

UNIVERSITY OF BIRMINGHAM

EXPLORING EPISTEMIC INJUSTICE AMONGST NON-CLINICAL AND CLINICAL GROUPS WITH UNUSUAL EXPERIENCES

by

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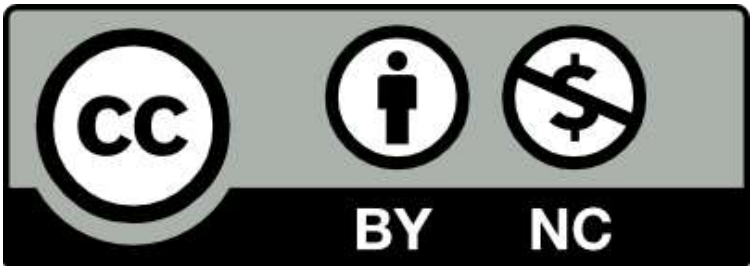
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Abstract

Current literature on the philosophical concept of epistemic injustice, the notion that marginalised individuals are dismissed as credible in their capacity as a knower, suggests that this occurs within healthcare settings, perpetrated against those with a diagnosis surrounding poor mental health. However, much of the literature in this field is theoretical, with limited empirical research on this concept in relation to mental health. Whilst the case has been made for why those with psychosis may be likely to face epistemic injustice i.e. due to their perceived identity as a mentally ill patient and subsequent lack of credibility based on unusual experiences e.g. delusions, this has yet to be explored empirically. The present thesis aims to bridge this gap by exploring incidences of epistemic injustice amongst those with unusual experiences and those with a diagnosis of a schizophrenia spectrum disorder, in order to understand any factors between the groups that may contribute to this injustice.

Firstly, to add to the theoretical literature reviewed, the thesis examines whether occurrences of epistemic injustice exists across the relevant qualitative literature through the use of a meta-ethnography. In order to operationalise the philosophical concept of epistemic injustice, the thesis then utilises an interpretative phenomenological approach to explore frameworks of understanding and meaning-making processes in people with unusual experiences, but without a medical diagnosis (non-clinical group). Relationships with others pre- and post-the experience are also investigated. Following this, the same line of exploration is then repeated with individuals who have been diagnosed with a schizophrenia spectrum disorder (clinical group). Finally, the thesis uses a multiperspectival approach to compare the findings of the non-clinical and clinical groups, identifying conceptual overlaps or conflicts of

perspectives between group experiential themes. Similarities and differences regarding the sense-making process as well as perceived treatment of others were examined between participants, in an effort to bring to light any incidences of hermeneutical injustice and testimonial injustice.

The analyses highlight hermeneutical injustices occur within the clinical group through poor timeliness and information-sharing surrounding the diagnosis, as well as dismissal of religious and cultural interpretations. In addition, testimonial injustices were also understood to occur through perceived changes in identity and subsequent lack of credibility afforded to clinical participants, leading to dismissal of testimony. The present thesis offers empirical support for the occurrence of epistemic injustice amongst individuals with psychosis in comparison to undiagnosed individuals with unusual experiences, suggesting that the injustice occurs in relation to diagnosis and perceived identity.

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Chapter 1

INTRODUCTION

1.1 Background and Aims

Psychosis has often been characterised as a set of experiences that encompass both positive and negative symptoms, including auditory and visual hallucinations or delusions. More recently however, research has shifted towards a more holistic approach to the disorder, including concepts such as anomalous or psychotic-like experiences (Brett et al., 2007). These unusual experiences have been found to occur in individuals without a medical diagnosis, despite potentially consisting of similar experiences as those seen in psychotic disorders (Unterrassner et al., 2017). This relatively recent phenomenon allows for a more dimensional approach to psychosis, shifting to the idea of unusual experiences or symptoms existing on a continuum, as opposed to a categorical approach towards understanding psychosis (Brett et al., 2007). The lack of distress associated with psychotic-like experiences may suggest that professional support is not always necessary (Boumans et al., 2017; Verdoux & van Os, 2002).

For individuals who do experience distress, a key feature of intervention is diagnosis. Previous research has found that receiving a diagnosis, not specific to psychosis, but rather generally being named a 'severe and enduring mental illness,' can be both a positive and a negative experience (Hayne, 2003). Although a diagnosis was viewed as de-legitimising the self through loss of identity, the positive impact of a diagnosis was also acknowledged by participants. The ability to make sense of their experience was provided and treatment felt possible, however, for the diagnosis to have a positive impact, it needed to be communicated in a way that allowed the individuals being diagnosed to feel more knowledgeable (Hayne,

2003). In a user-led study that researched the impact of a diagnosis of psychosis, again both positive and negative effects were experienced (Pitt et al., 2009). A diagnosis was a 'means of access' and helped by 'naming the problem,' but, it was also a 'cause of disempowerment' and unhelpfully labelled the person (Pitt et al., 2009).

One of the more negative impacts of being diagnosed is the public stigma and self-stigma associated with the diagnosis (Corrigan, Kerr, & Knudsen, 2005; Dickerson et al., 2002; Dinos et al., 2004; Knight, Wykes, & Hayward, 2003), with research showing that stigma surrounding mental health problems (Byrne, 2000; 2001), especially stigma towards individuals with a diagnosis related to psychosis (Dinos et al., 2004), is common and widespread (Stuart, Arboleda-Florez, & Sartorious, 2005; Walker & Read, 2002). Knight, Wykes, and Hayward (2003) found that avoidance and withdrawal were used by individuals with a diagnosis of psychosis as a coping mechanism from the prejudice and discrimination faced from society. This way of avoiding stigma can lead to both social exclusion (Link et al., 2001) and isolation (Knight, Wykes, & Hayward, 2003; Pitt et al., 2009; Thornicroft, Rose, and Kassam, 2007). Many of these negative reactions towards psychosis may contribute to an individual losing their sense of self through replacement of identity as an individual with psychosis and being negatively impacted by the diagnosis.

The current and most common method of approaching human distress is via a medical-biological model, with treatments consisting primarily of medication (Irarrázaval & Sharim, 2014). In an audit of clinical files in an adult mental health service, Lakeman (2008) found a premature foreclosure of aetiological exploration, with behaviours being viewed as 'symptoms' of the disorder instead of something to be explored. For example, one individual's

ambivalence within their relationship was labelled as a biochemical problem rather than a possible relationship or interpersonal problem. The medicalisation of mental distress can miss several opportunities to explore social, historical, or environmental factors, increasing the likelihood of epistemic injustice (Lakeman, 2010). Epistemic injustice is the concept that an individual is treated unfairly and their status as a knower is challenged by undermining their ability to share knowledge or make sense of their own experiences (Carel & Kidd, 2014; Fricker, 2007; Sanati & Kyratsous, 2015). Fricker (2007) proposes two types of epistemic injustice: testimonial injustice and hermeneutical injustice. Testimonial injustice occurs when something an individual says is ignored or not believed because their status as a knower is discounted based on belonging to a specific group, typically because of the prejudicial links between that group and negative stereotypes. For example, individuals with a diagnosis of schizophrenia have widely been perceived to be unreliable, potentially leading others to disbelieve what they say due to the occurrence of even one false delusional belief (Crichton, Carel, & Kidd, 2017; Sanati & Kyratsous, 2015). Hermeneutical injustice occurs when an individual is unable to interpret or make sense of their own experiences based on a lack of resources, due also to the fact that the individual belongs to a stigmatised group (Fricker, 2007). In the above example of Lakeman's (2008) study, the individual was impeded from making complete sense of their experience based on the hermeneutical injustice displayed by the mental health services.

It can be difficult to capture the heterogeneous nature of certain phenomena, for example, delusions, and the lack of a clinical model that takes into account all factors rather than just medical factors can lead to reductionist or social constructionist views (Sanati & Kyratsous, 2015). McCabe and Healey (2018) suggest that taking into account patients' perspectives when discussing phenomena with disputed meanings, for example, delusions, may lead to a better

therapeutic relationship. However, individuals themselves may also be prone to the same hermeneutical block as mental health professionals, as service users generally tend not to seek help with a clear, explanatory framework. Therefore, better outcomes may be attained by constructing a shared understanding of the phenomena (Irarrázaval & Sharim, 2014; McCabe & Healey, 2018), with patients being regarded as a source of information as well as actively participating in discussion about causes and treatment (Hookway, 2010).

Although there are studies of epistemic injustice relative to the assessment of delusions (Sanati & Kyratsous, 2015), healthcare (Carel & Kidd, 2014), psychiatry (Crichton, Carel, & Kidd, 2017), and illness (Kidd & Carel, 2017), there appears to be little research examining the occurrence and effects of epistemic injustice specifically within psychosis. The present thesis aims to understand experiences of epistemic injustice in individuals diagnosed with a diagnosis of a schizophrenia spectrum disorder as well as those who have unusual experiences without a medical diagnosis. Through comparison between these groups, it is hoped that novel understandings of the way in which epistemic injustice is perpetrated may come to light. Based upon the aims, the research questions for the thesis are the following:

(i) How do people who experience psychotic or unusual phenomena make sense of their experiences?

(ii) How do people who experience psychotic or unusual phenomena make sense of how they are treated by others?

(iii) What are the similarities and differences in sense-making and treatment by others between groups, and how do these experiences relate to epistemic injustice?

1.2 Overview of the Present Thesis

In order for the thesis to answer this, Chapter 2 will first begin with an aim of reviewing the existing literature surrounding epistemic injustice and its relation to mental health. A meta-ethnography in Chapter 3 explores the experience of stigma from the perspective of people with psychosis by synthesising the findings from relevant qualitative literature in order to examine any occurrences of epistemic injustice within past research, as well as understand the foundation upon which this may develop, whilst Chapter 4 establishes the methodology used for the following three empirical chapters. In Chapter 5, data is presented in an effort to understand the lived experience of people who have faced unusual occurrences but do not have a medical diagnosis. Whereas, in Chapter 6, data for the same is presented except participants do have a diagnosis of psychosis. For both Chapters 5 and 6, the focus is on understanding how the participants make sense of their experience and how they feel others make sense of this. Following this, Chapter 7 seeks to combine the previous two datasets and analyse the similarities and differences between the meaning-making processes of those with and without a diagnosis, as well as comparing the subsequent treatment of them by others by utilising a multiperspectival approach. Through this, incidences of epistemic injustice can be identified. The final part, Chapter 8, serves to discuss the implications of Chapters 3, 5, 6, and 7, and build upon the existing knowledge of psychosis and epistemic injustice.

Chapter 2

EPISTEMIC INJUSTICE IN PSYCHOSIS

2.1 Introduction

Miranda Fricker (2007) coined the term *epistemic injustice*; a concept that suggests certain wrongs of an epistemic nature are inflicted upon individuals specifically in their capacity as a knower. Fricker (2007) proposed two forms of epistemic injustice: *testimonial injustice* and *hermeneutical injustice*. The first section of the review will aim to explain both testimonial and hermeneutical injustice, utilising a fictional case review to use as an example for key concepts, whilst the following section will provide a review of the literature surrounding epistemic injustice in relation to the medicalisation of mental health, specifically psychosis. The chapter will end with consideration as to how the harms of epistemic injustice can be mitigated within this specific population.

2.2 Epistemic Injustice

> Joe[1] is a 25-year-old man who has been diagnosed with schizophrenia after experiencing both hallucinations and delusions. Many of his delusional beliefs surround police officers, typically that they are plotting to physically harm him. He notices tall dark shapes in his bedroom at night, unable to make out any concrete detail, a minimum of once a week, usually in his peripheral vision. As a child, Joe was physically abused by a friend of the family who

[1] The following case study describing Joe is a fictional example aiming to illustrate how epistemic injustice may occur.

happened to be a police officer and has since experienced ongoing nightmares and irritability. His frequent mood swings began to affect his performance at work and Joe sought help from his General Practitioner (GP), disclosing that his irritability stems from the abuse he experienced as a child, as well as his belief that the police are planning to harm him. He also disclosed feelings of anxiety and fear surrounding the tall dark shapes in his bedroom at night. After conducting blood and urine tests to rule out potential causes of what Joe is experiencing, his GP referred him to a mental health service specialising in psychosis and recovery. At his initial mental health assessment, the duration, severity, and frequency of his symptoms were questioned, and Joe was prescribed with antipsychotic medication in order to treat his illness. Six months later, during one appointment with his clinical team, Joe described an incident that had occurred the previous week, whereby he had the feeling of somebody following him home for a while, who then proceeded to threaten him with a knife and steal his belongings. Knowing that Joe experiences persecutory delusions, his team deemed this to be another delusion and decided to increase the dose of medication as the delusions were seemingly becoming more violent. However, two weeks after the appointment with his team, the police caught and arrested a man local to Joe who had been threatening members of the public with a weapon in an attempt to steal from them. Once the stolen possessions had been recovered, Joe's wallet containing his personal information had been discovered and returned to him, thus, corroborating his factual version of the events that

took place. The clinical team's decision to discount Joe's account as false based upon his previous experiences of delusions, rather than treating it as something to be explored and considered, means that Joe had been treated unfairly as a speaker and giver of information. Here, epistemic injustice has taken place.[2]

2.2.1 Testimonial Injustice

Testimonial injustice (Fricker, 2007) occurs when the things an individual says are disbelieved or ignored purely because of their identity, for example, because of their race or because they experience poor mental health. To understand the concept of testimonial injustice, there is first a need to understand the role of power and prejudicial stereotypes in society. According to Fricker (2007), as social agents, we have the capacity to either actively or passively influence the way things happen in the social world, including the way others behave. Known as agential power, this power can also operate structurally, so that no one individual is exercising it over another. Rejecting Foucault's claim that 'power exists only when it is put into action' (Dreyfus, Rabinow, & Foucault, 1982), Fricker (2007) poses the idea that power is a capacity, and therefore, exists during periods when it is not actively operating. As can be seen in Joe's case, active power is displayed via the administration of pharmacological treatment prescribed by his clinical team; a typical treatment option for individuals experiencing delusions (Slade, 2017). However, even if Joe had not been provided with any direct treatment, this would in no way retract from the power held by the mental health service in general.

[2] Joe's case will continually be referred back to throughout the upcoming sections titled *testimonial injustice* and *hermeneutical injustice* in order to illustrate key concepts.

Passive structural power still exists as, legally, the Mental Health Act (1983) would be able to detain Joe without his permission if it is deemed that he requires urgent help for his disorder and is at risk of harm to himself or others. Thus, his actions and behaviours may be influenced based upon the mere idea of power held by authorities.

Identity power comes into play when the operation of power is dependent upon shared conceptions of social identity (Fricker, 2007), for example, the collective societal understanding of what it means to be a man or woman, or in the case of the present thesis, what it means to have a mental illness. Fricker (2007) argues that identity power is a fundamental component of testimonial exchange because of the need for individuals to use stereotypes in their assessments of the speaker's credibility. These widely held associations about a given social group can be positive or negative, or indeed neither, based upon whether the attribute is offensive, complimentary, or indifferent. The prejudice will either result in the speaker receiving a credibility excess or a credibility deficit (Fricker, 2007). Although there may be times where an excess will be disadvantageous and a deficit will be advantageous, a majority of the time prejudice will result in an advantageous credibility excess and a disadvantageous credibility deficit. Even so, if credibility excess were to be disadvantageous at times, it would not demean or disrespect the speaker on the subject of knowledge, and therefore, would not constitute testimonial injustice. Rather, the speaker would be regarded as overly esteemed in their capacity as a giver of knowledge. As society is constantly susceptible to invoking stereotypes of the negative kind and for the sake of understanding testimonial injustice, prejudicial stereotypes that afford others a credibility deficit are what we will focus on.

Consider again the case study of Joe. Research suggests that negative stereotyping of individuals with mental illness occurs often (Corrigan, Kerr, & Knudsen, 2005; Dinos et al., 2004; Stuart, Arboleda-Florez, & Sartorious, 2005), however, there are times when a prejudicial stereotype may simply be a non-culpable mistake. Joe has noticed that since he informed his friends about his diagnosis, many of them have begun to distance themselves from him by replying to his messages less and constantly being unable to meet up. Although Joe has known one of his friends for 2 years, they informed him that they are worried he may be unpredictable and unexpectedly aggressive towards them based upon what they have seen of individuals with schizophrenia in the media, and so they no longer wish to continue their friendship with him. Simply believing that having schizophrenia means someone is automatically aggressive does not mean that Joe's friends are prejudiced as it is the only frame of reference they would have ever received up until the point where they were informed about Joe's diagnosis. However, having known Joe for years, his friends would now have a second point of reference to inform their opinions about schizophrenia. Still holding their original beliefs about the unpredictability of individuals with schizophrenia even though they have noted that their friend has been the opposite of the common depiction, then becomes a negative identity prejudice rather than a non-culpable mistake.

The impact of identity prejudice on a hearer's judgement of credibility is an operation of identity power (Fricker, 2007). This sort of prejudice is central to the case of testimonial injustice as two things happen when a speaker is negatively stereotyped: firstly, the exchange becomes epistemically dysfunctional, with the hearer judging the speaker's credibility as low, and secondly, an ethical wrong occurs, as the hearer wrongfully undermines the speaker's

capacity as a knower (Fricker, 2007). Testimonial injustice has been illustrated in the introduction of Joe's case. Joe chose to disclose to his psychiatrist an incident where he was followed, threatened, and robbed. The psychiatrist's treatment of this disclosure as simply another false belief concocted in Joe's mind means testimonial injustice has occurred, for they have undermined Joe's capacity as a knower or as a giver of knowledge. His credibility was judged as low based upon the fact that he experiences delusions, rather than the proof of evidence to reject the claim as false. Thus, testimonial injustice can be defined as an unfair deficit of credibility placed on a speaker, based upon a negative identity prejudicial stereotype on the hearer's part, that undermines the speaker's capacity as a knower.

As testimonial injustice has now been defined, it is imperative to consider the harm that the injustice may cause to the speaker. It may be that in some instances the negative impact of testimonial injustice is trivial, however, it can at times be seriously detrimental, especially if the injustice is continual and systematic. The most basic, and perhaps the most essential harm in that it is an intrinsic injustice, is that the speaker is undermined in their capacity as a knower and a giver of knowledge, and in essence, wronged in a capacity vital to human value. Rationality has long been known to lend humanity its distinguishing value (Fricker, 2007; Johnson & Cureton, 2004), therefore, being wronged in one's capacity as a knower and a giver of knowledge undermines the individual's very humanity. The social meaning of this harm lends itself to the idea that the individual is less than what it means to be fully human: they are devalued as a knower, and hence, symbolically devalued as an autonomous human being. In any case of testimonial injustice, the primary harm is not only the epistemic injustice in itself, but also the underlying meaning of being degraded as a giver of knowledge. In one

model, Williams (2002) describes a psychological mechanism by which individuals 'steady the mind.' Subconsciously, our various mental contents are sorted into either beliefs or desires, whilst wishes are in the process of being sorted into either category in order to steady the mind. The model depends on the idea that there are times when others need to rely on our outlooks, and similarly, times when we need to rely on theirs, thus, teaching us to present ourselves as individuals with fairly stable dispositions. The mind becomes 'settled' when individuals are mutually reliant upon others for engagement in trustful dialogue, providing us with reason to construct factual beliefs and stray from fantasy or wishful thinking (Williams, 2002). According to Williams (2002), steadying the mind is the most basic process by which we come to be who we are, shaping basic aspects of our identity through the settlement of beliefs and desires into stable states via dialogue. The conception of identity in this case is a social one, concerning an individual's self-declared association to a group identity, where the association tends to be experienced as vital to who they really are (Fricker, 2007). It can be seen then how the means by which the mind is 'settled,' is also the means by which we become who we are. Testimonial injustice prejudicially excludes the individual from trustful dialogue by demeaning them in the very activity that steadies the mind and ignoring a vital aspect of who they are – processes of essential psychological significance (Fricker, 2007; William, 2002). Not only does the injustice undermine them as a giver of knowledge that is important to their value as a human being, but it does so by displaying prejudice against some vital aspect of them as a social being.

The secondary, more practical harm that takes place is the perception others may have of the individual. Constantly being subjected to testimonial injustice may mean that the

individual is perceived by others as lacking the sure judgement required in certain situations. For example, in Joe's case, if he were consistently treated by his clinical team as if everything he said was false, even in instances where he was speaking the truth, this could potentially lead to his family and friends becoming wary of anything Joe tells them, and essentially disbelieving him. This lack of trust may cause Joe to lose faith in his own beliefs or justifications for them. Additionally, it may also lead to a lack of interaction with the clinical team, resulting in disconnection and isolation. This persistent experience of testimonial injustice may cause him to doubt his general intellectual abilities to such a degree that he becomes hindered in his intellectual growth (Fricker, 2007). It would be an exaggeration to suggest that every time testimonial injustice occurs, an individual's formation of identity is slightly disrupted, however, persistent systematic cases of injustice can potentially inhibit the development of social identity (Fricker, 2007). In some cases, the prejudicial stereotype may have a self-fulfilling power so that the individual subject to the injustice begins to socially act out and resemble the depiction of the stereotype operating against them (Fricker, 2007). Negative identity prejudicial stereotypes are typically accompanied by expectations, which in turn, may have a strong effect on the way individuals perform (Steele & Aronson, 1995). For example, if Joe's friends constantly treat him as if his temperament is unpredictable since he has been diagnosed, this poor perception of his character may produce feelings of frustration in Joe, in turn, causing him to lash out and seemingly fulfil his negative stereotype. The addition of secondary harm to the primary harm of testimonial injustice paints a picture of weakened self-confidence, hindered social identity development, and a face of oppression.

2.2.2 Hermeneutical Injustice

The second type of epistemic injustice described by Fricker (2007) is known as hermeneutical injustice. Hermeneutical injustice (Fricker, 2007) occurs when a lack of intellectual resources in society i.e. concepts used for self-understanding, disadvantages individuals, specifically marginalised groups, and restricts them from making sense of what they are experiencing. Hartsock (2019) states that the world is structured by dominant individuals to serve their own purposes; these purposes tend to negatively affect the development and existence of dominated individuals. Here, the use of the word 'structured' can be significantly understood in three ways. Materially, it implies that social institutions benefit powerful individuals; from an ontological stance, it implies that powerful individuals represent the social world; and from an epistemological stance, it implies that powerful individuals unfairly structure collective social beliefs via advantages they possess. Although Hartsock's (2019) statement was rooted in the history of gender and feminism, it can easily be transferred and understood from standpoints where individuals may be disadvantaged based upon things such as race or poor mental health. For the sake of determining what constitutes hermeneutical injustice, it is the epistemological stance that will be the key focus, even though the material and ontological points of view naturally overlap and cluster together when aiming to understand our knowledge of the social world.

Taking the epistemological stance that social power unfairly structures social understanding, it can be seen that an imbalance of power, as explained earlier under the heading of testimonial injustice, affects the balance of shared hermeneutical resources (Fricker, 2007). Powerful or dominant members of society are able to make appropriate sense

of their social experiences based upon the collective understandings available, compared to disadvantaged individuals that may find themselves experiencing things they struggle to make sense of. Consider Joe's delusions, the content of which centres around a belief that police officers are planning to harm him. The dominant medical approach to mental illness (Irarrázaval & Sharim, 2014) is likely to mean that the content of the delusion is less focused on than the experience of delusion itself. Joe's clinical team chose to provide him with medication, without exploring the potential historical, social, or cultural components of the delusion. As can be seen in the introduction to Joe's case study, if the team had explored these factors, they would have been more able to situate the context of the delusions within Joe's past and further support could have been offered, for example, trauma-informed care. Disregarding this does not allow Joe to make complete sense of what he is experiencing as the only resource that has been allocated to support Joe has been derived from the dominant approach. This example portrays how hermeneutical resources can have a void or a 'lacuna' (Fricker, 2007) for individuals whose position in society is unequal, whereby the name of a collective social experience should be.

Unlike testimonial injustice, hermeneutical inequality is inevitably difficult to detect. This is mainly due to collective social resources keeping the true meaning of experiences obscured from disadvantaged individuals, therefore, not making itself known as an inequality until after attempts to construct accurate meanings have been made in order to allow suitable interpretations of experiences. These disadvantaged individuals can be said to be hermeneutically marginalised (Fricker, 2007), a form of powerlessness meaning they have been excluded from something that would be valuable for them, in this case, the shaping of

collective hermeneutical resources. Although marginalisation can occur based upon material power, for example, somebody's socio-economic background, it is the impact of identity power and negative identity prejudicial stereotypes, as described earlier, that will be the focal point of the concept. This sort of marginalisation ensures that the collective resources are structurally prejudiced as there is insufficient input by the marginalised groups, therefore, rendering their interpretations susceptible to the bias of powerful groups. Morally, the structural prejudice is also discriminatory as individuals are affected based upon their social identity, thus, amounting to negative identity prejudice. Hermeneutical injustice can now be defined as the injustice of identity prejudice in shaping collective hermeneutical resources that causes marginalised individual's experiences to be obscured from collective understanding (Fricker, 2007).

In both hermeneutical and testimonial injustice then, it can be seen how an individual is epistemically wronged based upon structural inequalities of power and negative identity prejudice working against them in their capacity as a knower. Similar to Fricker's (2007) concepts of agential power and structural power within testimonial injustice, hermeneutical injustice can also occur either systematically or incidentally, the key difference being that no single agent perpetrates hermeneutical injustice. Owing to the collective construction of hermeneutical resources, it is entirely structural (Fricker, 2007). Incidental cases are not generally part of or due to structural inequalities of power, rather they tend to occur because of single instances of powerlessness. Again, considering the example of Joe, manifestations of hermeneutical injustice would likely be categorised as the systematic kind due to persistent, wide-ranging marginalisation. There may also be times when hermeneutical injustice is

exacerbated by testimonial injustice. Individuals who attempt to make sense of a poorly understood experience due to a lack of hermeneutical resources to a hearer is already susceptible to low credibility judgement based upon low comprehensibility. This is made worse if the individual in question is subject to negative identity prejudice, in turn, deflating the credibility of the individual even more. In this case, a double epistemic injustice has taken place.

Having defined hermeneutical injustice, we can now begin to consider the kind of harm that can result from it. The first kind of harm is similar to the primary harm of testimonial injustice, such that it relates to prejudicial exclusion of the individual from participating as a giver of knowledge. In testimonial injustice, the harm occurred as a result of identity prejudice on the hearer's part, whereas, in hermeneutical injustice, the harm occurs as a result of structural identity prejudice within the collective hermeneutical resource (Fricker, 2007). In this case, the marginalised individual is unable to articulate and communicate an experience significant to them, thus, hindering them from making appropriate sense of their own experiences as well as sharing knowledge. As with testimonial injustice, the primary harm of hermeneutical injustice also manifests itself during the construction of identity and selfhood. In any social context, the marginalised individual may appear to others to be something they are not or something that is not in their interests to be seen as, solely due to the negative identity prejudice that takes place. Consider, for example, the widespread stigma and negative perception of individuals experiencing psychosis (Corrigan, Kerr, & Knudsen, 2005; Dinos et al., 2004; Stuart, Arboleda-Florez, & Sartorious, 2005). If, as a young adolescent, Joe grew up with the perception of people with schizophrenia as 'aggressive' and 'unstable,' and then began to

experience the listed symptoms of schizophrenia himself, he would likely have internalised these negative beliefs and turned them towards himself. The self is then formed through various constructions as the collective societal understanding of psychosis is so powerful that it forms the individual's experiences.

The secondary harm of hermeneutical injustice occurs as a result of the primary harm taking place. The dissonance between the perception and understanding of others and a marginalised individual's own meaning of an experience tends to knock their belief in how capable they are of making sense of the world (Fricker, 2007). Like testimonial injustice, the loss of epistemic confidence may prevent the sharing and acquiring of knowledge, as well as prevent the benefit of certain epistemic virtues, for example, intellectual courage or judgement. The key difference here from the secondary harm of testimonial injustice is that whilst injustice is inflicted from individual to individual, no single agent is culpable in the occurrence of harm within hermeneutical injustice. Rather, it is caused by a void within the collective hermeneutical resource – a moment of powerlessness in incidental cases or a lacuna created by structural identity prejudice and hermeneutical marginalisation in systematic cases.

Additional forms of epistemic injustice have been constructed by other researchers based upon Fricker's (2007) version of epistemic injustice.[3] *Contributory injustice* is similar to hermeneutical injustice except for one key change. Dotson (2012) suggests that marginalised individuals do have the resources available to make sense of their experiences within the

[3] Although *contributory injustice* and *wilful hermeneutical ignorance* differ from hermeneutical injustice in a sense, they are similar enough to Fricker's (2007) original concept to be considered supplements, rather than rejections of the concept. Therefore, the term hermeneutical injustice will be used throughout the paper, with the former two versions considered if necessary.

relevant community, however, these understandings of their experiences are unable to be communicated to dominant social groups and are consistently dismissed. This differs from Fricker's (2007) version of hermeneutical injustice that suggests there is no collective hermeneutical resource within society, either within dominant groups or marginalised groups, to understand experiences of marginalised individuals. Similarly, Pohlhaus' (2012) concept of *wilful hermeneutical ignorance* suggests that dominantly situated knowers refuse to recognize hermeneutical resources created from the collective experiences of marginalised communities. To illustrate both contributory injustice and wilful hermeneutical ignorance, consider the frustration Joe feels at the way he has been treated by his friends after revealing his diagnosis. Hermeneutical injustice would suggest that there is no resource available in society for others, including marginalised groups, to understand this frustration he is feeling, and therefore, it is misinterpreted by dominant groups as aggression, a common stereotype of individuals with schizophrenia. Instead, contributory injustice and wilful hermeneutical ignorance suggest that members of the marginalised community i.e. individuals diagnosed with a severe mental illness, would likely recognise this emotion for what it is, simply frustration, based upon their own personal experiences of it. The former proposes that nobody in society would understand what Joe is experiencing, whereas the latter proposes that *at least* others with poor mental health would understand what Joe is experiencing having gone through it themselves.

2.3 Epistemic Injustice and Mental Health

2.3.1 The Medicalisation of Mental Health

A significant amount of research concerning epistemic injustice in the context of gender and race has been conducted (Fricker, 2007), however, this concept has been less explored within mental health. It has previously been proposed that the medicalisation of mental disorders contributes to the injustices faced by service users (Gosselin, 2019; Tate, 2019; Wardrope, 2015). Medicalisation can be defined as the process by which an individual's state becomes a medical condition requiring attention (Reiheld, 2010), as well as the adoption of a medical framework consisting of medical terminology in order to understand an individual's physical or mental "illness" (Conrad & Schneider, 2010; Davis, 2010). According to Crichton, Carel, and Kidd (2017), there are three conditions needed for epistemic injustice to take place: first, that there are issues associated with the disorder itself; second, that clinicians place a higher value on objective evidence rather than patient reports; and finally, that negative stereotypes are associated with the illness. In an attempt to demonstrate how individuals may face instances of epistemic injustice based upon their experiences of psychosis, the following section will identify ways in which difficulties with mental health are medicalised.

Several studies have found that individuals who are diagnosed with a mental illness suffer from common and widespread public stigma (Corrigan, Kerr, & Knudsen, 2005; Dinos et al., 2004; Stuart, Arboleda-Florez, & Sartorious, 2005), and are therefore led to feel socially excluded and isolated (Knight, Wykes, & Hayward, 2003; Pitt et al., 2009; Thornicroft, Rose, and Kassam, 2007). Through unconscious categorisation schemes of implicit bias (Gosselin, 2019), society tends to view individuals diagnosed with a severe mental illness as aggressive

and inept (Rüsch, Angermeyer, & Corrigan, 2005). By adopting this view of mental illness as something dangerous, individuals are likely to perceive all behaviour of mentally unwell individuals through the lens of violence and aggression. Just as negative identity prejudicial stereotypes play a role in judgements of what severe mental illness looks like, similarly in medical contexts, doctors may be affected by the same stereotypes when diagnosing an individual (Lewis, Croft-Jeffreys, & David, 1990; Spector, 2001). One example that serves to highlight this within past literature suggests that as Black men increasingly began to be diagnosed with severe mental illness in the 20th century, schizophrenia started to become synonymous with violence and aggression, attitudes that were connected to young Black men pursuing equality (Jarvis, 2008). Ignoring these behaviours within the context of the social situation at the time, the medicalisation of aggressive behaviour as psychotic is framed as a problem of individual biology (Gosselin, 2019), suggesting that individuals with a mental illness are to blame for their condition (Crichton, Carel, & Kidd, 2017).

Conceptualising mental illness as an individual defect supports the negative stereotype of mentally ill people as inept, and therefore, not able to make informed decisions about their treatment. This view of incompetency, and hence, lack of autonomy, means patients and service users are at risk of being perceived as having diminished credibility and experiencing epistemic injustice (Lakeman, 2010). The medical model has long been the dominant approach to treating mental illness, therefore, reduction of symptoms is the goal, with pharmacological treatment viewed as the initial and most appropriate path to recovery (Irarrázaval & Sharim, 2014). Prolonged antipsychotic treatment has been found to sometimes cause severe, frenzied movements in individuals, known as tardive dyskinesia (National Organisation for Rare

Disorders, 2015). Up until the 1980s, claims of these effects were dismissed by both psychiatrists and pharmaceutical companies, who instead suggested that the symptoms were either fictitious or a result of the psychotic disorder itself, thus, attempting to exploit the supposed incompetence of individuals diagnosed with schizophrenia (Gelman, 1999; Healy, 2009). Denying a relationship between antipsychotic medication and tardive dyskinesia left individuals without the hermeneutical resources necessary to make sense of what they were experiencing (Gosselin, 2019). Additionally, individuals may choose to not continue with their medication based upon a variety of reasons, including, but not limited to, the extrapyramidal effects. However, clinicians may misinterpret this nonadherence as noncompliance; the former suggesting that the patient *unintentionally* refuses their treatment, possibly because of feeling overwhelmed or concerns about side effects, and the latter suggesting that the patient *intentionally* refuses treatment, possibly due to questioning the competence of the provider. Ignoring other potential factors that cause individuals to discontinue treatment limits the ways in which mental health services understand service user's experiences (Gosselin, 2019). As a result, the epistemic environment needed for trustful dialogue becomes strained and patients are again denied the hermeneutical resources needed to understand what they are experiencing, as well as having their testimony undermined.

The medical model has previously been critiqued for the social-constructive power that allows it to shape collective hermeneutical resources and influence individuals to view their experiences through the lens of medical discourse (Smith, 2003; Wardrope, 2015). This power held through the medicalisation of mental illness deprives individuals of the means to situate their experiences within its social context, eclipsing all other understandings, and casting these

experiences as a problem of individual biology (Gosselin, 2019; Wardrope, 2015). Although there are some services, such as early intervention services, that adopt a recovery-focused approach and support service users with the development of a personal narrative to understand their experiences (Harris, Collinson, & das Nair, 2012), the period prior to entering services, that often involves hospitalisation or psychiatric units, creates a space in which hermeneutical injustice may be perpetrated. Highlighting the dominance of the medical model within mental health services, in a qualitative study of 25 individuals with psychosis, participants stated that doctors aim to fit patients into a standard medical framework, ignoring factors that do not fit their diagnostic criteria (Lovell, 1995). For example, standard medical questions such as "do you hear voices?" were of significant concern to the professionals, with little regard for any social or environmental difficulties the participants were facing outside of that (Lovell, 1995). This checkbox assessment demonstrates the rigidity of the medical model, where a lack of interest in situational factors that may contribute to the individual's experience, only places the person with psychosis at further risk of hermeneutical injustice.

Critique of the medical model also suggests that medical authority is afforded a considerably high amount of epistemic privilege (Carel & Kidd, 2014), such that it is constantly viewed as the most trusted approach (Ipsos MORI, 2011), permitting it to legitimise direct institutional involvement on a given issue (Conrad, 1992; Wardrope, 2015). However, critics of the medical model fail to acknowledge that medicalisation can serve to enlighten an individual's understanding of their experiences, rather than shape collective hermeneutical resources in a way that conceals them (Crichton, Carel, & Kidd, 2017; Wardrope, 2015). Although some individuals diagnosed with schizophrenia have voiced a negative view and

mistrust towards pharmacological treatment (Kikkert et al., 2006; Morant et al., 2018), others have found it to be a useful tool by which they were able to change their experiences in a desirable way (Kikkert et al., 2006; Patel et al., 2010). By neglecting the testimonies of the latter, it could be argued that critics of the medical model who argue medicalisation is a hermeneutical injustice, may effectively be committing a kind of testimonial injustice towards these individuals.

Testimonial injustice can be exhibited through testimonial smothering (Dotson, 2011); a service user's belief that their experience will be dismissed, and so a choice is made to silence themselves and not participate in discourse surrounding options of recovery. Individuals with previous experience of mental health services tend to be unwilling to inform clinicians of the symptoms they are experiencing, as they are aware that they are likely to be diagnosed with a psychotic disorder, and possibly even detained under the Mental Health Act (1984) (Crichton, Carel, & Kidd, 2017). From the psychiatrist's perspective, a complaint is made that patients often include time-consuming information irrelevant to their illness, for example, emotionally charged comments or a need for empathy. In an evaluation of communication between 264 patients and 29 clinicians, patients were given an average time of 23.1 seconds to voice any concerns before the clinician redirected their line of questioning (Marvel, Epstein, Flowers, & Beckman, 1999). In only 21% of the interviews, the clinician questioned these concerns further, reflecting both missed opportunities to collect information and an imbalance of communication between doctor and patient (Kurs & Grinshpoon, 2018). Additionally, the lack of medical discourse on behalf of the service user may cause the clinician to judge them as insufficiently articulate (Carel & Kidd, 2014), which could potentially be viewed as another

symptom towards a diagnosis of psychosis, for example, alogia. In general healthcare, there tends to be a higher value placed on objective evidence in comparison to subjective evidence communicated by service users. Within psychiatry, however, diagnoses are made almost purely on the basis of the behaviour of service users (Crichton, Carel, & Kidd, 2017). Still, some clinicians treat individuals as an object of epistemic examination, rather than a collaborative epistemic agent that can participate in a discussion about their own diagnosis and treatment. Service users are judged as having low credibility and therefore, designated a deflated epistemic status (Carel & Kidd, 2014). This denial of credibility is a kind of epistemic injustice, whilst the denial of contribution is a form of epistemic exclusion (Hookway, 2010).

2.3.2 Epistemic Injustice and Psychosis

Within the literature, a diagnosis of psychosis has consistently been found to both positively and negatively impact an individual, by providing a means of making sense of the unusual experience for some (Pitt et al., 2009), but also leading to a change in identity for others by forcing them into the unwanted role of a patient (Conneely et al., 2021). Consistently identified within past literature, one of the main sources of this negative impact stems from both external and internal stigma[4]. Considered to be one of the most stigmatised diagnoses one can receive (The Schizophrenia Commission, 2012), individuals with psychosis often face negative public perceptions in comparison to other diagnoses (Wood et al., 2015). Resulting in a poorer quality of life, the most common experiences relate to marginalisation within society, a reduction of social, romantic, and work-related opportunities, loss of autonomy, and

[4] An in-depth review on stigma towards individuals with psychosis will take place in Chapter 3.

withdrawal from society (Thornicroft et al., 2009). A recent systematic review and meta-analysis found that stigma was commonly experienced and detrimental to those with a diagnosis of psychosis, with strong associations between higher levels of stigma and poorer quality of life (Degnan et al., 2021).

Specific to their diagnosis and perceived status as a psychiatric patient, those with psychosis may be more likely to experience epistemic injustice. Due to the perception that the unusual phenomena experienced by individuals with a diagnosis, for example, visual and auditory hallucinations or delusions, means they are unreliable reporters or lack credibility as a knower, they may experience testimonial injustice from others who disregard their contributions (Hassall, 2024). Without identifying it as such, several examples of both hermeneutical and testimonial injustice have been identified in previous literature on stigma towards psychosis. More generally, the medical approach was described as dominant, heavily focused on medication as opposed to taking into account factors such as culture or religion in relation to the unusual experience (Rose et al., 2011; Vyas, Wood, & McPherson, 2021; Wood et al., 2018). Rather, it has previously been considered that the experiences associated with a diagnosis of psychosis, for example, delusions or spiritually significant hallucinations, can often be a positive source of comfort for some, providing meaning to people's lives, as opposed to being the meaningless, incomprehensible symptoms they are perceived as (Cullinan et al., 2024; Ritunnano & Bortolotti, 2022; Ritunnano et al., 2022). In one case study exploring the meaningfulness of delusions, the 'order within the disorder' appeared to provide a rational explanation for what the participant was experiencing, enhancing his purpose in life and bolstering his excitement regarding the future (Ritunnano, Humpston, & Broome, 2022).

