

Do you feel listened to? Your opinion valued?

Areas: Label, stigma Self and others mental health system

Appendix V – Consent form

Middlesex University School of Health and
Social Sciences

Psychology Department

Written Informed Consent

Title of study: **The Subjective experiences of Disagreeing with one's Diagnosis of Schizophrenia – a Phenomenological Study**

Researcher: **Moa Lundstrom**

Supervisors*:* **Niklas Serning**

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 VI – Debrief

Debriefing for a study on:

The Subjective experiences of Disagreeing with one's Diagnosis of Schizophrenia – a Phenomenological Study

This study was an investigation into the personal and subjective experiences of disagreeing with the diagnosis one has been given of schizophrenia. Some people who have received this diagnosis to feel that there is "nothing wrong" with them (sometimes feeling they have been wrongly diagnosed). This phenomenon is in clinical terms referred to as "lack of insight" into illness or unawareness of illness. However, this perspective implies that "the other" (e.g. psychiatrist or psychologist) has some insight which the person with the diagnosis doesn't have. This often leads to anger and frustration from the diagnosed person's side, feeling unheard and misunderstood, and unwilling to deal with professional services. This phenomenon has had very few studies from the diagnosed person's side, hence there is a lack of understanding on the "professionals" side on what it is like to have been diagnosed with schizophrenia when one does not agree with this diagnosis.

By having taken part in this study, you have contributed to knowledge of a new area of research which could be very important in the continued care of this population. It is the hope that studies like these will give voice to people in this situation and help to narrow the gap of the understanding, communication and cooperation between professional services and their users, resulting in better care and more satisfaction to service users.

If you have any questions about this study, or if there is anything else you would like to discuss, please get in touch with the researcher on this email address:

Lundstrom.research.mdx@gmail.com

Or you may contact my supervisor:

Niklas Serning

NSPC Ltd
258 Belsize Road
London NW6 4BT

office@nspc.org.uk

Thank you again for your cooperation!

Appendix VII - Transcript 4 (participant 5)

R1: So what I would like to start by asking if you could tell me a little about yourself and how you disagree with your diagnosis, and just a few things about, around that.

P1: Well, I suppose that for whatever reason, it's kind of very hard to tell but I have difficult with every relationship around me, with family and stuff and the community and when I was just a bit over twenty's, came back from college.. just a bit over twenty yeah, and I, I just like dissociated… completely. I just detached from reality for whatever reason it was. It must have been, I don't know, it could have been lots of reasons, it certainly was a lot of things happening about that time, you know, it weren't very good, and my kind of area, and sometimes really, and in family as well, erm and other, with the wider family. Erm, but basically so I ended up in hospital for about three years and it was pretty ghastly, pretty awful actually. But the whole thing is awful like I mean I suppose you ask why did this happen to me like you know, like why am I the one this kind of happens to you know. I suppose the first 10 years, 23 to 33 were very very difficult, touch, like you know, bullying and you're vulnerable and just a mess really like you know, I was just a mess really. I managed to have a few jobs and different things, hold down a few relationships for short periods but erm, when I got to thirty, mid thirties then things were picking up cause more or less coincided with I got involved with kind of movement like advocates and peer advocates and stuff and but I started thinking, interested in what it was, what had actually happened you know, so it took about 10 years and in all that time I suppose I was given a diagnosis in hospital I think I got my records and the first early record were destroyed, they were in hospital in -96, I was in there for three or 4 months, just a one off, erm and… I think it was severe depression, they change it all the time, it's very vague sort of thing you know that's why we would say you know best yourselves, you'd be the expert on the experience. That's what's generally kinda used.. erm .

So then I got a diagnosis, they came up with, they, they just lots of diagnoses so it's very vague and slippery it's like words, words with different meanings whatever you know, you don't wanna take it too seriously cause I didn't like the word, and I feel that you're normal John range, I don't know, that going to the psychology professor and Melbourne, lives in Liverpool, England. But very involved in the voices movement in England, but erm. De.. just deconstructed the whole word schizophrenia in a lecture, I saw it on youtube. A guy called Kraepelin, some guy in Victorian era, like coined it and you know, listed like, wrote a whole novel, the… whatever the detail of it that he pursuit, erm, but I just think it's, I don't like it. I don't like the word, like personally I, I'm, you know really talking about drama or trauma or when I was hospitalised the psychiatrist, a psychiatrist rang, just rang up my mum and said sorry but your son has schizophrenia, just like that. My mum nearly died of shock, literally, like you know, and she was like, you know, we'd kinda like you know never understood, known anything with this, and I was so showered (? 4:07) just like you know, too hearthaid but it was terrible because if, that's terrible, you know, like that word is like a curse really, like I hate it, I hate that word, like I reject it and I use other terms. I would see the condition more as like similar to more of a seizure, or, like similar to epilepsy, those conditions kind of overlap a lot. That's what I perceive, that I don't know, like I haven't had much medical input but erm, so I kind of perceive it more in neurological terms. Psychiatry doesn't really, is not evidenced, there's no evidence for it, but the thing you know. People are getting distressed and they want something so a lot of people want something, they want a quick fix and that's the way people are and that's why medication is so… like I've been on medication twenty years but I'm not on a dangerous level, I mean it's it's it's its, it's abused as well, like you know, my the medical professionals erm, but I don't like that term, because I just don't like it.. it's like being in a horror movie or something like you know, that's the sort of thing that conjures up to me, something like, you know, you know, like you're erm, people, it's like you're disgusting to people or something like you know why should you just (5:27) like if you have a medical condition or like suffered a trauma, that kind of stuff like I mean I suffer more and more and there's even the medicine, it's like harrowing, cruel like you know, treatments back in -96 anyway and worse as years gone by but erm you know, I just don't understand, it just seems to be cruelty, part of human nature. But erm like, you know..

R2: so people using the term schizophrenia makes your experiences worse?

P2: Makes the experiences worse..? Yeah well I suppose like I just don't like the term I felt very stigmatised for a long long time and very much so by the community and everything, kind of like people chasing you down the street and shouting at you and kind of things like that. Abused basically for over 10 years. But erm, (6:24) these are the get more careful and cleverer and it gets a bit more harder as the years go on like you know, you kind of hedge your bets up where you go and stuff like that, like a bar or stuff like that, especially on your medication, so erm, I just find it… it's not a thing I would ever have told any you know say to someone like you know oh by the way I have schizophrenia, it's like, it's just something you would never say. You would just you know, like in the olden days I suppose you, things were often kept quiet, those things were always kept quiet, people were kept and in coups, chicken coups and it were horrors of catalogues of abuse. And this country had the highest incarceration of sick, incarcerations in the world in the 50's and 60's. So erm.. yeah I never liked the term I don't like the language, the language is really important but it's really difficult, like you know, and I work, I work kind of like in that kind of area but more sort of peer support cause erm, there's no one really knows when you've gone through that much suffering others than themselves, people who've been through it you know (7:32).

R3: so that's.. I agree, there's not a lot of clear knowledge about it, so this…

P3: Well I think it was the term that was made up in Victorian time and it was this family that, like but it should really be abolished, like it should really be another word for it like you know. Well sometimes some people prefer like there's different words for diagnoses like, for me it's just I do suffer from voices and hallucinations and I get quite depressed, suffers from depression and various things.. like a lot of people, these things are probably a bit more amplified in me like you know, because of my sensitivity or whatever or kind of came crashing down when I was twenty, my early twenties and it's like I'm ported.. detached from reality and it's certainly not a very nice thing (8:28). But those terms, I don't think they help. People who have seen, it's like being Frankenstein, something like that like you know, that's what it's like you know like for me, in my community in a small town, small village, where I landed, being just dumped in a hospital I had to go back home, erm.. it's like you know.. people are, some people are very nice and they help you get through and you know, but like it's a.. probably a lot of people who don't get through this thing, there's a lot of suicide and things like that. Erm, and erm all that kind of stuff. Erm.

R4: So you would prefer if people saw your experiences for erm you know hearing voices or having hallucinations or being depressed at times, but taking this …

P4: Well I think it's like you know label, whatever, labels, I mean the psychiatrist are probably the most problematic thing I had now, I mean really deal with my psychiatrist, I find that troubling, looking all those there.., but I shouldn't really cause the thing is they don't really know what they're doing like you know, you know like, I talk to them erm from that.. a political or whatever movements.. survivor movements or, points sometimes, or send them stuff, but erm, erm… I don't think there, there non, they just use these terms erm, lots, there's lots of terms..., language, really like words have different meanings, they can be slippery and not to take them too seriously like anyone take them too seriously, I never liked that word but

I never think about it really. I don't like it but I think it's an antiquated (10:19) cruel, kind of Victorian term, and it doesn't really.., what it means in Greek is not really what this condition is, I don't know, maybe it is, it's debatable you know (coughs) so erm… But it's not something that erm, I just, from personal experiences it's not something I would ever go, first meeting or something and say oh by the way I have.. you know it's not something you would… stigmatising the term I think, you know. It really is like you know

R5: ok..