Additionally, participants from various studies noted how they felt discredited by both mental health professionals and others on the basis of their diagnosis (Gonzalez-Torrez et al., 2007; Mora-Rios, Ortega-Ortega, & Natera, 2015; Pyle & Morrison, 2014; Wood et al., 2018). Therefore, despite not being recognised as such, it appears from the literature that there may be a link between a diagnosis of psychosis and epistemic injustice.

Much of the literature in relation to epistemic injustice and psychosis is theoretical in nature, with only little empirical research in this area. In one piece of empirical research that did explore epistemic injustice amongst non-clinical and clinical voice hearers, it was found that substantial differences existed between the groups, with individuals with a diagnosis experiencing both hermeneutical and testimonial injustice (Harris et al., 2022). Despite both groups of voice hearers experiencing stigma, the existence of an accepting community, regarded as a 'safe harbour' where individuals were held in regard as epistemic equals, was thought to mitigate the risk of this stigma being internalised for those without a diagnosis. Sanati and Kyratsous (2015) examined the application of epistemic injustice in the assessment of delusional beliefs. Delusions have previously been viewed as prime examples of irrationality, and as a result, the prejudice associated with this means the label of irrationality is extended generally across all beliefs and behaviours of the individual. Due to the lack of nuanced conceptualisation as to what beliefs can be considered irrational, the clinical assessment of delusions is susceptible to epistemic faults (Sanati & Kyratsous, 2015). Psychiatrists may be more likely to assign the label of delusional to an individual if they have a history of even one false belief. In cases such as these, epistemic injustice is very likely to occur. Hermeneutically, an individual with the inability to articulate their experiences lack the resources necessary to

provide meaning to or make sense of their narrative. A diagnosis of psychosis, especially when delusional beliefs are involved, may result in true or non-delusional beliefs being viewed as delusional, as well as a perception of the individual as unintelligible (Sanati & Kyratsous, 2015), both forms of testimonial injustice. Describing a real case study about a Ghanaian lady (J.N.) who had been diagnosed with psychosis and believed her husband to be cheating on her, Sanati and Kyratsous (2015) say:

> "J.N. felt betrayed by the team and thought that they only wanted to make her appear 'the crazy one', 'this is what he wants everyone to believe'. Subsequently, her mental state deteriorated further, starting to accuse other nurses of having sexual relationships with her partner, who at this point stopped visiting her in the ward or responding to her calls. At the same point that the psychiatric team was able to formulate her beliefs as a case of delusional jealousy, they realized that her partner had left her for another woman. This was in fact confirmed by him." (p. 482)

Here, it is evident that testimonial injustice is being displayed. J.N.'s belief that her husband had been cheating on her was rejected as delusional jealousy and she was undermined in her capacity as a knower. She was perceived as having low credibility due to her social identity as an individual diagnosed with psychosis that is so often attributed to negative stereotypes, such as irrationality and incomprehensibility. Kious, Lewis, and Kim (2023) argue that this error was understandable on behalf of the professionals, on the basis that the service user was diagnosed with psychosis and the claim was improbable. However, even if the error can be regarded as a simple mistake, it brings to light a significant limitation of current practice. Clinicians lacked a more integrative model that would have enabled them to achieve a more complete understanding of J.N.'s experiences, in comparison to the medical approach that that failed to take into account any social or cultural factors. For if this was taken into account, the clinicians

may have achieved a deeper understanding of J.N.'s claim through insight into her culture, which believes when a wife is perceived to be behaving erratically, her husband is permitted to leave the marriage and begin a relationship with another woman (Sanati & Kyratsous, 2015). From this, it can be confidently stated that this was not a false belief with no basis that happened to be true, rather, J.N. had a valid cultural reason to believe that her diagnosis of psychosis would result in her husband cheating on her. When testimonial injustice like the previous example occurs, the harm resulting from it can affect future situations. Future testimonials may be loaded with self-doubt and become emotionally charged, in turn, damaging the epistemic space for genuine dialogue and reaffirming the perception of the individual as having low credibility (Carel & Kidd, 2014).

2.4 Overcoming Epistemic Injustice

It has been demonstrated how adopting the view that mental illness is a problem located within the individual, regardless of any social factors, whilst affording objective evidence a higher value than subjective evidence, and negatively stereotyping individuals as incompetent, allows for an environment where epistemic injustice is likely to occur. Viewing experiences labelled as mental illness through a medical lens is unpleasant for many individuals as it may not allow them to understand what they are experiencing, however, there have been alternative ways to conceptualise psychosis. For example, the Hearing Voices Network supports all explanations for the phenomena of psychosis, allowing individuals to explore what they are experiencing without having to subscribe to a pre-existing medical framework (Oakland & Berry, 2015; Tate, 2019). Lakeman (2010) suggests that although listening is essential, it is not enough to support service users if any attitudes or behaviours they display

is transformed into a symptom. Generally, service users are unlikely to seek help with a clear, descriptive outline of their experiences, and it is imperative that support to formulate any problem is provided (Lakeman, 2010).

According to Fricker (2007), in order to combat hermeneutical injustice specifically, the virtue of hermeneutical justice is necessary. In this case, an individual's difficulty to make sense of and articulate their experience would be attributed to recognising the existence of hermeneutical injustice within society, as opposed to innate deficiencies on behalf of the individual in their capacity as a knower. It has been suggested however, that the processes underlying the influence of prejudice on perception largely operates covertly, with individuals unable to cognitively identify to what extent this occurs and therefore how much to correct for it, especially in environments that require immediate response (Alcoff, 2010; Anderson, 2012). In addition to the virtue-based remedies proposed by Fricker (2010), Anderson (2012) suggests structural remedies to enable the functioning of individual virtues. In essence, changes at a structural or institutional level may prevent the issue of epistemic injustice arising in the first place, rather than overcoming instances of epistemic injustice solely at an individual level, which may prove incredibly cognitively taxing and impossible to monitor in a fast-paced environment.

In the context of healthcare then, mental health services should aim to work towards an open, epistemic space with service users that allows them to understand their experiences and assert epistemic authority (Gosselin, 2019). In one theoretical paper that explored spiritually significant hallucinations, the authors propose that further support should be offered in order to address spiritual needs, alongside increased awareness of own self and

epistemic injustice on behalf of the clinician (Cullinan et al., 2024). For those with spiritually significant hallucinations, chaplain support was recommended as a method that provides the necessary hermeneutical resources in order for individuals to explore the meaning made of their experiences. With regards to clinician support, it was also suggested that chaplains may play a significant role in providing continual knowledge and education in relation to individuals with religious needs, potentially mitigating the risk of epistemic injustice occurring through a person-centred approach that takes into consideration the service user's narrative and religious needs (Cullinan et al., 2024). It would be unwise to believe that the changes required to reduce epistemic injustice faced by service users are easy to implement. Clinicians typically have a limited amount of time with service users, as well as an abundance of caseloads and paperwork to deal with (Gosselin, 2019). However, this does not mean that strategies should not be put in place to challenge occurrences of epistemic injustice. Conscious effort should be made to be aware of and change any bias or negative stereotypes associated with mental illness. Drożdżowicz (2021) states that in order to prevent epistemic losses through interactions with patients, the onus is on healthcare professionals to solicit testimonies from individuals regarding their experiences, in line with their epistemic duty.

It has previously been suggested that obtaining a diagnosis may provide some individuals with the hermeneutical resources to make sense of their experience (Pitt et al., 2009), with failure to assign a diagnosis contributing to the hermeneutical injustice faced by individuals with unusual experiences. Hassall (2024) proposed that one way to circumvent the issue of a diagnosis either being a form of hermeneutical injustice or a hermeneutical resource would be to provide it only if the service user requests it. In addition, they suggest that clinicians

should aim to clarify to service users that a diagnosis is merely descriptive rather than explanatory, and that full recovery is possible (Hassall, 2024). Alternative to the traditional diagnostic assessment, adopting a case-formulation approach would facilitate the collaboration between clinician and service user, constructing a shared understanding of the phenomena in order to not only make sense of the experience, but also enhance the autonomy of the individual, allowing them to be active participants throughout the diagnostic process. Adoption of a more phenomenological stance provides an opportunity for an epistemically open space where interpretation between clinician and service user may take place. Within this space, complex dialogue and construction of coherent narrative may occur in order for the individual to focus on sense-making as opposed to the diagnosis itself (Hassall, 2024).

A phenomenological toolkit, developed by Carel and Kidd (2014) as a resource for patients, may also be useful for training clinicians. Promoting epistemic symmetry, the toolkit attempts to suspend the natural medical attitude towards illness, thematise illness, and explore how illness can affect an individual's being within the world (Carel & Kidd, 2014). Self-narratives should be created in order to construct a self-concept that goes beyond diagnostic identity (Tekin, 2011) and limit the environment in which epistemic injustice can take place. However, consideration surrounding the potential difficulties in the implementation of the toolkit within healthcare have been noted. According to Scrutton (2017), the phenomenological approach may pose a risk of secondary forms of epistemic injustice. First, it was suggested that if the toolkit was designed in light of the evidence-base regarding phenomenological research, there is a risk that lesser educated individuals who may not frequently participate in research are further marginalised. Second, the toolkit may rely on perceived expectations of experiences,

and utilising this in practice may result in an individual's description being skewed or forced into presumed categories (Drożdżowicz, 2021; Scrutton, 2017). It has been suggested that in order to avoid these secondary forms of testimonial and hermeneutical injustice, the toolkit may need to be modified in relation to specific diagnoses, developed in unison by both patients and professionals (Drożdżowicz, 2021), therefore taking into consideration both firsthand patient experience as well as professional knowledge (Scrutton, 2017). As such, there may be a need in the future for explicit guidelines surrounding patient-professional collaborations within healthcare services in order to mitigate some of the risks posed through the occurrence of epistemic injustice (Drożdżowicz, 2021).

The present chapter aimed to outline the concept of testimonial and hermeneutical injustice (Fricker, 2007), reviewing the literature surrounding epistemic injustice and psychosis specifically. Through the medicalisation of mental health and a dominant medical model, as well as the consistent literature highlighting stigma towards psychosis, it is evident how both hermeneutical and testimonial injustice have a higher likelihood of being perpetrated against those with a diagnosis of psychosis as opposed to other diagnoses. In light of this, Chapter 3 will utilise a meta-ethnographic approach to explore stigma towards psychosis within past qualitative literature. Given that the majority of literature on epistemic injustice currently is theoretical in nature, the review will aim to explore whether any incidences of this can be uncovered in past empirical research based on participant accounts. It is hoped that by firstly reviewing what is currently known, the empirical chapters (5, 6, and 7) can build upon this to understand the concept of epistemic injustice as a form of stigma.

Chapter 3

THE EXPERIENCE OF STIGMA IN PEOPLE WITH PSYCHOSIS: A META-ETHNOGRAPHY

Abstract

Aim: The meta-ethnography aimed to explore the experience of stigma from the perspective of people with psychosis by synthesising the findings from relevant qualitative literature, in order to explore any occurrences of epistemic injustice.

Method: A systematic search of three databases was conducted to identify articles that primarily focused on experiences of stigma within psychosis, resulting in twelve studies that matched eligibility criteria.

Results: Three main themes emerged from the synthesis: (i) '*Understanding Psychosis;*' (ii) '*Other's Response;*' and (iii) '*Own Response*.' The first theme included three sub-themes: '*Lack of Understanding;*' '*Psychosis in Comparison;*' and '*A Sense of Ab / Normality*.' The second theme included three sub-themes: '*Loss of Identity and Autonomy;*' '*Epistemic Injustice;*' and '*Social Exclusion*.' The third and final theme included two sub-themes: '*Conceal and Withdraw;*' and '*Difficulties Within Interpersonal Relationships*.' All sub-themes contained a central concept of stigma, via the source of stigma, the experienced stigma, and the response to stigma, in relation to people with a diagnosis of psychosis. Two line of argument syntheses were also identified once studies were reciprocally translated.

Conclusion: Stigma was experienced both internally and externally, resulting from a general lack of understanding towards the illness and a dominating medical approach. Interventions at a societal level that involve a biopsychosocial framework are necessary to improve understanding and reframe what it means to have psychosis, in order to tackle the associated stigma.

3.1 Introduction

The present meta-ethnography aims to serve as a bridging chapter within the thesis, between the literature review and the empirical chapters that utilise primary data. As the wider aims of the thesis pertains to the way that individuals make sense of their unusual experiences, as well as the way others make sense of this and perceive them following the experience, it first makes sense to systematically explore the literature regarding stigma in relation to psychosis. It is hoped that by having a comprehensive understanding of what is currently known about this topic, the philosophical concept of epistemic injustice, a specific form of stigma, can be identified through the future empirical chapters and compared between non-clinical and clinical populations.

3.1.1 Stigma and Psychosis

The modern notion of stigma was first described as a "mark" that tells others an individual contains a quality that reduces them from "whole" to "tainted." The marked person is devalued as "less than fully human" and is characterised by exclusion from others in society (Goffman, 1963). Although this is the most commonly accepted understanding of stigma, later conceptual papers argue that social and political questions are not included within Goffman's (1963) definition, for example, explorations of how both individuals and wider communities

use stigma to maintain a state of social inequality (Parker & Aggleton, 2003). For example, one of the more prominent messages of the international anti-stigma campaign, Heads Together, is that mental health is "the same as physical health" (Tyler & Slater, 2018), promoting a biological approach to understanding mental distress. On the other hand, this message may also serve to argue for the equity of resource and societal consideration of mental health alongside physical health. Research suggests however, that the lack of social explanations within these campaigns serve to exacerbate prejudice and discrimination (Read et al., 2006; Corrigan, 2007; Tyler & Slater, 2018).

One of the most stigmatised mental illnesses[5] is psychosis (Wood et al., 2015), with past literature highlighting significant amounts of prejudice held towards people diagnosed with either psychosis or schizophrenia (Baba et al., 2017; Longdon & Read, 2017; Eliasson et al., 2021). The Schizophrenia Commission (2012) found that 87% of service users with schizophrenia reported discrimination and stigma from others. As a result of this report from the United Kingdom (UK), the anti-stigma campaign, Time to Change, was developed to tackle this issue. Since then, general attitudes amongst the public have improved by 9.6%, whilst reports of discrimination fell from an average of 41.6% to 28.4%. This reduction in reported discrimination was mostly found to be due to changes in behaviour of family and friends (The Schizophrenia Commission, 2017), suggesting that interventions and anti-stigma campaigns targeting societal understanding of and behaviour towards people with psychosis was still required. Although the levels of reported stigma and attitudes within the UK changed in a

[5] The terms 'mental illness' and 'mental disorder' will be used interchangeably throughout the review in reference to psychosis. Although the use of this term implies a biological approach and reifies the body as a primary cause of psychosis, it is not indicative of the author's beliefs or position on the aetiology of psychosis.

positive way, a recent report originating from America suggests that beliefs of schizophrenia being associated with danger may have increased between 1996 and 2018 (Pescosolido et al., 2019). A third of service users still reported experiencing discrimination from professionals within the mental health system (The Schizophrenia Commission, 2017), supporting the idea that a biological approach to mental illness can lead to increased amounts of stigma and discrimination (Tyler & Slater, 2018).

3.1.2 Origin, Structure, and Impact

Stigma from society appeared to originate from two key places: misinformation and negative stereotypes associated with psychosis in the media, and the diagnostic label of 'psychosis / schizophrenia'. Research has found that the representation of mentally ill people in the media plays a pivotal role in forming and maintaining negative stereotypes within society, specifically the stereotype of psychosis being intrinsically linked to acts of violence (Delahunt-Smoleniec & Smith-Merry, 2020). For example, a sample of seven newspapers that included the word 'schizophrenia' within articles were analysed over a 24-month period, with findings indicating that the word 'schizophrenic' had a high frequency (n = 108) and was commonly associated with graphic language referring to acts of violence (Bowen et al., 2019). To examine public reaction towards the label of schizophrenia, Cheung et al. (2018) manipulated diagnostic label and symptom manifestation via vignettes, using the Western diagnosis of 'schizophrenia' and the Chinese diagnosis of 'thought and perceptual dysregulation.' Findings revealed that individuals labelled with schizophrenia were deemed to have greater control over their symptoms than those who were labelled as having thought and perceptual dysregulation. A majority of participants also perceived thought and perceptual

dysregulation to be less severe and more treatable than schizophrenia (Cheung et al., 2018). It has previously been suggested that perceiving greater controllability of psychiatric symptoms was connected to increased levels of discrimination and social exclusion (van't Veer et al., 2006).

Stigma has previously been thought to consist of two key components: societal stigma from others towards those with psychosis, and self-stigma that involves internalising societal stigma (Corrigan, Kerr, & Knudsen, 2005). Many existing methods of understanding stigma have utilised behavioural science in order to develop explanatory models for the phenomenon. At an individual level, these include cognitive models that seek to explain the formation and maintenance of stigma at a psychological level (Hilton & von Hippel, 1996; Krueger, 1996; Crocker, Major, & Steele, 1998), and motivational models that aim to describe the function that stigmatising behaviour serves on behalf of the stigmatiser (Biernat & Dovidio, 2000; Stangor & Crandall, 2000). However, a more complete understanding of stigma can be obtained from recognising both individual levels and societal levels of stigma processes. Therefore, other models consist of institutional and structural discrimination, developing the notion that statutory activities both intentionally and unintentionally inhibit the civil rights and opportunities of individuals with mental disorders (Link & Phelan, 2001).

Corrigan, Kerr, and Knudsen's (2005) model was supported by a recent thematic analysis of stigma in psychosis, with emerging themes identifying stigma processes and a stigma system that underpin the two key components (Wood et al., 2015). 'Stigma processes' represented the variety of mechanisms by which stigma operated within society, examples of themes including social exclusion, lack of understanding, and shame and secrecy (Wood et al., 2015).

According to Corrigan, Kerr, & Knudsen (2005), stigma-related processes are maintained via three key components as outlined in previous cognitive models: stereotypes, prejudice, and discrimination. The 'stigma system' was found to be socially embedded, referring to the environment in which stigma occurs i.e. through wider society, interpersonal relationships, or the self (Wood et al., 2015). Highlighting the interaction between these components that make up the structure of stigma, discrimination from society was thought to be internalised by individuals with psychosis (Vass et al., 2017), suggesting that societal stigma feeds into the development of self-stigma. Stigma is also thought to internalise when negative beliefs held towards the illness prior to diagnosis become personally relevant (Eliasson et al., 2021). In Corrigan and Watson's (2002) model of stigma, internalised stigma firstly involved a process of acceptance of and agreeance with negative stereotypes surrounding the illness, and secondly, application of these stereotypes to the self, leading to changes in self-image.

Both experienced or perceived societal stigma and internalised stigma can have severe negative impacts on an individual with psychosis, ranging from external structural inequalities to internal emotional distress (Corrigan, Kerr, & Knudsen, 2005). Structural inequalities include the lack of opportunities for people with psychosis to obtain employment or housing, such as an inability to live independently (Thornicroft et al., 2016). Discrimination is also understood to lead to concealment and withdrawal from the diagnosis, as well as reduced longevity of employment (Hampson et al., 2020). Stigma has previously been recognised as a barrier to pathways of care, with fear of diagnosis resulting in damaging coping strategies, such as ignoring symptoms (Boydell et al., 2006; Kular et al., 2019; Hardy et al., 2020). Findings from a recent meta-analysis revealed that internalised stigma based on negative beliefs surrounding psychosis had the strongest influence on poor quality of life outcomes (Degnan et al., 2021).

In a quantitative exploration of the relationship between stigma and emotional distress, it was found that both perceived and experienced stigma were significantly associated with feelings of depression, hopelessness, and low self-worth (Wood et al., 2017). Reduced self-worth was also identified within a previous qualitative study on service users' perspectives, alongside a sense of abnormality and difference from others, low self-confidence, and changes in identity / self-image (Burke et al., 2016). Wood and Irons (2017) found that stigma was significantly linked with shame, poor personal recovery, and depression / anxiety, highlighting the effect of stigma processes on an individual's ability to establish a meaningful life and positive sense of identity (Allott, Loganathan, & Fulford, 2002).

3.1.3 Rationale and Aims

The negative impact of stigma on people with psychosis has been demonstrated to result in poor quality of life, emotional distress, and structural inequalities, potentially hindering pathways to care (Corrigan, Kerr, and Knudsen, 2005; Hardy et al., 2020). Recommendations for promoting recovery for psychosis by the National Institute for Health and Care Excellence (NICE, 2014) include the provision of care in an environment that reduces stigmatisation as much as possible. Although anti-stigma campaigns have previously been used to tackle stigma within the wider society (Tyler & Slater, 2018), findings from research within the past five years suggest that this is still a prevalent issue amongst people who experience psychosis. To reduce the negative impact outlined and achieve equality for people with psychosis, it is imperative for research to continue examining stigma models and processes, leading to more complete understandings and therefore, effective solutions to reduction.

A previously published systematic review explored stigma in psychosis (Wood et al., 2015). The utilisation of a thematic approach to analysis of the literature was beneficial for identifying themes that mapped on to previous models of stigma and psychosis (Corrigan, Kerr, and Knudsen, 2005), however, the use of a meta-ethnography in analysing past research has the potential to add to the existing body of knowledge by reinterpreting meaning (Atkins et al., 2008). Despite a similar purpose to the existing review (Wood et al., 2015), a meta-ethnographic approach allows for a more interpretative analysis that builds on the current understanding of stigma in psychosis, leading to insights that may not have been readily apparent in individual articles, rather than a thematic approach that summarises the relevant articles as a whole (Atkins et al., 2008). Furthermore, the present review aims to be as stringent as possible with the eligibility criteria. As the wider aims of the thesis focus solely on understanding the way epistemic injustice is demonstrated against individuals with a diagnosis of psychosis, it is imperative for the present review to only include the relevant target population so that findings can be understood in the context of this specific sample. Additionally, it is imperative that a review of stigma towards psychosis is undertaken in order for the empirical chapters (5, 6, and 7) of the thesis to build upon what is currently known and understand epistemic injustice in the context of these findings. The previous thematic synthesis aimed to explore stigma in psychosis, however, as part of the eligibility criteria, studies were included if at least 50% of participants were service users with experiences of stigma and at least 25% of the sample had received a diagnosis for a schizophrenia spectrum disorder (Wood et al., 2015). Further review of stigma that concentrates only on experiences from people with a diagnosed psychotic disorder will allow for findings that can more

confidently be attributed to the diagnosis itself. Therefore, the aims of the present review are as follows:

i) to use a meta-ethnographic approach in order to examine current qualitative literature,

ii) to develop an understanding of the ways in which stigma is created and faced by people with a diagnosis of a schizophrenia spectrum disorder, and

iii) to explore whether occurrences of epistemic injustice can be observed within the relevant literature on stigma.

It is expected that following these aims will allow for a comprehensive answer to the research question: how do people with psychosis experience stigma?

3.2 Method

A meta-ethnography following the seven phases of Noblit and Hare (1988) was conducted to meet the aims of the research. Following this approach to review and synthesise qualitative studies, the first phase involved *getting started.* With an initial interest in psychosis, preliminary searches were conducted to identify both qualitative literature and meta-syntheses surrounding the topic, leading to a more specific interest in experiences of stigma in relation to psychosis.

3.2.1 Systematic Search

The second phase, *deciding what is relevant to the initial interest* (Noblit & Hare, 1988), took place via a systematic search of the literature surrounding psychosis and stigma. The search strategy, including search terms and method of search within each database, is outlined in Table 3.1. The search was limited to articles published in peer-reviewed journals, with the

decision to exclude grey literature. Although the inclusion of grey literature may reduce the effect of publication bias, addition of unpublished studies may also present a new type of bias, whereby the difficulty in locating all grey literature can lead to the potential that any included studies are unrepresentative of all unpublished studies, as well as being of a lower methodological quality than peer-reviewed articles (Egger et al., 2003).

Given the difficulties in searching for qualitative literature due to poor indexing (Shaw et al., 2004; Booth, 2016), the SPIDER framework was adapted and used to inform the search strategy (Cooke, Smith, & Booth, 2012). This included terms used to describe the **S**ample (Construct 1: Psychosis), the **P**henomenon of **I**nterest (Construct 2: Stigma), and the methodological criteria of **D**esign, **E**valuation, and **R**esearch type (Construct 3: Qualitative) (see Table 3.1). In addition to this, search terms were chosen and expanded on from a previous thematic synthesis examining stigma in psychosis (Wood et al., 2015). In an effort to enhance transparency within qualitative literature (Hannes & Macaitis, 2012), the lack of information in the previous synthesis (Wood et al., 2015) concerning the screening process and quality appraisal of papers has been noted and explicitly outlined within this paper.

Search terms within each construct were combined with 'OR' and search terms between each construct were combined with 'AND.' Databases were searched individually on 02/11/2021, and results were exported to reference managing software RefWorks for screening to take place.

Table 3.1
Database search terms

Construct	Search Terms	Method of Search		
		PsycInfo	Medline	Social Sciences Citation Index
1. Psychosis	schizo* psychosis "psychotic disorder"	Abstract Title Original Title Heading Word Key Concepts MeSH Table of Contents	Abstract Title Original Title Keyword Heading Word Floating Sub-Heading Word Subject Heading Word Synonyms	Topic: Abstract Title Author Keywords Keywords Plus
2. Stigma	stigma discrimination marginalis*			
3. Qualitative	qualitative "grounded theory" "thematic analysis" narrative "focus group*" interview* perspective experience phenomenolog*			

3.2.2 Eligibility Criteria

Articles were selected for review according to the following inclusion criteria: (1) participants have a clinical diagnosis of a primary psychotic disorder; (2) the focus of the paper is to explore participant's experience of stigma; (3) methods of data collection and analysis must be qualitative or mixed-method in order to draw out meaning as opposed to statistics; and (4) studies must be written in English and published in a peer-reviewed journal. Articles that did not meet all of the inclusion criteria were excluded from the review.

Articles that included participants with bipolar disorder were excluded from the review due to the disorder primarily being a mood disorder that may or may not involve psychotic features (World Health Organisation, 2020). Previous research has suggested that stigma resistance is higher in patients with bipolar disorder compared to schizophrenia, potentially owing to the greater amount of discrimination faced by people with schizophrenia in society (Sarisoy et al., 2013). Therefore, the review focuses on psychotic disorders and excludes mood disorders with psychotic features as experiences of stigma may differ based on the diagnosis. Articles were also excluded if data for the population of interest was combined with data of others, for example, experiences of carers, family members, or professionals, and could not be extracted separately in studies that included only a subset of participants relevant to the review.

3.2.3 Systematic Screening

Adopting PRISMA guidelines for identification, screening, and eligibility of articles (Page et al., 2021), a total of 3976 articles were identified from 3 databases: PsycInfo (1283), Medline (691), and Social Sciences Citation Index (2002), with no additional records identified through reference searching from included articles (Figure 3.1). After screening and excluding articles based on title and abstract, 53 remained for full-text review. Reasons for exclusion have been listed in Figure 3.1, with a final total of 12 studies matching the eligibility criteria and being included in the review.

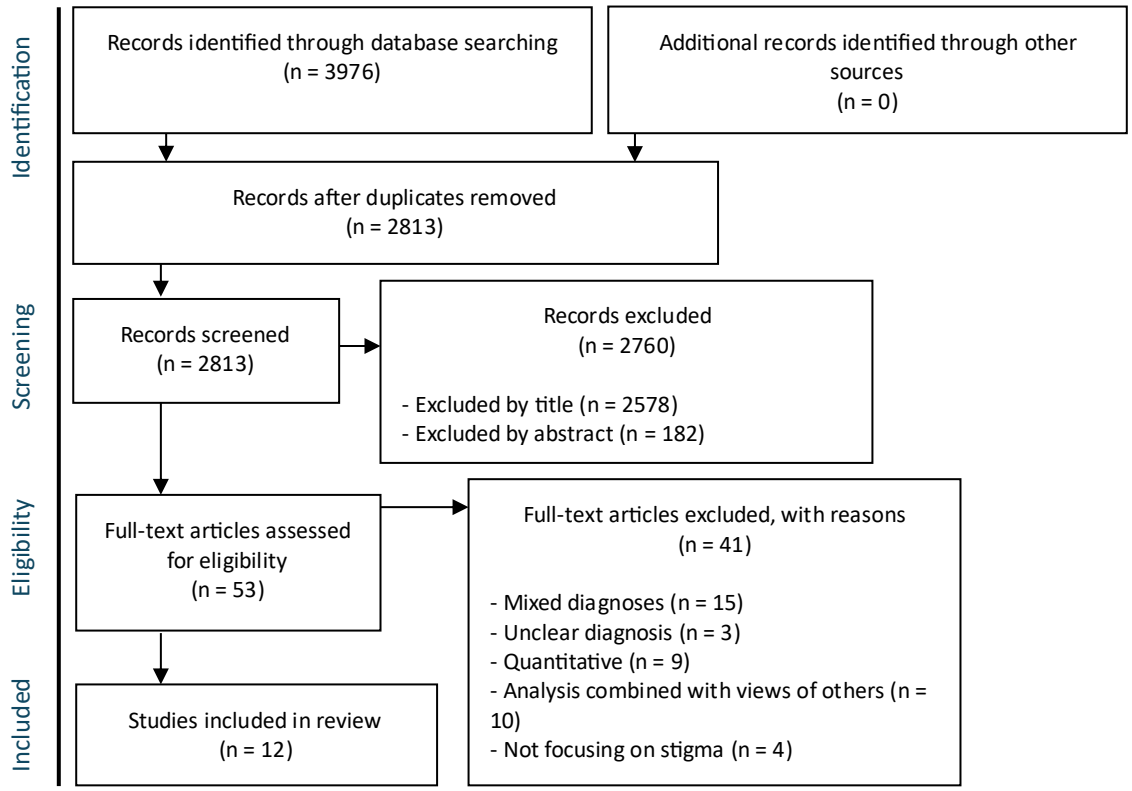


***Fig* 3.1.** PRISMA flowchart for search strategy

3.2.4 Characteristics of Included Studies

The twelve included articles comprised of 498 participants diagnosed with a clinical psychotic disorder (Table 3.2). Across ten of the studies, a total of 436 participants were diagnosed with schizophrenia, 18 with schizoaffective disorder, 8 with psychotic episodes, 3 with paranoid schizophrenia, 2 with psychosis not otherwise specified, and 1 with persistent delusional disorder. In one study (Paul, 2016), 20 participants were diagnosed with either schizophrenia and/or a schizophrenia-related disorder, however, no further information on this was provided. Another study (Vyas, Wood, & McPherson, 2021) stated that participants were recruited from an early intervention in psychosis service. Contact with the author of the paper (Vyas) confirmed that all participants had a diagnosis of psychosis.

Across all of the studies, 290 participants were male and 208 were female. Three studies did not report data on the range of ages (Gonzalez-Torrez et al., 2007; Jenkins & Carpenter-Song, 2009; Loganathan & Murthy, 2011), however, in the remaining articles, ages of participants ranged from 19 to 63. Nine studies reflected the smaller sample size (*range* = 6 to 25 participants) usually representative of qualitative literature, whilst three studies included a relatively larger sample size (*range* = 75 to 200 participants) making up 365 of the total number of participants included in the review (Jenkins & Carpenter-Song, 2009; Loganathan & Murthy, 2011; Rose et al., 2011). Participants were recruited from both outpatient and inpatient settings in 19 different countries. Semi-structured interviews were the most commonly used method of collecting data, with Interpretative Phenomenological Analysis and Thematic Analysis being the most common method of analysing the data (Table 3.2).

Table 3.2
Characteristics of studies included in the review.

Year	Author(s)	Aim	Design	Recruitment	Participants	Main Themes
2003	Knight, Wykes & Hayward	To provide an account of the life experiences of people with schizophrenia, focusing on issues of stigma and discrimination	Semi-structured interviews Interpretative Phenomenological Analysis (IPA)	Central urban districts UK	N = 6 M = 4, F = 2 Age range = 31-50 (M = 43) Schizophrenia (N = 3) Paranoid Schizophrenia (N = 3)	(1) Judgement (2) Comparison (3) Personal understanding of issue
2007	Gonzalez-Torrez et al.	To explore actual stigma and discrimination experience recalled by people with schizophrenia	Focus groups Framework analysis	Community Mental Health Centres and inpatient units in General or Psychiatric Hospitals Spain	N = 18 M = 9, F = 9 No data reported on age Schizophrenia (N = 18)	(1) Mental illness vs. lack of willpower (2) Prejudice related to dangerousness (3) Over-protection-infantilization (4) Daily social discrimination (5) Discrimination in health care (6) Descendants (7) Avoidance-social isolation
2009	Jenkins & Carpenter-Song	To investigate the subjective experience of stigma attached to schizophrenia-related disorders	Semi-structured ethnographic interviews (Subjective Experience of	2 community mental health outpatient facilities in a north eastern metropolitan area	N = 90 M = 49, F = 41 Age (M = 40.7, SD = 7.9) Schizophrenia (N = 73)	(1) Social relations (2) Identity domains

			Medication Interview - SEMI) Grounded theory	USA	Schizoaffective disorder (N = 17)	
2011	Loganathan & Murthy	To look at the differences in the impact of stigma among Indian men and women with schizophrenia	Semi-structured interviews Framework Analysis	(i) Outpatient services of six adult psychiatry units (ii) 6 outreach centres in the rural community India	N = 200 M = 118, F = 82 No data reported on age Schizophrenia (N = 200)	(1) Marriage and related myths (2) Dilemmas associated with pregnancy and childbirth (3) Frustrations of securing a job and working
2011	Rose et al.	To examine the extent of stigma and discrimination as reported by people with a diagnosis of schizophrenia	Mixed-methods scale (Discrimination and Stigma Scale v10 - DISC) Thematic Analysis	(i) In-patient (ii) Out-patient (iii) Home (iv) Day care 15 countries included*	N = 75 M = 45, F = 30 Age range = 19-51 (Median = 37) Schizophrenia (N = 75)	(1) Shunned (2) Lack of understanding / well-meaning but negative (3) Social withdrawal (4) Entitlements because of mental illness (5) Positive discrimination
2014	Howe, Tickle & Brown	To explore service users' experiences of receiving a diagnosis of schizophrenia and the stigma associated with the diagnostic label	Semi-structured interviews IPA	Community Mental Health Team UK	N = 7 M = 3, F = 4 Age range = 29-60 (M = 44) Schizophrenia (N = 7)	(1) Avoidance of the diagnosis of schizophrenia (2) Stigma and diagnostic labels (3) Lack of understanding of schizophrenia (4) Managing stigma to maintain normality (5) Being 'schizophrenic'

2014	Pyle & Morrison	To explore the experience of stigma relating to psychosis	Semi-structured interviews IPA	Mental health services across Greater Manchester UK	N = 9 M = 4, F = 5 Age range = 19-54 (M = 23) Schizophrenia (N = 6) Schizoaffective disorder (N = 1) Psychosis NOS (N = 2)	(1) Judgement (2) Disclosure (3) Psychological distress and possible exits
2015	Mora-Rios, Ortega-Ortega & Natera	To explore the most common forms of stigma and discrimination faced by people with schizophrenia	In-depth interviews Thematic analysis	4 psychiatric clinics in Mexico City Mexico	N = 23 M = 11, F = 12 Age range = 22-63, (M = 40) Schizophrenia (N = 23)	(1) Cultural factors, meaning, and attribution surrounding schizophrenia (2) Experiences of stigma and structural discrimination (3) Resources for coping with stigma and discrimination
2016	Paul	To investigate coping responses of people living with schizophrenia to stigma-related stressors	In-depth interviews Thematic analysis	(i) Private psychiatric clinics (ii) Mental health agencies (iii) Schizophrenia support groups India	N = 20 M = 10, F = 10 Age range = 22-59 (M = 40.85, SD = 8.52) Schizophrenia and/or a schizophrenia-related disorder (N = 20)	(1) Coping with the 'illness' label (2) Coping with labelling, violence and abuse (3) Coping with rejection (4) Coping with job loss (5) Coping with anticipatory discrimination
2018	Wood et al.	To examine the subjective experiences of stigma with acute psychiatric inpatients	Semi-structured interview measure of stigma (SIMS)	Inner London acute psychiatric inpatient unit	N = 25 M = 20, F = 5 Age range = 21-58	(1) Stigmatising social environment and networks

		who experience psychosis	Thematic Analysis	UK	(M = 36.48, SD = 9.98) Schizophrenia (N = 16) Psychotic episode (N = 8) Persistent delusional disorder (N = 1)	(2) Stigmatised person with psychosis (3) Stigma interactions
2020	Yen, Huang & Chien	To explore the self-stigma of patients with schizophrenia	Unstructured interviews Colaizzi's phenomenological method of analysis	Outpatient clinic Taiwan	N = 15 M = 9, F = 6 Age range = 25-62 (M = 43.67) Schizophrenia (N = 15)	(1) Experience of the origin of the self-stigma (2) Suffering experience of self-stigma (3) Experience of coping with self-stigma
2021	Vyas, Wood, & McPherson	To explore the stigma experiences of second-generation British South Asian people using an early intervention in psychosis service	Semi-structured interviews Thematic Analysis	London NHS Trust – Early Intervention in Psychosis Service UK	N = 10 M = 8, F = 2 Age range = 19-39 (M = 23.5) Psychosis (N = 10)	(1) The burden of silencing (2) Unrecognised aspects of their situation by services (3) Experience as "the other" (4) Finding ways to cope

Note: *Countries include: Brazil, Bulgaria, Cyprus, England, Finland, France, Greece, Italy, Lithuania, Malaysia, Romania, Slovakia, Slovenia, Turkey and the USA.

3.2.5 Quality Appraisal

The NICE (2012a) methodology checklist for qualitative studies was used to assess the quality of each included article as it was found to best represent Yardley's (2000) quality criteria for qualitative research. This includes sensitivity to context (Q1, Q2, Q3, Q6, Q13), commitment and rigour (Q4, Q5, Q7, Q10), transparency and coherence (Q8, Q11), and impact and importance (Q12). The checklist is outlined in Box 3.1 however, minor modifications were made to some of the questions (Q1, Q3, Q8, Q10, Q13) in order to make it more relevant to the review.

Box 3.1. NICE (2009) Methodology Checklist for Qualitative Studies. * denotes changes made to the checklist.

Theoretical approach

1) Is the qualitative approach chosen appropriate for the study? *
2) Is the study clear in what it seeks to do?

Participants

3) Do participants have a clinical diagnosis of a primarily psychotic disorder? *

Study Design

4) How defensible/rigorous is the research design/methodology?

Data Collection

5) How well was the data collection carried out?

Validity

6) Is the context clearly described?
7) Were the methods reliable?
8) Is the role of the researcher clearly described? *(this has been extended to include how clear the researcher's position has been made in the article)

Analysis

9) Are the data 'rich'?
10) Is the analysis sufficiently rigorous and reliable? *
11) Are the findings convincing?
12) Are the conclusions adequate?

Ethics

13) How clear and coherent is the reporting of ethical considerations? *

For each criterion met in the checklist, the item would receive a tick (✓). For each criterion not met, the item would receive a cross (✗), and if there was insufficient information to judge whether or not the criterion was met, the item would receive a question mark (?). Following the NICE (2012b) guidance on assessing the study as a whole, an overall methodological quality rating was provided. Each study was graded according to the following: no weaknesses (++) if all or most of the criteria have been met, where they have not been met the conclusions drawn from the study are unlikely to change; few weaknesses (+) if some of the criteria have been met, where they have not been met or insufficient information has been provided, the conclusions drawn from the study are unlikely to change; some weaknesses (-) if few or none of the criteria have been met and the conclusions drawn from the study are likely to change. An overview of the quality appraisal for each study can be found in Figure 3.2, with a more detailed breakdown of the appraisal in Appendix 1.