P5: so erm, and there…yeah a few other, like I see it's more like neurological that sort of way it is, you know and…

R6: is that a difference, if you talk about sort of erm, mental health or erm, so you see it more as something neurological, rather than like

P6: well it's complex because I disagree with erm the kind of psychiatrics biogenetics, like edm which they would have held, and I was always told that.. which I don't absolutely think, I think that, that evidence has shown that like the wider population base in general in humans and has, anyone who can be prone to this, they're relating it a lot more to trauma and stuff like that so

R7: yeah..

P7: Erm, and I erm, so erm so and I think in terms of actually seeing it, like I think for me, I, I recently you know come to see like with like the epilepsy or the what they call it? Temporal epilepsy when they can have like the seizure sort of thing, I would just say to some, like if I were explaining to someone, like I would go, I went to this swimming pool and were playing this really loud dance music and it was kind of really crushing on my head so I would say, in the future you know if I were to go back there again, the next thing I'm gonna say is listen I've got a brain seizure, you know that music is really hurting me you know like can you turn it down. But erm the last thing I would say to people is oh you know like I have schizophrenia. It's a very.., it does seem to mean any, like it's a meaningless, it doesn't seem to mean anything to me you know. It doesn't mean anything to me, it really doesn't mean anything. And all it describes is 110 symptoms the diagnostic manual but that's meaningless, like it's so vague and smoke emerge, there's no real, like, I, I like evidence, I like some evidence for stuff like you know, I'd be quite scientific in that way and I just don't like and that you know

R8: No erm…

P8: but they can have their denials (13:08) I don't f-ing care like, you know I just don't care about the, what they, shrinks or whatever, what they wanna, whatever. If they can help me I don't know, I suppose it destroys your faith in medicine which is the only thing but you know, you would like to have some faith in, because there are a lot of good people in medicine as well and you know… but I just think psychiatry is, I don't know, they I suppose, I don't know how they work or whatever you know but..

R9: So you, it feels like they don't really know what they're doing and your experiences hasn't been..

P9: do in terms of, erm like my old prescription or whatever, nah I don't know if they do a lot, everything's anecdotal it's like what I'm saying, so I can steer it anyway I wanted like potentially.. (13:50)

R10: But I see what you mean, it's quite a big difference from saying, you know, the music you're playing, the way you were describing it, like I get sort of seizures to my brain..

P10: people, people seem to, you know, I feel like you know, like a horror, like you know, this thing oh you know, my cousins erm mutant or something, my cousin's a zombie, can you turn the music down (laughs). I don't know it's just.. in the realm of science fiction or horror or something like you know, and that's where it's meant to stir from mentally and we don't really use that. Apparently people are using the term alright but, I don't like it. Personally. I don't really care to think about it, I don't give a damn, like it's just a word you know, words I don't have a problem with that, you know I've got enough words going through my head that kind of thing

R11: how do you make sense of that? How is that for you?

P11: what like hearing like..? Erm… how is it for me..? erm… Oh well I cope it with, you know, I use distraction, whatever, music or whatever. Erm, I sometimes talk to myself but just a little louder than most people probably talk to themselves, but I'm tying to manage it, I always try to get better like you know and I'd be careful you know normally with the whole thing about mental health is why people end up in trouble in the first place is that they lose control and that's not a very nice thing to happen to people, like they lose control. It's dangerous, it can be dangerous you know. Erm, you can end up in all sorts of uncertain situations (15:36). But I can try, I can accept it and I got to known in the last couple of years in the voices network and done training with Jackie Dillon, of the voices network and different stuff, and erm, I'm kind of educated, learning as I go along, you know, but like actually, they, just because you hear a voices you know, a psychiatrist often will want to give you a pill if you tell them you hear voices but if you're like, if you feel good about it you know or whatever, it's just like part of you, whatever you know, erm, I'm ok, I deal with it, you know, I don't, I, I, I manage you know. But I can't say it's always easy.

R12: No.. I get the sense when you say I deal with it and I manage it that it's sort of intruding..

P12: Well it's not that I don't mind it like the voices I've come to accept them, I did use to fight them for a long time, like you know like a psychotic or a psychopathic even, like you know not to like a dangerous extent but I suffered some sort of generals.. but I've learnt to manage it to deal with it a lot better now like, and stuff like anxiety all that kind of stuff you gonna manage like going on an aeroplane or whatever it is erm, I getting like I'm controlling, self-control, so you know, all that is really, obviously, I'm partnered for her to get along and get a, get places you know, progress and work you know, it's relations you know, and you've got to have the relations that you're not very, like I wasn't very good for a good while yeah, I mean it wasn't very… erm, psychologically with other people like you know, I was…

R13: Did you not like being around..

P13: Well for a long time I was, like I kind of approve, like you know it's been a long journey but I still have really weird talking to other people, you know you really see yourself like any other person like you know it's not like you're any different. I mean a lot of people hear voices and stuff it's quite a lot of the human population who hear voice, you know, they've done work on that. It's no big deal and a lot of people don't go through psychiatry. Erm, a lot of people don't go through psychiatry, but erm.. how do I feel.. but it's just like, I hear voices like every cou, like, episode, like sickles of every couple of few days and… I just.. Have preparation for it when I'm at home and you know, home and in a safe space, like social housing and safe, kind of secure tenancy, kind of like, that matters too. That matters too for not other people arrange for certain periods, cause erm, (18:21)

R14: why is that?

P14: because I get a little bit urg.. like I want to be on my own, people irritate me a little bit like erm, (coughs) so I want to be by myself listen to my headphones, probably lie in bed for a few hours until it passes. So it's annoying so I suppose your life it affects you behaviourally, really like in terms of dealing with it, the world, but with just certain times I have to kind of drop out you know. I might do it like you know, I might try and have food made and stuff like that so I'm gonna… kind of or whatever, try to prepare myself, for those things, like of like it's my life like it's so.. but I, I it is like whatever. Yeah.

R15: So you said you've been training and stuff and now you work in support groups. It seems you've been sort of seeking out learning more? Like, I get that impression that you've been sort of ..

P15: well I kind of had denial all for a long time, you know, like a lot of denial for about three years, but erm, and there was no talk about it but like this is like an opening up and kind of coming out and having a dialogue with certain people, who understand it, like you know, weather health professionals or carers or you know families improved, you know since people have started talking about these things. A lot of them weren't really ill, looked really ill but they didn't like that.. erm (19:45)

R16: How did you, how did you get involved with that?

P16: Which?

R17: erm, sort of being part of groups and

P17: Erm well training came up and there were a few things happening that [the local] nurses are very kind of really good in terms of erm providing treatment for voices and stuff and maybe other stuff but I wouldn't know but it would be irrelevant, people from the voices network getting ruled over and they're getting a lot over this year (20:24) So I just got involved in advocacy and various things along the way and I've been various things, mostly unpaid, it usually like most other survivors usually the bottom actual ones you know (laughs), class whatever, if you have that sort of thing. But erm I actually get a little bit of pay now, from the health service, so maybe things are cert… erm I don't know, you don't wanna get too hopeful either but erm, so that's how I.., I get involved with the voices network I got involved with years ago. Cause there was really no support for people who had this sort of.. schiz, schiz shit I just don't like the term, it jarres big time. But erm so I got involved with the voices network two years, I did training with a health professional locally who are trying to set up a support network for voice hearers but we haven't got there yet, but we're still trying.

R18: Mmm, so that's been helpful to be more open about your experiences and have other people

P18: Erm err, well ya, it's definitely helping, like the Facebook page is, I mean there's a lot of fucking mad, crazy stuff, what I would consider crazy stuff erm, but there's a of of, there's some good stuff you know, it's a good network to have. And a few networks, but there's probably a lot of work to be done in term of up and up like.. I can say that more readily now, like yeah I hear voices yeah, it's.. (laughs) I make jokes about it now you have to make jokes about it sometimes you know.. erm but I feel more freer than I have for a long time which is, just like suffer in silence that sort of thing like you know

R19: is that.. that sounds very much like sort of anti-stigma, is that what it means for you to be sort of more open and you can say like, yeah I hear voices and it's.. not.. I guess if more people are saying it, it's not such a weird thing?