	1	2	3	4	5	6	7	8	9	10	11	12	13	Overall Quality
Knight (2003)	✓	✓	?	✓	✓	?	✓	×	✓	✓	?	?	?	-
Gonzalez-Torrez (2007)	✓	✓	?	✓	✓	✓	✓	?	?	?	✓	✓	?	-
Jenkins (2009)	✓	✓	✓	✓	✓	?	✓	×	✓	✓	✓	?	?	+
Loganathan (2011)	✓	✓	✓	?	✓	?	✓	?	✓	✓	✓	✓	?	+
Rose (2011)	✓	✓	?	✓	✓	?	✓	×	✓	✓	✓	?	×	-
Howe (2014)	✓	✓	?	?	?	?	✓	✓	✓	×	✓	✓	✓	-
Pyle (2014)	✓	?	✓	✓	✓	?	✓	?	✓	?	✓	✓	✓	+
Mora-Rios (2015)	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	✓	++
Paul (2016)	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	?	✓	✓	+
Wood (2018)	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	✓	++
Yen (2020)	✓	✓	?	✓	✓	?	✓	×	✓	?	✓	✓	✓	+
Vyas (2021)	✓	✓	?	✓	✓	✓	✓	✓	✓	?	✓	✓	✓	++

***Fig* 3.2.** Methodological quality of the included studies using the NICE Quality Criteria for qualitative research (2012a). The overall quality rating has been provided following the NICE Quality Appraisal for qualitative research (2012b).
Note: Columns 1-13 correspond with the numbered questions listed in Box 3.1.

Overall, three studies were rated as having no weaknesses (Mora-Rios, Ortega-Ortega & Natera, 2015; Wood et al., 2018; Vyas, Wood, & McPherson, 2021), five were rated as having few weaknesses (Jenkins & Carpenter-Song, 2009; Loganathan & Murthy, 2011; Pyle & Morrison, 2014; Paul, 2016; Yen, Huang, & Chien, 2020), and four were rated as having some weaknesses (Knight, Wykes, & Hayward, 2003; Gonzalez-Torrez et al., 2007; Rose et al., 2011; Howe, Tickle, & Brown, 2014). The majority of criteria rated as a weakness (i.e. × or ?) was due to insufficient information provided by the authors, which in turn, did not allow for clear appraisal of particular criteria.

Generally, most of the studies provided sufficient information concerning the theoretical approach, study design, and data collection, along with a 'rich' analysis of the data and convincing findings. The majority of weaknesses concerned the validity of the studies, namely the description of context provided as well as the role of the researcher within the study, with only two studies providing sufficient information on the role of the researcher (Howe, Tickle, & Brown, 2014; Vyas, Wood, & McPherson, 2021). Although the studies had been presented clearly to participants in many of the studies, the positionality and reflexivity of the researcher were rarely discussed. The quality of information provided on ethical considerations was also mixed, with four studies failing to state ethical approval had been granted (Knight, Wykes, & Hayward, 2003; Gonzalez-Torrez et al., 2007; Jenkins & Carpenter-Song, 2009; Rose et al., 2011) and two studies failing to discuss any ethical considerations (Loganathan & Murthy, 2011; Rose et al., 2011).

A sample of five papers were appraised by an external rater following the same NICE (2012a) guidance, with few inconsistencies between ratings identified. To resolve these inconsistencies, a discussion took place with the rater on the rationale for the appraisal provided, leading to a mutual agreement on the final grade for the criterion in all cases. Although the quality appraisal of qualitative research is subjective in nature (Dixon-Woods et al., 2004), the minimal inconsistencies identified across both ratings suggests that the specific checklist utilised within the NICE (2012a) guidance, along with the ability to tailor questions to the review, was an effective tool for assessing the literature.

3.2.6 Data Extraction and Analysis

In order to become familiar with the articles, the third phase of Noblit and Hare's (1988) approach was completed by *reading the studies*. Using only the results section of the articles, data was extracted to a data extraction table. Firstly, the themes, as well as any sub-themes, were extracted as the original author had labelled them. This was noted along with a description of what each theme represented, and finally, quotes that illustrated the author's meaning were extracted (Appendix 2).

The analysis of the data was guided by phases four: *determining how the studies are related*; five: *translating the studies into one another*; and six: *synthesising the translations* (Noblit & Hare, 1988). After becoming familiar with the data extraction table and the author's interpretation of their findings, proposed concepts of the findings were noted for each theme (Appendix 3). These concepts emerged from initial interpretations of either the author's interpretation or directly from the participant's quotes and included labels such as 'inequality,' 'infantilisation,' and 'sense of difference.' Concepts were labelled depending on what was judged to be most representative of a particular quote or subtheme. To understand the initial concepts in the context of the other studies, a process of reciprocal translation occurred, whereby similar concepts across articles were grouped together. This process involved cross-comparison of labels used across papers, with quotes or author interpretation restructured into initial concepts. Once similar concepts emerged from the data, they were translated against each other and grouped into sub-themes, whereby labels that had similar connotations, such as the way in which the labels "physical abuse" and "infantilisation" were associated with a power imbalance in relation to others, were clustered together. These sub-

themes were finally compared against one another and restructured into overarching themes. For example, the concepts of “infantilisation / loss of autonomy,” “epistemic injustice,” and “social exclusion” were grouped to create the overarching theme, “Other’s Response.” It is key to note that analysis of papers was not a linear process, but rather it was iterative, with labels and concepts continually changing throughout phases four, five, and six (Noblit & Hare, 1988).

The third aim of the review focuses on whether epistemic injustice can be identified in past literature. Despite this however, the researcher attempted to remain aware of biases throughout the analysis, in order to allow for the second aim to be comprehensively explored. Given that the literature on epistemic injustice had been examined prior to conducting the meta-ethnography, examples of testimonial and hermeneutical injustice were brought to the fore. In light of these potential biases that may have impacted the analysis, the researcher presented themes for feedback to an external group of researchers, who were either conducting a meta-ethnography or had previous experience in conducting one, consulting them throughout the synthesis process. Through this, it was hoped that any potentially biased findings, for example, attributing findings to epistemic injustice where it may not have been warranted, would have been highlighted and amended. Discussion about grouped concepts took place, supporting the development of the final themes and sub-themes.

The analysis revealed three main themes: the first and second containing three sub-themes each, and the third containing two sub-themes. Two line of argument syntheses were also identified within the meta-ethnography. Coined by Noblit and Hare (1988), a line of argument synthesis reveals connections between themes, highlighting hidden concepts across papers that are unlikely to be recognised within individual articles. To ensure that the sub-themes

were evident across papers, quotes from studies that represented each of them were also retrieved from the original data extraction table. The seventh and final phase of the meta-ethnographic approach, *expressing the synthesis*, is represented in the Results section below (Noblit & Hare, 1988).

3.3 Results

Analysis of the data resulted in three main themes, consisting of a total of eight sub-themes, all of which were found to represent the articles collectively (Figure 3.3). Similarly, each sub-theme reflects the main focus of the review relating to participant's experiences of stigma surrounding their diagnosis of a psychotic disorder. Each sub-theme is explored below within the main themes, illustrated with quotes from the original articles representing the concept, as well as discussion of the relevant articles.

	Understanding Psychosis			Other's Response			Own Response	
	Lack of Understanding	Psychosis in Comparison	A Sense of Ab / Normality	Loss of Identity and Autonomy	Epistemic Injustice	Social Exclusion	Conceal and Withdraw from Society	Difficulties Within Interpersonal Relationships
Knight (2003)	✓		✓	✓			✓	
Gonzalez-Torrez (2007)	✓			✓	✓		✓	✓
Jenkins (2009)	✓		✓			✓	✓	✓
Loganathan (2011)		✓		✓		✓	✓	
Rose (2011)	✓		✓	✓	✓	✓		✓
Howe (2014)	✓	✓	✓	✓	✓		✓	✓
Pyle (2014)	✓	✓	✓	✓	✓	✓	✓	✓
Mora-Rios (2015)	✓	✓	✓	✓	✓			✓
Paul (2016)			✓			✓	✓	✓
Wood (2018)	✓	✓	✓	✓	✓	✓	✓	✓
Yen (2020)	✓	✓	✓			✓	✓	
Vyas (2021)	✓		✓	✓	✓	✓	✓	✓

***Fig* 3.3.** A visual illustration demonstrating which study contributed to which sub-theme.

3.3.1 Theme 1: Understanding Psychosis

The first theme relates to how psychosis is understood by both the participant and others, including family, friends, and others who experience the disorder. Along with these discrepancies in understanding, that are often exacerbated by the media, the theme also examines the disorder in comparison to other illnesses, as well as the sense of difference experienced by the participants with others.

1.1: Lack of Understanding

Ten papers contributed to the sub-theme *lack of understanding* (Figure 3.3). The behaviour of people with psychosis and their medication use was misattributed, with others displaying a

lack of knowledge surrounding the cause of their experiences. Participants felt they were negatively stereotyped by a variety of people, including family, friends, and mental health professionals. This negative perception was often maintained and sometimes brought on by media portrayals of people with the diagnosis.

Across the relevant articles, there was an overwhelming sense of a lack of understanding surrounding psychosis displayed by other people in the participant's lives, with one participant describing how "they'll say, is it split personality or something basic like that" (Knight, Wykes, & Hayward, 2003, p. 214). Confusing psychosis with an entirely separate illness reveals a fundamental ignorance as to what a diagnosis of psychosis generally entails. Participants also felt that as though professionals themselves did not have enough knowledge about the diagnosis in order to communicate the cause of their experiences to them, stating that "they think it's some kind of chemical imbalance in the brain…they can't explain it" (Howe, Tickle, & Brown, 2014, p. 156). Both quotes illustrate that regardless of whether someone has knowledge of what psychosis is or not, participants still feel there is an overall lack of understanding towards the illness. This was thought to derive from an absence of information regarding the nature of the diagnosis (Rose et al., 2011), leading to avoidance of both discussion and the individual with psychosis (Jenkins & Carpenter-Song, 2009; Vyas, Wood, & McPherson, 2021).

> "They never want to talk about it. They never want to discuss it. They never bring it up." (Jenkins & Carpenter-Song, 2009, p. 524)

> "It does show you just how even the informed middle classes, even you (interviewer), know about mental illness. Everybody knows very little about it…There's no information for people, is there? And also they don't like talking about it." (Rose et al., 2011, p. 198)

The avoidance of the topic by others caused feelings of bother and numbness within participants (Jenkins & Carpenter-Song, 2009; Vyas, Wood, & McPherson, 2021). For some participants, the issue lay with a lack of "open-minded[ness] towards mental health," with some South-Asian communities believing that the individual was "going coo-coo," mistakenly fearing that "they'll get it off" the participant (Vyas, Wood, & McPherson, 2021, p. 308). Others did not understand the impact of the illness on the individual, with one participant noting that their family expected them to "function as though… [they] don't have schizophrenia" (Jenkins & Carpenter-Song, 2009, p. 524). This lack of understanding regarding the impact of psychosis is further demonstrated through the casual use of symptoms as a source of amusement by "normal people", for example, "walk[ing] around with t-shirts that say 'I hear voices and they don't like you'" (Pyle & Morrison, 2014, p. 198). The diagnosis was treated as a taboo topic, with others actively avoiding discussing it, thus contributing to the absence of information and lack of knowledge amongst society (Rose et al., 2011). According to some participants, those who are viewed as "informed middle classes" (Rose et al., 2009, p. 198), as well as professionals themselves (Howe, Tickles, & Brown, 2014), do not have a complete understanding of mental illness, suggesting that true understanding may come from experience.

Behaviours and medication use as a result of the illness were also misunderstood by others, with family, friends, and mental health professionals claiming that the person with psychosis was "lazy," "overdramatic," and "trash" (Gonzalez-Torrez et al., 2007, p. 17; Yen, Huang, & Chien, 2020, p. 31). Behaviour was 'misattributed as a lack of willpower' with one participant stating that their "doctor…didn't believe what…[they] had" and instead believed that they were "asking for sick leave because…[they] didn't want to work" (Gonzalez-Torrez et al., 2007,

p. 17), demonstrating a failure to appreciate both the participant's experience of psychosis and the impact this had on them, resulting in their need for leave from work. Similar experiences were noted about the participant's use of medication (Jenkins & Carpenter-Song, 2009).

> "I removed myself from her life for months because that's where I drew the line. She said umm, I told her about somebody who was in bed for about fourteen years with chronic fatigue and she said that's because they wanted to be. And I said something about, 'well you know my psych drugs make me tired too.' Which I think they do… She said, 'Well you need to get off those!' Well I just didn't speak to her for months and months, because I thought somebody with an attitude like that, uh uh…" (Jenkins & Carpenter-Song, 2009, p. 526)

Medication use was misattributed by the participant's friend as a choice, subsequently causing the participant to withdraw from a friendship due to the lack of understanding displayed (Jenkins & Carpenter-Song, 2009). Misunderstandings were also experienced via family, where they complained that the participant could not "work to earn a living even though…[they are] physically healthy" (Yen, Huang, & Chien, 2020, p. 31). This demonstrates a fundamental lack of appreciation as to how mental illnesses can often be as severe and debilitating as a physical illness. Although much of the ignorance towards psychosis was demonstrated by others, some participants experienced being both a 'perpetrator' and 'victim' of the stigmatising attitude (Knight, Wykes, & Hayward, 2003; Wood et al., 2018; Yen, Huang, & Chien, 2020). The participant's own lack of knowledge about psychosis prior to being diagnosed accentuated self-stigma and affected feelings about their current self, with their "attitude before…cause[ing] some friction…in terms of healing" (Knight, Wykes, & Hayward, 2003, p. 214). The "friction" the participant felt suggests that the previously held beliefs were inherently negative.

Stigma towards psychosis was also demonstrated via negative stereotypes held by others that were exacerbated by the media. Negative media portrayals of people with psychosis was sometimes thought to be the only source of information society had access to, therefore, strengthening and sometimes causing negative prejudices to form (Rose et al., 2011; Pyle & Morrison, 2014). Others showed fear due to the stereotype of people with psychosis being "aggressive," (Gonzalez-Torrez et al., 2007, p. 18), "dangerous," (Wood et al., 2018, p. 8), and comparable to "serial killers" or "murderers" (Pyle & Morrison, 2014, p. 198; Yen, Huang, & Chien, 2020, p. 31). Mora-Rios, Ortega-Ortega, and Natera (2015) labelled the media as a reinforcer of negative stereotypes, adding that it was a "major source of social exclusion" (p. 704). Participants had concerns of stereotyping by others because of their diagnosis, noting that the media was "all grim and bad news and it's all the bad side of mental health" (Pyle & Morrison, 2014, p. 199).

> "It's really bad information . . . because everything you watch on television, if there's [a murder] and that the person has always suffered from [schizophrenia] for a number of years, they always seem to say that" (Howe, Tickle, & Brown, 2014, p. 155)

> "You read in the papers all the time "oh this guy just got out of hospital and he went and killed 3 people" or whatever, you know what I mean? You read about it all of the time. I mean you don't see people … a story in the paper saying, "Peter had a mental health problem for 12 months and he is all better now and he is living happily ever after and met someone and is doing a lot more with his son and doing great"…" (Pyle & Morrison, 2014, p. 199)

As illustrated in the above quote (Pyle & Morrison, 2014), participants felt there was an absence of positive portrayals in the media. They failed to represent the "normality" of people with psychosis, treating them as though they were different to others in society (Pyle & Morrison, 2014). Instead the diagnosis was especially highlighted by the media if something

negative had taken place (Gonzalez-Torrez et al., 2007; Jenkins & Carpenter-Song, 2009), implying it as the cause of the incident (Howe, Tickle, & Brown, 2014). Media was viewed as a primary source of education about psychosis, with people who "are not educated about schizophrenia" associating individual, negative events with the diagnosis as a whole (Pyle & Morrison, 2014, p. 199). Interestingly, other participants felt that even mental health professionals who should be educated about psychosis also labelled them as "certain aggressive people," grouping them because of their diagnosis and negatively labelling them as a whole (Gonzalez-Torrez et al., 2007, p. 18). This was further demonstrated by family and friends whose perception of the participant changed after their diagnosis, with one participant stating that "I've had friends that have seen me in that way, I'm a…schizophrenic so must be a murderer" (Wood et al., 2018, p. 5). Others, including family and friends, failed to recognise that people with psychosis have "run into difficulties in their life," instead viewing them as aggressive and dangerous (Pyle & Morrison, 2014, p. 198), therefore contributing to the stigma faced due to the diagnosis via an unsophisticated and inaccurate understanding of the nature and manifestation of psychosis.

1.2: Psychosis in Comparison

Six papers contributed to the sub-theme *psychosis in comparison* (Figure 3.3). Across the relevant articles, participants described how their diagnosis of psychosis, specifically schizophrenia, differed in comparison to other mental illnesses. A comparison was also made with physical illnesses, leading participants to substitute the diagnosis for another as an explanation of their symptoms to others.

Psychosis was viewed as being the “lowest class” of mental illness (Pyle & Morrison, 2014, p. 199), suggesting a hierarchy of mental health problems with different levels of stigma attached. Participants felt labels such as ‘psychosis’ and ‘schizophrenia’ were not socially acceptable terms to use and opted to state to others that they had what they felt were more acceptable diagnoses or symptoms. Supporting the view of an existing hierarchy within mental illness, schizophrenia specifically was compared to illnesses such as depression and bipolar disorder (Pyle & Morrison, 2014). This hierarchy was felt to exist not only within society external from the participants, but also within internal friendship groups where others faced depression. Bipolar disorder was downplayed as being “just” depression, leading to the idea that unlike with schizophrenia, concealment was not necessary and “you can tell anybody” you have it (Howe, Tickle, & Brown, 2014, p. 155). The stigma surrounding schizophrenia was considered to be more shameful than other diagnoses due to its distinctive nature of being “always associated with violence” (Howe, Tickle, & Brown, 2014, p. 155), as was demonstrated in the previous sub-theme *lack of understanding*.

> "Yeh, if it is people that don’t know me I will use the word ill and if it is people like yourself, medical people I will use the word psychosis and with my family just that I have been ill [...] if you use the word psychosis with someone who doesn’t know you they look at it as though you are a psychopath or something. You know what I mean, like there is something wrong with you. I feel like that word is taboo you know." (Pyle & Morrison, 2014, p. 201)
>
> "You can tell anybody you’ve got bipolar [disorder], it used to be called manic depression, they just say ‘‘oh you’re just depressed’’ . . . I think schizophrenia is a unique thing on its own, because it’s always associated with violence, which breaks my heart. It’s always associated with violence." (Howe, Tickle, & Brown, 2014, p. 155)

The above quote (Pyle & Morrison, 2014) illustrates how the participant recognises that the label “psychosis” is more specifically deployed in a medical context compared to the use of the

more generic term “ill” with others. Negative connotations are attached to the diagnosis itself, with participants believing that others conflate psychosis with psychopathy. Participants felt a label of schizophrenia allowed others to judge them as second-class citizens or different to the rest of society, in comparison to mental illnesses such as depression which was viewed as a “better” problem to have (Pyle & Morrison, 2014). For one participant, they were stigmatised within their friendship group where “most of…[their] friends were suffering from depression or manic depression” and they “felt like they thought they were better…because they were a depressive” and not “as bad” as the participant who was “a schizophrenic” (p. 199). The negative perception of schizophrenia is evident, where the diagnostic label was treated as an individual’s identity rather than an illness.

Comparisons were also made between psychosis and physical illness. Physical illnesses were generally thought to be taken more seriously by others, namely by family, in one study complaining that the participant could not work to earn a living even though they were “physically healthy” (Yen, Huang, & Chien, 2020, p. 31). Physical health was equated with the ability to function at a job, suggesting that physical illness was deemed to be more significant and debilitating than mental illness with regard to overall wellbeing and capability (Yen, Huang, & Chien, 2020). The impact of psychosis was less appreciated, leading participants to feel that the stigma surrounding it was an additional struggle to cope with on top of an already difficult experience (Pyle & Morrison, 2014). A lack of acceptance for those with mental illnesses and a wariness towards them was described, with one participant noting that others avoided associating with them because “it’s not like if a person has a physical illness…you can approach them and ask how they are” (Pyle & Morrison, 2014, p. 200). This led to feelings of upset and shame within participants, highlighting the higher levels of stigma attached to mental illness

versus physical illness. Participants also felt that there was less understanding from others as to the seriousness of mental illness due to the increase in concern shown towards those with a physical illness (Wood et al., 2018).

> "They will visit a relative who's got cancer but they don't give me any time. So they don't understand it." (Wood et al., 2018, p. 9)
>
> "I would say it has knocked my confidence. I just feel so ashamed of it and it's really upsetting because it's not something I have inflicted on myself and it would be really nice if everybody just accepted someone who has got my illness as the same as accepting someone who has got diabetes or cancer, do you know what I mean? The illness is hard to deal with anyway without having to deal with the stigma." (Pyle & Morrison, 2014, p. 202)

Physical illnesses such as "diabetes or cancer" were generally accepted by society, whereas individuals with psychosis were avoided and viewed as unapproachable, leading to feelings of upset and shame (Pyle & Morrison, 2014, p. 202). As a result of the difference in response to illnesses, participants chose to state that they had something they found to be "more acceptable" in discussion with others, such as "some sort of an allergy" (Loganathan & Murthy, 2011, p. 573) or being "sick with nerves" (Mora-Rios, Ortega-Ortega, & Natera, 2015, p. 701). For some participants, they experienced insulting language such as "crazy" in reference to their illness, leading to negative feelings and a response of verbal and physical aggression for some (Mora-Rios, Ortega-Ortega, & Natera, 2015, pp. 702-703). One participant stated that they told a friend "you can call me hunchback…but that's it, don't call me crazy ever again, because I won't put up with that" (Mora-Rios, Ortega-Ortega, & Natera, 2015, p. 703). The term "crazy" was felt to be intolerable, more so than having a physical defect negatively acknowledged by others, further demonstrating the discrepancy between stigma of mental illnesses and physical illnesses.

1.3: A Sense of Ab/Normality

Ten papers contributed to the sub-theme *a sense of ab/normality* (Figure 3.3). Participants were made to feel abnormal by others, sensing a difference between themselves and mainstream society. However, a sense of solidarity and positive social inclusion occurred with peers who share similar experiences and diagnoses. These groups were also key to providing information about the diagnosis, allowing the participant to understand their experiences.

One of the most common themes throughout the papers was participants with psychosis sensing they were "extremely different" to others, either through self-stigma or negative stereotypes, and feeling they were not normal (Knight, Wykes, & Hayward, 2003). This sentiment was echoed by several participants who stated that they felt "unacceptable" to others, worried that they would "never be normal again" (Knight, Wykes, & Hayward, 2003, p. 216), believed that they "never fit in and…never belong[ed]" (Jenkins & Carpenter-Song, 2009, p. 525), and sensed they were "different from normal people" (Yen, Huang, & Chien, 2020, p. 31). This induced negative feelings of worry, fear, and shame, as well as uncertainties about the future (Mora-Rios, Ortega-Ortega, & Natera, 2015). Participants felt there was an irreversible shift in life once they received a diagnosis of psychosis, discussing their life events in terms of before and after (Knight, Wykes, & Hayward, 2003). This shift highlighted functional deterioration as a result of psychosis, where "before" they were "normal" and "could go to work" and "could live…life" (Knight, Wykes, & Hayward, 2003, p. 216). Some participants stated they were "out of place" with the rest of society or "living in a separate world" (Mora-Rios, Ortega-Ortega, & Natera, 2015, p. 701), which for another participant resulted from the

inferiority they felt compared to “ordinary people” based on their difficulties in academia and work (Yen, Huang, & Chien, 2020, p. 32).

> "I don’t know, they [people with psychosis] are not seen as equals and having the same rights as normal people…I still feel like a second class citizen. I don’t feel accepted" (Pyle & Morrison, 2014, p. 199)
>
> “Just really critical and yeah, really aware that the person might not think I am normal, or they might have a bad judgement” (Wood et al., 2018, p. 7)

Wood et al. (2018) note how participants held a self-critical viewpoint, internalising negative labels and being overly concerned about other’s perceptions of them. Self-stigma also had an impact on confidence and self-worth, increasing feelings of inferiority compared to others. Being “different” and “in hospital” negatively affected the way participants felt about themselves as the admission process highlighted differences between them and others in society (Wood et al., 2018, p. 7). Any semblance of being normal was impacted by negative responses from others, making it difficult to resist self-stigma (Howe, Tickle, & Brown, 2014). The lack of acceptance for people with psychosis restricted their opportunities for social interaction, further emphasising their sense of difference (Pyle & Morrison, 2014). For one participant, however, the desire still remained for inclusion in mainstream society (Knight, Wykes, & Hayward, 2003). They described putting themselves “on a spectrum” to make themselves “feel comparable and acceptable to society,” expressing that really they were “part of the same rail but on a different part of it” (Knight, Wykes, & Hayward, 2003, p. 217). This suggests that for some, viewing the diagnosis as reflective of a spectrum that exists for all of society (rather than a cut-off point between normality and abnormality) was helping in managing the impact of stigma.

Where participants found it difficult to find acceptance within mainstream society, the opposite was found in groups of people that had also experienced psychosis. Common experience was associated with understanding and tolerance, with people who have been diagnosed with mental illnesses experienced as “more friendly, more compassionate” (Knight, Wykes, & Hayward, 2003, p. 217). Separation was felt from groups without psychosis, whereas “solidarity” was felt with groups with psychosis, demonstrating a positive group identity between those who shared similar experiences. Friendships were easier to form due to the absence of discrimination from service users, allowing the participant to feel ‘safe’ enough to not have to conceal their diagnosis (Rose et al., 2011). As one participant stated, “people who are ill…and know that I am ill, do not avoid me, but those who are not ill but know that I am ill, do avoid me” (Rose et al., 2011, p. 200).

> "My friends that I meet at the voices group, it's weird that voices group because they are all about as mental as each other but there's a solidarity in people" (Knight, Wykes, & Hayward, 2003, p. 216)

> "I use to be ashamed. I use to be sitting up all night crying because I couldn’t handle it. But now I’m on meds I’m seeing a lot more people who experience it too and I realise we might be a bit eccentric and a bit different but we still breathe and eat, we cry when you hurt us, we laugh when you make us laugh, we are still normal but we just experience some unusual symptoms" (Pyle & Morrison, 2014, p. 202)

This illustrates how there is “a solidarity” between people who are “as mental as each other,” highlighting that shared experiences allow inclusion for participants (Knight, Wykes, & Hayward, 2003, p. 216). Unlike the abnormality felt within mainstream society, participants realised that even though they “experience some unusual symptoms,” they are “still normal” people who feel and act the way that others do (Pyle & Morrison, 2014, p. 202). Negative feelings such as shame and hopelessness were also discarded once solidarity was found with

peers (Pyle & Morrison, 2014). Significant value was placed on the ability to have trustworthy others that "know what you're going through" to share experiences with (Vyas, Wood, & McPherson, 2021, p. 309). Another benefit of this positive relationship with peers was the understanding they were able to gain about their diagnosis. For one participant, the absence of information surrounding schizophrenia caused them to turn to others with a shared experience, where they felt they "related to some of those things more so than [to] what doctors have said" (Howe, Tickle, & Brown, 2014, p. 156). More was learned through lived experience than medical professionals, stressing the importance of peer support as a "source of empowerment" and a useful tool for "normalising information" (Pyle & Morrison, 2014, p. 202).

3.3.2 Theme 2: Other's Response

The second theme contains an overarching sense of a power imbalance between people with psychosis and those without, exploring the overwhelmingly negative response from others towards the disorder. This response includes infantilisation of the participants, injustices of a testimonial and hermeneutical nature taking place, as well as rejection and avoidance by others.

2.1: Loss of Identity and Autonomy

Nine papers contributed to the sub-theme *loss of identity and autonomy* (Figure 3.3). Within the following sub-theme, participants felt they were struggling with their identity, either through their own self-stigma or perceived stigma by others. Being over-protected and infantilised by family members with good intentions was also found to be harmful to their

autonomy, as well as abuses of power displayed by both family members and medical professionals.

Participants found themselves stripped of their identity by society, including by family, friends, and professionals, once people knew about their diagnosis of psychosis. They felt doctors “don’t see you as a person that’s…acceptable” and even family and friends viewed them as “dangerous and unacceptable” (Knight, Wykes, & Hayward, 2003, p. 214). Participants also described the damaging impact on the way they view their own identity as a result of the stigma connected with the diagnosis (Vyas, Wood, & McPherson, 2021). The identity of “a schizophrenic” and someone who was “disabled” was negatively adopted, with participants feeling like “aspects of…[themselves] are just degrading,” with “reality…looking bleak” (Vyas, Wood, & McPherson, 2021, p. 307). According to Vyas, Wood, & McPherson (2021), this identity struggle results in a “critical self-view, shame, and distress” for participants (p. 306).

> "We’re not accepted when we go back to work, no matter that you do the job. They don’t treat you as an equal, they’re always a bit wary of you, [break] from my experience" (Knight, Wykes, & Hayward, 2003, p. 214)
>
> "When the doctor comes here, she always turns to my social worker to ask him. They’re treating me like I’m subnormal because I think they saw me as not being able to understand" (Howe, Tickle, & Brown, 2014, p. 156)
>
> “I don’t like or know who I am now…I feel like I’ve hit rock bottom…I don’t think I can get any lower” (Vyas, Wood, & McPherson, 2021, p. 307)

Negative stereotypes of people with psychosis led to discrimination within the workplace, with participants not being treated equally to others, regardless of their ability to fulfil the responsibilities of their job (Knight, Wykes, & Hayward, 2003). This also extended to other situations outside of the workplace, where professionals treated the participant as though they are incompetent and unable to speak on behalf of themselves (Howe, Tickle, & Brown,

2014). Wood et al. (2018) also noted how participants were viewed as their illness within an inpatient setting, and not as a person. Admission to an institution increased negative stereotyping in itself, not only by society viewing the person as "crazy" for being "in a mental hospital," but also by professionals themselves (Wood et al., 2018, p. 7). Participants were dehumanised on account of their diagnosis and became their illness to others rather than a person. Doctors "didn't talk" or "pretended not to see" participants "before," however, this changed once they became "more stable and began outpatient visits," where the professionals "now…say hello" (Mora-Rios, Ortega-Ortega, & Natera, 2015, p. 702). This was further demonstrated by the impression that mental health professionals were forcing patients into a passive role via medication, treating them as an anomaly that needed to "conform" to society and be kept under control (Mora-Rios, Ortega-Ortega, & Natera, 2015, p. 704).

Participants were also kept in passive roles through infantilisation and loss of autonomy by family and friends (Pyle & Morrison, 2014). Overprotection came as a result of fear surrounding potential relapse, restricting growth and individuality within participants (Gonzalez-Torrez et al., 2007). According to Rose et al., (2011), relatives chose to conceal things from the participants that they deemed to be too stressful or difficult for them to handle. Although this protection was meant with good intentions in some cases, it was experienced negatively by the individual (Rose et al., 2011; Mora-Rios, Ortega-Ortega, & Natera, 2015). Treating the participant in this way "contributed to their marginalisation and invisibility" (Mora-Rios, Ortega-Ortega, & Natera, 2015, p. 702) and was a common form of discrimination (Wood et al., 2018).

> "Well, my closest relatives like to decide for me, all the time. Sometimes it's almost like I was declared incapable of managing my own affairs" (Rose et al., 2011, p. 198)

> "There's a feeling that I'm not fully adult, since I can't rent a room, even a modest one, because it wouldn't be certain that I could pay the rent and live independent of my family" (Mora-Rios, Ortega-Ortega, & Natera, 2015, p. 702)

The first quote demonstrates the more classic theme of infantilisation that was apparent across the relevant articles (Rose et al., 2011), however, the second quote provided another dimension of how participants can be made to feel like a child through structural inequalities (Mora-Rios, Ortega-Ortega, & Natera, 2015). The loss of opportunities that stem from the stigma associated with psychosis can cause a feeling of childishness within participants. According to Mora-Rios, Ortega-Ortega, and Natera (2015), social inequality has an impact on opportunities such as jobs, housing, and education, keeping people with psychosis "economically and emotionally dependent on family" (p. 702). Changes in behaviour, for example, "getting up early in the morning," were noticed by family and interpreted as relative to the diagnosis (Gonzalez-Torrez et al., 2007, p. 18). Consequently, family members believed that the person was changing and "did everything" for them, believing them to be incapable of looking after themselves and doing "anything on…[their] own" (Gonzalez-Torrez et al., 2007, p. 18). A general disregard as to the participant's wants and needs was demonstrated through such overprotection and infantilisation (Rose et al., 2011).

Loss of autonomy was not only experienced though infantilisation, but also through what is arguably a more severe abuse of power by others, where women were the primary target, and professionals and family members adopted the role of abuser. Due to the genetic element of psychosis having a potentially hereditary nature, some women's choice to have biological child was removed by others (Gonzalez-Torrez et al., 2007). The responses provided by mental health professionals to the idea that a woman with psychosis wanted a child ranged from "no,

that's not possible, don't even think of it" (Gonzalez-Torrez et al., 2007, p. 19) to "they would turn out the same as…[you]…better to have surgery," and "what would…[you] do with a child, with…[your] illness" (Mora-Rios, Ortega-Ortega & Natera, 2015, p. 702). There are even reports that professionals and families went so far as to engage in illegal and immoral practices, severely violating the power they held within the doctor-patient relationship.

> "My mother had my (fallopian) tubes tied. I was under legal age; they did it to me when I was 17" (Gonzalez-Torrez et al., 2007, p. 19)
>
> "It happened in the hospital. I don't want to mention the ward. I was 'on remote control' because of the medication, when somebody from the medical staff, I don't know if he was a psychiatrist or a psychologist, asked to see me in his office. He kissed me and he touched me and he asked me to masturbate myself. I was so submissive because of the medication that I did it" (Rose et al., 2011, p. 198)

Both of the above quotes illustrate an abuse of power. In both incidents, professionals removed the participant's bodily autonomy from their own control, making harmful choices for them. Rose et al. (2011) also notes that sexual abuse of participants was not limited to medical professionals, but also occurred via family, friends, partner, and the police. For one participant, they were abandoned by their husband due to their diagnosis and were forced to have an abortion by their parents-in-law due to the notion that "the children will also be mentally ill" (Loganathan & Murthy, 2011, p. 573). In this particular instance, Loganathan & Murthy (2011) note that it is a cultural expectation for a woman of Indian descent to have a child early in the marriage. Therefore, the participant in this case has not only experienced an abuse of power via family but has also been unwillingly stripped of the 'identity' that is expected of her within her community.

2.2: Epistemic Injustice

Seven papers contributed to the sub-theme *epistemic injustice*[6] (Figure 3.3). For this sub-theme, participants provided examples of times they felt they were dismissed or not believed by professionals due to their experience of psychosis. The dominant medical approach was described across articles, with individuals feeling like passive participants within the information-receiving and decision-making process.

Within a mental health setting, participants described how professionals frequently discredited their testimonies when attempting to report their experiences (Gonzalez-Torrez et al., 2007; Pyle & Morrison, 2014; Wood et al., 2018). For example, this was demonstrated in cases where the severity of symptoms that a participant was experiencing was downplayed (Gonzalez-Torrez et al., 2007) and where there was a lack of belief in one participant's use of substances (Pyle & Morrison, 2014). This dismissal extended outside of services to wider society, with some participants feeling invalidated by social workers and support agencies due to their illness (Mora-Rios, Ortega-Ortega, & Natera, 2015).

> "Until they discovered what I have (kidney stones), they didn't listen to me, it was all due to nerves, whenever I said my stomach ached, this side ached, it was nerves..." (Gonzalez-Torrez et al., 2007, p. 18)

> "A while ago I had to go to that family violence agency, and it was the same as with the women's agency, no support. I didn't want to tell them, but they ask, "Do you have any disabilities?" I told them, yes, actually, this is my disability, and they tell me, "Oh, it must have started with that, it's all because of your illness, so we can't help you." (Mora-Rios, Ortega-Ortega, & Natera, 2015, p. 705)

[6] For detailed information on epistemic injustice, see definitions within Chapter 2 of this thesis.

In the latter quote, as a direct result of dismissing the participant's testimony of abuse, the agency also denied their legal rights as a citizen (Mora-Rios, Ortega-Ortega, & Natera, 2015). In a medical sense, individuals were denied the medical attention they required as patients (Gonzalez-Torrez et al., 2007). The occurrence of testimonial injustice has negative ramifications not only for the individual (e.g. missed diagnoses), but also for the stigma of a diagnosis of psychosis as a whole. People with psychosis are viewed through the lens of their diagnosis, and treated differently to those without such a diagnosis, as demonstrated through specific examples of testimonial injustice, more broadly supporting the previous sub-theme *loss of identity and autonomy*.

The second kind of epistemic injustice that occurred, hermeneutical injustice, was made apparent through the lack of information provided to participants about their diagnosis, thus not allowing them to fully understand what they were experiencing (Howe, Tickle, & Brown, 2014). This lack of understanding led to feelings of being passive rather than active parties within the doctor-patient relationship (Gonzalez-Torrez et al., 2007). Participants also felt that acceptance of what they were experiencing may have occurred had more information been provided during the initial period of contact with the professional (Howe, Tickle, & Brown, 2014).

> "They ran all kinds of tests. They left me in hospital…they put me in a cubicle, they gave me serum and they didn't tell me anything. The next day they allowed me to leave the hospital. They didn't explain what I had or what I no longer had." (Gonzalez-Torrez et al., 2007, p. 18)

> "Maybe if I'd have had it explained better to me in the beginning I might have accepted it better, and I think that would have helped me ...a great deal." (Howe, Tickle, & Brown, 2014, p. 156)

Being considered an equal in the doctor-patient relationship, as well as being kept informed of each step in the diagnosis / recovery process, is an important part of allowing understanding and acceptance to take place for people with psychosis (Howe, Tickle, & Brown, 2014). The language used in the above quote (Gonzalez-Torrez et al., 2007) illustrates the lack of power and helplessness felt by the participant during their time in hospital. Rather than being an active party throughout the process, they describe how they were "left" in hospital, "put" in a cubicle, and "allowed" to leave the next day. They also note the lack of explanation provided by the hospital, leading to them not understanding what they "had or… no longer had" (p. 18). Although some participants felt the amount of information they received was inadequate, others felt as though the focus on the medical approach alone was problematic in itself.

The medical approach dominated the explanation of participant's experiences, with a heavy focus on diagnosis and "I'll give you a tablet, I'll give you medication" by medical professionals as a means of treatment (Wood et al., 2018, p. 6). Participants noted the uncertainty they felt around their diagnosis, due to it being labelled as the more generic term of psychosis rather than schizophrenia (Howe, Tickle, & Brown, 2014). Withholding information about a diagnosis from a patient did not allow them the opportunity to understand their experience or look elsewhere for information on it. However, labels of psychosis and schizophrenia felt inherently negative to participants, suggesting that the dominant medical approach maintains stigma against people with psychosis due to the diagnosis itself (Wood et al., 2018). As another form of hermeneutical injustice, providing only one way of understanding, may not allow space for some people with psychosis to make sense of their experience, discounting factors such as ethnicity, culture, or religion (Vyas, Wood, & McPherson, 2021). One participant described how ward staff would tell them "it's all in your head," which led to feelings of professionals

themselves not fully understanding the diagnosis in the way the participant did (Wood et al., 2018, p. 9). Others felt that medication was offered too quickly and that professionals used this as a first resort "rather than sitting and talk(ing)" to them (Wood et al., 2018, p. 6).

> "Nobody really explained to me properly that I'd got schizophrenia...I had one of those [care programme approach reviews] and with the paperwork that got mailed through...I noticed it on there...for years I've been told that it was psychosis." (Howe, Tickle, & Brown, 2014, p. 155)

> "All of it [medical diagnosis] is so wrong. Even psychosis is wrong because it's got psycho in it. Paranoid schizophrenic . . . there is no good connotations anyway." (Wood et al., 2018, p. 6)

> "…I think it's something that people don't really pick up on in services. It's kind of mainly focusing on what voices you're hearing or what you're feeling. I think other factors aren't paid attention to. I think they'll look to things like childhood trauma, things like bullying. I don't think culture is off the bat, considered and therefore reinforced…Just be a bit more careful in your approach." (Vyas, Wood, & McPherson, 2021, pp. 307-308)

The second issue with a dominant medical approach is outlined by Rose et al. (2011). One of the negative symptoms of a diagnosis of psychosis is listed as 'social withdrawal,' medicalising a behaviour that specifically relates to the illness. However, quotes from participants throughout the papers, for example, as discussed within the themes *Other's Response* and *Own Response*, suggests there is a legitimate reason for participants to avoid society. Anticipated negative consequences, whether by personal experience via reaction from others or perceived stigma of the diagnosis, validates a response of socially withdrawing. Rose et al.'s (2011) statement on social withdrawal supports the concept of hermeneutical injustice taking place, suggesting that certain behaviours by people with psychosis are medicalised as 'negative symptoms' due to this being the leading approach to understanding the illness, regardless of whether there are other plausible ways of making sense of these experiences.