P19: yeah it's… stigma, I felt up to quite recently quite stigmatised and very you know, there's a you know a punk song, aims to see it as victim (?), it's like, you know you don't want to see yourself as a victim because that's kind of pathetic, but I mean really, the stigma I really just come to realise it, I didn't know what it meant for a long time, but I started to realise that now. You just don't feel like you're getting on you just feel like excel, like an alien in your own community you know. You probably only want to be part of the community, like talk to people and stuff like that you know. So that definitely put a lot of baggage I wouldn't say, probably mostly came from psychiatry all that..

R20: the stigma..

P20: It's a heavy kept sort of not just pharmacologically but the drugs and treatments and the.. all that stuff, but just the whole thing it's just a very a.. but there's a lot of them aren't the change some of them are good shrinks as well.. (laughs 23:44). But like erm, I just find that erm just.. kind of like oppressive, you know, repressive very much, erm I'm kind of fucking fed up with the repression of the station areal to be honest with you, cause we're the catholic church and we're growing up and they were bad enough and you know, they're pretty awful actually. But erm it's just this system as well it's like repression trying to close you down, there's an organisation here called mind freedom which I really like, you know have your fucking, have your fucking mind freedom, do what you have to do to get your mind freedom, you don't have to feel like inadequate or less than somebody else just because you know, but they're talking about things, obviously meaning and engagement and understanding and just.. and understanding kind of grows all the time, and it's like, you know and I can say to people like you know, try and de, demystify it, that's the thing with schiz, that word is, it's just a toxic meaning like you know.. erm but erm I would just say if I were talking to people and you know trying to explain or whatever just saying like it's like a brain seizure or whatever and I get psychosis or you know.. it's no big, people get you know, try and demystify it to people cause you know…

R21: yeah I think you're right, I think people don't really know what it is and to say like a brain seizure

P21: it's too vague like.. it's it's not a positive thing it's usually a kind of like… it's ghastly.. ghastly board where they're looking for the colour of people (25:28) stuff like that. In my mind anyway, and I would try and demystify things, make it a bit more understandable you know, kind of common terms that's what I think about it.

R22: do you feel people react differently then if you..?

P22: well I certainly starting to use it a little bit more like you know like that kind of more kind of, more real I would call it, sorry what were.., that word?

R23: If you say things like brain seizures, if you explain more about what you're experiencing rather than just using the term schizophrenia, do you think that people react differently to you like they understand it a bit better?

P23: well you have to discover more really about that, I kind of just feel… a bit, it's a bit liberating you know. Like the, that I actually know that I can say.. I feel a bit more confident about it you know, whereas I would have been just… I don't, I feel like I'm confidently explain it that way you know… and that's enough for me that I know that I can you know. So.. I don't know how they will react you can't tell other people how to react you know so many different.. people who you may meet, but I would fee from my point of view erm I feel confident about words I previously wouldn't like you know, I would have just sat there like you know and been a bit like being passive like aggressive or whatever like not aggressive but passive, bottling it all up. You know

R24: Mm, so this view of.. has it changed through the years? Have you been in the position you are now about your view of schizophrenia and explaining it like brain seizures, has that changed erm? Have you always disagreed with the label?

P24: Well, like erm… I complained about it that I had a lot of problems with it, like it hurt me a lot. It made me very agitated and angry and sort of all that, I suffered a lot and it hurt me a lot I would say, really it did. It probably taken years out of my life, possibly, I don't know. Maybe we're tougher than we think possible, but erm.. certainly a lot of hurt over the terms like that over like you know.. I still get quite depressed sometimes you know but erm, I don't know these things, you kind of like hope you'll get better and things get better but erm… Sorry I've kind of forgotten what the question was like, I do get some memory loss.

R25: just if you've changed perspective in the times since you first..

P25: ah well I mean recently it's been like you know I suppose it's been like… it just mean that I can feel basically like everybody else you know, whereas I suppose that, erm I don't know.. I don't know I don't know…

R26: I think that.. to me it sounds like

P26: I think it shocked my mum that's, that's an example, she was just horrified.. you know she just phoned up and said bluntly oh your son has got schizophrenia, there was no like, you know, no compassion or that it was just shock you know. That wasn't very nice no and I feel bad about that. I would like, you know.., how do I feel? I.. the whole system is kind of like a survey kind of like it's already what Laing said it's a…an enslavement, like an existential death but it's also like a mad, this is like a breakthrough in a way. It's kind of like an escape mechanism as well as a survival mechanism as well for whatever the reason may be, some people will think that there's a lot of people out there, people have, there's a lot of different theories about it. Erm, I suppose like with the enslavement like you would have felt for a long time you would have felt like almost like you would have been a psychiatrists salve you know like a mind slave of the psychiatrist like you know can be totally ah you like you know psychiatrists can you help me you see this, like this people today, they go to their psychiatrist and like of can you help me ah di do.. you're like pleading with them in a kind of guilt, confessional way, it's just like shit in a way, it's like, it's no way to be you know. You can be a slave to somebody in your mind like and all that's what the whole gender like the whole thing, like just specifically if it is that word or whatever diagnoses or whatever you know it's all kind of vague, it could be anything like I say to myself like theoretically I could be, if people want to pathologise me and see me in that way then I don't really wanna be around them, like you know. If people wanna come to me and say start pathologising me or whatever you just say go ahead, pathologise me if you want whatever, I don't care like you know. I know who I am. If I know who I am myself and I know more about myself and see things a bit more.. I mean like there's no test for any of this stuff, you know, there's not like any other condition or whatever where there's mostly evidence.

R27: yeah, so you start to make sense of it yourself and coming to a psychiatrist and sort of can you help me and then you know they can give you a label and give you medicine but they don't know you like you know yourself and you've had to learn that..

P27: yeah I mean when you're in trouble I suppose it's just like you know, you're just vulnerable, you know it's like the end of the end of the most kind of places and (31:16) it's true and it's new, modern, crude if you know what that is? But erm and mostly ridiculous I would say like you know it's not based on any.. erm I'd say that I just felt like I was abused, like I, you know..

R28: in what way?

P28: well you know like, the treatments like you know they're so heavy and they're so severe and very cruel you know, it's like being tortured or something, and then being medicated. It destroys your personality, it destroys so much about people, and it's just too much. I don't know if they're adopting a more light touch approach, I kind of perceive that they are adopting a more like a light touch kind of method, erm, but they used to erm throw it at you you know, it was quite tough. So I don't know, the words that they bound me about these days.. I think you know, they're just grateful that there's an opening up to some extent, with media and different things, they're publishing different things about it and stuff, cause erm, yes, you suffer a lot like you know, and you don't really (23:40) deserve it, you need help like, you probably need talking to someone, like people don't talk to you like they just, look into your eyes and puts you on drugs and the next thing you know, very traumatic you know, very cruel. Rubbish system really, rubbish medicine like you know, I mean, I don't know.

R29: It sounds like the human element has been sort of missing in your experiences like

P29: well yeah I mean there was always enough to get me by, I tell you the fist ten years were very tough and like you know but it was just enough, whether it was kindness or whatever, I don't know, to get me through that.. I never would have been this, I don't know maybe because I had a happy childhood you know erm, had a good childhood I would never been this person who would erm, just end it all, but I tell you there's probably people who would, the shit you go through, erm

R30: what do you think would have been better for you? Or what would you have liked

P30: probably erm talking and a lot less that drug treatment and all that and no heating, that definitely electro thing, all that stuff erm (34:00) I just don't wanna think about it anymore and try to get on, things are pretty good at the minute, trying to get some job kind of security with the health services, all these things take a lot of time but erm but things are pretty good, there’s things happening, like there’s stuff getting us involved which is pretty good, it makes a difference you know compared to just being seen as a patient, I think they are changing their kind of their philos.., their outlook, rather than when you’re seen just as a patient, you know what I mean. I mean years ago you would have just been like you know the stories you hear about people who were kept behind these high walls, their whole life. I suppose I think in some ways I’m lucky because I’m not locked behind, I’m not in, in an institution my whole life like people were up to 20-30- years ago. But erm, and like you know the fear that was bread in society about like people with mental health like you know the fear of it you know that people have of people with mental health.. is erm, it’s all such a lie, it’s a lie you know. It’s like propaganda or something. I don’t know why it exists you know, did people feel like… they used to shut down factories and stuff is someone escaped from the.. you know.. there’s so many stories and they’re not, there’s stuff that’s horrible you know, really horrible you know. But I just get by you know..

R31: that sounds like, you know, lack of knowledge this extreme stereotype and then people get frightened..