2.3: Social Exclusion

Eight papers contributed to the sub-theme *social exclusion* (Figure 3.3). Across the relevant articles, participants provided descriptions of and reasons for why they may be avoided by others, as well as descriptions of how they manage this exclusion, and how it affects their emotional wellbeing. In some cases, participants were outright rejected rather than avoided, usually by romantic interests and within the work force.

For many participants across the relevant papers, avoidance from family and friends following a diagnosis of psychosis was a common theme. Participants found themselves excluded by others, under the belief that their diagnosis and the subsequent behaviours associated with the illness were a cause of shame and embarrassment (Jenkins & Carpenter-Song, 2009). One participant felt that avoidance may be a "defence mechanism" for some family members, stating that "they might see something in themselves that might disturb them…they'd rather avoid you" (Jenkins & Carpenter-Song, 2009, p. 524), whilst others thought that family may just be unsure of how to approach the topic (Pyle & Morrison, 2014). Viewed as a close-minded stance within South Asian communities, some participants described a belief where "a person could 'catch' or be infected by psychosis," resulting in situations where they were "othered within the community to avoid contagion" and "relatives…literally got up and moved a couple of spaces away" (Vyas, Wood, & McPherson, 2021, p. 308). Avoidance commonly occurred within interpersonal relationships, with loss of friendships being one of the more common responses to the diagnosis (Jenkins & Carpenter-Song, 2009; Rose et al., 2011; Pyle & Morrison, 2014; Yen, Huang, & Chien, 2020).

> "I have not, um, there's a lot of people since this happened that I used to work with who have never called to see what happened, what's gone on, people that I

> thought were my real friends. So yeah, I'd have to say yes. (Uh hm.) Some people have avoided me. And it's not my imagination. It's the real thing" (Jenkins & Carpenter-Song, 2009, p. 525)
>
> "Yes. All my friends turned away of me. They start to avoid contacts with me. They just stopped to communicate with me, broke the relations. My illness was strong disadvantage for me" (Rose et al., 2011, p. 197)
>
> "My friends were all willing to interact with me before I was diagnosed with schizophrenia. However, after I became schizophrenic, no one wanted to interact with me." (Yen, Huang, & Chien, 2020, p. 31)

These loss of relationships caused significant amounts of emotional distress for some participants, inducing feelings of "hurt," "upset" (Jenkins & Carpenter-Song, 2009, p. 525), and "numb[ness]" (Vyas, Wood, & McPherson, 2021, p. 308). Others tried to find ways of coping with the stigma and avoidance by "get[ting] on with it, and not…get all bummed out" (Jenkins & Carpenter-Song, 2009, p. 525). The shame and exclusion felt hurtful due to the belief that others could not see that the participant had "come a long ways from what….[they] used to be," causing them to "seem like…[they were] still the same way" that others thought they were (Jenkins & Carpenter-Song, 2009, p. 524). One participant gave others the benefit of the doubt as to the reason for exclusion, stating that "sometimes it's hard to tell why you're being excluded…so you have to be careful about these things" (Rose et al., 2011, p. 197). Most participants were ignored as if they "don't exist" (Wood et al., 2018, p. 6), however, one described how others "either…don't want to be around you or (it's) where you can't even have any privacy" and "they mention your name all the time in their conversation" (Jenkins & Carpenter-Song, 2009, p. 524). This highlights two of the common responses of others towards a diagnosis, as mentioned in the previous sub-theme *loss of identity and autonomy*, where participants are either avoided or infantilised.

One of the forms avoidance took to present itself was via rejection. For women, the consequence of their diagnosis was divorce, separation from their child, and rejection by a previously arranged marriage (Loganathan & Murthy, 2011; Rose et al., 2011). As stated in their study (Loganathan & Murthy, 2011), it is a cultural expectation for women in India to get married and have children at a young age, however, one participant stated that they were told "not to get married because of…[their] illness" (p. 572). Participants also felt themselves that they had limited romantic prospects, expecting rejection from potential partners, and therefore, experiencing both perceived and actual rejection due to the view of them as being inadequate by others (Rose et al., 2011; Paul, 2016).

> "Once, an aunt of mine tried to set me up with somebody. As soon as he and his family met me they told me that I was not good enough for their son and that hurt me very much" (Rose et al., 2011, p. 200)

> "Due to the stigmatization, it is very difficult for me to find a job…Patients may not even be given a chance to be hired on probation and may be directly rejected" (Yen, Huang, & Chien, 2020, p. 31)

Following disclosure of a diagnosis of psychosis, the experience of rejection led to isolation (Rose et al., 2011) and feelings of hurt (Pyle & Morrison, 2014). Rejection was not only experienced via romantic partners, but also via friendships. One participant noted they "had a lot of rejection from friends at university" and that on one occasion a friend who had written to them "just didn't write back" once they knew of the participant's involvement with a mental health charity (Pyle & Morrison, 2014, p. 201). According to Paul (2016), people with a diagnosis of psychosis who did not have support groups were more likely to experience to loneliness and social exclusion, supporting the benefits mentioned by other participants in the previous sub-theme *a sense of ab/normality*. The negative impact of stigmatisation included

the loss of opportunities for “patients” (Yen, Huang & Chien, 2020, p. 31). Rejection was experienced in the work force, where one participant noted that some people may not be given a chance based on their skills or qualifications, but rather “be directly rejected” due to their diagnosis (Yen, Huang & Chien, 2020, p. 31). This form of rejection is based in structural inequalities and is just one of the effects of the broader community’s stigmatisation.

3.3.3 Theme 3: Own Response

The third and final theme represents the participant’s own response to the disorder, typically stemming from the negative response of others. This includes concealment of the diagnosis and withdrawing from social contact to avoid the associated stigma. Difficulties with family, friends, and partners were also described, with a focus on the loss, maintenance, and formation of these relationships. A potential third sub-theme was identified that examined the participant’s acceptance of their diagnosis, however, due to the minimal amount of papers this was identified in (five out of twelve), this sub-theme was removed from the analysis and will be explored in the discussion.

3.1: Conceal and Withdraw from Society

Ten papers contributed to the sub-theme *conceal and withdraw from society* (Figure 3.3). Participants concealed their diagnosis for several reasons, including concerns about hostility and stigma from society. The diagnosis was also hidden for fear that they may be considered frightening to others due to the sense of difference between them and the lack of understanding from others. To cope with the stigma, participants felt that it was not enough to just conceal the diagnosis, but also that withdrawing from society was necessary.

Concealment of diagnosis was a significant theme across the relevant papers, with many participants fearing that disclosing this information to the public would lead to hostility and negative behaviour towards them. Worries surrounding others thinking of them as a "f**king [break] nutter" (Knight, Wykes, & Hayward, 2003, p. 217), or that they "won't be treated the same" (Vyas, Wood, & McPherson, 2021, p. 306). Participants perceived the way others communicated with them as "strange" or "scary," feeling that they could be a "target of vulnerability" based on their condition (Jenkins & Carpenter-Song, 2009, p. 523). Expected responses by others were described as "really cruel" where people may "talk about you" and "downgrade you" (Jenkins & Carpenter-Song, 2009, p. 525), "judgement" (Pyle & Morrison, 2014, p. 202), and fear of being labelled with negative stereotypes, leading to avoidance, such as, "everyone's going to think I am crazy and like no one is going to talk to me" (Vyas, Wood, & McPherson, 2021, p. 306). According to Paul (2016), the constant expectation of discrimination was an ongoing stressor for people with a diagnosis of psychosis, causing emotional distress such as anxiety, low mood, and low self-esteem (Pyle & Morrison, 2014).

> "Well, the nurses, the nursing system, the whole, I'm not telling my problems to my nurses because of stigma, it's not the only reason but it's definitely an element" (Wood et al., 2018, p. 9)

> "It's better not to say anything, peoples won't say nothing to you then, they won't judge you then" (Vyas, Wood, & McPherson, 2021, p. 306)

Participants felt it necessary to 'silence' their experiences due to fear of judgement, from both professionals as well as more widely in society (Wood et al., 2018). Concealment was also deemed essential in order to not "hamper…[their] job or opportunity for promotion," suggesting that a diagnosis of psychosis may have a significant impact on an individual's work situation (Loganathan & Murthy, 2011, p. 575). This sentiment was echoed by another

participant, who stated that many times they had to “lie and cover up about…[their] inability to attend work, which is mostly due to…[their] mental illness, stating it as a family problem” (Paul, 2016, p. 11). For some, their behaviour changed in order to hide their illness, for example, by “avoid[ing] places where people might think…[they are] unemployed [due to stigma],” such as going to the gym earlier in the morning (Wood et al., 2018, p. 7). Participants tried to “not make it obvious” and “carry…[themselves] in a proper way not to let people know there’s something wrong with…[them] (Jenkins & Carpenter-Song, 2009, p. 523). This also extended to professionals, where stigma prevented some people from disclosing (Wood et al., 2018) , as well as initially avoiding help-seeking due to fear of the negative associations with a diagnosis of psychosis (Howe, Tickle, & Brown, 2014).

The majority of reasons provided for concealing the diagnosis was due to fear of hostility from others, however, for some participants, they were more concerned about others potentially fearing them and recognising that “something ain’t right” with them if they happen to not “have a good day” (Jenkins & Carpenter-Song, 2009, p. 525). Worries surrounding medication use also emerged, with participants fearing that others “might back away.” There was an expectation of “most people…[being] frightened about it,” even if the participant “explained what it was and why…[they] take it (Jenkins & Carpenter-Song, 2009, p. 525). Alongside concerns of being considered frightening by others, participants also explained how they felt others did not understand the diagnosis, and viewed themselves as different to others, contributing to both the stigma towards the person with psychosis and their concealment of their experiences.

> "I'm at a stage where I would like to tell anybody OK, but [break] it's not understood by people" (Knight, Wykes, & Hayward, 2003, p. 217)

> "I always feel like the odd one out and like they are going to find out that I am not normal. I go for so long but then I just think they are going to find me out" (Pyle & Morrison, 2014, p. 201)

Participants noted a sense of difference with others leading to concealment, where they worried about others finding out they are "not normal" (Pyle & Morrison, 2014, p. 201). They felt it was necessary to "try to keep it a secret about…[their] mental illness when…[they were] in the normal outside world" (Knight, Wykes, & Hayward, 2003, p. 218), suggesting that participants felt themselves to be 'abnormal' (Pyle & Morrison, 2014), living in a separate "world" to others who did not have a diagnosis. This led to treatment of the diagnosis as a secret that they feared others may find out about (Pyle & Morrison, 2014). Some participants found it difficult to tell others, with one stating that their diagnosis was "not so easy to…explain to people" (Knight, Wykes, & Hayward, 2003, p. 217). The lack of understanding by others, as described in the quote above (Knight, Wykes, & Hayward, 2003) and in a previous sub-theme, led to concealment even when some participants felt they had reached a point they were ready to discuss their illness.

Alongside concealment of the diagnosis, withdrawal from the public was also felt necessary to cope with the stigma of the illness. Participants chose to "stay in…[their] house" (Knight, Wykes, & Hayward, 2003, p. 217), and "stay self-contained and escape from the public," suggesting a feeling of being trapped or under public scrutiny when around others (Yen, Huang, & Chien, 2020, p. 32). Alienation from social interactions may potentially have negative consequences in the long run by reinforcing the feeling of exclusion. According to Yen, Huang, & Chien (2020), concerns regarded the "strange attitude" of others towards them, their inability to "express opinions during communication," and the occurrence of their own

"strange deeds during interaction" with the public (p. 32). Participants wanted to avoid any conversation surrounding the illness (Wood et al., 2018), and the sense of difference they felt with others not only led to concealment, but also withdrawal (Gonzalez-Torrez et al., 2007). Society was described as "all like sheep" by one participant, who was bothered with how people with psychosis "stand out" because "you can tell their mental traits (Gonzalez-Torrez et al., 2007, p. 19).

> "Yeah, I just keep to myself and avoid socializing in general. I was definitely keeping myself to myself and keeping quiet, and I knew people were going to ask me about it [mental health] so I just avoided it" (Wood et al., 2018, p. 7)

> "I kind of ostracised myself from people . . . I don't want them to see me differently . . . being by myself was easier" (Vyas, Wood, & McPherson, 2021, p. 309)

For many of the males in one study, the diagnosis more commonly affected them in the workplace, with low self-esteem and stigma causing "people to avoid…[them] and…[them to] avoid people" (Loganathan & Murthy, 2011, p. 575). Participants described withdrawing and self-isolating due to the emotional distress as a result of public stigma (Vyas, Wood, & McPherson, 2021). Concern surrounded anxiety about how they would be perceived in society, with self-isolation feeling protective (Vyas, Wood, & McPherson, 2021), supporting the notion that being amongst the public was associated with feeling trapped for some participants (Yen, Huang, & Chien, 2020). Within inpatient settings, participants expressed being "worried about people around" them, which "added to…[their] anxiety" and caused them to "eat quickly so…[they] could just get to…[their] room" (Wood et al., 2018, p. 7). For another participant, they described how when they are in their "room and…haven't been out, [the] stigma goes away" (Wood et al., 2018, p. 9), suggesting that the stigma they feel originates primarily from others (rather than internalised self-stigma).

3.2: Difficulties Within Interpersonal Relationships

Nine papers contributed to the sub-theme *difficulties within interpersonal relationships* (Figure 3.3). Concealing and withdrawing was common – both from society and also within interpersonal relationships. The following sub-theme concerns the difficulties participants have with maintaining these relationships in particular, as well as the issue with forming new relationships. Participants described how family shame keeps their illness hidden, as well as how their own fear of loss and rejection from friends and partners forces them to withdraw and self-isolate.

Participants felt they needed to be careful about who to disclose to, in some cases choosing only trusted people like "immediate family and professionals" to tell in order to avoid the risk of stigma (Wood et al., 2018, p. 9). This selective concealment led to one participant no longer feeling as if the diagnosis was "a secret," but rather that it was just "an illness that's a little painful…and difficult" (Mora-Rios, Ortega-Ortega, & Natera, 2015, p. 705). Disclosing to others outside of the family was discouraged due to shame and embarrassment felt about the diagnosis on the family's part (Wood et al., 2018), contributing to the "silencing and stigmatisation" of participants (Vyas, Wood, & McPherson, 2021, p. 306). Shame felt by family led to participants "know[ing] not to talk about it" and stating that "it's a bad thing to tell people" (Vyas, Wood, & McPherson, 2021, p. 306). Another significant issue surrounding the diagnosis was fear of the effect this would have on relationships with family and friends, with one participant not wanting to "jeopardise or spoil" their relationship with their stepsons by disclosing their diagnosis of schizophrenia (Howe, Tickle, & Brown, 2014, p. 155). Some participants withdrew from family to avoid any chance of abuse (Paul, 2016). As mentioned in

several of the previous sub-themes, stigma as a result of the diagnosis limited opportunities for people with psychosis, causing financial dependence on family in several cases, leaving no escape from the abuse and the only option of "avoid[ing] meeting…[them] as much as possible so that…[they don't] get any chance to abuse" the participant (Paul, 2016, p. 9).

> "I feel like with my family there was always that need to make sure everything looked good . . . If something came up about my mental health, my family wouldn't tell people which kind of made it worse . . . it's a lot about pride, family pride" (Vyas, Wood, & McPherson, 2021, p. 306)

> "I've had mental health problems then you worry that they aren't going to like you so I don't have friends because of that really. Great big gap in my life really, I don't have any friends" (Wood et al., 2018, p. 9)

Withdrawal and the subsequent loss of friendships / relationships were common occurrences once a person was diagnosed (Wood et al., 2018), with one participant stating, "I don't have any friends because I left them all" (Gonzalez-Torrez et al., 2007, p. 19). According to Rose et al. (2011), a lack of confidence and embarrassment about the illness led participants to avoid social situations, with concerns surrounding the ability to maintain friends causing friendships to drift (Paul, 2016). In a Catch-22 situation, the diagnosis was hidden to try to maintain friendships in case of stigma, however this concealment prevented relational closeness, leading to participants withdrawing and self-isolating (Howe, Tickle, & Brown, 2014). As described by one participant, "I don't want to be in a position where people get to know me…nobody likes rejection" (Howe, Tickle, & Brown, 2014, p. 156). According to Wood et al. (2011), there were concerns of being disliked once others knew about the illness, leading to a lack of friendships that caused participants to feel they had a "great big gap" in their lives (p. 9). This is again an example of a Catch-22 situation, where individuals with psychosis have a desire to connect with others, however, the fear of stigma and rejection holds them back from

doing this, leading to withdrawal and emotional distress. Regardless of whether or not the participant maintains, loses, or forms friendships, the negative emotions remain even when trying to circumvent this.

The most common fear of rejection was from romantic partners, with participants concerned about their ability to get into a relationship (Rose et al., 2011) or get married (Paul, 2016). As illustrated in the quote above (Jenkins & Carpenter-Song, 2009), there was again a sense of being 'abnormal' or different to others due to the illness, leading to reluctance to reveal the diagnosis due to fear of rejection. One of the key issues for one participant surrounded their lifelong use of medication, leading them to feel that this would be "complicated" to discuss within a relationship, possibly ending with the person becoming "frightened and disappear[ing]" (Rose et al., 2011, p. 200). In this case, the illness was viewed as a lifelong "problem" where disclosure would be necessary in a relationship, and the common expectation of fear from others supported the negative stereotype of people with psychosis as being 'frightening' (Rose et al., 2011).

> "I think that there's really, only, not much choice in the way of, you know, dating people because I think if you're a girl that has mental problems, or whatever, you know, well at least I know, normal guys don't look at me twice" (Jenkins & Carpenter-Song, 2009, p. 524)

> "I avoid from starting a personal relationship because I fear that my partner would say 'you are ill and that's why you speak like that' even if I'm right" (Rose et al., 2011, p. 199)

Romantic relationships were a source of conflict for participants, where it was avoided in order to reduce the potential stigma from partners. As illustrated in the quote above (Rose et al., 2011), worries surrounded partners potentially using their illness against them and this being a source of contention within relationships. One participant was afraid of their partner finding

out about their illness, and their reluctance to disclose this led to them stating that they "won't get a boyfriend the way…[they are] now" (Pyle & Morrison, 2014, p. 201). Anticipated rejection was a common cause of fear and withdrawal across the relevant papers (Pyle & Morrison, 2014; Mora-Rios, Ortega-Ortega, & Natera, 2015). Participants described getting into relationships as "complicated" and "very difficult" for them, leading to negative emotions and the wish that they no longer had the illness (Rose et al., 2011, p. 200).

3.3.4 Line of Argument Synthesis

Two line of argument syntheses were identified within the present review, visual illustrations of which can be seen in Figures 3.4 and 3.5.

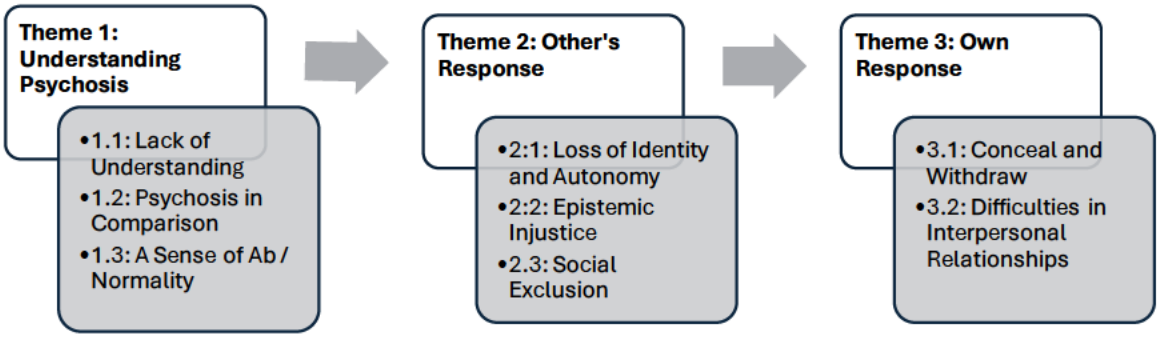


***Fig* 3.4.** First line of argument synthesis displaying a conceptual model of stigma in psychosis

The first emerged as a conceptual model of stigma within psychosis (Figure 3.4), highlighting how every sub-theme interacts with each other, unidirectionally connecting the three main themes. *Lack of understanding* about psychosis was identified as the source of stigma, with negative media portrayals and the sub-theme *psychosis in comparison* illustrating this. Stigma was a direct result of this, namely via a *loss of identity and autonomy*, *epistemic injustice*, and *social exclusion*, causing participants to feel *a sense of ab/normality*, and only allowing feelings of normality around peers with similar experiences. Stigma from society initiated a response

of dysfunctional coping strategies, such as *conceal*ment *and withdraw*al from both society and people known to the participants, leading to strain and *difficulties within interpersonal relationships.* Overall, a clear connection between each main theme emerged during the data analysis, whereby the difficulty in understanding psychosis directly led to negative reactions by others, resulting in dysfunctional coping strategies by those with psychosis.

The second line of argument that emerged was more specific in nature compared to the first overarching model, connecting four sub-themes across two main themes (Figure 3.5). The central focus of this synthesis was that the dominating medical model contributed to the stigma and lack of information surrounding psychosis, directly resulting in struggles with identity and autonomy, and therefore, contributing to occurrences of epistemic injustice. Fricker (2007) states that for testimonial injustice to take place, participant's testimonies are dismissed based solely on their identity, and for hermeneutical injustice to take place, a lack of information that does not allow the marginalised group to make sense of their experience must be present. Both of these philosophical concepts became evident within the present review during the reciprocal translation of the relevant articles.

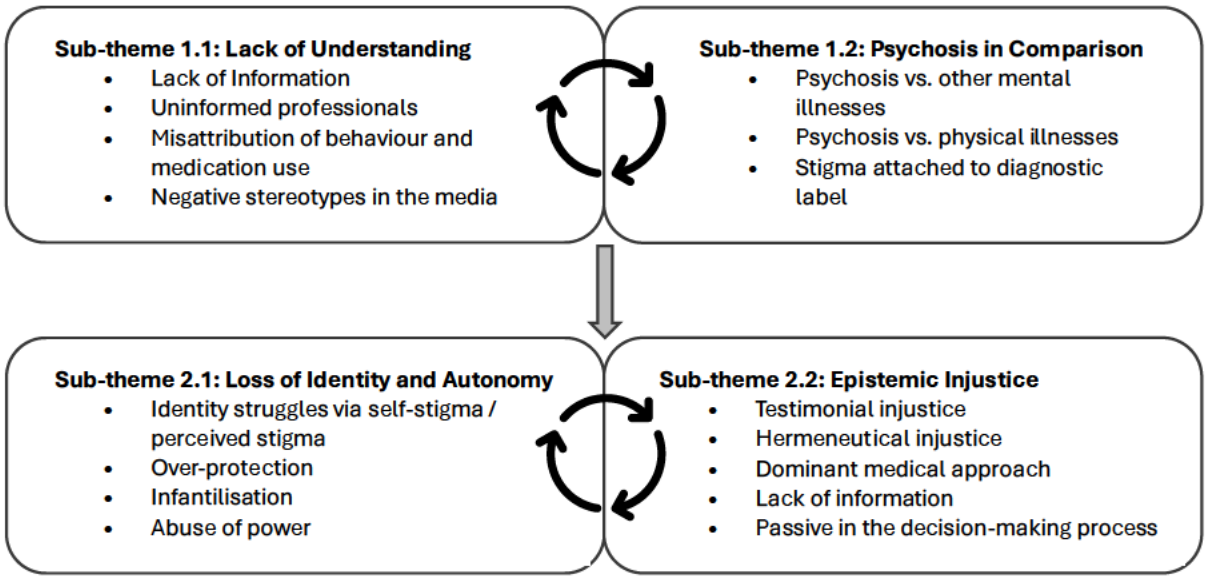


***Fig* 3.5.** Second line of argument synthesis displaying the interaction between sub-themes that contribute to epistemic injustice.

Participants felt the *lack of understanding* surrounding psychosis was due to a lack of information about the illness, with this feeling of not being understood by society extending to mental health professionals. Staff were viewed as having a sole focus on the medical interpretation and imposing an explanation of psychosis being a biological issue, with others in society misattributing behaviours relating to psychosis and subsequent medication use as 'laziness' and 'drama.' In the sub-theme *psychosis in comparison*, the diagnostic label itself was the source of stigma for people, further highlighting the negative impact of the medical approach. As a result of the stigma associated with the medical diagnosis and the lack of clarity surrounding their experience, participants were stripped of their identity and dehumanised by society, including professionals, as outlined in the sub-theme *loss of identity and autonomy.* Sense of agency and bodily autonomy were removed from participants on behalf of professionals, with decisions being made for them leading to feelings of infantilisation and passivity. As conceptualised by Fricker (2007), this lack of information about their experience

combined with a dominant medical approach is reflective of *epistemic injustice* taking place, described by participants using examples of both testimonial and hermeneutical injustice.

3.4 Discussion

The experience of stigma by people with psychosis was explored through a meta-ethnography of existing qualitative literature. Supporting the previous literature, the review highlighted external sources of stigma, through a power imbalance with others, social exclusion, and poor media representation that serves to exacerbate the prejudiced view held towards those with a diagnosis of a schizophrenia spectrum disorder. As expected from the method of using a meta-ethnographic approach (Noblit & Hare, 1988), novel sub-themes such as *psychosis in comparison*, *loss of identity and autonomy*, and *epistemic injustice* were discovered across the literature. However, some sub-themes such as *lack of understanding*, *conceal and withdraw from society*, and *social exclusion* were supportive of the themes identified in previous reviews and models of stigma and psychosis (Corrigan, Kerr, & Knudsen, 2005; Wood et al., 2015; Gronholm et al., 2017). In line with the wider aims of the thesis, the present meta-ethnography has the potential to add to the existing literature by recognising and highlighting instances of epistemic injustice (Fricker, 2007) so that the concept is recognisable, both within healthcare and future research. By identifying examples of epistemic injustice organically through past literature on stigma and psychosis, it is possible to draw on this to inform future empirical chapters that aim to break down the philosophical concept into understandable components.

The sub-themes identified within this meta-ethnography highlight the several kinds of stigma faced by people with psychosis from society, and how this occurs through a process of

a loss of autonomy and identity, epistemic injustice, and social exclusion. The source of this stigma was connected with a lack of understanding about the illness, often due to negative media portrayals and diagnostic labels. This was illustrated through comparisons of psychosis with other mental and physical disorders, leading to people with the illness feeling a sense of difference from others they considered 'normal'. Further results of the experienced stigma were concealment and withdrawal from society, as well as difficulties regarding the maintenance, formation, and loss of relationships. The sub-themes that emerged from the review were grouped under three key themes: *understanding psychosis*, *other's response*, and *own response*.

3.4.1 Understanding Psychosis

The first theme *understanding psychosis* describes the origin of stigma towards people with psychosis, highlighting how negative media portrayals contribute to a lack of understanding about the illness. According to Chan et al. (2019), reports from media surrounding violence and schizophrenia increased the societal belief that people with psychosis are dangerous. Disparaging language has been highlighted in previous research on language used within the media surrounding the topic of mental health, for example, the use of words such as 'lunatic,' 'psycho,' 'deranged,' and 'schizo' (Murphy et al., 2013; Thornicroft et al., 2013; Anderson et al., 2020). It has previously been suggested that there is a need for specific strategies that target dissemination of information within media outlets (Chan et al., 2016), as well as tools that monitor newspapers and mass media regarding broadcasting appropriate information concerning psychosis (Kim et al., 2000). Stronger regulations surrounding what information is considered pertinent to the news article and is therefore broadcast, may help reduce the

overwhelmingly negative portrayal of psychosis that contributes to misunderstandings and stigma associated with the illness.

The general lack of understanding surrounding psychosis has been noted several times within past literature, as well as emerging as a key theme in a previous thematic synthesis of stigma in psychosis (Wood et al., 2015). In the present review, lack of understanding displayed itself as a hierarchy of 'acceptable' mental illnesses with comparisons made between psychosis and physical illnesses. It has been noted previously that there is significantly less acceptance for mental illness in general compared to physical illness within society (Corrigan & Watson, 2002), however, there is a lack of research on the hierarchal structure of levels of stigma between mental illnesses, for example, psychosis vs. depression vs. anxiety. In an exploratory study of attitudes on Twitter towards depression and schizophrenia, 5907 and 451 tweets respectively were found to display more stigmatising attitudes towards schizophrenia, with 52% of the 451 tweets on schizophrenia reflecting inaccurate beliefs about it being multiple personality disorder (Reavley & Pilkington, 2014). This generally highlights the inaccurate knowledge about and increased stigma towards psychosis, however, more research is needed on direct comparisons between attitudes towards a range of mental illnesses to increase understanding of the hierarchy that appeared within the present review.

A sense of abnormality leading to an increase in self-stigma has long been a reported experience of those with psychosis (Gronholm et al., 2017), including within the present review. This negative experience was found to diminish however once people with psychosis found support from others with a similar diagnosis, suggesting that this is a key component for reducing self-stigma during the early stages of the illness. In a recent meta-analysis, it was

found that when peer support is formalised and provided as an intervention for people with psychosis, it significantly improved feelings of empowerment and self-efficacy compared to treatment as usual (Burke et al., 2019). Peer support has been recommended as an appropriate intervention for addressing issues of self-stigma (Pyle et al., 2018), with the development of a group treatment to reduce internalised stigma in psychosis showing promising results (Best et al., 2018). Although the pilot study was small and consisted of 15 participants, the intervention labelled 'Be Outspoken and Overcome Stigmatising Thoughts' (BOOST) combined peer support with techniques from Cognitive Behavioural Therapy (CBT), leading to improvements in self-stigma, as well as general satisfaction with life and self-esteem (Best et al., 2018). Where peer support may not be a viable option for some with psychosis, for example, due to social withdrawal and negative symptoms (Castelein et al., 2015), it may be useful for individual options that work to reduce the sense of abnormality felt. Therapies such as Acceptance and Commitment Therapy (ACT) and Compassion-Focused Therapy (CFT) have previously been suggested as treatment options due to their ability to reduce feelings of shame and facilitate self-acceptance and feelings of equality with others (Wood et al., 2015). Recent literature have shown ACT to be effective in reducing rehospitalisation rates, negative symptoms (Tonarelli et al., 2016; van Aubel et al., 2020), and positive symptoms (Shawyer et al., 2017) compared to treatment as usual, however, the efficacy of ACT on reducing internal stigma and feelings of abnormality is yet to be explored.

3.4.2 Other's Response

A common theme in previous research is the disturbance of one's sense of self after a diagnosis of psychosis, impacting on experiences of stigma, parenting, and work (Firmin et al.,

2021). Similar themes presented themselves within the meta-ethnography, particularly struggles relating to the person's ability to make decisions for themselves regarding starting a family (for females) and discrimination within the workplace (for males). Identity was found to be disrupted by both symptoms of psychosis and the diagnostic label, leading to an increase in emotional and behavioural risk, for example, depression and suicide (Ben-David & Kealy, 2020). According to Berkhout, Zaheer, and Remington (2019) however, struggles with identity may not be entirely indicative of psychopathology, but rather in some instances, stem from external circumstances themselves, for example, power imbalances in clinical situations and the mental health system more generally. This was reflected in the present review, whereby many participants felt they were dehumanised and treated as if they were their illness by professionals, leading to emotional distress and feelings of shame. Furthermore, power imbalances were represented via a loss of autonomy for people with psychosis, undermining their sense of agency and linking back to perpetration of stigma by the mental health system. It has been suggested that increasing a sense of personal agency is significant for recovery within psychosis (Bjornestad et al., 2017). Houlders, Bortolotti, and Broome (2021) propose that when sense of agency and identity is already under threat, clinicians can be key to combatting this. Within the clinical encounter, positive outcomes and engagement are often constructed, therefore, allowing space for self-agency here may have significant effects on an individual's identity and sense of self (Houlders, Bortolotti, and Broome, 2021).

The experience of a dominating biomedical approach towards understanding psychosis was prevalent within the sub-theme *epistemic injustice*, supporting a recent systematic review that identified a majority of medical professionals endorsed this model of recovery in psychosis, choosing pharmacological treatments over psychosocial interventions (Morera, Pratt, & Bucci,

2017). According to Longdon and Read (2017), public health initiatives that aim to educate the public about mental illness by explaining it as a biological problem can actually exacerbate the issue, proving themselves to be ineffective at reducing stigma (Tyler & Slater, 2018). Although the intention is to promote a message of acceptance for and understanding of mental illness being like any other illness, in reality, it increased avoidance and rejection towards people with psychosis (Read, Haslam, & Magliano, 2013; Svensson & Hansson, 2016). The biological message of "it is not an individual's fault that s/he is unwell," unwittingly led to the belief that behaviour is beyond the individual's control, leading to an increase of negative stereotypes such as the person with psychosis being unpredictable and dangerous (Canadian Health Services Research Foundation, 2013; Longdon & Read, 2017). Instead, it has been suggested that mental health campaigns should adopt a psychosocial approach (Wood et al., 2015), especially as people with psychosis place more significance on psychosocial models of recovery (Morera, Pratt, & Bucci, 2017). According to Longdon and Read (2017), framing psychosis as a meaningful response to difficulties within public health initiatives are more effective than a biomedical framework due to its ability to humanise people with complex and severe illnesses. Allowing for additional ways of understanding by utilising a biopsychosocial model towards psychosis may reduce occurrences of epistemic injustice, specifically hermeneutical injustice, from taking place. This supports Sanati & Kyratsous' (2015) argument that adopting a holistic view of psychotic symptoms tackles stigma against people with psychosis and could potentially challenge negative prejudices that pre-empt epistemic injustice.

The sub-theme of social exclusion, outlining society's efforts to reject and avoid people with psychosis, has been a recurring theme in previous literature (Wood et al., 2015). Apart from being an expression of stigmatising behaviour, social exclusion also plays a role in aggravating

positive symptoms (Tarrier et al., 2007), such as paranoid beliefs (Lincoln et al., 2018), by negatively impacting on the individual's emotional wellbeing (Lincoln et al., 2021). Significant cognitive decline in people with psychosis was also reported after experiences of rejection and avoidance (Reddy et al., 2019; Lincoln et al., 2021), suggesting that although pharmacological and behavioural treatments targeting cognitive deficits may be necessary at this point (Bowie & Harvey, 2006), methods that target the source of the stigma and exclusion by increasing acceptance and engagement may be more beneficial as a preventative measure. The benefits of social inclusion have been noted within research, with one study suggesting that identifying with social groups increased self-esteem and reduced negative feelings of depression (McIntyre et al., 2018). CBT was found to indirectly improve emotional distress and reduce social exclusion through the positive impact it had on reducing negative symptoms and dysfunctional beliefs (Staring, Ter Huur, & van der Gaag, 2013), likely due to its primary aim of encouraging changes in thinking and behaviour (Wood et al., 2015), supporting its use as an effective core psychological intervention for psychosis (NICE, 2014). However, as mentioned within the sub-theme *epistemic injustice*, avoidance and withdrawal from society may also be considered a valid response towards experienced or perceived stigma, rather than a direct medical symptom of psychosis (Rose et al., 2011). Therefore, although CBT is useful for changing thought processes and resulting behaviour for the person with psychosis, it does not address the more critical issue of changing negative attitudes of the public towards the person with the illness, which may be more useful for reducing instances of avoidance and rejection. This, however, is a larger societal problem, where the lack of understanding surrounding psychosis should be addressed.

3.4.3 Own Response

Concealment and withdrawal were common themes across the included articles and are also constant emerging themes within past literature on psychosis and stigma, often connected with feelings of shame surrounding the illness (Wood et al., 2015). Concealing the diagnosis was utilised as a coping mechanism in order to reduce feelings of distress, however, as noted by Michail and Birchwood (2013) and found within the present review, this resulted in a Catch-22 situation where the method was counterproductive due to its contamination of social interactions and resulting effect of withdrawal. Thoits and Link (2016) found that a response of concealment to stigma was higher in individuals who felt devalued within society, experienced discrimination, and dealt with internalised stigma. In comparison, attempts to resist stigma via challenging stereotypes and deflecting beliefs was linked to higher esteem and less depression (Thoits & Link, 2016). The negative consequences of perceived discrimination, for example, loss of social support, were thought to be partially mediated by dysfunctional coping strategies, such as concealment and withdrawal (Kleim et al., 2008), potentially explaining the findings of the present review and suggesting that concealment tactics are used to offset poor outcomes as a result of stigma towards psychosis. Although Thoits and Link's (2016) findings would suggest that CBT may be useful for reframing dysfunctional coping strategies to stigma-resistant strategies, a recent meta-review examining the efficacy of CBT for psychosis across 20 meta-analyses found no clear advantages for social functioning compared to other psychological interventions (Barbieri & Visco-Comandini, 2019).

The sub-theme *difficulties within interpersonal* relationships outlined the struggle people with psychosis had in forming and maintaining relationships with family, friends, and romantic partners, with the response to experienced stigma being withdrawal. One of the issues identified with the formation and maintenance of romantic relationships within the present review was the use of medication, however, this was in the context of having to disclose medication use to potential partners, rather than the medication itself being the cause of sexual problems as a previous literature review found (McCann, 2003). A recent systematic review including 58 studies reported an association between romantic partners and self-esteem, with findings showing an increase in feelings of depression for those in a relationship (White et al., 2021). The findings of the present review could possibly explain the increase in depression, where the thought of disclosing a diagnosis of psychosis and medication use, as well as fear of rejection, was a source of distress. A study that employed interpretative phenomenological analysis in order to "give voice to the patient's perspectives," found that illness onset was a pivotal point in life, where there was a more pressing need to deal with stigma and face challenges with identity struggles, leading to strain on interpersonal relationships (Budziszewska, Babiuch-Hall, & Wielebska, 2020). Maintenance of social networks have shown to provide strong clinical benefits for people with psychosis, with one study suggesting that the development of a 'friends for interventions' model, whereby professionals work with both the service user and their friendship group, may be useful for promoting social inclusion (Harrop et al., 2015).

3.4.4 Line of Argument

As a result of both the first and second line of argument synthesis that emerged from the review, claims can be made regarding the potential social processes by which stigma is formed and maintained towards people with psychosis. Supporting Corrigan, Kerr, and Knudsen's (2005) stigma model, findings from the first line of argument fall in line with individual cognitive models (Hilton & von Hippel, 1996; Krueger, 1996; Crocker, Major, & Steele, 1998). Negative stereotypes, prejudice, and discrimination towards psychosis were prevalent throughout the first two themes *understanding psychosis* and *other's response*, contributing to the conceptual model of the present review and outlining the formation and maintenance of stigma within society. Discrepancies in understanding the fundamentals of what psychosis is and how it presents itself led to the formation of stigma, whilst negative media portrayals maintained this. The first line of argument then can be recognised as an individual cognitive model of stigma, similar to Corrigan, Kerr, and Knudsen's (2005) model, extended to include the coping strategies used by those with psychosis via the third theme, *own response*.

The second line of argument connected the dominant medical approach to explaining psychosis and the resulting response to this, namely a loss of identity and autonomy for people with psychosis, and instances of epistemic injustice by others in society, including medical professionals. The philosophical concept of epistemic injustice (Fricker, 2007) occurs due to an individual's identification with a marginalised group, in this case, psychosis. The processes involved in the occurrence of this concept were demonstrated in the present review via a dominant biological approach towards understanding psychosis, a label that stripped individuals of their identity and autonomy, and dismissal of testimonies due to the label of

psychosis. This line of argument also supports previous individual cognitive stigma models (Corrigan, Kerr, and Knudsen, 2005), however, it does so at a deeper and more focused level than the previous overarching conceptual model, drawing light to a philosophical concept (Fricker, 2007), that as of yet has not been well-researched within this field. It has previously been suggested that micro-levels of stigma, i.e. the source, leads to another micro-level of stigma, i.e. the impact (Corrigan, Markowitz, & Watson, 2004). This has also been demonstrated within the present review as direct links can be made between the medical model and the loss of autonomy and identity this affords to those with psychosis.

3.4.5 Limitations

One of the limitations of using the meta-ethnographic approach is the reliance upon interpretation of data that has previously undergone interpretation by researchers of the relevant literature. The understanding of the true meaning of participant's experiences can be limited to the meaning that has been provided to it by the original authors (Atkins et al., 2008). To mitigate this issue, participant's quotes were used directly where possible to support the sub-themes identified across the articles. Another potential limitation of a qualitative synthesis is the subjective nature of the original articles as well as any subjectivity that may be present within the review itself. However, it is important to note that authors of qualitative literature often aim to ensure rigour regarding both the method and analysis of the research, for example, through inter-rater reliability during the coding process and development of themes, triangulation, and transparency via reflexivity and positionality within the methodology (Jonsen & Jehn, 2009; Dodgsen, 2019). Additionally, as previously mentioned within the method section, an external group of researchers were consulted throughout the

synthesis process for the present review, supporting the development of the identified themes and increasing reliability of the interpretations.

Although the approach towards screening and identifying relevant articles was systematic and followed the usual search strategy for qualitative literature (Cooke, Smith, & Booth, 2012), there is the potential that papers suitable for inclusion were missed, particularly due to the exclusion of grey literature and articles that have not undergone a peer-review process. For the articles that were included however, quality appraisals were undertaken to obtain an overall decent quality of research (NICE, 2012a; 2012b), ensuring that the extracted themes were based upon a foundation of methodologically strong literature. Whilst the findings drawn from the meta-ethnography are not representative of all people with psychosis, the review has generally provided some more insight into the stigma associated with psychosis.

3.4.6 Clinical Implications

Throughout the discussion, potential methods and interventions that aim to reduce the stigma and negative perception associated with psychosis have been explored, particularly within the context of the findings from the present review. More broadly however, the dominating medical approach identified across some of the sub-themes reduced scope for alternative methods of diagnosis and treatment, as well as understanding of psychosis. Along with the sub-themes, both line of argument syntheses suggest there is a need for integration of a biopsychosocial model that explores all aspects of psychosis and offers a range of ways for service users to understand their experiences, rather than solely from a biological standpoint.

One example of a system that includes all of these factors and serves as an alternative to traditional psychiatric diagnosis is the 'Power Threat Meaning (PTM) Framework' (Johnstone

& Boyle, 2018). The framework assumes that 'symptoms' are understandable reactions to difficult environments, serving a protective function and demonstrating an individual's ability to create meaning and develop a sense of agency. The PTM framework reframes the question of "what is wrong with you?," as demonstrated via the lack of understanding displayed, negative response from others, and resulting negative coping strategies within the present review, by instead asking: "(i) what has happened to you? (power), (ii) how did it affect you? (threat), (iii) what sense did you make of it? (meaning), and (iv) what did you have to do to survive? (threat response)" (Johnstone & Boyle, 2018). However, this model garnered significant criticism, mainly in reference to whether an alternative to a psychiatric diagnosis is necessary, the focus on trauma being a central factor of the framework, as well as ambiguity surrounding the practical application of the framework (Johnstone et al., 2019). Nonetheless, the widespread attention the framework has received may imply that alternatives, or at the very least, an additional model to the dominant psychiatric approach is necessary.

Clinicians shifting their own understanding of psychosis and adopting a more holistic viewpoint, for example, via the language used when providing information or by creating an equal relationship between themselves and the service user so that agency and autonomy is maintained, has strong implications for the understanding of psychosis as a whole, both within society and for the individual experiencing psychosis. This was supported by Clement et al. (2010), who found that professionals recommended a person-centred approach and portrayal of mental health as a continuum to tackle stigma within society. However, it is necessary for understanding to firstly change at the source of the misunderstanding i.e. within the mental health system that heavily promotes a biomedical approach. As demonstrated within the present review, lack of understanding towards the illness led to overwhelmingly negative

responses by others, therefore, targeting what it means to experience psychosis may be more effective at reducing the associated external and internal stigma. As noted by McCann (2003), clinicians have a duty of care towards their patients, specifically towards ensuring that there is no further escalation in the discrimination of an already marginalised group within society.

At a societal level, changes that adopt a less stigmatising view of psychosis may be necessary, for example, via current and future anti-stigma campaigns that promote a biopsychosocial approach towards understanding these experiences. Alternative frameworks of understanding are important for acceptance of individuals with psychosis to take place, both within the mental health system and more broadly, within the wider community. As has been discussed in previous literature, as well as within the present review, the use of psychiatric diagnoses are potentially harmful in a variety of ways; perhaps most relevant to this research by the way in which it increases stigma towards individuals with a diagnosis (Timimi, 2014). It has been noted previously that barriers towards accessing care include fear of stigma that may follow after being labelled with a diagnosis (Watson & Corrigan, 2001), leading to the suggestion that psychiatric labels should be abolished altogether (Timimi, 2014). It may be more prudent at this stage, however, to revise the reliance on diagnostic categories at the initial point of access to mental health services. Rather than categorisation, there is a need for individual experience and context to be recognised within services; primarily, deeper understanding as to how these experiences may be situated within the individual's beliefs, culture, or personal life.

3.4.7 Future Research

As the review has produced novel themes and understanding about different types of stigma associated with psychosis, it would be useful for future research to explore these in more detail. In particular, the more recent philosophical concept of epistemic injustice (Fricker, 2007) within healthcare and psychosis. This sub-theme strongly identified with a lack of understanding about psychosis, from both society and professionals, and was linked to an identity struggle for the person experiencing the illness. Therefore, examining instances of testimonial and hermeneutical injustice against people with a diagnosis of psychosis via case studies and interviews may provide even more insight into the structural inequalities present that lead to injustice taking place. Quantitative analysis via survey and questionnaire data to both service users about injustices faced and to the public in general about their understanding of psychosis may be useful for a larger dataset that can be generalised to both samples. Further exploration into the differences between understandings of psychosis may be beneficial for the development of an information tool that is easily accessible within society and contributes to reducing the negative stereotypes associated with the diagnosis.

Future research should also focus on the ways in which some individuals show acceptance towards their diagnosis. Five papers included in the review described how some participants felt receiving a diagnosis enabled access to treatment, leading to acceptance of their experiences by confirming what they "already knew" (Howe, Tickle, & Brown, 2014, p. 157). Acceptance resulted in feelings of relief and happiness rather than distress (Pyle & Morrison, 2014; Yen, Huang, & Chien, 2020), with participants feeling the diagnosis was an "opportunity to know…[themselves] better" (Mora-Rios, Ortega-Ortega, & Natera, 2015, p. 706) and

"discover some things that…[they] don't think…[they] would have known about had…[they] not gone through this" (Knight, Wykes, & Hayward, 2003, p. 216). Although the majority of participants found the process of being diagnosed was a negative experience, it is imperative to also include the participants who experienced this process as a positive part of their life that allowed for acceptance of who they are. Exploring the processes that lead towards acceptance and relief rather than distress could be valuable for learning what is and is not beneficial during the help-seeking phase of the illness.

In conclusion, the present meta-ethnography identified three main themes that contribute towards the way a person with psychosis experiences stigma: understanding psychosis, other's response, and own response. The method of utilising a meta-ethnographic approach allowed for the emergence of novel themes to add to the existing literature, as well as two line of argument syntheses, rather than the more commonly used thematic approach to analysing relevant articles. Additionally, the review uncovered instances of epistemic injustice perpetrated towards participants across the articles, providing a solid basis of evidence for the theoretical arguments presented in Chapter 2. Following this, Chapter 4 will now seek to outline the methodological approach for Chapters 5, 6, and 7, in order to add to the existing theoretical and empirical evidence base on epistemic injustice and psychosis.

Chapter 4

METHODOLOGY

4.1 Introduction

The wider aim of the thesis seeks to understand the lived experience of people who have unusual experiences, both with and without a medical diagnosis. In order to understand the way epistemic injustice presents itself in the context of psychosis specifically, it is key to explore the way in which those without a diagnosis make sense of their unusual experience, as well as how others make sense of this and subsequently treat or perceive them, in comparison to those with psychosis. By adopting this approach, the nuances of epistemic injustice can be explored, particularly in relation to whether it occurs as a result of the unusual experience itself or of the diagnostic label. Given the aims of the thesis, the research questions are as follows:

(i) How do people who experience psychotic or unusual phenomena make sense of their experiences?

(ii) How do people who experience psychotic or unusual phenomena make sense of how they are treated by others?

(iii) What are the similarities and differences in sense-making and treatment by others between groups, and how do these experiences relate to epistemic injustice?

Having reviewed the literature surrounding epistemic injustice in psychosis, and stigma, the present chapter will outline the rationale behind the chosen methodology for the following three empirical chapters. This chapter will begin by examining the basis for adopting a

qualitative methodology, including the researcher's epistemological standpoint. The choice of using Interpretative Phenomenological Analysis (IPA) will then be explored, detailing the philosophical and theoretical underpinnings of IPA, as well as a critical appraisal of the framework. Finally, the chapter will end by carefully considering issues surrounding quality, rigour, and reflexivity.

4.2 The Basis for Adopting a Qualitative Methodology

According to Giorgi (1975), psychological research should not emulate the research process of natural sciences, but rather it should look to authentically describe and then question those descriptions of phenomena, allowing the "unfolding of the phenomenon itself to guide the logic" of the researcher's investigation (p. 5). In line with this position, the decision to employ a qualitative methodology was led by the research question itself, with the aim of exploring the lived experience of psychosis and unusual experiences naturally lending themselves to a phenomenological approach. Given that epistemic injustice (Fricker, 2007) is a relatively new concept as it pertains to healthcare, and more specifically psychosis, the present thesis aims to provide foundational research, as well as support the limited empirical research that currently exists. For understanding the lived experience of epistemic injustice, by first determining whether it is present within healthcare and recognising the situational contexts in which it presents itself, qualitative methods appear to be most appropriate in achieving this.

According to Strauss et al. (1985), "it is important in such an inquiry, as in any other scientific effort, to be faithful to the phenomena being studied, even though this may lead to shifts in research method" (p. 296). As the researcher aims to identify occurrences of a philosophical concept within a target population, it became imperative first and foremost to operationalise

epistemic injustice, breaking it down into understandable actions that could be understood and identified as part of daily life. For this task, it appears that qualitative research would be particularly well suited, particularly in relation to examining how this concept may initially present itself within a set of individuals. Davidson (2003) suggests that qualitative methods are based on the assumption that there are additional contexts to reality or experience than can be captured by quantitative methods alone, such as experiences being embedded in meaningful relationships. The present thesis seeks to not only understand how people make sense of their own experiences, but also how they make sense of others' interpretations of their experiences. It can be seen here then how certain nuances regarding meaningful relationships, perceptions of unusual experiences within society, and participant interpretation of how they are treated by others may be lost or significantly reduced without the use of a qualitative methodology. Phenomenology provides the ability to not only apply rigorous method to psychological research, but also to ground this method "in an explicit theory of human subjectivity," therefore making it particularly appropriate for describing the meaning making processes of individuals with unusual experiences (Davidson, 2003, p. 27).

Although there is usefulness in quantitative approaches depending on the type of research, for example, investigations that aim to provide generalisable findings on cause and effect relationships, the aim of the present thesis to engage with subjective lived experience led to consideration of a qualitative analytical position. As quantitative approaches assume that specific methods can reveal generalisable data for an objective reality (McLeod, 2011), it would have been inconsistent with not only the current research aims, but also the researcher's epistemological standpoint. The objectivist epistemology of quantitative approaches assume that any form of knowledge is measurable, and that perceptions and experiences of reality are

objective, with the researcher being detached from the phenomena being investigated. This is incompatible with the subjectivist epistemological standpoint of qualitative approaches that deem it impossible to quantify independent thoughts, feelings, and behaviours, acknowledging these as subjective and contextual (Langdridge, 2007).

The subjective nature of lived experience in the investigation of phenomena, as also indicated by exploration of past literature, was unable to be engaged with in a quantitative, measurable way, therefore, exploration of this lived experience justified the use of a qualitative method. For the reasons mentioned above, the following sections will describe the ontological and epistemological standpoints of the researcher, as well as the phenomenological approach that was adopted to address the research question.

4.2.1 Ontology

Ontologically, a critical realist position was adopted on the basis of recognising reality as 'out there,' rooted in society and experienced by individuals in multiple ways (Grbich, 2010). This ontological standpoint allows for a nuanced exploration of individuals' subjective realities, whilst acknowledging the possibility of multiple interpretations. Access to these realities is affected by the beliefs, experiences, and perceptions held by participants, and is subject to further interpretation by the researcher (Cuthbertson, Robb, & Blair, 2020). It is presumed through this ontology that meanings and realities evolve throughout the process of data collection and that through this, the phenomena that is generated is demonstrative of their existence (Finlay & Ballinger, 2006). In order to better understand the complex realities subjective to each individual, critical realists combine interpretation and explanation, utilising a critical approach towards the connection between phenomena and potential findings. As

explained by Cuthbertson, Robb, and Blair (2020), the onus is on the researcher to develop true knowledge of participant's experiences that can be viewed as one reality that has taken place. For the present thesis, the researcher's ontological assumption is that each participant has a subjective view of reality and that there is no existence of one universal reality outside of the multiple realities experienced by individuals.

4.2.2 Epistemology

An interpretivist epistemological position was adopted on the basis of the subjective meaning-making processes that individuals employ to make sense of their experiences, and the understanding that knowledge is shaped by individual perceptions and cultural contexts. Given that epistemic injustice is a conjunction of both epistemological and ethical issues, the investigation of this concept brings epistemology to the fore, particularly through questioning the justifiability of dismissing contributions of others to shared knowledge. The importance of understanding individuals' subjective experiences is recognised within phenomenological approaches, acknowledging that multiple meanings can emerge from the same phenomena. An interpretivist epistemology, via the double hermeneutic, attempts to understand the perspective of participants and how they make sense of their experiences, as well as the way the researcher attempts to comprehend these meaning-making processes. According to Husserl (1900/1970), there is no meaning attached to anything in the world until it is provided via subjective interpretation of individual consciousness, a feature that is characteristic of both mental state and experiences (McIntyre & Smith, 1989). It is expected then through IPA, that via the facilitation of the researcher and thoughtful questioning, participants may have the

ability to more accurately reflect upon their reality and perceptions of experiences (Smith, Flowers, & Larkin, 2021).

4.3 The Phenomenological Method

For the purpose of answering the research questions, a phenomenological approach has been adopted for the thesis. According to Osborne (1994), a phenomenological component exists in most qualitative approaches due to its focus on individual, first-person perspectives, in comparison to third-person perspectives. In addition to this, it has been suggested that the key aim of phenomenological research is to generate a comprehensive and authentic account of the way a particular phenomenon is experienced, either subjectively or intersubjectively (McLeod, 2003). Since the aim of the research involved understanding the lived experience of participants and the way they make sense of specific phenomena i.e. psychosis and other unusual experiences, a phenomenological method was deemed most suitable (Van Manen, 2016). The following section will now aim to discuss in more detail the philosophical and theoretical underpinnings of IPA, as well as the rationale for adopting this methodology.

4.3.1 Employing an Interpretative Approach

Once the decision was made to employ a qualitative, phenomenological method for the research, the next step involved deciding between a descriptive or interpretative approach (Finlay, 2012). Phenomenological reduction, a method that is primarily descriptive, focuses on recognising the essence of the phenomenon under investigation through thorough explanation of experience as it develops (Langdridge, 2007). However, the lack of interpretation within the descriptive approach appeared to be inconsistent with the researcher's epistemological standpoint. It is the researcher's position that it is impossible to

separate oneself from all preconceptions, or from the "social, cultural, and historical evolution" of which we are ourselves are a part of, in order to reflect on phenomena from a distance (Davidson, 2003, p. 33). It is the implicit assumptions that operate externally to thematic awareness that may prove detrimental to research. Therefore, by recognising this and making explicitly aware these preconceived notions, researchers can examine the potential influence of this on limiting our understanding.

In comparison to phenomenological reduction, the interpretative approach views this as an inevitable facet of research, highlighting the impossibility of detaching from automatic processes such as meaning making. Additionally, it deems it impossible to completely bracket off personal knowledge and experience regarding any phenomenon under investigation (Smith, Flowers, & Larkin, 2021). The aim of the research to understand the lived experience of a certain phenomenon, as well as the researcher's epistemological position, appeared to be more compatible with a method that allowed for an interpretative component, without over-reliance on the bracketing process that descriptive approaches engage with. According to Becker (1996), researcher interpretations are always implicitly or explicitly applied to the set of individuals under research. To uncover the way in which meaning is made subjectively for each participant, it is necessary for researchers to immerse themselves into the participant's world (Krauss, 2005), empathising with their underlying motivations, thoughts, and behaviours.

4.3.2 Philosophical and Theoretical Underpinnings of IPA

Initially developed by Smith (1996), IPA is grounded in three key areas of phenomenology, hermeneutics (including the double hermeneutic), and idiography; drawing on these to inform

its methodology and epistemological framework (Shinebourne, 2011). According to Smith and Eatough (2006), a thorough analysis of individual experience could be achieved through IPA by considering participant's personal and social worlds. The following section will now delve into each of these three areas, exploring their connection to and informing of the IPA methodology.

Founded by Husserl, the phenomenological underpinning of IPA allows for an in-depth way of exploring the lived experience of individuals. To examine this, Husserl utilised a series of processes to conduct a phenomenological analysis of his own experiences, however some amendments were required in order to engage with other's experiences (Giorgi, 1997). From the perspective of IPA then, phenomenological research is viewed as an attentive reflection of lived experience, via "first-order activity or second-order mental and affective responses to that activity" (Smith, Flowers, & Larkin, 2009, p. 33). Aside from Husserl, the perspectives of Heidegger, Merleau-Ponty, and Gadamer have been influential in the development of IPA, viewing people as immersed in the world, situated within social, cultural, and historical contexts. The significance of understanding a phenomenon in regard to historical and cultural contexts has been noted previously within this chapter, however, situating the phenomena in its social context is especially important within this research. In relation to the aims of the thesis, one of the research questions concerns the way others interpret the unusual experiences that individuals are experiencing. Here, especially for the participants with psychosis, understanding the social context of a psychiatric diagnosis is key for answering the research question.

In line with Heidegger (1962), IPA also views the phenomenological method as a process of interpretation. Embracing this hermeneutic turn in phenomenology, the lived experiences of

both the participant and the researcher is viewed as embedded within the world and the context of the research, considering intersubjectivity a fundamental aspect within the IPA methodology and throughout the research process. According to Moran (2000), the aim of phenomenology is to explicitly study and reveal that which is hidden or covered, and therefore "to let that which shows itself be seen from itself in the very way in which it shows itself from itself" (Heidegger, 1962, p. 58). In order to uncover the potentially hidden, Heidegger (1962) highlights the process of interpretation in order to facilitate the process of uncovering the phenomenon. The assumption of this dynamic interplay has the potential to significantly impact findings. In order for participants to uncover the concept of epistemic injustice in relation to their unusual experiences, the researcher's facilitation of this through the use of semi-structured interview questions is necessary. Additionally, the way people make sense of their unusual experience requires interpretation on part of the researcher, in order to situate these processes in participant's individual personal, social, and cultural worlds.

In addition to this, Smith (2004) describes the double hermeneutic: an integral element of IPA that suggests whilst the participant is attempting to make sense of their experience, the researcher is also attempting to make sense of the participant making sense of this. Access to individual experience is via participant account and researcher 'fore conception,' therefore, making it crucial for researchers to utilise reflexivity throughout the research process and evaluate the ways in which these prior understandings may impact the findings (Finlay, 2008). According to Gadamer (1960/1996), interpretation was the process by which understanding occurs, viewing this as an inseparable part of being-in-the-world. Key to his view was the notion of 'horizon;' a range of vision that combines all that is seen and experienced from a particular vantage point. Interpretation then, was the 'fusion of horizons' for Gadamer,

encompassing an interaction between the assumptions of the researcher and the participant's meaning (Smith, Flowers, & Larkin, 2009). Allowing for the potential development of multiple horizons, the interview process is considered an integral element of the interpretative process.

The third theoretical underpinning of IPA, idiography, focuses on the detailed exploration of individual subjective experience as opposed to the nomothetic approach, which is concerned with aggregated data and the generation of objective laws regarding human experience (Smith, 2004). As participants can provide unique viewpoints on the way they make sense of certain phenomena, they are able to become the unit of study for researchers via detailed analysis of either single cases or small groups (Smith, Flowers, & Larkin, 2009). Aside from the potential of detailed individual accounts to shed light on "significant aspects of a shared humanity" (Smith, 2004, p. 43), the researcher can also illuminate existing nomothetic research by linking the data to existing literature (Smith, Flowers, & Larkin, 2009). This theoretical underpinning is significant for the wider aims of the thesis as it relates to understanding the way individuals make sense of their unusual experiences. Given that an unusual experience is unique to the individual that experienced it, who indeed will have their own subjective interpretation of what they experienced and why, it logically follows that the most appropriate way to uncover these meaning-making processes is through an idiographic approach.

4.3.3 The Choice of IPA

IPA was deemed to be the most suitable phenomenological method for the research as it comprises of both descriptive and interpretative elements, emphasising subjectivity and interpretation via an idiographic approach (Smith, Flowers, & Larkin, 2021). It was also

compatible with the researcher's ontological and interpretivist epistemological standpoints, and therefore with the research itself. The method of IPA allows for a rigorous exploration of lived experience, allowing this experience to emerge and be expressed on its own accord without the need for predefined classifications. Due to the focus on interpretation of subjective lived experience, a smaller sample size of 10 was recommended (Smith, Flowers, & Larkin, 2021, p. 46). Therefore, a small number of participants were recruited for the research (n=11), as the focus was on in-depth experiences of people with psychosis or unusual experiences. By examining individual perceptions, IPA provides the possibility for development of novel and valuable insights, potentially uncovering subjective realities of human experiences through detailed descriptions by the participants and interpretation by the researcher (Creswell & Poth, 2016).

As data was collected between November 2021 and January 2022, one of the unique challenges faced as a result of COVID-19 within research employing the method of IPA was the issue of online interviewing as opposed to face-to-face interviewing. Within qualitative research generally, online interviewing has been utilised over the past two decades due to several benefits, such as access to more diverse samples (Sedgwick & Spiers, 2009), reducing the need for travel (Winiarska, 2017), and flexibility and convenience (Deakin & Wakefield, 2014). Comparing the two modes, participants were described as more open and expressive with online interviewing (Mabragaña, Carballo-Diéguez, & Giguere, 2013), and the quality of online interviews appeared to remain the same as those conducted face-to-face (Cabaroglu, Basaran, & Roberts, 2010). Despite this, ethical considerations remain, for example, the potential issue of participant privacy and data confidentiality or security (Lobe, Morgan, & Hoffman, 2020). The methods used to reduce this risk will be discussed in Chapter 5.

The method of IPA also allowed for the interpretation of meaning to be situated within context via intersubjective investigation and analysis, understanding the individual's lived experience of certain phenomena by the meaning they prescribe to it, but also acknowledging this as researcher dependent and socially situated (Harper & Thompson, 2011). The ability of IPA to focus on context whilst also providing rich descriptions of participant perspectives, allows for in-depth examination of findings comprised of descriptive, linguistic, and conceptual elements. It was expected through use of this methodology that meaning of phenomena would be created, negotiated, and interpreted by individuals, allowing for extension of understanding beyond the scope of description, and the development of knowledge surrounding the lived experience of psychosis and unusual experiences through researcher interpretation (Cuthbertson, Robb, & Blair, 2020). It was therefore decided that the core characteristics of IPA were compatible with and had the ability to fulfil the aims of the research.

4.3.4 A Critical Appraisal of IPA

Despite the explanation of IPA as the most suitable methodology for the research aims, it is vital to also recognise its limitations. According to Smith (2011), there should be an expectation of amendments to these methodologies in the future based upon the recency of qualitative research methods in psychology. Therefore, this section will now continue with an examination of some of the criticism surrounding IPA, especially due to the fact that limitations inform considerations regarding quality and rigor. Explicit awareness of the drawbacks of IPA prior to conducting the research allows for thoughtful reflection on how these can be managed throughout the research process.

It has been previously argued that IPA neglects to situate experiences within social and cultural contexts, focusing almost completely on the individual (Kaptein, 2011; Todorova, 2011). This is thought to be a result of 'methodolatry;' a strict adherence to method at the expense of substantial content (Chamberlain, 2000). However, in a review of eight researcher's experiences of using IPA as a methodology, the critique of neglecting being able to situate experiences within specific contexts remained absent from the paper (Wagstaff et al., 2018). It has also been demonstrated through the discussion of IPA's philosophical and theoretical underpinnings that all experience occurs in context, and that social and cultural dynamics influence the meaning made of these experiences (Smith, Flowers, & Larkin, 2021). As such, the present thesis aims to take into consideration during analysis the participant's ways of making sense of their experience within a societal context. By exploring the perceived interpretations and treatment of participants from the people around them, and highlighting the perception of unusual experiences or psychosis within society, the researcher will ensure that context is not lost throughout the analysis.

According to Chamberlain (2011), IPA is a 'poor' method of analysis due to its emphasis on procedural processes rather than philosophical and theoretical background. It was argued that rather than being informed by hermeneutics as stated, IPA is a thematic guide, encouraging researchers to develop subthemes through close reading of the data, categorising these as broader themes, supported by quotes within an analysis. Chamberlain (2011) recommends that in order to produce a high quality piece of research using IPA, researchers should clarify their position within the research, as well as the philosophical and theoretical underpinnings of IPA, utilising this as a methodology rather than a method. In recognition of this, and in line with the recommendations offered, the researcher has used this section within the thesis to

provide clear justification for the use of IPA, as well as providing clarity surround ontological and epistemological standpoints, and discussing the foundations of IPA.

IPA has also been challenged as being dependent on the social cognition paradigm, displaying certainty in the way that participants make sense of their experiences through specific beliefs, and relying on the notion that researchers can access internal cognitions (Langdridge, 2007; Willig, 2013). However, Smith (1996) has always considered these internal cognitions as an aspect of being-in-the-world rather than isolated and distinct. Informed by the underpinnings of IPA, the researcher's ontological and epistemological position acknowledges lived experience as both subjective and intersubjective, understanding experiences by the context in which they occur. In this sense, it is key for the researcher to take into account their potential impact on the participant's cognitive and affective accounts of their experiences. Evidence of this will be demonstrated within the reflexivity section of the methodology.

The present section of the methodology aimed to outline the phenomenological method of IPA, justifying it a well suited choice to answering the research questions of the thesis. Employing a more thorough understanding of the philosophical and theoretical underpinnings of IPA, as well clearly considering the aims of the research and personal epistemological standpoint, were significant in applying IPA as a methodology to meet the requirements of the thesis, as opposed to solely utilising it as a procedural guide. To address some of the criticisms mentioned above, a section on quality and rigor will now follow in order to demonstrate some of the principles utilised that helped guide the production of a high quality piece of research.

4.4 Ensuring Quality and Rigour

One of the key challenges when employing qualitative methods has consistently been the assessment of rigour throughout the process of research (Finlay, 2006). Given that the present thesis is intrinsically qualitative, the concepts of quality and rigour are developed on the basis of subjective and intersubjective foundations, distinct from their quantitative counterparts. Rigour may generally be understood as the robustness, appropriateness, and cohesiveness of concepts, epistemology, and methodology (Smith & McGannon, 2018; Harley & Cornelissen, 2022). To address this and ensure high quality throughout the research process, as recommended by Smith, Flowers, and Larkin (2021), the principles outlined by Yardley (2000) were adhered to, including sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. Each factor is addressed below with examples of how this will be monitored and managed throughout the research.

4.4.1 Yardley's (2000) Principles for High Quality Research

Sensitivity to context is inclusive of several facets of the research, for example, the theoretical context that informs the rationale for empirical research, sociocultural settings that may influence the participant's perspectives as well as researcher interpretation, and the ethical considerations of potential power imbalances between researcher and participant. A thorough review of the literature on both psychosis and epistemic injustice, as well as a meta-ethnography researching the stigma of psychosis, encompasses the context in which the empirical research is situated. The analysis of data has followed the framework of IPA and the guidelines set out by Smith, Flowers, and Larkin (2021), to help the context of the participant's perspectives remain central throughout and be reflected in the findings of the thesis.

Additionally, a section on researcher reflexivity is included in the methodology in order to further illuminate the sociocultural settings and relevant ethical considerations.

Commitment and rigour correspond to in-depth engagement with the research, and the 'completeness' of both data collection and analysis, for example, the ability of the sample to provide enough information, both rich and high in quality, to reach a stage of comprehensive analysis. It also refers to the observation of complexity and variance at different stages of the analytic process. The thesis involves the development of several literature reviews and empirical chapters over a period of three years, throughout which the researcher undertook a range of activities, including but not limited to: training in the use of qualitative methods and IPA specifically, discussing and developing themes with peer input, engaging in regular monthly supervision, as well as writing, rewriting, and editing multiple drafts of chapters. To add to this, the researcher's engagement with the topic of psychosis extends prior to this period, with it being the focus throughout a Master of Research degree (Griffiths et al., 2021), and previous research experience developing personalised prognostic tools for early management of psychosis. As such, the researcher's commitment to the field of psychosis extends beyond the scope of the thesis, demonstrating in-depth engagement with the present research. As the study uses IPA as its framework, there are no strict parameters for sample size as the primary concern is a high quality, detailed account of individual experience (Smith, Flowers, & Larkin, 2021), rather than a high number of participants as is the focus within quantitative research. Therefore, on the basis of achieving best quality in the amount of time possible, a minimum of 10 total participants was aimed for. Exploration of the dataset was prolonged and comprehensive, and the use of a multi-perspectival approach allowed the researcher to

include and transcend beyond an individual level, observing the complexities both within and between groups.

Transparency and coherence relate to the researcher's ability to not only describe participant's perspectives, but also construct this using a narrative approach in order to provide clarity and consistency. It also refers to the level of detail provided regarding each aspect of the data collection and analytic process. In this sense, the choice of a qualitative method, more specifically IPA, was a suitable one to answer the research question, as it concerned the lived experience of those experiencing psychosis and unusual phenomena. Given that personal assumptions influence the way we perceive or construct our reality (Bless & Fiedler, 2014), it is also key to reflect on the way in which the researcher's own beliefs were identified and managed so that the potential effect on methodological decisions and analysis can be understood. As mentioned in the section discussing sensitivity to context, an account of reflexivity is provided, outlining researcher experiences, beliefs, and assumptions and the way in which these factors affected decision making throughout the research. In further relation to transparency, the ontological and epistemological standpoint of the researcher, as well as the methodological decisions to employ first a qualitative approach and then IPA specifically, have been accounted for in this chapter, with detail provided where necessary for the purposes of clarity and coherence.

Impact and importance refers to the way in which the value of research can be assessed. Yardley (2000) states that it may not be enough for the researcher to provide a coherent and detailed account of findings if this has no impact on other's beliefs or actions. Rather, the value of the study is assessed via the objectives of the analysis and the sample population for whom

the findings relate to. Aside from the empirical data itself, research may also hold theoretical worth that allows for novel perspectives that contribute to new ways of understanding topics or concepts. To demonstrate the impact and the importance of the research, the first four chapters of the thesis identify a clear rationale for the importance of the research, justifying the necessity for and aims of the three empirical chapters following the methodology. This has been further explored in each discussion section, with distinct sections on the impact of the research provided throughout. Similarly, the overall discussion of the thesis will allow for further consideration of the impact and importance of the study, situated within the wider context of the literature review chapters.

4.4.2 High Quality Research Utilising IPA

Aside from adhering to the principles of Yardley (2000) for qualitative research, Nizza, Farr, and Smith (2021) outlined four markers of high-quality research specific to IPA, that also fall in line with some of the high quality markers listed by Smith, Flowers, and Larkin (2021). These factors include construction of a compelling and unfolding narrative, development of a vigorous experiential account, close analytic reading of transcripts, and attendance to convergence and divergence. In order to achieve these markers, the data will be analysed in analytic detail, going beyond description and ensuring coding for linguistic and conceptual points of interest. Individual transcripts need to be read closely at multiple points throughout the process, for example, initially, after the development of personal and group experiential themes, and then for a final time after the data has been analysed from a multi-perspective approach. Multiple readings allow the researcher to ensure that developed themes are reflective of all participant's and that nothing of importance was missed. Similarly, vignettes

have been created following the initial reading of transcripts for each participant in order to summarise the idiographic context, capturing and situating the individual within their lived experience, prior to the group analysis taking place. Similarities and differences both within and between groups are written into a narrative account that aims to coherently describe and reflect upon participant's experiences.

4.4.3 Reflexivity

In relation to the choice of topic, the comprehensive literature reviews, participant recruitment, data collection, analysis, and discussion, a reflexive stance has been implemented throughout. Reflexivity has previously been considered to be one of the key indicators when assessing the quality of the research method and that researchers should be considerate of their epistemological standpoint and personal reflexivity throughout (Finlay, 2006; Willig, 2017). This follows in line with the emphasis placed on auditing the research process within IPA, resulting in the development of a reflexive diary throughout that allowed for recognition of biases and assumptions and the impact of this on the data. The present chapter demonstrates throughout the way in which the researcher's ontological and epistemological standpoints corroborate with the philosophical and theoretical underpinnings of IPA. The researcher's personal assumptions surrounding both knowledge and the world, as well as the adopted critical realist ontology and interpretivist epistemology, have influenced the decisions made throughout the research process. With regards to personal reflexivity, both personal and professional experiences of the researcher have had an impact on the development of the research, the method of engagement with participants, and the analysis of the dataset. What

follows is a section of personal reflexivity with examples of how assumptions emerged and potentially impacted the research process.

As mentioned previously within this chapter, I have previous experience working with individuals who have a diagnosis of psychosis. Within my Master of Research in Clinical Psychology thesis, one chapter was dedicated to methods of differentiating between a religious belief and a delusion, intended for use as a tool during clinical research interviews. In examining the literature on psychosis for the research proposal, epistemic injustice emerged as a relatively unexplored topic, and appeared to bridge the gap between my interest in both psychosis and social justice.

My occupation as a research fellow for three years on Operation Soteria, researching the process of police investigation on rape and serious sexual offences, also provided the skills necessary to conduct interviews of a sensitive nature, as well as gain a deeper understanding of social injustice generally in its various forms. As a member of the Institute of Social Justice and Crime within the University of Suffolk, I regularly engage in meetings discussing themes such as equality and injustice. Although this is in relation to policing and survivors of rape or sexual violence, the underlying thread of injustice in society drives me to create change for those who are let down by systems that should serve to protect them. Having seen real change throughout my work in Operation Soteria, for example, an increase in suspect-focused investigations with improved contact and outcomes for victims, it is key for me that similarly, positive changes are also experienced by those with a diagnosis of psychosis in order to improve their quality of life. Psychosis and injustice have played a key role for most of my

academic life within higher education and work, and therefore, naturally led to a deep interest in epistemic injustice and psychosis specifically.

In consideration of bringing to awareness any preconceived assumptions (Davidson, 2003), particularly during data collection and analysis, I first considered my own understanding of psychosis and unusual experiences, and where these beliefs developed. In my previous work surrounding psychosis, the phenomenon was understood by the research team to exist as an illness or disorder that required medication and treatment in order to recover. As the present thesis aimed to explore the participants sense-making and understanding of the experiences defined as "unusual" or "psychosis", I attempted to understand and bracket off my previous assumptions, such as through careful consideration of terminology throughout the empirical chapters. Additionally, close discussion with the primary supervisor of the research (APF) was particularly important for reflecting upon these terms, especially given that APF is a senior clinical psychologist who works in an applied setting with the target population, and adopts a non-medical approach towards understanding psychosis. Although rationale was provided for the use of these terms throughout previous chapters, the following three empirical studies aim to reflect the participant's subjective experience of this phenomenon as opposed to the way that psychiatry and dominant medical models make sense of it. Throughout the write-up therefore, I have aimed to use the participant's own language where possible and avoided using terminology with potentially negative connotations such as illness or disorder, unless it was deemed to be reflective of the participant's understanding.

With regards to unusual phenomena, I acknowledge my own personal experience of this, as well as the way in which my culture and religion play a significant role in making sense

of these experiences. As a Muslim, I relate to the way in which other Muslim participants within the research understood what they were going through, identifying similar beliefs surrounding the way Jinns are a heavily emphasised and taught component of Islam during childhood and growing up, and their relation to nature in the world. Concerns were recognised around the analysis potentially leaning heavily on an Islamic point of view as a way of making sense due to three of the non-clinical participants adopting this viewpoint, in comparison to one supernatural, one spiritual, and one preternatural interpretation. However, by remaining mindful of the aims and objectives throughout the research process, analysis and write-up of the data were framed in a way that aimed to answer the research questions i.e. by exploring the way that participants made sense of their experiences, regardless of whether these converged or diverged from my own. Additionally, close supervision with the primary supervisor (APF) helped to illuminate my own views, especially in terms of the plausibility of interpretation and analysis, given that he is a White, non-religious male. The communication of some participants within interviews across both clinical and non-clinical groups was observed to be influenced by a perception of a shared religion and culture. For example, although I made no personal reference to either of these, different languages were used in places by participants, suggesting that they felt comfortable to open up and describe things in a way that was possibly easier for them, but also indicating an expectation of me based on perceived cultural similarities. Two examples of this are provided below, along with how this was managed.

In the first example within the quotes below by Yusuf, during some difficulty describing his experience, he questioned my belief in the phenomenon of Jinns, perhaps making assumptions about similar religious beliefs due to my name or appearance. Here, shared

religion and culture felt as though it had an impact upon the interviewer and interviewee relationship, where both descriptions and understanding could come easier than with an interviewer of different beliefs. Hence, the use of Arabic and Punjabi/Urdu within any participant interview was followed up with further prompts and questioning, despite the personal understanding that I may have derived from it.

> "I'm, I'll like, it's, the-the Jinn like, like obviously you believe in them, yeah?"
> (Yusuf – p. 36, 1326-1327)

Through observation during this moment in the interview, Yusuf appeared to relax after confirmation that I shared in his belief in Jinns, and was able to articulate his experience in relation to them where previously he had difficulty. Despite acknowledgement of this shared understanding, I aimed to remain neutral and not allow personal assumptions to provide meaning that had the potential to be different to Yusuf's reality.

> "Yeah well, they don't, we don't really discuss things. I mean, we're aapne."
> (George – p. 6, 189-190)

Similarly, in George's quote above, the use of "aapne," meaning Asian but more literally translated to 'your own/yourself,' provides a wealth of context that would possibly go unidentified if I had less understanding of the cultural background. For example, although George states that his family "don't really discuss things," the explanation of "we're aapne" situates this lack of communication within a cultural context, and for me personally, relates to specific elements such as shame, honour, stoicism, and concerns of community judgement. Whilst this allowed for deeper understanding of the way George may perceive the response of his family to his experience, I remained careful during analysis to only analyse the transcript and interactions with the participant, without being clouded by potential meanings applied by

my own understandings i.e. not assuming the response to his experience to be one of 'shame' if George had not alluded to this himself.

The influence of shared culture and religion that appeared to play a role within interviews had the potential for implicit meaning to be usefully shared and illuminated; however, many participants did not share the same cultural heritage as me. For example, South African cultural beliefs were significant to one participant and present throughout the transcript. This may mean that an interviewer with a South African background may have been more likely to understand cultural contexts without extensive elaboration, and the interviewee may also have been more likely to explain certain elements of the phenomenon in a way that came more naturally to them. With regards to my personal beliefs, there was an authentic and strong interest in learning about how others make sense of similar phenomena and how they are impacted by this understanding, and therefore, it was not felt that religion or culture influenced the findings of the studies. Whilst I have my own beliefs and interpretations regarding unusual phenomena, utilising Islam as a framework of understanding, I also hold the belief that this is not the case for everyone and that individual's subjective interpretations are also a truth for them. In order to bridge any gaps and make sense of the way the participant interpreted their experience, several prompts were utilised throughout the interview, and I attempted to relate to all participants in both groups as a person, outside of any shared cultural or religious beliefs.

Despite being familiar with qualitative methods and analyses generally, I was unfamiliar with IPA specifically, with the resulting empirical chapters being the first outputs where I have utilised this analytic method. This first attempt at using a qualitative approach within an interpretivist paradigm developed as a steep learning curve, whereby the philosophical

underpinnings in relation to the preparation and execution of data collection and analysis led to difficulties throughout the process, alongside new understandings. The guidance from the primary supervisor of the research (APF) throughout was crucial to the knowledge gained regarding IPA and for following the correct process of data analysis, as well as for engaging with the write-up in a method that was both reflective of my epistemological standpoint and accurately representative of the participants at a group level.