P31: well the cruelty is, it’s just the cruelty like why the fuck is, you know, and I was getting into hospital when they were getting out of that period but it’s taken them a long time up until now to kind of like.. start like you know… I don’t wanna think too much about the past either because it’s like.. it’s tough. So erm. Yeah

R32: so a lot of your disagreement sounds to be quite a lot on a political level, so to speak erm, about the system and the

P32: erm yeah I mean certainly yeah, it would, some people are critics and I think you need to look, but I don't wanna.., it's a big piece of work cause it's a big, you know, psychiatry whatever like you know, is a big.. erm, a potent force with pharmacology and stuff like that..

R33: Mm, so when you've been in different erm, settings, not necessarily only when you've seen a psychiatrist, but when you talk about how things are from your perspective do you feel that your opinion is being valued?

P33: I think so, no, but I think so as it's got to do with, just like learning to be, it's also it's two ways, learning to be clever, clever with the words you use. And not saying like you know, like people would laugh at you, like literally, my peers and everybody would laugh at you if you brought up anything like mental health up until a point recent and it's just like you know, endless. Erm you know, endless, like I literally call it like psychological oppression or abuse or whatever, just like stigma, but like no, but people.. they seem to be a bit more caring or understanding about it you know.

R34: what do you think that's down to? What do you think has changed?

P34: Well it's just an evolution I suppose.. I don't know erm. I don't know. The media seems to have caught on you know, or search the libraries or stuff like that. But I don't like the term, I wouldn't call myself schizophrenic. But erm, it shouldn't even be., it hurts my head even to use the word, but I wouldn't want like one of those celebrities, I wouldn't use it, I wouldn't say, like I've explained it already, I don't want to go over my words again. But it's just a reason, I don't know, why it's changed again, I'm not really an observer, like I don't watch TV or read papers, but I look at the online with social media. It just seems to be more people talking about it, there's more information out there or something I don't know, more of an understanding, it just so happens these ways like you know. Most places, in the western world anyway, maybe in the, certainly not in a lot of the world.

R35: No yeah, I agree, there's a lot more you know "it's time to talk" all of that kind of stuff on TV and ..

P35: I don't think, yeah I don't really watch that stuff but erm, erm.. I have no problem, I would be cautious about media cause you know, can be quote tough, like you know can make a real, be real prejudice, through the stuff but erm, but I can go through the more subtle ways like through emails or stuff like that, I prefer that kind of method, just information sharing, sharing of information, probably that social media has probably helped a good bit, you know it's a larger picture.. but erm.. yeah, yeah

R36: so what do you think about other psychiatric diagnoses? I know schizophrenia is like a an umbrella term..

P36: well there's so many I don't even care what they are to be honest with you. I mean there's certainly laziness, intellectual laziness I have to have, I suppose it's just for my own, whatever, reasons.. erm.. There's a lot of them yea, apparently. And I suppose like things, like certain things like you know, you can use like, anxiety is real, you know

R37: Anxiety is, you can really understand it cause it's an everyday term but

P37: yeah I' feeling anxious or whatever and I want to relax for a while and step back.. I mean it's kind of hard like it's, saying those kind of things, it is difficult and I always found it difficult like, to explain myself, to be understood you know. It's always different, but you have to, there's always more that you just have to do it for yourself you know, I feel a bit down or you know whatever, that's a normal thing as well you know, people understand depression terms a lot more.

R38: yeah, so it’s being understood, that’s a key thing?

P38: well it’s.. people can connect with it on a general level, like you know, I can feel a bit down, I can feel a bit depressed or whatever, or whatever, or high or whatever,

R39: yeah but saying I’m feeling

P39: there’s so many diagnoses, like the whole thing is, you wanna see life from a point of view from pathology, is what I would say like you know, you know everything can be a pathologies if potentially. Or maybe I don’t know, but it just kind of boggles the head to think about these things so much erm. There’s sometimes.. yeah but, they have a lot of terms and a lot of.. the thing though is that they’re getting more of an understanding they’re not as hard as they used to be you know, about these things, they’re also Victorian you know they were pretty brutal as the years gone by.. so but generally they’d be, mostly they would be a little bit more, they’re easier to get on with like psychiatrists, and people in general. You can chat like if… yeah I think it’s just..

R40: I think that’s a great point

P40: like comrade to yourself, like a have little more confidence you know but like learning how to ta, like how people understand, kind of connect with people, rather than, you know a term, like conversation stopper or like really like you know.

R41: Mmm

P41: can I just use the toilet? Or how long do you wanna go on for? Do you have more things to ask or have you covered most of it?