The present chapter aimed to outline and justify the methodological decisions made to fulfil the wider aims of the thesis. This includes the basis for adopting a qualitative methodology, but more specifically an interpretative phenomenological approach to data collection and analysis. It was determined that IPA (Smith, Flowers, & Larkin, 2021) was the most well suited approach to data collection and analysis, in order to answer the research questions:

(i) How do people who experience psychotic or unusual phenomena make sense of their experiences?

(ii) How do people who experience psychotic or unusual phenomena make sense of how they are treated by others?

(iii) What are the similarities and differences in sense-making and treatment by others between groups, and how do these experiences relate to epistemic injustice?

Chapters 5 and 6 will seek to explore these research questions using the method of IPA, with Chapter 7 utilising a multiperspectival approach to analyse any similarities or differences between the two perspectives of those with an unusual experience and those with a diagnosis of psychosis.

Chapter 5

EXPLORING FRAMEWORKS OF UNDERSTANDING AND MEANING-MAKING PROCESSES IN PEOPLE WITH UNUSUAL EXPERIENCES

Abstract

Aim: The study aimed to explore how individuals make sense of their unusual experience and how they feel they are treated by others.

Method: Six individuals (F=4, M=2) between the ages of 22 and 31 were interviewed over Microsoft Teams. Transcripts were analysed in accordance with the steps of IPA, first undergoing a case by case analysis, before a group analysis.

Results: Four main themes emerged from the findings: (i) '*Rationalising the experience as simply unusual;*' (ii) '*Sense-making can be inherent or taught dependent on the individual;*' (iii) '*The significance of the other in society*;' and (iv) *'Legitimacy and validity of the unusual experience'*. The themes outlined how participants felt the experience was not severe enough as to cause distress or seek professional support, deeming it simply unusual, as well as making sense of their experience through supernatural beliefs or individual personality types. Participants described their fear of being perceived as mentally unwell, leading to concealment of the experience from others. The final theme highlighted ways in which the unusual experience was validated or invalidated by both the self and others.

Conclusion: Some ways of making sense of the unusual experiences were accepted by others depending upon shared religious beliefs and knowing personal backgrounds, however, fear of

stigma remained for all participants due to the potential links between unusual experiences and illnesses such as psychosis. This research provides insight into the lived experience of these individuals and suggests ways that public perception can be improved.

5.1 Introduction

5.1.1 The Psychosis Continuum

The term 'psychosis' is encompassing of several types of symptoms, including but not limited to, positive symptoms such as auditory and visual hallucinations or delusions. More recently however, it has become evident that these symptoms are not constrained to psychosis itself, but also occur in individuals without a medical diagnosis (Unterrassner et al., 2017). Research has also evolved to consider a more dimensional approach towards psychosis rather than a categorical approach, including concepts such as anomalous or psychotic-like experiences (Brett et al., 2007). These experiences occur in the general population at an estimated prevalence of 5-10%, in comparison to 0.7% for psychosis, often described as temporary and not associated with distress (Bosma et al., 2023). This shift to symptoms associated with psychosis being on a continuum suggests that not all psychotic-like experiences are pathological, with the lack of distress implying that professional care is not always required (Boumans et al., 2017; Verdoux & van Os, 2002).

Similarities have been noted between non-clinical and clinical[7] populations experiencing phenomena associated with psychosis, for example, adverse childhood experiences (Campbell

[7] The term non-clinical refers to the group of participants that have an unusual experience but do not have a clinical diagnosis, whilst the term clinical refers to the group of participants that do have a diagnosis of a schizophrenia spectrum disorder.

& Morrison, 2007; Schreier et al., 2009), substance use (Mackie, Castellanos-Ryan, & Conrod, 2010), and social risk factors (Laurens et al., 2008; Scott et al., 2006). In fact, much of the research on psychotic-like experiences is from the viewpoint of it being a non-clinical psychosis phenotype that has distinct developmental trajectories of being persistent and increasingly severe (Kelleher & Cannon, 2011; Mackie, Castellanos-Ryan, & Conrod, 2010). Supporting this, a systematic review on the definition of psychotic-like experiences found that the majority of studies defined this quantitatively via the use of assessments, and that there was no recognised phenomenological definition for this (Lee et al., 2016). They also found that only 8 out of the 76 studies they reviewed examined psychotic-like experiences from a phenomenological standpoint, suggesting a significant limitation of the current literature. Given that psychotic-like experiences are a relatively recent phenomena (Brett et al., 2007) and no current consensus exists on the definition of this, a phenomenological approach is necessary to allow for a deeper and more holistic understanding of the lived experience of this target population (Lee et al., 2016).

According to current consensus, there is a need to develop a 'gold standard' assessment tool for psychotic-like experiences, as well as a clear and universal definition (Hinterbuchinger & Mossaheb, 2021; Lee et al., 2016). Taking this into account, the present study will refer to these phenomena as 'unusual experiences' for two reasons. The first being that despite there being no clear definition, much of the literature points to this being a specific stage of the continuum, where individuals may be prone to developing psychosis (Mackie, Castellanos-Ryan, & Conrod, 2010). Given that the aim of the present study is to understand the way in which individuals themselves make sense of these experiences, as well as how they are treated by others in relation to this, no specific assessment tool was necessary for inclusion. Rather,

individuals with a minimum of one unusual experience within the last 5 years were deemed eligible, distinct from the persistent and increasingly severe development thought to be associated with these experiences (Kelleher & Cannon, 2011). Secondly, considering the fact that there is a wealth of literature surrounding stigma towards psychosis[8], the present study aims to distinguish whether this stigma is relative to the label or to the actual experience. Therefore, by removing the term 'psychotic-like,' this may potentially remove any bias or negative associations with the term, so that focus can remain on the experience itself. The introduction will proceed through a review of the current literature on psychotic-like experiences, despite it being limited (Lee et al., 2016), and thereafter the term 'psychotic-like' will be replaced with 'unusual.'

5.1.2 The Experience of Psychotic-Like Phenomena

In the aforementioned systematic review (Lee et al., 2016), the 8 studies that examined psychotic-like experiences from a phenomenological perspective appeared to focus on the types of symptoms experienced. For example, some of the findings included lower levels of distress, preoccupation, and conviction associated with the experiences (Lincoln, 2007; Peters, Joseph, & Garety, 1999), and emerging subtypes of psychotic-like experiences, such as bizarre experiences, perceptual abnormalities, persecutory ideas, and grandiosity / magical thinking (Armando et al., 2010; Yung et al., 2009). Very few studies were found that explored this phenomena qualitatively, indicating a gap in the literature for understanding the lived experience of this. Of the research identified, two aimed to explore how individuals made

[8] See Chapter 3 (Meta-Ethnography) for a detailed systematic review on stigma in the context of psychosis.

sense of this (Pigeon-Gagné et al., 2022; Yehya et al., 2022), one examined how they coped with the experience (Boumans et al., 2017), and the final one attempted to distinguish between psychotic-like experiences and psychosis via the context in which they occurred (Heriot-Maitland, Knight, & Peters, 2012).

In comparing clinical and non-clinical experiences, similarities were noted, mainly the occurrence of both during a time of significant negative emotion (Heriot-Maitland, Knight, & Peters, 2012). Similarly, in both groups, the experience provided participants with emotional fulfilment and were interpreted as being an adaptive and psychologically beneficial problem-solving process. Supporting this, Boumans et al. (2017) also found that psychotic-like experiences served as a functional 'safe haven' that individuals could retreat to when difficulties in life became overwhelming. Additionally, the ability to maintain relationships with others was identified as a way of coping outside of requiring professional support (Boumans et al., 2017). Others also played a significant role in participants being able to handle their psychotic-like experiences, both personally and socially (Heriot-Maitland, Knight, & Peters, 2012). It was found that alongside an open attitude towards the experience, individuals also received acceptance and validation from others, in comparison to those with psychosis facing invalidation. Despite both groups showing awareness as to the potential negative reaction and pathologisation of their experiences by others, in line with past literature, only the group with psychosis actually received this (Heriot-Maitland, Knight, & Peters, 2012). It may be theorised here that the difference in treatment from others is due to the label of psychosis rather than the experience itself, potentially explained by Fricker's (2007) concept of epistemic injustice. This suggests that psychosis as a label may be the clinical lens via which individuals are

perceived by others, thereby treating and invalidating them in accordance with the associated stigma, despite the fact that those without a diagnosis can have similar experiences.

Using thematic analysis to explore the way people made sense of what they were going through, Yehya et al. (2022) found that psychotic-like experiences were shaped by religion and culture. Interviewing 12 female students in Qatar, it was found that the content of their experience was heavily influenced by their religion, for example, hallucinations that involved the call to prayer, as well as religious garments. Kovess-Masfety et al. (2018) found that in a review of data from the World Health Organisation surveys, more religious Christians were increasingly likely to report psychotic-like experiences, in comparison to their less religious counterparts, supporting the idea that religion can play a significant role in the occurrence of this phenomena. Similar to previous literature (Boumans et al., 2017; Verdoux & van Os, 2002), Yehya et al. (2022) also found that these experiences were not distressing for the individuals, nor did they have an impact on daily functioning. In a study that interviewed 107 participants from Burkina Faso and utilised thematic analysis, explanatory models for psychotic-like experiences were rooted in the supernatural and were validated by those with shared beliefs in spirits and Jinn within the community (Pigeon-Gagné et al., 2022). Despite this shared interpretation, participants reported concealment of these experiences from direct family members, fearing potential classification as a 'mentally ill' person. The social ramifications of this could be seen to be particularly harmful for females, as it is males that are held in higher esteem with regards to access to the supernatural (Pigeon-Gagné et al., 2022). Yehya et al. (2022) found that in Qatar, males were less willing to participate in the study, potentially due to the stigma surrounding mental health. Despite this, both studies highlighted the significance culture and religion can play in shaping psychotic-like experiences, as well as the way perceived

judgement from others can lead to concealment (Pigeon-Gagné et al., 2022; Yehya et al., 2022).

5.1.3 Rationale and Aims

Having considered the limited literature surrounding psychotic-like experiences, the present study will now replace the term with unusual experiences. Although a case can be made that changing the terminology of a concept that currently exists within the literature may not be beneficial in moving towards a clear and universal definition (Hinterbuchinger & Mossaheb, 2021; Lee et al., 2016), the present study does not seek to build upon the phenomena as it appears to be currently understood. Rather, shifting from the view of these experiences as related to the aetiology of psychosis, the current study aims to simply understand the lived experience of those who face unusual phenomena without a medical diagnosis.

Despite the lack of research in this area, some key findings can be noted in the literature, mainly the way in which these experiences are shaped, made sense of, and viewed by others in comparison to psychosis (Boumans et al., 2017; Heriot-Maitland, Knight, & Peters, 2012; Pigeon-Gagné et al., 2022; Yehya et al., 2022). Although these studies made significant contributions towards understanding the lived experience of this group of people, the use of 'psychotic-like experiences' as assessed via tools means that there is the potential for some bias to be involved. It is possible that this term was used during the method of recruitment for the research, and potentially during the interview. Given what is known in past literature regarding the stigma towards psychosis, there is the potential that for individuals who participated in the study, responses could be influenced by stigma they themselves may hold

towards psychosis. The term ‘psychotic-like’ may also influence recruitment, particularly as Yehya et al. (2022) noted that males did not participate in the research, speculating that this was due to the stigma they face surrounding mental health. Framing these experiences as unusual, rather than associating them with a well-known, stigmatised medical diagnosis, may offer an alternative route to understanding and recruitment.

Another difference between past research and the present study is the key focus. In previous studies (Boumans et al., 2017; Heriot-Maitland, Knight, & Peters, 2012; Pigeon-Gagné et al., 2022; Yehya et al., 2022), the aim was to understand the ways in which sense was made of the unusual experience, as well as how they compared in context to psychosis. The present study aims to build on this by making the perceived and actual treatment of others a focal point. Concerning the wider aims of the thesis, in order to better understand the underlying processes of stigma towards psychosis, it is key to explore whether this stigma is relative to the diagnosis or label of ‘psychosis,’ or to the experience itself. By exploring the lived experience of those who have faced unusual phenomena but are not diagnosed with a medical disorder, we can go some way in comparing and understanding this. Previous studies utilised a variety of methodological frameworks, including grounded theory (Boumans et al., 2017), thematic analysis (Pigeon-Gagné et al., 2022; Yehya et al., 2022), and IPA (Heriot-Maitland, Knight, & Peters, 2012). Given the nature of the research questions outlined below, the present study seeks to add to the existing literature that utilises IPA in order to elicit rich data that will allow for inter-group comparisons in future chapters of the thesis. Based upon the aims mentioned, the research questions are as follows:

(i) How do people who experience unusual phenomena make sense of their experiences?

(ii) How do people who experience unusual phenomena make sense of how they are treated by others?

5.2 Method

5.2.1 Design

The study was approved by the Surrey Research Ethics Committee (REC reference: 20/PR/0616; date 09/03/2021; Appendix 4) and the Health Research Authority (IRAS number: 286804; date 01/04/2021; Appendix 5). The design has been reported in line with the Consolidated Criteria for Reporting Qualitative Research (Tong, Sainsbury, & Craig, 2007). As the research was concerned with understanding the lived experience of people facing unusual phenomena, a qualitative, phenomenological approach was utilised and data was collected via semi-structured interviews. Adopting a critical realist epistemology, it was assumed through analysis that a 'real' world exists for each participant, however, this reality cannot be known by researchers with certainty[9].

5.2.2 Participants

Participants were recruited via purposive and snowball sampling methods. Inclusion criteria were: (a) adults (18+ years); (b) English as a first language; and (c) at least one unusual experience in the last 5 years. The experience must have occurred within the last 5 years to ensure that participants would be able to recall significant details surrounding the experience.

[9] For more discussion on the suitability of IPA to the study, see Chapter 4 (Methodology) of the thesis.

These unusual experiences may include but were not limited to: (i) seeing or hearing something that they find, or others may find, to be unusual; (ii) having beliefs that others find unusual (these may be spiritual / religious in nature); (iii) having an out-of-body experience or feeling like they are not themselves; and (iv) feeling like their thoughts may not be theirs at times. These examples were chosen as they take into account the core domains in the Appraisals of Anomalous Experiences Interview (Brett et al., 2007). Feeling suspicious or paranoid about others talking about the individual were not included within the scope of examples as this may have led to recruiting participants who have more distressing experiences rather than unusual. Individuals were excluded from the study if they: (a) had a past or current diagnosis of a psychiatric condition; or if the unusual experience (b) occurred whilst waking up or falling asleep due to the possibility of hypnopompic or hypnagogic hallucinations; (c) occurred whilst unconscious; or (d) was related to alcohol, medication, or drug use.

Participants were recruited via posters (Appendix 6) and adverts (Appendix 7) uploaded to commonly used social media sites. All individuals who contacted the researcher were provided with a copy of the information sheet (Appendix 8) and a screening questionnaire to complete if they were interested in taking part (Appendix 9). Individuals had the opportunity to ask questions about the research prior to deciding whether to participate. At this stage, if individuals were eligible to take part and expressed their interest in participating, a suitable date and time was set for interviews to take place via an online platform. Informed written consent (Appendix 10), along with demographic details (Appendix 11), were obtained at the online meeting, and verbal consent was obtained at the beginning and end of the interview to ensure participants were still willing to take part. A total of 8 individuals expressed interest in

participating, however, due to difficulties identifying a suitable time, 2 individuals declined to participate prior to interviews taking place. A total of 6 participants were recruited and interviewed for the research (Table 5.1). Unusual experiences of the participants included: seeing people that others could not see; feeling a physical presence; movement of objects; feeling held down by an external force; and possession.

Table 5.1
Demographic details of participants

Pseudonym	Age	Gender	Ethnicity
Madeline	27	Female	White
Rayna	27	Female	Pakistani
Zeke	22	Male	Mixed White and Black (Afro-Caribbean)
Sara	29	Female	Pakistani
Yusuf	29	Male	Pakistani
Chloe	31	Female	Mixed White and Black (Caribbean)

5.2.3 Data Collection

Data was collected via semi-structured interviews and conducted solely by the primary researcher. The interview schedule (Appendix 12) was developed in consultation with two members of the research team: a philosopher (LB), and a clinical psychologist (APF). Careful consideration was also given to the questions and prompts during the development of the interview schedule to minimise any potential distress surrounding the sensitive nature of the topic. In consideration of this, participants also had the opportunity to take a break or stop the interview at any point without providing a reason why.

Smith, Flowers, and Larkin (2021) noted how online interviewing may affect the researcher's judgement on the participant's level of distress, and indicators of when to intervene and implement appropriate action may be missed. As recommended, this was

discussed prior with the primary supervisor (APF) and a risk protocol was developed (Appendix 13) (Smith, Flowers, & Larkin, 2021). Additionally, the researcher's occupation as a research fellow involves online interviewing of police officers on sensitive topics (rape and serious sexual offences)[10], and therefore, the researcher had a level of confidence in not only ethical considerations and their interviewing capability, but also their ability to identify distress and take suitable action.

Participants were provided with a list of support services (Appendix N) they could access once the interview was complete. Interviews were conducted remotely via an online platform between November 2021 and December 2021 due to the Covid-19 pandemic, lasting between 22 and 84 minutes. Interviews were audio-recorded via a secure Dictaphone and transcribed within 2 weeks from the point of interview, during which time participants had the opportunity to withdraw their data from the study. After this point, recordings were deleted and transcripts were pseudo-anonymised so data could not be traced back to individual participants.

5.2.4 Data Analysis

Interpretative Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2021) was used to analyse the dataset due to its focus on exploring the lived experience surrounding a certain phenomenon. Table 5.2 outlines the steps followed in order to analyse the transcripts following the method of IPA.

[10] See Chapter 4 (Methodology) for a full reflexive account.

Table 5.2
Steps followed to conduct the data analysis using IPA (Smith, Flowers, & Larkin, 2021)

Non-technical description	Phases	Technical description
Step 1 Get to know the data		
Step 1a Get to know your interests and preconceptions		Reflexive reading
Step 2 Conduct detailed exploratory analysis, staying close to the account		Exploratory notes
Step 3 Articulate the main claims you are making about the meaning of the person's experience on the basis of their account		Experiential statements
Step 3a Summarise the idiographic context in order to capture and situate the individual within their lived experience (Appendix 15)	**Phase 1:** Working towards experiential statements	Vignettes
Step 4 Organise the work you have done around the main claims and supplement it with 'at a glance' annotation		Preliminary clustering of statements Supplementary annotation Reflexive threads
Step 5 Consolidate your case analysis in a case level summary (Appendix 16)	**Phase 2:** Working towards case-level summaries	Structured consolidation of case-level work mapping to Personal Experiential Themes (PETs)
Step 6 Repeat 1-5 for each case, allowing time and space to go back a step and add	**Phase 3:** Working towards cross-case themes	

further reflections, interpretation, or notes		
Step 7 Review the case-level summaries and identify candidate themes which cut across the cases (Appendix 17)		Group experiential themes (GET) Shuffle and sort components of the PETs Reflect on contributions made by each PET to developing each GET
Step 7b Review the emerging analytic structure in supervision Add further reflections, interpretations, or notes Revise themes as appropriate		Discuss proposed structure and revise accordingly
Step 8 Finalise the analytic structure	**Phase 4:** Working towards a linear account of the thematic structure	Finalise subthemes and structure Use structure to make a plan for writing up each section Use PETs to identify quotes to support each theme
Step 8b Review work for audit trail		Make sure plan includes opportunities to reflect on variations across cases
Step 9 Work with supervisor to decide how to present some or all of the structure in a linear, written report		Reflect on the level of granularity you can include

5.3 Results

Analysis of the data resulted in four main themes, consisting of a total of nine sub-themes. The contribution of participants across the subthemes can be seen in Table 5.3. Each sub-theme reflects the main focus of the research relating to the participant's unusual experiences and how this is made sense of by themselves and others. Each sub-theme is explored below

within the main themes, illustrated with quotes from the participants, as well as researcher interpretation.

Table 5.3
Demonstration of which participant contributed to which sub-theme.

Theme	Subtheme	Participants					
		M	R	Z	S	Y	C
1: Rationalising the experience as simply unusual	1.1: The experience is justified as unusual, and interpreted as mostly connected to the supernatural	✓	✓	✓	✓	✓	✓
	1.2: The unusual experience is not severe enough to require professional support	✓			✓		✓
2: Sense-making can be inherent or taught depending on the individual	2.1: Individual beliefs and personality types affect the way sense is made of the experience	✓	✓				✓
	2.2: Religious beliefs are taught by others and contribute to understanding the experience		✓		✓	✓	
3: The significance of the other in society	3.1: The other is key for determining both normality and reality	✓					✓
	3.2: Fear of being perceived as ill and not being believed leads to concealment of the experience from others	✓		✓	✓	✓	✓
	3.3: Others understand the unusual event if they have personal experience or shared interpretation of it		✓		✓	✓	✓
4: Legitimacy and validity of the unusual experience	4.1: The unusual experience is validated by others on the basis of identity and shared beliefs	✓	✓	✓		✓	
	4.2: The unusual experience can be invalidated by others and the self	✓	✓	✓	✓		

5.3.1 Theme 1: Rationalising the Experience as Simply Unusual

The first theme relates to the way in which participants made sense of their experiences, categorising what they went through as unusual and disconnected from reality, but not as severe as to require professional support. For all participants, there was an attempt to justify the unusualness of what they went through, differentiating it from more common experiences, with some choosing to adopt a supernatural explanation. Additionally, for Madeline, Chloe, and Sara, they also outlined the distinction between the unusual experience that they had and what would be considered a clinical experience.

1.1: The experience is justified as unusual, and interpreted as mostly connected to the supernatural

All six participants contributed to this subtheme, justifying their experience as unusual and in most cases, confident that there was a supernatural explanation for it. Madeline, Sara, and Chloe all highlighted different factors that made the experience unusual. This included the mundanity of the experience, the recurrence of it, and the impact of it.

> "I think it's quite funny that my one that stood out to me was just, there wasn't anything that I can think of why it would happen, that the person that I saw wasn't anybody I knew, it was just kind of there, it was so uneventful [laughs], and so uninteresting actually, as a situation." (Madeline – p. 5, 155-158)

> "But when it happens to you loads and loads and loads and loads, there's only so many coincidences that can happen in life. It's like you can look at your clock and it just turns to say 11:11, for example. Those things can probably be a coincidence. But then when you look later on and it's 12:12, and it's 13:13, it isn't that I'm being mindful to man it, like watch the clock. Because I definitely ain't. But I notice these things." (Chloe – p. 13, 459-464)

Madeline noted how the juxtaposition of the experience being unusual on the basis of the surrounding circumstances being ordinary "was a bit surprising" (p. 3, 97). She acknowledges that this is unusual due to occurring on "a very average day," unable to link it to "sleeping" or being "under any drugs" (p. 2, 52-53). This suggests that context surrounding an experience matters, especially during the process of rationalisation. Madeline also displayed some certainty surrounding her unusual experience not being grounded in reality, stating that her "brain can just imagine stuff that isn't there" (p. 16, 569). For Sara, she experienced a physical "rush through my body" that caused her to think the event had "something more to it" (p. 2, 46-49), whereas, for Chloe, the recurrence of the experience negated the chance of it occurring due to a coincidence. For all participants except Madeline, they were comfortable

with not linking their experience to real-life stressors, but rather accepting supernatural explanations to make sense of it.

> "After a bit I'm like, 'no, there is something downstairs and it definitely knows I'm here.' And especially when that telly's [television] come on as I'm going upstairs, that's when I'm like, 'there's something knows I'm down here.'" (Zeke – pp. 2-3, 68-70)

> "Sometimes you can differentiate between, 'okay, that's like my pipes because the heater's cooling down. Oh, that's the boiler.' But when you know there's nothing on at all and you hear certain noises, it is a bit, 'oh, okay. What is that?' Which does make you think, it's not to say all the time it's spiritual related, but sometimes it is obvious that it is, if that makes sense." (Chloe – p. 15, 521-525)

> "I'm Muslim and whatever happened obviously, it's always linked back for me to our religion. So, it's linked to Jinn possession." (Yusuf – p. 1, 11-13)

In order to make sense of the experience, Rayna, Sara, and Yusuf linked the explanation back to their religion, using Islam as a framework to rationalise. Rayna described how she was "a firm believer that it's not just humans that walk this earth" (p. 5, 155-157), labelling this as her "natural instinct or natural way of thinking" (p. 13, 467). Whilst he makes no mention of his religious beliefs, Zeke also alludes to belief in the supernatural, making sense of his experience as "something downstairs." For Chloe, her lack of any other explanation for her experience led to spiritual reasoning as an alternative interpretation. She also provided justification regarding the strangeness of her experience, differentiating it from other more common events. In the absence of a supernatural interpretation, the experience was still not rationalised as grounded in reality for one participant, attempting to instead make sense of this biologically.

1.2: The unusual experience is not severe enough to require professional support

Although all participants justified their experience as being unusual, Madeline, Chloe, and Sara added to this justification by differentiating between an unusual experience and one that

required professional support. All three highlighted different ways to make this distinction, but for Madeline, the mundane description of her experience caused her to reflect on this as simply being something unusual as opposed to clinical.

> "But I think the funny thing is, I remember thinking, obviously with doing some stuff in psychology, you think about that and you're like, 'oh right, is this like a clinical, worrying thing?' But it's so anti-climactic that I know will sometimes be.. I just see like you're on a street and I see a person there but they're not doing anything, they're just like another person so it's not anything. It's not a very exciting…'something' that is happening, it doesn't really disrupt any bit of my day." (Madeline – p. 2, 59-67)

Again, Madeline describes the juxtaposition of the unusual experience being ordinary and mundane, however, she also utilises this as a reason for it not to progress to the level of concern. From this, it can be assumed that the level of distress surrounding an experience is indicative of where or not this is something to worry about from a medical point of view. The lack of distress she associates with her experience also means that her functioning during the day is not disrupted. This also suggests that for Madeline, whether or not an unusual experience is disruptive and has an effect on functioning is a method of distinguishing between the two types. For Chloe, her way of making this distinction included the level of preoccupation an individual demonstrated with their experience.

> "I've actually finally found a friend who's into it [tarot readings] as well. And if anything, she's into it more than me, so she'll send me things. I don't sit and practice anything. I'm not like a worshipper or anything of the sort like that. But it's just more, 'ah, I actually really like this. I find comfort from it. It's really interesting.' As opposed to sitting and worshipping it, if that makes sense." (Chloe – p. 5, 173-179)

> "I think it depends on what behaviours they're displaying, because some people can kind of become overly obsessed. So, at best it becomes like, they hear the slightest noise and they're like, 'oh my gosh, the spirits are in here.' Or whatever, when the reality is your pipes are probably making noise or your heating or whatever it is." (Chloe – p. 8, 268-272)

Chloe highlights the differences in the intensity of a belief, acknowledging where one may verge on a problem if the individual becomes "overly obsessed." She views this distinction as a fine balance between "overbearing" and "obsessive" (p. 8, 277), and just "something I enjoy looking into" (p. 15, 538). She also believes that when it comes to diagnosis, "there would be additional needs" present (p. 9, 306), "as opposed to someone's general beliefs" (p. 8, 274). Chloe also commented on the fact that others around her never suggested she needs any additional help, as it is simply something she enjoys looking into that provides her with comfort. Aside from distress and preoccupation, the final distinction was made by Sara, who felt that recurrence of an experience can advance it from unusual to an experience that requires professional support.

> "It's not affected us in a big way. Obviously, I did feel that rush in my body and I do feel like if it happened again and again, then I would definitely feel like I have to see someone, because it would obviously play with me mentally." (Sara – p. 19, 704-707)

Despite Sara's explanation of the experience being the result of something supernatural, she still acknowledges that continuous experiences may lead to help-seeking behaviours. She states that due to it being "just that one time," she was able to "get over it;" however, if this did "carry on happening, I would definitely need to talk to someone about it" (p. 20, 714-715). She felt the same was true for others having unusual experiences too, believing that it is the constant psychological impact of the experience that potentially leads to medical support. For Madeline, Chloe, and Sara, the lack of distress, the preoccupation, and the recurrence of an unusual experience respectively, were all ways of distinguishing between something unusual and something clinical.

The first theme highlights how participants with unusual experiences made sense of these as disconnected from reality but deemed professional support unnecessary due to the lack of distress associated with the experience. For all except one, a supernatural or spiritual-based explanation was used to understand the unusual experience. Notably, all of the participants who adopted this framework of understanding were from ethnic minority (within the UK) backgrounds, in comparison to one participant (White) who made sense of the unusual experience as her brain potentially imagining things. This potentially suggests that cultural background and/or religious background may play a key role in understanding and interpreting unusual experiences. This is explored further in the next theme, where participants consider the ways in which both culture/religion and individual personality type contribute to the way they made sense of their experiences.

5.3.2 Theme 2: Sense-Making can be Inherent or Taught Depending on the Individual

The second theme relates to how participants felt they made sense of their experiences and what factors significantly contribute to this. Madeline and Chloe describe this process as entirely dependent upon individual personality types, compared to Sara and Yusuf who related their sense-making to religious beliefs taught during childhood. For Rayna however, she acknowledged that both processes of rationalisation could exist simultaneously, as they did for her.

2.1: Individual beliefs and personality types affect the way sense is made of the experience

For Madeline and Rayna, they felt they were able to make sense of their unusual experience based on predisposition to certain things or personality type. Despite Rayna's religious beliefs

contributing to her understanding of the experience, she still acknowledges her individuality within this interpretation.

> "I feel like even if I wasn't a Muslim, I'd believe that these things exist. I'm very open to the idea of all these things so, religion or not, I would still have the exact same answers." (Rayna – p. 12, 422-425)

> "I've always been inherently quite like a creative person and I have a really strong imagination and I've always had that as a child and I can really immerse myself into my own world, so I think… while that gives me lots of really wonderful benefits to have a mind like that, I think sometimes the side effect is that I can have weird experiences 'cause of the way my mind might be able to work and imagine things." (Madeline – pp. 4-5, 143-148)

For Madeline, her creative personality type lent itself to an active imagination that influences her unusual experiences. Aside from inherent personality traits, she also felt she was predisposed to experiencing unusual things. With reference to the experiences, she views herself as "the kind of person that is more likely to be inclined to that" (p. 2, 40-41), and as being "really susceptible" to that (p. 3, 107). Although it can be difficult to remove biases about the world we know, Rayna separates her religious beliefs from her "very open" individual personality and frames her sense-making as a result of both. It also suggests that religious beliefs, for her especially, can simultaneously exist with other beliefs or viewpoints. The notion that sense-making is dependent upon individual personality also extended to shared cultures or religions, where Madeline felt that different worldviews still exist within collective communities. For Chloe, an event could also be perceived differently depending on individual beliefs, further suggesting that individual personality determines the sense that is made of an experience.

> "When you have something so weird that you don't know… that you can have so many different explanatory models to it and it's probably one of those ones where, without realising, there's so many different people who would have such strongly

> different ways of looking at it, even within the same culture." (Madeline – p. 17, 611-616)

> "It's about manifesting and believing in the spiritual.. in terms of believing in it, say for example, if you want something to happen so much, they promote you manifesting it. So, manifest it in the sense that it's almost happened. So, by putting it out to the universe, saying, 'I will pass my master's degree. I will.' So then, you can look at it from two perspectives, such as it's the belief of the spirit world guiding you, or you can look at it from the psychology aspect of it in that actually, by doing those positive affirmations each day, you kind of promote that confidence, promote that motivation to keep you going." (Chloe – p. 6, 185-190)

Sense-making was thought to be subjective to all individuals, regardless of any culture or faith they subscribe to. Madeline describes how events that are so far out of what is typically expected within society, naturally lends itself to several explanatory models, that differs with each person. Supporting this viewpoint, she described herself as being on the "constructivist side of life," believing in the idea that "there is a reality, but we also construct it in many different ways" (p. 17, 634-635). The subjectivity of the interpretations applied to unusual experiences was thought to arise from personal backgrounds or interests. For example, she describes how a friend's explanation of her experience was "ghost-esque," attributing this to their love of "horror films and ghost stories" (p. 8, 278-279). Similarly for Chloe, she also acknowledges the way in which someone views something is down to "personal beliefs" (p. 5, 156). In her quote above, she explains how one way of doing things can be perceived and made sense of in different ways. Both Chloe and Madeline suggest that the impact of unusual experiences will also affect people differently based on their individual beliefs.

> "I wasn't freaked out, because I was like, 'oh, I don't believe in ghosts.'" (Madeline – p. 18, 648-649)

For Madeline, her lack of belief in the supernatural made the experience neutral for her, and allowed her to feel connected to not only herself, but to the world and others around her. The

unusual experience acted as a natural check-in to her mental wellbeing for her as it tends to occur during periods of stress. She also describes feeling "connected" to others with shared experiences, viewing it as a "nice human bonding experience when you realise how many times people had unusual experiences throughout time" (p. 14, 510-512). In this sense, the experience may have even had a positive impact on her. Similarly for Chloe, despite what she believes as spiritual activity being described as frightening to people around her, particularly due to experiences of heavy objects falling over, her ex-partner being dragged out of bed, and lampshades swinging, she felt this to be a comforting and pleasant experience in most cases due to her belief in spirituality as a tool of guidance and protection.

2.2: Religious beliefs are taught by others and contribute to understanding the experience

Although some participants believed sense-making is dependent upon individual personality types, others used their religious beliefs as a framework of understanding. Sharing the same religion, Rayna, Sara, and Yusuf all explain how religious beliefs regarding Jinns are taught from a young age growing up.

> "Obviously, I heard these stories growing up." (Rayna – p. 20, 713)

> "Growing up, what I've heard is that they'll have more like Jinns living under trees. Or around trees or you know, places where, a lot of bushes and grass and stuff. And if you disturb their peace or if you're around that area doing something that they don't like, they will tease you or let you know that they're there." (Sara – p. 7, 222-227)

> "Even my little cousins from the age of about six, seven years old, again as sad as it sounds, they won't even get scared of seeing what they've seen because they just know straight away.'" (Yusuf – p. 12, 432-434)

According to Rayna, the reason she was taught about supernatural beliefs at a young age was due to her mother trying to "educate us on these things that are real" (p. 20, 747). She also

notes how this is taught via stories that are told about other people's unusual experiences. For example, she says her "mum told me about her uncle and my dad told me about himself" (p. 20, 743-745), suggesting open communication surrounding unusual experiences for the purpose of education. Though he describes it as sad, there appears to be an element of protection within Yusuf's life in relation to how they are taught to understand and cope with unusual experiences from childhood. This has the ability to normalise unusual events, lessening the potential negative impact if they were to occur. Similar religious beliefs were taught to both Rayna and Sara growing up, who both describe the connection between Jinns and nature. These taught beliefs in childhood contributed strongly to the way they made sense of their experiences as adults.

> "You tend to believe that all these paranormal things live amongst the trees and stuff. So growing up, we always heard stories about Jinns and all these different things. Then living across the road from like a really big park too, I do think at some point that it might have been something that came from that park." (Rayna – p. 6, 210-214)

> "I guess with our religion, we believe that there is Jinns, so we always question every time if something happens. Like the cottage time, we were in the middle of nowhere. Usually where there's grass around or trees around, we grew up hearing that there will be more Jinns around those places. And same with Turkey, there was a lot of trees around, so we thought the same thing." (Sara – p. 6, 202-207)

In both quotes, the belief of trees being the home of Jinns played a role in how they made sense of their unusual experience, identifying their surroundings as a reason for the event occurring. Sara also describes how other friends had interpreted their experiences as due to Jinns, relating it to their garden being "a bit of a jungle" with a "big bush at the back" (p. 15, 523-525). Her faith provided her with certainty and clear answers for her interpretation, stating that "as Muslims, we 100% believe what we believe" (p. 16, 587). The lack of room for alternative explanations meant that for Sara, this belief also extended to non-Muslims who

faced unusual experiences. She felt that due to the lack of shared faith, "they might not know what it is," but she feels "it would be that [Jinns]" (p. 20, 730-732). For Yusuf, with regards to how he made sense of what he was going through, he "always linked it back to my faith" (p. 26, 977), because "that's what gives the understanding" of what he was experiencing (p. 38, 1402). Whilst all three participants provided reasons for what they were going through, Yusuf also offered some additional insight into why he felt he had unusual experiences.

> "But for me, whenever anything happens, I see it as, 'okay, where am I going wrong in my life? Am I slacking in my prayers? Am I doing this? Am I just getting too comfortable in life, where I'm not really thinking about like, you know, my deen [religion] and my prayers? Or I'm praying a bit too fast, I'm not going to the Mosque and praying.' So, whenever something like this happens, rather than for me, this is how I see it personally, for me seeing it as a bad thing, I see as a good thing." (Yusuf – pp. 15-16, 557-564)

Similar to Madeline describing her experiences as a natural check-in to her wellbeing in subtheme 2.1, Yusuf also views his experiences as a check-in to his faith. For him, this is a positive measure of his current state in life, as it allows him to self-reflect and make changes where he feels necessary. He acknowledges that the experience is difficult, however the potential negative effect of this is mitigated by the idea that "some hardship.. keeps me intact" (p. 23, 839). Without this, he imagines that he would "probably be off the rails doing God knows what," and he deems the unusual experiences as necessary in order to "keep me in line" (p. 23, 840-842). In addition to this, in line with Islamic teachings, Yusuf also interprets it as a "test" from God that he "just has to deal with" (p. 6, 185-186), signifying the importance of religion to him for both the 'what' and 'why' of his experience.

The second theme highlights what participants considered as integral to the 'what' of the way they made sense of their unusual experience. For half of the participants, this was related to

individual personality type and potential predispositions playing a role in understanding what they were going through. For the participants who were Muslim, understanding originated from their religious background and provided a way to make sense of experiences. Despite these differences, it appears that having a way to make sense of things contributes to reducing distress that may be associated with unusual sensory experiences. Being able to understand what they are experiencing allowed participants to view the event as neutral, or even positive, suggesting that individuals having a sense of 'knowing' is key to managing both the perception and subsequent impact of the unusual experience. Having discussed the way they manage this as individuals, the next theme draws on participant's experiences of the way they feel others potentially view them in relation to their experience.

5.3.3 Theme 3: The Significance of the Other in Society

The third theme relates to the role the other plays in society and the impact this has on individuals. For Madeline and Chloe, this role involves determining both reality and normality, affecting the way mental health is generally viewed by others. For all participants except Rayna, there was an expectation of a negative response from others, leading some to avoid disclosing their experience. However, there were some instances where the experience would be discussed, but only with those who Rayna, Sara, Chloe, and Yusuf felt they could relate to.

3.1: The other is key for determining both normality and reality

Others play a significant role in determining how people feel about experiences, according to Madeline and Chloe. Finding others useful as a sounding board for identifying a "normal unusual experience" in comparison to a clinical one (p. 13, 487), Madeline also acknowledges the negatives of viewing all experiences through a lens of illness.

> "We've made mental health… kind of, pathologisation of mental health, but we've really alienated ourselves from health and from our minds and from our bodies, and while I obviously agree with a lot of the clinical definitions and having medication, I don't think that's everything to it." (Madeline – p. 8, 262-266)

She describes one of the dangers of pathologising things we deem unusual in society as disconnecting from the self, suggesting that others may have an effect on identity, but also the way we view and interpret experiences. Whilst clinical definitions may be one way to explain things, she feels it is not the only way. By society viewing unusual experiences as a potential illness, individuals may lose the ability to make sense of what they are going through in a way that may be more appropriate for them. In this sense, there is a perception of the other's role as determining of an objective reality. Chloe also shared a similar sentiment to Madeline, implying that others play a key role in how experiences, but also certain diagnoses, are viewed.

> "But I do think in terms of the medical aspects, people are labelled and I think they are automatically judged and I think it stems down to identity. That people are first, their name first. Like, I'm Chloe. I'm not, you don't label me as somebody who looks into spiritual stuff or whatever. And again, with somebody with a mental health diagnosis, they tend to have that, 'oh, you've got psychosis,' or 'oh, you've got mental health.' So, then people tend to change the way that they're around them then, and I do think that's really bad." (Chloe – p. 18, 647-655)

Viewing experiences via a medical lens can lead to stigma within society, on the basis that some illnesses have been deemed as dangerous. Chloe describes how "society has a massive impact" in the way that mental health is viewed, perceiving it "as a fearful thing" (p. 18, 667-668). She suggests this stems from the media surrounding certain diagnoses, such as psychosis, and feels that the negative associations society has created causes avoidance from these individuals. She notes how labelling has an impact on identity itself, acknowledging a distinction between the treatment of those with unusual experiences and those with a diagnosis. Despite the view of others in society as impacting perceptions of mental health in a

negative way, Madeline also describes the positive ways in which others who are close to her help to determine reality and take on a protective, monitoring role.

> "I think it's also really hard because you don't know. How do you know what's real or not real because it all seems real to you? So one of the few times is when it comes up in conversation and other people don't see it or hear it." (Madeline – pp. 2-3, 69-72)

> "So actually opening up about that and then, maybe also just that person realising, 'oh, this is happening in your life. This is something just to keep an eye on. Is this just a… a set experience or is this an actual regular thing that needs to be worrying?' So I think it's almost kind of a bonding thing within friends." (Madeline – p. 7, 229-234)

Here, Madeline describes how others are useful for helping her to determine what is and is not real around her, in some instances letting her know that "there's nothing there" (p. 2, 34). Rather than this being alarming for those around her to manage, for Madeline, it felt like a "bonding thing" with her friends. She notes how this role within friendships becomes one of a monitor, where her unusual experiences are something to "keep an eye on" and observe for potential progression. With regards to her worrying about her unusual experiences, she acknowledges her "privilege" in having friends around her "who would pick up on it and be there for me and support me" (p. 13, 459-461).

3.2: Fear of being perceived as ill and not being believed leads to concealment of the experience from others

For all participants except Rayna, there was a concern that opening up and disclosing the unusual experience to others would cause them to be perceived as "crazy" and potentially be viewed through a medical lens. The fear of this led to concealment of the experience in order to avoid ramifications such as being taken to a doctor by family or friends.

> "I wouldn't want to say anything to them. Just in case they think it's crazy." (Zeke – p. 10, 339-340)

> "I feel like if they're of the same beliefs as me, then they'd understand more. But if they're not, then I'd be worried like, 'oh, are they going to think I'm crazy as well?" (Sara – p. 20, 719-721)

> "I don't always share these things with people because I think you can be deemed as crazy. You can be deemed as like, 'okay, have you got a mental health issue?" (Chloe – p. 7, 250-252)

The use of "crazy" by most of the participants suggests that it may be a common feeling for those who have unusual experiences, and that the way in which they are perceived by other people is significant to them. "Crazy" has negative connotations of someone who is 'out of their mind,' unpredictable, and potentially aggressive. This stigma that is attached to disorders such as psychosis, has disconnection from reality in common with unusual experiences. It is therefore reasonable for the participants to assume that the perception of "crazy," which is commonly associated with psychosis, may also be attached to their experiences. This fear led to most participants choosing to conceal their experience from others, especially from those who do not share the same interpretation as them. For Madeline and Yusuf especially, this extended into concerns around actually being diagnosed by a doctor.

> "So when I had any kind of unusual experiences when I was really unwell, I had a counselling mandate from work. I had to see a GP, but I didn't specifically mention that. I think I was a bit cautious to open up too much because I didn't really want that to be a kind of label or further thing." (Madeline – p. 4, 118-122)

> "If I was to speak to someone who doesn't believe in this, they'll 100% diagnose me with some mental health issue, probably say I'm schizophrenic or anything like that." (Yusuf – p. 19, 681-683)

Although Yusuf believes he has a way to make sense of his experience due to his religion, he feels that for others without this framework of understanding, psychiatrists would "definitely just diagnose them with something" (p. 24, 883-884). For Madeline, there were concerns that

disclosing to her family would result in them wanting to "take me to a hospital right away" (p. 9, 308). This fear arose from the fact that her sister has a "diagnosis of bipolar and potentially other illnesses," and that her family's judgement of her unusual experience would be clouded by this (p. 6, 208). Along with family, she also chose to conceal her experience from her doctor out of concern that they would view it as "something that was severe and clinical" (p. 4, 123-124). Aside from worry about being perceived through a clinical lens, Sara and Chloe also avoided disclosing to others due to a lack of shared interpretation.

> "I don't feel any type of way, only because I understand that they will never understand what we do. It just makes me think that there's just certain things that I won't be able to share with them, 'cause they won't understand. So, if I had an experience again, I don't think I'd be sharing that with them." (Sara – p. 18, 650-654)

> "I didn't tell him that three weeks prior I saw that dark shadow by my room. I didn't say that to him because he doesn't believe in it." (Chloe – p. 12, 410-412)

A lack of similar understanding of the unusual experience led to Sara and Chloe choosing to no longer disclose to others. Chloe felt that in previous discussions around the topic, others who do not believe in her explanation would say things like, "oh God, whatever" (p. 2, 45), "that's not the truth" (p. 15, 546), and "that's stupid, why in the world would you even think that?" (p. 18, 643-644). Similarly for Sara, she notes that whilst her relationship with acquaintances who do not share her religious beliefs has not changed, she does choose more carefully what she shares with them based on their response of "it's not true" (p. 16, 564-565). This perceived categorical rejection of the spiritual world, as well as use of negative language about Chloe due to her belief in it, seems to have been associated with avoidance of the topic for both.

3.3: Others understand the unusual event if they have personal experience or shared interpretation of it

In addition to the concealment due to disbelief by others, Sara goes on to explain how it is only those who share her faith that are able to truly understand her experience and believe her. For Rayna, Sara, and Yusuf, who all share the same religion, they found it easier to disclose to others who also followed Islam.

> "My family do believe about the Jinns in Turkey and cottage, so. They just make sense of it the same way as I would as well. Think, 'ah yeah, it's in, you know, a location where there's no one and it was bound to happen. So, just basically same kind of beliefs that I have, they're the same thing." (Sara – p. 21, 758-764)

> "I wouldn't really go up to a non-Muslim anyway and be like, 'look, I go through these things.' They pro- [laughs], 'yo, this guy's crazy.' Like, they'll probably phone the hospital or something and try to get me sectioned [laughs]. So, obviously I'll speak to, and I'll open up to people who have got the understanding." (Yusuf – p. 25, 908-913)

To avoid any negative repercussions of people who don't understand, Sara and Yusuf chose to open up to people who share the same understanding. In relaying her unusual experience to friends, Sara felt that they believed her and there was no change in their relationships. With regards to her non-Muslim coworkers, she felt that she "can't really explain to people that are not of the same beliefs" (p. 16, 578), and that "they wouldn't understand" because their "beliefs are completely different" (p. 15, 554-558). For Rayna, she would only disclose to people if she could "relate to them" via a similar interpretation of the unusual experience (p. 9, 317). For all three participants, the ability to connect with others due to shared religion was key to whether or not they felt they were able to communicate their experiences. On the other hand, Rayna, along with Chloe, also held the idea that aside from shared sense-making, if the other had not had their own unusual experiences, then they would not be able to understand.

> "I definitely believe it's just not something that probably exists in these people's minds if it hasn't happened to them. Like it's only real if you've experienced it and if you haven't experienced it, then it's not. It's not going to be be real to them because what is it that they're expecting, what are we expecting them to believe? 'Cause it's something that we've felt, so you can't really make someone feel a feeling that you felt." (Rayna – p. 11, 392-398)

> "Well, my mum's actually stayed at my house, like if I've gone away or whatever. Over the years, she's watched my house for me and she's actually said she's heard things in my house. So, when I tell her, she doesn't look at me like I'm crazy. Well, not that I think anyway. Because she can half relate, not to the severity of what I've witnessed in my house, but she's recognised certain things, like a loud bang she's heard, and it's like no-one's in the house, it sounded like it was in the house, and she's heard like mad things in the house. So, I remember coming back, she's like, 'I know what you mean. It does happen like, you do hear mad noises here, don't you?'" (Chloe – p. 14, 510-519)

For Rayna, she explained how it might be difficult to believe an experience that has not been felt personally. Again, this idea of being able to relate, this time via the experience itself rather than the explanation for it, is significant for both believing and understanding. According to Rayna, "unless people have gone through it themselves, they don't get it" (p. 11, 387-388). The reality of unusual experiences being attributed to the supernatural is only "real when you experience it; otherwise, it doesn't exist" (p. 9, 328). Similarly for Chloe, she felt understanding of the spirit world can only be gained through experience of an unusual event, citing her mother as an example of someone who only believed once they felt it for themselves.

This third theme highlights the multiple ways participants felt that others in society perceived them as an individual after learning about the unusual experience. For some, there was fear of being judged negatively by others due to fearful perceptions of illnesses that share similarities with unusual experiences, for example, psychosis. This led to concealment of the experience, except for with those that participants felt would share similar frameworks of understanding, for example, similar religious backgrounds. Additionally, some participants felt

that those who also had their own unusual experiences would be able to understand them and not perceive them negatively through a lens of being "crazy," or with judgement. Explored further in the next theme, the reaction that participants felt they received from others had the ability to legitimise or validate both the experience itself, as well as their identity.

5.3.4 Theme 4: Legitimacy and Validity of the Unusual Experience

The final theme relates to the way in which unusual experiences are either validated or invalidated. For Madeline, Zeke, and Yusuf, this was validated by close friends based on knowing their personality. Additionally, shared religious beliefs contributed to the way others validated Yusuf and Rayna's experiences. Madeline, Rayna, Zeke, and Sara also describe several different ways they felt they were invalidated, including different beliefs, perceived identity, and the inability to relate within society.

4.1: The unusual experience is validated by others on the basis of identity and shared beliefs

Interpretations of the unusual experience were found to be validated by those around them, particularly for Madeline, Rayna, Zeke, and Yusuf. Both their identity and unusual experience were viewed as legitimate, either on the basis of what others knew about the individual's identity, or on the basis of shared religious beliefs. In the case of Madeline, Zeke, and Yusuf, they felt others accepted or would accept their experience as real due to the way they present their personality.

> "I think people with me can, even though I think I can be a jokey person, see me as quite like a serious person with my work and stuff as well. So, I don't think they would say it to me or treat me any differently. I think they would just kind of accept it and accept that it was sort of legitimate and because I've not had any issues around then. I don't think it was brought up as like, 'oh, that was sort of the start of maybe a mental breakdown.'" (Madeline – p. 8, 291-297)

> "I feel like he listens because like I wouldn't just make up a lie and just, you know, come and tell you for jokes. But he knows I'm scared of that type of stuff… So, I think he believes me when I've said it." (Zeke – p. 7, 251-256)

> "The people that I've told are close to me, understand who I am, know who I am, and know that I wouldn't really be making it up." (Yusuf – p. 36, 1313-1314)

For Madeline especially, she notes how others may perceive her on the basis of her work, potentially influencing whether or not her interpretation would be believed. In instances where she has opened up to close friends, she feels her interpretation of the unusual experience was validated due to her "psychology background" and that for them, it "makes sense that I think of it in terms of brains and perceptions and things that happen around me" (p. 5, 181-183). Interestingly, she also suggests that her lack of history of poor mental health would also have an effect on how her unusual experience and the interpretation of it is perceived, implying that individuals may lose credibility with others on the basis of their mental health. For Zeke and Yusuf, there is a sense of certainty in their tone regarding the way they believe their friends "know" and "understand" their personality. In addition to identity, Yusuf and Rayna both felt their unusual experience would be accepted by others who hold the same beliefs.

> "Coming from a Muslim background, we do believe in Jinns and stuff, so. There definitely wouldn't be any like, 'are you sure?'" (Rayna – p. 12, 407-409)

Certainty is also expressed here with the way in which Rayna is definite about the reaction she would receive by those of the same faith. She stated that those around her "know that Jinns exist," and therefore, "they wouldn't find it abnormal" (p. 16, 560-561). Similarly, Yusuf expresses how experiences and interpretations related to Jinns would be believed by friends and family as they are "all from the same understanding" (p. 10, 363-364). Here, shared religion acts as the framework via which people's beliefs are validated and considered

legitimate. Despite the differences in the way the participants felt they would be validated, they all had in common the idea that the way they were treated would not change with family and/or friends.

> "In my experience alone, I don't think I would be viewed negatively, and I haven't been viewed any… less or in a negative manner because of what I've been through." (Rayna – p. 16, 565-567)

> "So, they, obviously because we're all from like the same understanding and all of that stuff, they were just like, 'yeah, look, however much time you need off work, you take time off work. Get better. Once you're ready, fit, healthy, then obviously just return to work.'" (Yusuf – p. 10, 363-367)

For Yusuf, the negative impact a Jinn experience could have on an individual was understood by people of the same faith. The treatment of Yusuf after disclosing this not only remained the same, but rather extensive support was shown with regard to taking time off work and looking after his wellbeing. Similarly for Rayna, whilst she felt that those around her would not perceive her negatively, but would in fact be "accepting" of her (p. 15, 548), she also experienced better treatment than usual. For example, she sensed that within her family, she had "gone up in the ratings" due to her unusual experience making her "special in some sense" (p. 15, 542-545). For Zeke, acceptance and kind treatment was demonstrated through the way in which his friends would validate his fears and respond accordingly by avoiding horror-related media to keep him comfortable. Contrary to changing their perception of him, if anything, Zeke feels "they gathered a deeper understanding" (p. 8, 285-286).

4.2: The unusual experience can be invalidated by others and the self

Just as the participants described people close to them or people with shared faith validating their experiences, they also experienced or expected dismissal of this from others in society. For Sara, acquaintances who did not share the same religion as her invalidated the way she

interprets her unusual experiences by denying the existence of Jinns, whereas for Madeline, there was an expectation of not being believed if she were to disclose to others.

> "They know what we believe in because we did have a conversation once about how we believe in Jinns. And they were like, 'no, that's impossible. There can't be Jinns. No, it's made up. You know, it's in your head. It's a mind thing. You know, when you hear too many stories about ghosts, every noise you hear or everything you see, you start to think that "yeah, it's ghosts" because you've been told that.'" (Sara – p. 16, 568-574)

> "But I think also people sometimes have the explanation of, 'oh, you must have just mistaken it. You must have not seen somebody. You know, it's like dark at night, raining, it's not the best visibility kind of thing.' So, I think you also have some people who would go the other way of being like, 'oh, you saw nothing,' and like not believing you that what you experienced is what you experienced, which I think can also be a, a tricky [laughs], but interesting barrier to that sort of conversation." (Madeline – p. 8, 280-286)

For Sara, her experience and interpretation was reduced by others to a form of cognitive bias, dismissing her beliefs as "impossible" and "made up." This in turn affected their relationship and hindered open conversation regarding unusual experiences, leading Sara to change her behaviour and be "a bit distanced from them" (p. 21, 779), and "more cautious about what I tell them" (p. 21, 752). This "barrier to that sort of conversation" was also highlighted by Madeline, who felt that certain types of individuals, who were not open to alternative explanations, may be more difficult to disclose to. She, along with Zeke, describes how others may dismiss unusual experiences and certain interpretations due to a lack of understanding.

> "If you say you have cancer, people take it seriously right away. Kind of universally understood for how horrendous it is and how hard it is." (Madeline – p. 15, 555-556)

> "As far as I'm aware, those kind of professional, medical, and clinical settings don't accept that as a thing that can happen, like it's more of a science thing to my understanding.. I feel like it would just be a waste of time telling them. Just because I would assume in the medical field that you're not supposed to accept.. you know, 'cause it's not exactly science or facts that ghosts are real. So, I think a doctor would

> work off facts and science and biological stuff rather than paranormal activities." (Zeke – pp. 10-11, 361-373)

In the quotes above, there appeared to be a hierarchical way in which society views illness. For example, physical illnesses such as cancer were "universally understood," and the credibility of both the experience and the impact of cancer is highly unlikely to be deemed as invalid. Unlike unusual experiences, the ability for the majority of people to be able to relate with cancer through personal experience, either via self or others, may also contribute to the credibility of it within society. As noted by Zeke, others, notably medical or clinical professionals, would be unlikely to believe in his interpretation of his experience. Rather, he feels they would "definitely think I'm loopy or crazy" on the basis of his experience not being rooted in science and biology (p. 10, 361). Although Zeke and Madeline held an expectation of others invalidating the way they make sense of their experience, for Madeline and Rayna, this invalidation was experienced closer to home.

> "Being the older sister, she does sometimes think that I just say stuff for the sake of saying stuff." (Rayna – p. 12, 442-443)

> "They always saw me as the kind of youngest one, and so in conversations, I feel as though sometimes when I bring up stuff, it's almost as if they doubt me." (Madeline – p. 10, 358-359)

Similar to Madeline's friends accepting her unusual experience as real on the basis of how they view her identity, on the same basis, she felt her family rejected her experience and interpretation. While she is perceived as a serious and accomplished individual by friends, she is positioned within her family according to being "the youngest." Similarly for Rayna, her unusual experience was trivialised by her older sister who told her to not "be silly" and that "it's not that deep" (p. 6, 181). Both women's roles within their family led to questions surrounding their credibility, and for Madeline especially, she felt as though she was not "being

taken as seriously as I want to be taken and as I feel I deserve to be" (p. 10, 367-368). Although so far the legitimacy of unusual experiences has been felt to be doubted by others in general, for Zeke and Sara, others played a significant role in validation of the experience itself.

> "I don't think I've even told like anyone in my house. I just feel like if I keep it to myself, it doesn't make it real, but as soon as I start bringing it up, it just makes it like reality, so. Makes it a part of my reality, like something that actually happened." (Zeke – p. 4, 116-119)

> "I feel like they believed me about my experience because there was more than one of us who heard it. And with my sister in law's experience, she only heard the knocking and I'm the only one who felt weak after it. So, they all had excuses ready for both." (Sara – p. 12, 410-415)

For Sara, her experience was invalidated by family if she had experienced it alone, in comparison to experiences shared with others. This potentially indicates that others play a significant role in constructing reality and the legitimacy of experiences increases if it is shared by multiple people as opposed to one person. For Zeke, although there was a strong desire to invalidate his own experience due to fear, he highlights the role others play in validating this. From the above quote, it appears that he recognises the role of the other in the construction of his reality, and that his experience does not exist unless it is communicated with others. He also avoids discussion with friends who have had their own unusual experiences for fear that this will provide legitimacy to his own and "make everything more real" (p. 5, 147). For both Sara and Zeke, via others and self respectively, their experiences are invalidated unless the other has participated in some capacity to legitimise this.

The final theme highlights the way participants felt they were either validated or invalidated through the perceived responses from others. Family and friends who either shared similar religious beliefs or who participants felt knew them as a person, contributed to validation of

the unusual experience, as well as validating the participant's way of making sense of this. Others were also viewed as playing a role in the construction of reality for some, with the notion that unusual events for multiple individuals legitimises the existence of unusual experiences generally. However, participants also felt invalidated in several ways. This took place via those without shared religious beliefs invalidating participant's interpretation, and therefore, their experience, and via a perceived hierarchy of role within family and of illness within society.

5.4 Discussion

The present study draws on the lived experience of unusual phenomena for 6 individuals who did not seek support from a mental health professional. The subsequent themes and sub-themes are reflective of the way in which sense was made of unusual experiences, as well as how participants felt they were treated by others pre- and post-experience. The experiences were rationalised and categorised by participants as unusual and disconnected from reality, but not disruptive enough to require professional support. Although the majority of participants adopted a supernatural or spiritual interpretation, there were differences in the way they came to these understandings. For some, the process of sense-making was entirely dependent upon individual personality types, whereas for others, religious and cultural beliefs taught during childhood helped develop frameworks of understanding. In relation to understanding unusual experiences, participants felt that others had the power to determine what is considered socially acceptable and 'normal,' and that this impacted the way mental health is viewed as a whole. Despite this leading to avoidance of disclosing unusual experiences due to an expectation of a negative response, some participants did feel they

could open up to those they could relate to, particularly those with similar religious beliefs or understandings. This shared understanding, by family and close friends, validated both participant's experiences and their explanation of it. However, several instances of being invalidated were also described by participants, either through different belief systems or the inability of those without unusual experiences to relate to those who do have these experiences.

5.4.1 Rationalising the Experience as Simply Unusual

The first theme describes how unusual experiences are justified as being unusual, with participant's interpretations mostly consisting of spiritual or supernatural explanations. The ease of accepting the experience as simply unusual was dissimilar to previous studies (Boumans et al., 2017; Ered et al., 2017; McCarthy-Jones et al., 2013; Yehya et al., 2022), where individuals were thought to normalise the experience by linking back to real-life stressors, viewing 'hallucinations' as a way to cope when life became difficult. On the contrary, within the present study, most participants viewed the experience as either occurring due to a reason unknown to them or due to the spirit world / supernatural trying to communicate something. For Madeline, who described herself as commonly having unusual experiences and making sense of this as her brain imagining things, she noted how she deemed the experience unusual in this instance due to her inability to link it back to real-life stressors, the way she was able to with her other experiences. Within and across participants, distinct types of unusual experiences can be observed: those that are linked to 'real life' in an attempt at normalisation; and those that are simply unusual, where although the 'what' is known, the 'why,' or the purpose, is either unknown or connected to supernatural explanations. In either type however,

distress is reduced and professional support is deemed unnecessary. Despite the previous research (Boumans et al., 2017; Ered et al., 2017; McCarthy-Jones et al., 2013; Yehya et al., 2022), findings from the present study suggest that employing a framework of understanding may be one of the key factors in reducing potential distress and coping with the unusual experience, as opposed to trying to normalise the event by connecting it to real-life stressors.

Although the experience was rationalised as unusual, the lack of distress associated with this meant to participants that professional support was deemed to be unnecessary. Although it is premature to suggest that it is the ability to make sense of the experience itself that reduces the level of distress, and in turn, the need for professional support, some connection can be made between the two on the basis of the findings and previous research (Yehya et al., 2022). Despite focusing on coping strategies, Boumans et al. (2017) highlighted the concept of "personal medicine," noting the importance of this in relation to avoiding outcomes such as hospitalisation or clinical intervention. This can also be applied to the present findings, whereby the meaning and purpose of unusual experiences, created by individuals within the context of their own lives, contain the ability to reduce potential distress. Similar to the present study, not only was a lack of distress one of the reasons to not seek help, but additional "deviant behaviours" were also thought to distinguish an unusual experience from an 'illness', such as psychosis (Pigeon-Gagné et al., 2022). It was felt that an unusual experience in itself did not warrant professional support, but rather the individual must present with additional difficulties that impact upon daily life in order to require this. As has been suggested within the literature on psychotic-like experiences, there are several subtypes that vary in relation to level of distress and help seeking behaviours (Turley et al., 2019; Wigman et al., 2012; and Yung, 2009). Supporting the quantitative standpoint of psychotic-like experiences

(Hinterbuchinger & Mossaheb, 2021), the present findings suggest that one of the key distinctions between unusual experiences, even from a phenomenological standpoint, and diagnoses like psychosis is the ability for the experience to have an impact on functioning and cause distress.

5.4.2 Sense-Making can be Inherent or Taught Depending on the Individual

The second theme describes what participants believe contributed to their way of understanding, with half viewing this as due to individual personality type and potential predispositions, and the other half attributing sense-making to religious beliefs. From the available qualitative literature, two studies took place in Africa and the Middle East (Pigeon-Gagné et al., 2022; Yehya et al., 2022), one focused on coping strategies (Boumans et al., 2017), and another aimed to compare non-clinical and clinical groups (Heriot-Maitland, Knight, & Peters, 2012). Due to this, there was very limited research related to understanding the way participants made sense of their unusual experience, specifically with non-religious individuals. According to Yehya et al. (2022), further research on comparing unusual experiences between religious and non-religious individuals is necessary in order to understand what factors contribute to the way these experiences are shaped and made sense of. Within the present study, half of the participants did not identify with any religion, with two out of the three attributing their way of understanding to individual personality types. For example, having a creative personality type was thought to predispose some people to hallucinate due to an overactive imagination. One religious participant also noted that having an 'open' personality type contributed to open-mindedness surrounding supernatural explanations, regardless of religion. In comparison to previous studies conducted in heavily

religious communities or countries (Pigeon-Gagné et al., 2022; Yehya et al., 2022), the findings from the present study may suggest that in locations where religion is not a significant part of an individual's daily life, factors such as personality type may influence understanding of unusual experiences. For the one participant who did not hold supernatural interpretations, it may be that the lack of external attribution e.g. jinn or spirits, leads to an internal way of sense-making i.e. personality type.

The other half of the participants highlighted taught religious beliefs during childhood as central to developing their framework of sense-making. This was consistent with research where participants had strong religious or cultural ties, for example, in Arab regions (Yehya et al., 2022), with Christian participants (Kovess-Masfety et al., 2018), and in Burkina Faso (Pigeon-Gagné et al., 2022). Unusual experiences took place in the form of 'jinn' for participants that followed Islam, similar to the entity of 'djinn' described by African participants (Pigeon-Gagné et al., 2022). Across cultures then, the supernatural as a way of making sense appears to corroborate with the individuals religious beliefs, and is similarly learned by individuals as part of their surroundings or cultural background (Yehya et al., 2022). Interestingly in the research conducted by Yehya et al. (2022), religion also shaped the content of the unusual experience, for example, "hallucinations" involving the Islamic call to prayer or Islamic dress (abayas). This was not found for the three Muslim participants within the present study, where the unusual experience, although interpreted as jinn, involved non-religious events such as being held down, possession, and movement of objects. This may suggest that the daily environment itself has a potential impact on the type of unusual event experienced, whilst religious beliefs taught during childhood contribute to the interpretation of it. According to Yehya et al. (2022), societies where religion and culture are intrinsically connected may

influence individual consciousness more often, contributing to the content and understanding of unusual experiences. For religious participants in the present study, it appears that religion plays a role in making sense of the experience, but dissimilar to previous studies, it plays no role in shaping the content of the experience.

There are mixed findings regarding attributional bias in individuals with unusual experiences, with studies finding differences between whether positive or negative experiences are externally or internally attributed (Gawęda et al., 2015; Janssen et al., 2006; So, Tang, & Leung, 2015). However, it was found that those who externally attribute their unusual experiences, for example, to supernatural or paranormal explanations, may be more psychologically adaptive, with these beliefs providing a positive context to the experience (Coleman, Croft, & Barkus, 2022; Drinkwater et al., 2017). In line with a cultural anthropological perspective, the current findings suggest that individuals perceive their experiences through an interplay of social and cultural contexts (Larsen, 2004; Csordas, 2015; Dutta et al., 2007). According to Coughlan et al. (2022), utilising a known cultural framework to make sense of the unusual experience may serve a dual purpose by avoiding the stigma of mental illness, as well as grounding the experience in an accepted frame of reference. Consistent with past literature, participants making sense of their experiences through a supernatural interpretation meant that their experiences were not considered as expressions of psychosis or as a source of distress to themselves (Unterrassner et al., 2017). There has been an increasing cultural acceptability of supernatural beliefs within the general population (Dagnall et al., 2016), which along with the absence of distress or help-seeking behaviours, suggests that this interpretation may not be unusual at all, but rather a way to protect the self from external stigma and make sense of an otherwise disturbing event (Coughlan et al., 2022).

5.4.3 The Significance of the Other in Society

The third theme highlights the way participants felt that others viewed unusual experiences negatively in society, leading to concealment for fear of being perceived as ill or not being believed due to differences in beliefs. It has been suggested previously that 'normalising' the unusual experience by linking it to real-life stressors was a way for individuals to avoid any associated stigma from others (Yehya et al., 2022). Although this wasn't found in the present study, the fear of potential stigma remained present across all accounts. Yehya et al. (2022) theorised that the association between unusual experiences, such as hallucinations, and "severe mental illness" was the reason people attempted to normalise their experience. This notion was made more explicit for the participants in the present study who discussed the dangers of labelling individuals with a diagnosis like psychosis and verbalised their fear of being perceived through a clinical lens as 'crazy.' The stigma towards psychosis has been well documented within past literature (Colizzi, Ruggeri, & Lasalvia, 2020; Degnan et al., 2021; Wood et al., 2015), with detailed exploration of this in the meta-ethnography (Chapter 3) within the thesis. Others were found to play a key role in perpetuating stigma towards psychosis, leading to concealment and withdrawal for many diagnosed individuals. Pigeon-Gagné et al. (2022) reported mistrust in open communication of unusual experiences with family due to potentially being mislabelled as mentally ill. Similar behaviours of concealing the unusual experience for fear of judgement was displayed by participants, despite the lack of impact on their ability to function, highlighting the potential widespread impact of stigma towards experiences that resemble anything remotely similar to psychosis. The present findings can be understood in the context of Goffman's (1963) stigma theory, whereby others in society label and marginalise those who are perceived as behaving outside of societal

norms, often resulting in social exclusion and internalisation of negative stereotypes. Public stigma has been thought to affect an individual in three ways; through enacted stigma, felt stigma, or internalised stigma (Bos et al., 2013). Through felt stigma then, participants in the present study may have anticipated stigma from others, leading to concealment of unusual experiences.

Whilst the fear of being perceived negatively led to concealment from others, including family, friends, and acquaintances, all participants felt they could relate to and disclose the experience to those who shared similar interpretations i.e. through religious beliefs, or to those who had their own unusual experiences. Minimal research has been conducted on the way participants perceived others response to the unusual experience within the literature, as the majority has focused on individual understanding and coping strategies. However, it was found in one study that supernatural entities such as "djinn" were unquestioned in communities where supernatural explanatory models were the norm (Pigeon-Gagné et al., 2022). This supports the accounts of participants within the present study who felt more comfortable communicating with those who shared a similar belief system. Additionally, it was easier to relate to people who had also had unusual experiences, suggesting shared experiences are valuable for connection and communication. This is a common finding within psychosis literature, where peer support groups have been found to reduce feelings of isolation and enhance personal recovery (Castelein et al., 2015). Based upon the findings of the present study, and perhaps to a lesser extent, it appears that peer support is also useful for feeling able to discuss unusual experiences. This may also play into the concept of "personal medicine" (Boumans et al., 2017), where communication with others and

subsequently, validation of the experience, are significant to reducing both distress and the need for professional support.

5.4.4 Legitimacy and Validity of the Unusual Experience

The final theme describes feelings of both validation and invalidation by participants, in reference to both self and the experience, based upon perceived responses from others. Through shared frameworks of understanding, as well as through knowing an individual's identity, the unusual experience and its interpretation was validated by others. In a study comparing people with unusual experiences (non-clinical) with those diagnosed with psychosis (clinical), the non-clinical group experienced higher levels of acceptance and validation from others, despite both groups demonstrating awareness of ways in which their experience could be invalidated (Heriot-Maitland, Knight, & Peters, 2012). Validation was also noted as being a key protective factor in normalising the unusual experience (Heriot-Maitland, Knight, & Peters, 2012). Boumans et al. (2017) highlighted the importance of people being able to create their own meanings within their own context, and therefore develop their own coping mechanisms, reducing the need for professional support. Others displaying acceptance then for the way sense is made of unusual experiences may be key to supporting an individual's ability to cope with an unusual experience and normalise it, as opposed to associating it with illness. A novel finding that does not appear to be apparent within past literature is the way *knowing* someone contributes to validation of the experience. For some participants, it was felt that friends who *knew* who they were as people i.e. their likes, dislikes, and personal background, validated their experience by accepting their interpretation as it aligned with their identity. Here, shared beliefs are unnecessary, as long as the way that an individual makes

sense of the experience also makes sense for who they are as a person. It appears that *knowing* an individual and valuing them as a person as opposed to perceiving them as their experience, as is often the case for those with psychosis (Wood et al., 2015), may inoculate individuals against the potential stigmatising consequences of disclosing unusual experiences.

Some participants noted how those who did not share similar interpretations i.e. religious beliefs, invalidated their way of sense-making, although this did not appear to influence the way sense was made of the unusual experience. Additionally, hierarchy played a key role, either through role within family or illness within society, and had the ability to invalidate the way participants felt about the experience. According to Kendell (2001), mental illnesses are perceived as less 'real' than physical illnesses, with Madeline suggesting that unusual experiences would be at the very bottom of this ladder due to a lack of universal understanding regarding the experience of it. Some participants also noted how others played a key role in constructing reality, where shared experiences and communication of experiences afforded credibility to the event itself. In line with a social constructivist perspective, it may be that interaction with others who also experience unusual phenomena contributes to validating the experience for both the self and others (Berger & Luckmann, 2016; Galbin, 2014). Perceived invalidation has previously been found to predict affective experiences, leading to negative emotions and more commonly intense stressors, impacting the way a person views the world around them (Zielinski et al., 2023). Specifically with experiences of psychosis, this 'invalidation' by others resulted in feelings of being "de-authored," where the right to author a personal story was denied (Geekie & Read, 2007). For participants within the present study, not being believed by others led to concealment of experiences and caution with further communication, however, the impact did not appear to be as emotionally intense as described

by Geekie and Read (2007) and Zielinski et al. (2023). This may suggest that whilst invalidation of unusual experiences still occurs, the higher levels of validation received may offset the potential negative consequences (Heriot-Maitland, Knight, & Peters, 2012).

5.4.5 Limitations

One of the limitations of the present study is the small number of participants. Within the discussion of the findings, comparisons have been made between participants, based upon the way they make sense of unusual experiences. This has the potential to dilute the findings within the sample, more than was initially intended. Although generalisations cannot be made due to the methodology and the sample size, it is key to note that IPA acknowledges this and does not attempt to make this an aim of research. Rather, the focus is on understanding lived experience of a certain phenomenon (Smith, Flowers, & Larkin, 2021). Perhaps more pertinent within qualitative research however is the notion of transferability as opposed to generalisability. The present study contains detailed description of method and aimed to present the analysis in a logical narrative that evokes a sense of familiarity, thereby allowing for the relevance of findings to be evaluated within other contexts (Stalmeijer, Brown, & O'Brien, 2024). Therefore, whilst small sample sizes are a limitation in terms of contributing to general knowledge on specific concepts, there is value in understanding the lived experience of individuals in order to contribute to qualitative literature. The potential to identify novel ideas about specific samples of people with unusual experiences allows for detailed analysis of a particular phenomenon, increasing general knowledge of associated meaning making processes, and potentially generating future research in previously undiscovered areas.

Another limitation of the research is the majority of the interpretation being rooted in spirituality and the supernatural. With only one participant adopting a non-supernatural way of making sense, and due to the general lack of research in this area, the discussion points regarding this individual solely reflect her views. Adapting the screening questionnaire to include a question on how the experience is made sense of may have led to more balanced findings where comparisons could be drawn. Additionally, the two participants that declined to participate due to unavailability were both males, and as also highlighted by Yehya et al. (2022), their views may have contributed to a more balanced sample of participants, in terms of demographics. Despite this however, there were no specific gender differences identified between ways of making sense and reaction by others to the experience. Rather, differences were found in relation to religion and individual personality type.

5.4.6 Clinical Implications

Within the present study, unusual experiences were accepted as simply unusual, mostly framed as part of the spirit world or as having a supernatural explanation, and deemed not to be severe enough as to require mental health support due to the lack of distress associated with the experience and having a personal framework of understanding. Understanding this process of rationalisation, in addition to normalising the experience by linking to real-life stressors as found in previous research (Boumans et al., 2017; Ered et al., 2017; McCarthy-Jones et al., 2013; Yehya et al., 2022), may provide further understanding on different types of unusual experiences, and therefore provide supplementary ways of distinguishing between non-clinical and clinical experiences. Whilst many of the findings were similar with past research, especially with regard to religious or cultural interpretations (Pigeon-Gagné et al.,

2022; Yehya et al., 2022), there were also some novel findings, particularly in relation to how environment and individual personality type can influence the process of rationalisation. Different frameworks of understanding may have implications for the way others respond, depending on their cultural background. As identified within the findings, others play a significant role in determining whether the individual with unusual experiences feels validated or invalidated.

It is possible that increasing awareness of unusual experiences within the general population may normalise the phenomena and separate it from the stigma of categories of illness such as psychosis or schizophrenia. Although the stigma of psychosis is also an issue in its own right and reducing this is necessary, for those with unusual experiences, avoiding the association with a label of psychosis entirely may prove easier than attempting to remove this perception once it is held. With one anti-stigma campaign (Time to Change) aiming to tackle prejudice against schizophrenia, general attitudes towards the diagnosis improved, whilst reports of discrimination decreased (The Schizophrenia Commission, 2017). Although these changes were attributed to family and friends, there is the potential that for those with unusual experiences, increased knowledge and awareness may extend to improving attitudes of acquaintances, with whom some of the participants in the present study reported as being a source of negative judgement. Public knowledge on different cultural interpretations, for example, predispositions for certain personality types or religious beliefs, may decrease negative responses and contribute to the validation of individuals and their experiences. The present findings support an argument that suggests the language used to describe and make sense of unusual experiences should be carefully considered in order to develop a clinically

sensitive model that acknowledges the phenomenological, environmental, and cultural context within which they occur (Coughlan et al., 2022).

The research has also highlighted the use of 'unusual experiences' as separate from the typical use of 'psychotic-like experiences' within the literature. The use of psychotic-like experiences returns mixed results, with the use of various assessment tools and no universal phenomenological definition contributing to this (Hinterbuchinger & Mossaheb, 2021; Lee et al., 2016). The present study has aimed to create some distinction to this commonly used term, in order to distinguish between its clinical and quantitative use versus the experience as subjective and qualitative. It is hoped that this may go some way in developing clearer definitions for both phenomena for the purposes of systematic research. Although 'unusual subjective experiences' (Preti et al., 2012) has previously been suggested as a way of avoiding the stigma associated with 'psychotic-like' (Hinterbuchinger & Mossaheb, 2021), the authors of this label associated the definition with increased distress and difficult emotional processing. Indeed, there appears to be, both based on the participants within the present study and across the literature, several types of unusual experiences, not all of which are characterised as being distressing. By recognising and researching different types of experiences, including those that do not cause significant levels of distress (Boumans et al., 2017), a holistic understanding of the psychosis continuum can begin to develop.

5.4.7 Future Research

As the research appears to have identified a novel finding in relation to how environment and individual personality type can influence the process of rationalisation as opposed to simply religion, it would be useful for future research to explore this further. The present study

only included one non-religious, White participant within the sample, whose interpretation differed substantially from the remainder of the sample. Previous research has focused upon Middle Eastern or African cultural influences (Pigeon-Gagné et al., 2022; Yehya et al., 2022), whilst other studies made no reference to this (Boumans et al., 2017; Heriot-Maitland, Knight, & Peters, 2012). However, the perception of Madeline within this study warrants further exploration with others of similar non-religious, White backgrounds, as it provides the ability to highlight differences in frameworks of understanding. Further research is also required on relative age of individuals within their family or peer group and how the dynamics of these relationships can contribute to dismissal or invalidation of the participant's rationalisation of their unusual experience. In the present study, both Madeline and Rayna referenced their identity of being the younger sibling or child in their family and how this played a role in feeling invalidated in relation to their unusual experience. Therefore, it would be interesting for future research to focus on how perceived identity and family or peer dynamics can negatively (or potentially positively) contribute to the sense-making process.

To the researcher's knowledge, the present study is also the first of its kind to explore perceptions of other's responses to unusual experiences as a focal point of the research. Similarly, perceptions of invalidation, but higher levels of validation from others were found in previous research (Heriot-Maitland, Knight, & Peters, 2012), suggesting that others play a significant role in determining the way people feel about their unusual experiences. Therefore, future research should aim to make this a significant factor in understanding the phenomenon of unusual experiences, in order to examine what elements of interactions with others contribute to either validating or invalidating the individual's perception of both self and their framework of understanding. Recruiting a sample of individuals without unusual experiences

would be beneficial in learning about societal attitudes towards this phenomena, with both those who have had contact with someone who has had this experience and those who have not. Future research may also benefit from exploring both sense-making and other's responses to different interpretations within different types of unusual experience; for example, unusual experiences as they are defined in the present study, unusual subjective experiences (Preti et al., 2012), and psychotic-like experiences (Brett et al., 2007), in order to further understand any differences between these terms.

In conclusion, the present study identified four main themes that contribute to understandings of unusual experiences: rationalising the experience as simply unusual, sense-making can be inherent or taught depending on the individual, the significance of the other in society, and legitimacy and validity of the unusual experience. The method of utilising IPA allowed for deeper understanding of the lived experience of unusual phenomena, both supporting previous literature as well as building on this with novel findings. Although some ways of making sense of the unusual experiences were accepted by others depending upon shared religious beliefs and knowing personal backgrounds, fear of stigma remained for all participants due to the potential links between unusual experiences and illnesses such as psychosis. This research provides insight into the lived experience of these individuals and suggests ways that public perception can be improved.

Chapter 6

EXPLORING FRAMEWORKS OF UNDERSTANDING AND MEANING-MAKING PROCESSES IN PEOPLE WITH EXPERIENCES OF PSYCHOSIS

Abstract

Aim: The study aimed to explore how individuals with a diagnosis of psychosis make sense of their experience and how they feel they are treated by others.

Method: Five individuals (F=4, M=1) between the ages of 20 and 40 were interviewed over Microsoft Teams. Transcripts were analysed in accordance with the steps of IPA, first undergoing a case by case analysis, before a group analysis.

Results: Four main themes emerged from the findings: (i) '*The process of rationalisation*;' (ii) '*The other's role as a monitor of society*;' (iii) '*The importance of communication for inclusion, sense-making, and connection*;' and (iv) *'The effect of a psychosis diagnosis on identity'*. The themes outlined how all participants grounded their experience in real-life stressors, as well as religion and culture for some. Others played a significant role in participant's lives, through monitoring of behaviour and dismissing them as lacking credibility due to their diagnosis. For most, the diagnosis allowed them to make sense of what they were going through, despite this not being communicated effectively, however it also had a negative effect on the way changes in identity were perceived.

Conclusion: Improvements on the way a diagnosis is communicated to individuals is warranted, as is further interventions that involve family members in order to support

individuals effectively and reduce negative impacts of monitoring. This research provides insight into the lived experience of these individuals and suggests ways that information sharing can be improved.

6.1 Introduction

6.1.1 Making Sense of Psychosis

The subjective experience of psychosis has been widely researched in recent years. Aside from what is currently known about the potential causes of and treatments for psychosis, research has also developed to consider the lived experience of these individuals in order to capture a more holistic understanding of the phenomenon (Noiriel et al., 2020). Characterised by symptoms such as hallucinations and delusions, the very nature of the primary symptoms experienced make them difficult to both comprehend and articulate (Ruocchio, 1991). This was further reiterated by individuals with psychosis themselves, who stated that although psychosis provided a sense of something being wrong, this was difficult to communicate to others (Leiviskä Deland, Karlsson, & Fatouros-Bergman, 2011; Ritunnano et al., 2022). According to Jaspers (1913), these primary symptoms are incomprehensible to others due to the inability to relate empathically. Despite this, several publications have emerged examining the subjective experience of psychosis qualitatively.

In a meta-synthesis that aimed to explore the lived experience of psychosis and included 98 studies with a total of 1945 participants, some individuals made sense of what they were going through as illness based upon the way in which medication use allowed them to recover (McCarthy-Jones et al., 2013). Although this attribution to psychosis was difficult, it also allowed for a way to interpret the so-called problem, and therefore, recover from it. However,

Boydell et al. (2010) suggests that the meaning made of these experiences need to be situated in context and understood from within the individual's personal framework. One of the key ways of making sense of the phenomena was by connecting the experience with real-life stressors, with psychosis representing the peak of a mental health crisis that emerged as a result of significant adversities within childhood (Bergström et al., 2019). Being able to apply meaning to the experience, even through mystical or spiritual interpretations, allowed participants to move forward and create a coherent narrative (Noiriel et al., 2020), providing a potential resolution to the aforementioned difficulties typically experienced with comprehension and articulation (Ruocchio, 1991; Leiviskä Deland, Karlsson, & Fatouros-Bergman, 2011; Ritunnano et al., 2022). Evaluating a 'Making Sense of Voices' intervention within experience-focused counselling, Steel et al. (2020) found that the approach was able to construct the way individuals understood the voices they were hearing. For example, in making sense of these as linked to real-life stressors, the intervention was able to formulate voice-hearing as a meaningful psychosocial response. In turn, distress was reduced for some individuals, suggesting that the way sense is made of experiences may be significant for mental wellbeing and recovery.

Aside from meaning-making processes, in the meta-synthesis conducted by McCarthy-Jones et al. (2013), loss was identified as a significant part of the lived experience of psychosis. Loss included factors such as sense of self and relationships with others. The loss of a stable world, control over life, and common sense i.e. the ability to recognise and filter thoughts and feelings, were also highlighted in another study (Leiviskä Deland, Karlsson, & Fatouros-Bergman, 2011). This feeling of estrangement was experienced not only with reality, but also within the individual in relation to their identity. The ability to move through the world in a

perceptual-embodied way is interrupted with the onset of psychosis, yet still occurring in the background. Hence, the experience of being-in-the-world is reduced to a frightening here-and-now existence, where interconnectedness with self and others is lost, and hopes and goals for the future are effaced (Leiviskä Deland, Karlsson, & Fatouros-Bergman, 2011). However, in a more recent review, the criticism of top-down approaches were expressed, with concerns over the idea that narrow academic aims and terminology may not allow for an authentic understanding of the subjectivity of lived experience (Fusar-Poli et al., 2022). However, even through adoption of a bottom-up approach and collaboration with experts by experience who selected the primary themes, similar losses of sense of self, immersion in the world, and common sense were identified. Additionally, as recognised in past literature, loneliness was a core concept, with participants experiencing a need to conceal their inner turmoil, and expressing a lack of ability to socialise and communicate with others (Leiviskä Deland, Karlsson, & Fatouros-Bergman, 2011; Fusar-Poli et al., 2022; Ludwig et al., 2022).

6.1.2 Psychosis and Others

One of the more significant themes that frequently arose within qualitative studies of lived experiences of psychosis was the topic of others in relation to the diagnosed individual. Interpersonal distress related to personal relationships was commonly identified across 33 studies (Griffiths et al., 2019). Participants reported a sense of disconnect from social networks, in some cases leading to the loss of friendships. This was further supported in a study that identified both withdrawal and social exclusion as contributing to the breakdown of friendships (Huckle, Lemmel, & Johnson, 2021). More widely, expectations of negative judgement and treatment within society led to concealment and withdrawal, as well as

internalised stigma towards the self (Griffiths et al., 2019; Noiriel et al., 2020). These findings can be understood within the context of the social identity theory (Tajfel et al., 1979), with the categorisation of individuals with a diagnosis of psychosis leading to social identification of this group, and comparison with others in society. Self-stigma may present itself due to the prejudice and discrimination inflicted by others towards those in the category of being diagnosed with psychosis, leading to comparisons that result in feelings of being different or abnormal for those who identify with that group. In one of the largest studies on self-stigma and schizophrenia, data from 14 countries and 1229 individuals found that 41.7% reported moderate or high levels of internalised stigma and 69.4% reported moderate or high levels of perceived discrimination (Brohan et al., 2010). The idea of these negative perceptions from society potentially stems from the stigma attached with the label and associated behaviours. For example, in an analysis of news reports within 5 years, 27 articles related to youth psychosis linked this to substance use, aggression, and violence, promoting negative and stigmatising perceptions of individuals with this diagnosis (Delahunt-Smoleniec & Smith-Merry, 2020). From the perspective of caregivers of relatives with first-episode psychosis, help-seeking was discouraged at an early stage of the illness due to the social stigma embedded within their social network of family and friends (Mui et al., 2019).

Aside from relationships with family, friends, and within society generally, one of the most significant relationships within the context of illness is of that between professionals and diagnosed individuals. It has previously been found that individuals who receive delayed treatment for psychosis experience poorer prognosis than those who receive it earlier on, indicating that help-seeking is key during first-episode psychosis or for those with at-risk mental states (Perkins et al., 2005). An increase in functioning and potentially milder

symptoms were also highlighted as a possibility for those who sought early intervention (Hegelstad et al., 2012). Additionally, early intervention appeared to reduce the risk of further illness as well as decrease the risk of suicide (Larsen et al., 2006; Larsen et al., 2011). From review of the literature then, it can be assumed that early intervention services are significant for those diagnosed with psychosis in order to improve the trajectory of the experience.

In a meta-synthesis of 17 studies examining how people with psychosis experience early intervention services, staff were described as helpful in dealing with societal stigma due to the understanding, support and care they displayed throughout treatment (Hansen et al., 2018). Although the relationship with their care coordinator was described as positive, in another study, pre-existing stigma towards mental health services was displayed, with participants viewing these institutions as a representation of power and control (Harris, Collinson, & das Nair, 2012). Despite this initial perception, the lived experience of early intervention services altered the way participants felt, leading to a more positive and less stigmatised view. In addition to this, care coordinators were regarded as influential in the way that participants were able to make sense of their experiences, supporting the normalisation of individuals with psychosis, and interpreting symptoms as connected to adversity or stress. However, participants were also able to make sense of their experiences beyond the explanations offered by professionals, demonstrating the flexibility with which individuals are able to utilise their own personal frameworks for understanding psychosis within services (Harris, Collinson, & das Nair, 2012). Despite this, it has previously been indicated that the dominant medical model often dismisses subjective experiences of the individual, making it increasingly difficult for both professionals and patients to understand the phenomena encountered (Borchers, 2014).

6.1.3 Rationale and Aims

Review of past literature indicates that the ability to make sense of psychosis, either through personal interpretations or support from professionals, as well as early help-seeking and intervention are significant parts of the lived experience of psychosis (Hansen et al., 2018; Noiriel et al., 2020). Additionally, there remains an overarching finding of stigma faced by those with psychosis, especially in relation to social networks and society (Griffiths et al., 2019; Mui et al., 2019). One of the key noticeable differences between past research and the present study is the key focus and aims of the study. In previous studies (McCarthy-Jones et al., 2013; Bergström et al., 2019), the aim was to understand the lived experience of psychosis broadly, with meaning-making processes or relationships with others emerging amongst other themes. By focusing on these two areas in relation to psychosis specifically, there is the possibility that novel findings may emerge, particularly in relation to the wider aims of the thesis and the philosophical concept of epistemic injustice (Fricker, 2007) under investigation.

Due to the significance of early intervention services in improving the prognosis of psychosis and supporting individuals with the way sense is made of their experience (Perkins et al., 2005; Harris, Collinson, & das Nair, 2012), the present study aims to explore the lived experience of those with psychosis who received treatment from an early intervention care coordinator. Although early intervention is not a focal point of the study, the ability of the professional to assist in the construction of meaning with patients will assist with the part of the study that relates to meaning-making processes. By exploring the way sense is made of psychosis, as well as the way individuals with psychosis are treated, this chapter fits in with the wider aims of the thesis by allowing for the concept of epistemic injustice to be studied in relation to

participants without a diagnosis in chapter 5. Based upon the aims mentioned, the research questions are as follows:

(i) How do people who experience psychosis make sense of their experiences?

(ii) How do people who experience psychosis make sense of how they are treated by others?

6.2 Method

6.2.1 Design

The study was approved by the Surrey Research Ethics Committee (REC reference: 20/PR/0616; date 09/03/2021; Appendix 4) and the Health Research Authority (IRAS number: 286804; date 01/04/2021; Appendix 5). The design has been reported in line with the Consolidated Criteria for Reporting Qualitative Research (Tong, Sainsbury, & Craig, 2007). As the research was concerned with understanding the lived experience of people diagnosed with a schizophrenia spectrum disorder, a qualitative, phenomenological[11] approach was utilised and data was collected via semi-structured interviews. Adopting a critical realist epistemology, it was assumed through analysis that a 'real' world exists for each participant, however, this reality cannot be known by researchers with certainty.

6.2.2 Participants

Participants were recruited via purposive sampling methods. Inclusion criteria were as follows: (a) adults (18+ years); (b) English as a first language; (c) diagnosed primarily with a

[11] For more discussion on the suitability of IPA to the study, see Chapter 4 (Methodology) of the thesis.

schizophrenia spectrum disorder; and (d) spent between 1 and 5 years under the care of an Early Intervention Service (EIS). This must have occurred within the last 5 years to ensure that participants would be able to recall significant details surrounding their experience. Due to previous research suggesting that experiences and treatment from others may differ depending on the diagnosis (Sarisoy et al., 2013), the diagnosis had to be a psychotic disorder, excluding mood disorders with psychotic features e.g. bipolar.

Participants were recruited via a care co-ordinator within an EIS (Appendix 18). All individuals who contacted or consented to being contacted by the researcher were provided with a copy of the information sheet (Appendix 19). Individuals had the opportunity to ask questions about the research prior to deciding whether to participate. At this stage, if individuals were eligible to take part and expressed their interest in participating, a suitable date and time was set for interviews to take place via an online platform. Informed written consent (Appendix 20), along with demographic details (Appendix 21), were obtained at the online meeting, and verbal consent was obtained at the beginning and end of the interview to ensure participants were still willing to take part. A total of 6 individuals expressed interest in participating, however, due to not meeting the inclusion criteria (diagnosis of bipolar), 1 individual was unable to participate. A total of 5 participants were recruited and interviewed for the research (Table 6.1). In order to protect the anonymity of participants and prevent potential identification, both ethnicity and diagnosis have been reported separately. Participant's ethnicities included: Indian, White British, Black British, Black African, and Thai. Participant's diagnoses included: First-Episode Schizophrenia, Schizophrenia, Paranoid Schizophrenia, and Psychosis. Unusual experiences of the participants included: hearing voices

and feeling controlled; being spoken to by objects; being on a divine mission from God, and being controlled by a devil / demons.

Table 6.1
Demographic details of participants

Pseudonym	Age	Gender
George	20	Male
Keeley	30	Female
Christine	25	Female
Nandi	25	Female
Jet	40	Female

6.2.3 Data Collection

Data was collected via semi-structured interviews and conducted solely by the primary researcher. The interview schedule (Appendix 22) was developed in consultation with two members of the research team: a philosopher (LB), and a clinical psychologist (APF). Both perspectives allowed for the philosophical concept of epistemic injustice to be broken down into tangible and understandable components. A pilot interview was conducted with an Expert by Experience (EE); firstly, to confirm that the questions were appropriate for the sample of participants, and secondly, to ensure that the views of someone with lived experience of psychosis was represented within the research. Careful consideration was also given to the questions and prompts during the development of the interview schedule to minimise any potential distress surrounding the sensitive nature of the topic. In consideration of this, participants also had the opportunity to take a break or stop the interview at any point without providing a reason why. A risk management protocol (Appendix 13) was developed in order to manage any risk as a result of the distressing content and the participants gave consent for

their care co-ordinator to be informed of their participation in the research. Participants were also provided with a list of support services (Appendix 14) they could access.

Interviews were conducted remotely via an online platform between November 2021 and January 2022 due to the Covid-19 pandemic, lasting between 48 and 61 minutes. Interviews were audio-recorded via a secure Dictaphone and transcribed within 2 weeks from the point of interview, during which time participants had the opportunity to withdraw their data from the study. After this point, recordings were deleted and transcripts were pseudo-anonymised so data could not be traced back to individual participants.

6.2.4 Data Analysis

The analytic process followed the steps outlined in the Data Analysis section within Chapter 5. Examples have been provided for the vignettes (Appendix 23), personal experiential themes, (Appendix 24), and the group experiential themes (Appendix 25) of the clinical dataset.

6.3 Results

Analysis of the data resulted in four main themes, consisting of a total of nine sub-themes, all of which were found to represent the participants collectively (Table 6.2). Similarly, each sub-theme reflects the main focus of the research relating to the participant's experience of their diagnosis and how this is made sense of by themselves and others. Each sub-theme is explored below within the main themes, illustrated with quotes from the participants, as well as researcher interpretation.

Table 6.2
Demonstration of which participant contributed to which sub-theme.

Theme	Subtheme	Participants				
		G	K	C	N	J
1: The process of rationalisation	1.1: The experience is grounded in real-life stressors in order to make sense of it	✓	✓	✓	✓	✓
	1.2: Spiritual and medical beliefs are not mutually exclusive for sense-making			✓	✓	
2: The other's role as a monitor of society	2.1: The Other is significant for monitoring behaviour and determining normality		✓	✓		✓
	2.2: Personhood is contingent upon social and economic contribution			✓	✓	
3: The importance of communication for inclusion, sense-making, and acceptance	3.1: A diagnosis of psychosis is concealed from others for fear of judgement and avoidance	✓		✓	✓	✓
	3.2: The communication of the diagnosis is important for making sense of their experience	✓	✓	✓	✓	✓
	3.3: Communication is key for connection and understanding psychosis	✓		✓	✓	✓
4: The effect of a psychosis diagnosis on identity	4.1: Identity is changed as a result of being diagnosed with psychosis		✓	✓	✓	
	4.2: An individual's credibility is questionable based upon their diagnosis of psychosis	✓	✓			✓

6.3.1 Theme 1: The Process of Rationalisation

The first theme relates to the process of rationalisation for participants, including the ways that they make sense of their experiences. For all participants, there was a point in time after their first episode of psychosis where they attempted to make sense of it by grounding it in real-life events and linking it to traumas or stressors in their lives. For Christine and Nandi, their faith and/or culture played a role in the way they made sense of their experience, appearing to coexist with the medical interpretation, as opposed to clashing with it.

1.1: The experience is grounded in real-life stressors in order to make sense of it

Within this subtheme, it is key to note that the process of rationalisation being described occurred after what most participants described as an initial period of no insight (George, Keeley, and Jet). Whilst the first episode of psychosis was unfolding, all participants believed

these to be real visuals, audio, or beliefs, and only two described the sense they made at the time the unusual experiences were occurring (Christina and Nandi). Although there is some clarity throughout Jet and Christine's interviews regarding their rationalisation process developing as a direct result of their care co-ordinator, no assumptions can be made for how the remaining participants came to their conclusions.

For all participants, attempts were made to understand what they were going through during their unusual experience. In all of these attempts, the experience was rooted in reality, with participants making connections between what they were currently going through and what they had previously went through.

> "I thought I was hearing and seeing things that were related around a trauma that I'd experienced as a child." (Jet – p. 1, 25-27)
>
> "I believe it is just the cannabis and the trauma.. and there's the stress that comes along with that. All two, three of those factors, sort of are what made it happen, to be honest." (George – pp. 12-13, 444-447)
>
> "I think it was happening because I've had some really bad experiences in my life. I got bullied at secondary school really badly." (Nandi – p. 3, 97-98)

For Jet, George, and Nandi, their experience was connected to traumas they had experienced growing up, as well as participation in substance use for Jet and George. A visit to the police as an adult regarding abuse in Jet's childhood "brought something else up to the surface in [her] brain" (p. 17, 629-630) and "triggered off the early warning signs" (p. 6, 184). Whereas, for George, "past traumas wrapped up and got entangled" (p. 4, 125), and he rationalised his symptoms as "an expression of the subconscious" in relation to expressing these repressed traumas (p. 4, 133). Similar to George also recognising "stress" as a way to make sense of his

experience, Christine and Keeley appeared to view psychosis as a coping mechanism for the stress of reality.

> "I think it was because I wasn't really getting the answers that I knew I needed back then. So, I was fresh out of university and things weren't going as expected. I had expected to be in a job straight away. And expected to be in the job that I wanted exactly. Whereas, it took me, I think about a year and a half, to get a job. Maybe two years. And it wasn't anything to do with what I wanted to do. And I know now that I was pretty much, kind of giving up on my whole idea of like things that I knew, how life worked, if that makes sense." (Christine – p. 3, 73-81)

> "I think it was a lot of stress, 'cause I've got a son who has got ASD. There was work as well, that was stressful during the first one. I was having stresses at work, stresses at home. I think that my body was just like, or my mind was just like I need, I need a break. And I think, yeah, it's just, just took too much. Tipped me over the edge." (Keeley – p. 13, 443-453)

The disconnect between expectations and reality for Christine appeared to trigger her experience of psychosis. She describes not "getting the answers.. [she] needed back then" and spoke about "giving up" on her idea of the way life worked. Throughout her interview, Christine described her symptoms as 'fixed' or fixated on her faith, which she also viewed as a "failsafe" (p. 3, 85). This could potentially suggest that the way in which Christine rationalised her experience and expressed symptoms was also dependent on who she was as an individual prior to the psychosis. Having to 'give up' on a life which she seemed to view as negative, resulted in a positive experience for her, where she felt fulfilment and "instant gratification" from the way psychosis allowed her to cope with this (p. 3, 97-98). Similarly, although Keeley's experience was wholly negative for her, she felt the reason for this occurring was an "overloaded" brain that eventually had a "break down," allowing her a reprieve from reality (p. 12, 439-440). Aside from the participants themselves, mental health professionals around Jet and Christine also explored ways to ground the experience in reality.

> "She explained to me that I was extremely stressed. And she'd asked me about my past." (Jet – p. 4, 143-144)

Christine describes how university as a potential stressor was something "constant" that they "kept asking" about (p. 5, 144-148). A similar need to understand was expressed by Jet, who did not want to believe the interpretation of the mental health professionals, but "had to because it was the only explanation as to what was happening" (p. 5, 165-166). From the conversations described with their care co-ordinators, it can be assumed that this led to the development of the way Jet and Christine began to understand what they were going through. Whilst in this sense the professional environment may have been beneficial, for Nandi, a similar environment, but in a different capacity, was felt to contribute to her experience itself. While volunteering within a mental health service, she describes the effects of being around others with poor mental health, believing that over-exposure to this "had an impact" on her and triggered her own experiences (p. 2, 57).

1.2: Spiritual and medical beliefs are not mutually exclusive for sense-making

Although all participants made sense of their experience as connected to real-life sources of stress, for Nandi and Christine, their religion also played a role in the rationalisation process. For Nandi especially, a struggle was described between her mother's cultural and religious approach towards treating her psychosis and her father's medical approach.

> "My mum's Black South African and my father's White British. So, with my mum, she believed that it was a spiritual thing. With my dad, he knew that it was a mental illness. So, what happened is my mum got people to pray for me, from my country. And then on the other side, my dad, he took me to the GPs and got me help." (Nandi – p. 5, 173-179)

> "I was a bit unsure, I was a bit 50/50. Like, a part of me thought it's spiritual, another part of me thought it's a mental illness." (Nandi – p. 18, 648-649)

Despite Nandi stating that she was "50/50" regarding the interpretation of her experience, the language she uses when discussing her parents may provide an insight into which explanation she deems to be more valid. In reference to her mother's approach, she uses the word "believes" several times throughout the interview, in comparison to what her father "knows." Similarly, whilst she provided a description of the treatment process in her mother's culture, she depicts her father's approach as getting her "help." Despite the terminology used, however, she also makes several references throughout to her religion also being a source of support.

> "I pray every day. My mum prays for me. I feel as if being close to God is another reason why I've been able to recover." (Nandi – p. 20, 740-741)

> "I think that it's 50/50 with my point of view. It's 50/50 because 50% one of the reasons why I recovered as quickly as I have is because of the prayers. And then 50% is because of the medication. So, I'm in between really." (Nandi – p. 21, 780-786)

Her "relationship with God" was described as a significant and important part of her life (p. 12, 417), however, she also acknowledges that "sometimes prayer doesn't always work" and "sometimes you need to actually go to the doctors and.. take the medication" (p. 12, 430-431). Nandi's ability to believe in both approaches as a way of rationalising and recovering suggests that the two concepts are not mutually exclusive, but can in fact, coexist for people. Similarly for Christine, she felt that the medical way of making sense of her experience was "quite accurate," however she also viewed her experience as an expression of faith (p. 6, 187).

> "Being fixed on pleasing God in a specific way. Like, I have to do this and I have to do that and not really giving myself a choice in that. Things like that… So, I just thought I was doing the right thing and kind of following what I knew was right and nothing could sway me from doing the "right thing," in inverted commas [laughs]. I didn't feel any different really. I just felt really determined and really driven and to me, it seemed like quite a positive thing." (Christine – p. 1, 23-32)

The subjectivity regarding ways of making sense suggests that the way individuals view their experience is a matter of perspective. For example, the 'fixation' that appeared in conversations with her care co-ordinator was viewed as 'determination' by Christine. Both Nandi and Christine's interpretations altered in time, highlighting the fluidity involved in rationalising experiences. Multiple ways of making sense, including faith and science, appeared relevant for developing a sense of understanding and finding support, suggesting that psychosis can be perceived as more than just a biological mental health issue.

The first theme demonstrates how individuals with a diagnosis made sense of the experience they were going through, with clear development of this interpretation resulting from interactions with mental health professionals for some. For all participants, the unusual experiences they had linked back to real-life stressors, including trauma and substance abuse, occurring as a way for the brain to cope with the stress of reality. For two of these participants, religion and culture also played a role in the way they approached both understanding and 'treatment' of what they were going through.

6.3.2 Theme 2: The Other's Role as a Monitor of Society

The second theme relates to the authoritative role taken by the Other in society, as experienced by the participants, monitoring the way individuals behave and deeming them a valid member of society depending on whether or not they can function and contribute. This theme displayed itself strongly within Christine's experience, but manifested in different ways for Jet, Nandi, and Keeley.

2.1: The Other is significant for monitoring behaviour and determining normality

Others in society were described as observers, monitoring participants for changes in behaviour. For Christine, any changes in what was constituted as her typical behaviour were felt to be "disturbing" to family members (p. 1, 11), who wanted to be able to "monitor me from home" (p. 16, 575).

> "Um so, if I was to ever [sighs] um, do anything that was a bit out of the ordinary or be insistent on something, then they would kind of be triggered and start asking more questions and say, 'you know you used to be like this,' et cetera, and, 'you know the symptoms of psychosis are this and this is how you're behaving,' kind of thing, to line them up basically." (Christine – p. 12, 416-421)

Although this monitoring by the Other appeared to be unwilling on behalf of Christine, for Jet, the Other was significant for reality testing. Although she acknowledges that she "couldn't quite register [what] was real or not" regarding auditory and visual experiences (p. 1, 11), she notes that "the closest people around me kind of noticed that," suggesting that others are significant not only for reality-checking, but also monitoring changes in behaviour (p. 1, 7-8).

> "I couldn't understand why no-one around me couldn't see or hear these things. That's what made me think that there's not, there's something not right here. This can't be true. This can't be real because nobody else is hearing and seeing it. Because when I asked them, they would say, 'no, I can't see what you're seeing. I can't hear what you're hearing.'" (Jet – p. 2, 56-60)

The wanted versus unwanted nature of the Other's guarding role in society also appeared to have an effect on the way participants viewed themselves and their experiences. For Jet, the ability to test and confirm her sense experiences via others was reassuring, compared to Christine who perceived the monitoring by others in a negative way.

> "I could hear a noise in my flat and um, and I can remember saying, 'can you hear that?' And him saying, 'yes, I can hear that. You're not hearing it um you know, um. I can hear it too.'" (Jet – p. 15, 541-543)

> "Um a bit um [tuts] kind of, uh what's the word now? A bit in cotton wool, like wrapped in cotton wool, protected and shielded." (Christine – p. 12, 438-441)

> "It is like walking on eggshells around them. So, I'm aware that they're literally kind of hanging on my every word [laughs]. Um and watching my behaviour. Uh just to kind of see if there's anything that I say that could link me back to that uh that season in my life." (Christine – p. 13, 447-452)

Although Christine states that the monitoring felt protective, within the context of her interview this could be understood as unwanted overprotection by others. Aside from being overprotected, the idiom "wrapped in cotton wool" implies that she also felt infantilised by those around her. This also linked to behaviour changes for Christine, who became mindful of the fact that her current behaviour was now evaluated against her past experiences with psychosis in order for others to judge her level of 'normality.' Behaviour changes involved not doing anything "different or drastic" and "keeping to a routine" (p. 16, 578-580). Although this theme was significant through Christine's and Jet's interviews, for Keeley this was only a brief mention. She noted that she also experienced a change in response towards her by friends, who appeared to display a wariness they had not previously, monitoring the way they behaved around her in order to avoid triggering "an episode" (p. 15, 546).

2.2: Personhood is contingent upon social and economic contribution

Aside from the role of a monitor, the Other's role was also perceived as judging the validity of a person based upon their contribution to society. One of the key factors determining the worth of both Christine and Nandi was their inability to go to work.

> "My dad would come back from work and be like, 'why do you spend all day hiding in your room? Some kids your age at, uh university, they're studying, they're making something of their life and you're just sitting at home. You're hiding in your bedroom all the time. You're not coming out, you're not trying to get a job, you're not trying to get into university, you're not doing anything with yourself. You're not

> studying, you're not accomplishing anything, you're just hiding away in your room because of your mental health.'" (Nandi – p. 7, 227-234)

For Nandi, the withdrawal due to her experiences displayed itself as "hiding away" to her family, who appeared to view her mental health as a barrier to gaining accomplishments. Her description of her father's view of her "just sitting at home…because of my mental health" may suggest that the impact of psychosis is not well understood by those without personal experience of it. At the very least, it suggests that in comparison to a physical illness or potentially other mental illnesses, the experience of psychosis is minimised and it is expected that individuals with this diagnosis should still be able to function in society at what is considered a 'normal' level. Alternatively, for Nandi's father, it is also possible that rather than not understanding the impact of psychosis, there are instead certain hopes and expectations that most parents have for their child, that he fears will not come to fruition. For Christine, being able to go back to work was one of the ways that she felt able to "prove" herself to the Other, in order to be viewed as a person rather than as her diagnosis.

> "I think that now that time has gone on a little bit and I've proven that I'm able to go back to work, I can be reliable at work, uh take care of myself and be in charge of where I move to and things um consistently. I think things are starting to get back to normal. Uh so, I'm able to present an idea and for it to be taken seriously rather than taken as something to be dissected and investigated, and maybe labelled as something to do with a symptom. So, it's just taken now, it's just taken as an idea." (Christine – p. 13, 473-481)

> "I do feel like I have to control my behaviour. Like, to still show that I'm not that anymore. That I'm well, if you want. Um and I really hate that phrase [laughs]. Uh but, yeah, just to say that I'm valid on my own now, that I don't need to be associated with that, and I'm still able to make a valid contribution." (Christine – p. 14, 500-504)

The ability to contribute to society again provided Christine with the benefit of being "taken seriously" by others. Whilst her unusual experience affected her functioning, it also had an

impact on the way her identity was perceived. A decrease in function and contribution led to an increase in scepticism regarding her testimony, resulting in feelings of being "funnelled into the diagnosis" and feeling "less human" (p. 12, 437). Similarly for Nandi, once she was able to begin contributing in some way to society again, expressed anger associated with her lack of functioning decreased within others.

> "People my age were off to uni and working and doing things with their lives, and I wasn't. So, that's why they were very angry with me during that time. But um, they've gotten over that now because I'm a lot better now, and I'm doing things, I'm having driving lessons." (Nandi – p. 19, 674-680)

Although the anger towards her withdrawal dissipated once others felt that Nandi was able to function within society, some anger remained towards her medication use. She experienced annoyance from her family towards the fact that she "couldn't find another way to get better without taking medication" and that "it had come to that point" (p. 8, 277-287). The influx of negative emotions expressed by others during her experience of psychosis "lowered my self-esteem and my confidence," indicating that the role of the Other in Nandi's case, as well as Christine's, was one of judgement and identity replacement (p. 19, 685).

The second theme highlighted the mostly negatively perceived role of others in society, with only one participant viewing this monitoring as positive for reality-testing. For others, this authoritative role of 'watching' for changes in behaviour was felt to be judgemental, as well as difficult to traverse. This monitoring by others led to changes in behaviour for some participants. Their value as a member of society was perceived to be dependent upon whether they could contribute as a functioning member. This was displayed from two different perspectives: a father potentially concerned with their child's loss of potential, and a

participant determined to 'prove' their worth to society and be perceived as more than a diagnosis, both attesting to the value that is placed on social and economic activity.

6.3.3 Theme 3: The Importance of Communication for Inclusion, Sense-Making, and Connection

The third theme relates to communication and the significance of this in several areas of the participant's lives. For George, Christine, Nandi, and Jet, they feared judgement due to their diagnosis of psychosis, and instead chose to conceal this from others and withdraw for both their own sake and for the sake of others. They also described how shared experiences helped to feel a connection to others and played a role in their understanding of and recovery from psychosis. For all participants, the way their diagnosis was communicated to them had an effect on the way they were able to make sense of what they were going through.

3.1: A diagnosis of psychosis is concealed from others for fear of judgement and avoidance

There was a strong sense of fear across some of the participants regarding judgement and subsequent treatment from others if they were to reveal their diagnosis. For Nandi especially, this theme was strongly present across her quotes, with fear being experienced for a variety of reasons, both within and outside of the mental health community.

> "I feel as if I wouldn't be open about my mental health problems to someone who wasn't a part of my family, 'cause I feel as if they'd judge me. Because they may not understand about my mental health, and so I feel as if I wouldn't want to tell them, because I wouldn't want them to treat me in a certain way." (Nandi – p. 19, 696-700)

> "I didn't want to tell the other service users about my mental health because, about the spiritual part, because I didn't want them to think that, 'oh my God, she's a weirdo.' I didn't want them to, I didn't want to be judged by them, so I didn't tell them." (Nandi – p. 13, 451-455)

Whilst with others generally, there was fear regarding judgement of the diagnosis itself, with those who had shared experiences, Nandi felt fear concerning her spiritual interpretation of what she was going through. This led to voluntary social withdrawal to avoid "judgement and bullying" (p. 6, 206). This method of protection was also utilised by Jet who aimed to "steer away from talking about my diagnosis" by avoiding non-diagnosis related questions, for example, about her lack of work, that had the potential to lead to diagnosis related questions (p. 11, 374). Although Nandi describes the current status of mental health as becoming more open due to celebrities discussing their experiences with it, the fear still remained that for her, treatment would be negative and different to others. Whilst Nandi viewed society as "not understanding about mental health", George provided reasons for why society reacts the way they do to psychosis.

> "So, like, there's this societal stigma about it, which of course, you'd expect 'cause it's like, it's not like depression or anxiety. It's someone walking down the street naked whilst screaming. Obviously, I didn't do that, but that's like what they do. And there's obviously the violence aspect of someone killing their family, or someone, I don't know, cutting their finger off, or trying to operate on themselves. Like, it's scary and unpredictable and why would you want to associate with that?" (George – p. 18, 635-643)

> "It's probably some primal basis for it or something. But like, it's just the way that we react to those sorts of things, to be honest."(George – p. 16, 559-561)

From the above quote, there is a sense that for George, a hierarchy of mental health problems exists that is dependent upon how violent or unpredictable people with a diagnosis are deemed to be within society. In this instance, it is people with psychosis that are associated with violence and aggression, in comparison to diagnoses such as depression or anxiety that may be considered more socially acceptable to discuss in society. George also suggests a biological or evolutionary reason for avoiding people who display behaviours viewed as

abnormal, with exclusion of these individuals deemed to be natural. He also noted himself as holding "bias" towards other service users despite sharing the same environment as them (p. 15, 556), "mocking them" due to his perception of them as "crazy people" (p. 10, 353-358). This distinction between himself and others with a similar diagnosis is also highlighted in the above quote where George states "I didn't do that, but that's like what *they* do." Although Nandi and George discussed the stigma towards psychosis, Jet and Christine expressed concealment of the diagnosis out of concern for how it would affect others.

> "It's a very sensitive subject with my friends and family that, well, the family that's [sighs] still connected to me. Um… uh yeah. It's hard talking about it sometimes. Not hard for me, but it's hard, I can see it's hard for people, other people that I'm telling it to, you know, especially close people." (Jet – pp. 9-10, 331-335)

> "I don't think I would want to bring it up for them, because I know that it was quite a painful time for them." (Christine – p. 11, 399-400)

Although Jet also felt a need to "protect myself by steering away from questions" (p. 11, 378-381), for her and Christine, the diagnosis was primarily concealed to avoid bringing up painful memories associated with the psychosis for the sake of others. This suggests that although the experience of psychosis has an impact on the person experiencing it, there is also a negative effect on the people closest to the individual. For most participants, withdrawal was an active choice, whereas for George, the disconnect from society was experienced as social exclusion. With hospitalisation came "an absolute shedding of acquaintances" (p. 21, 777-778) and "everyone cutting contact" (p. 15, 547), leading to feelings of sadness and isolation.

3.2: The communication of the diagnosis is important for making sense of their experience

Whilst communication regarding the diagnosis with others was difficult for most participants, initial communication of the diagnosis to them by mental health professionals also appeared

to be complicated. Jet, Christine, Keeley, and George, all note how the way they received their diagnosis was delayed, ambiguous, and confusing, causing them to feel as though they were neither active nor autonomous with their recovery.

> "I saw it on a piece of paper. Yeah. I saw it on a piece of paper. It was when I was at [psychiatric ward], I remember I had to either make a phone call or something like that… And um the woman over the phone asked me what my diagnosis was and next to me was a piece of paper with my name on it. And it had schizophrenia underneath my name and I remember asking the nurse if that was my information and she said, 'yeah.' Yeah, I remember that day." (Jet – pp. 12-13, 444-455)

> "So, I didn't know I was diagnosed with schizophrenia until I was in [psychiatric hospital] and I had a copy of my ward round and it said that I was diagnosed at [treatment centre] with schizophrenia. So, they were quite new to me. Um what schizophrenia is, do you know what I mean? So, I'm still learning myself." (Keeley – pp. 7-8, 248-256)

> "Well, there was [sighs], I didn't realise at the time [laughs]. I didn't realise that was the diagnosis 'cause no one sort of formally, it was only recently when I formally saw a piece of paper that actually said it on." (George – p. 13, 466-469)

For Jet, Keeley, and George, they described how they all learned about their diagnosis incidentally through documentation and there was no active communication of the diagnosis to them. Christine also noted how she received her diagnosis "quite late on" in the process (p. 5, 156-160), whilst Keeley found it "a bit strange" that they "don't tell the patients what they're diagnosed with" (p. 8, 266-270). The lack of communication had the potential to delay them from making sense of what they were experiencing, leading instead to assumptions of what they might be going through. Here, it appears that communication surrounding the diagnosis was neither direct nor timely. Aside from the diagnosis, George and Keeley found there to be insufficient explanations regarding information in general, seemingly associated with a resigned acceptance of their situation without understanding.

> "I don't know why we have the symptoms that we do. Like with psychosis, you know, like the radio talking to you and the tele. I don't know why but it just happens. I don't understand why, but it's just how it is." (Keeley – p. 13, 453-456)

> "So, the leaflet was from Mind. It was a Mind leaflet. So, I don't think through the years, sort of the system, I've been explained anything more than that, to be honest." (George – p. 9, 319-321)

Communication from services appeared to be limited for George and Keeley throughout their experience of psychosis, with information provided through documents as opposed to conversations with the mental health professional. For Keeley, a lack of information surrounding medication use resulted in a limited understanding as to why it was needed, and eventually led to relapse. Being able to make sense of the experience appears to be key for understanding and recovery for most participants. As George explains, "as soon as I knew the word [psychosis], it was jump straight to Google Scholar" (p. 13, 474-475). Similar to Keeley, both found themselves having to learn about psychosis through their own research rather than communication with experts. Along with George and Keeley, having confirmation of the diagnosis was also significant for Jet to make sense of her experience.

> "And a kind of relief as well, you know… Now that it's got a kind of name, it's just easier to work with, I guess. Knowing what I have." (Jet – p. 13, 470-474)

Jet describes a sense of relief having a name to put to her experience and found the hospital "became a bit of a sanctuary" for her (p. 4, 138). The information helped her "to understand what goes on with me now… unlike before" where she "didn't know who to go to or who to talk to" (p. 12, 431-436). The use of the word "sanctuary" in reference to a hospital could also be viewed as a refuge not only for the relief it provided, but also from judgement of others, where she struggled with others believing her experience. A distinction was made between the hospital versus the EIS for Keeley, who found that she was only able to make sense of her

experience once she was in communication with her care co-ordinator in EIS. Nandi found that for her, being able to have access to mental health professionals exposed her to other interpretations and provided a different way for her to make sense of her experience and recovery. For Jet, communication regarding the diagnosis provided validation and legitimacy to her experience, where she felt "relieved because somebody knew what I was talking about for once" (p. 5, 154-155). Collectively, it appears that early communication of the diagnosis would have been useful for participants, who noted several benefits to both rationalisation and recovery once they had a way to make sense of what they were dealing with.

3.3: Communication is key for connection and understanding psychosis

Aside from the validation that communication and clarity around the diagnosis provided, the ability to relate to those with shared experiences was key to experience a sense of community and normality for Jet, Nandi, and George.

> "I have a good friend also with the same diagnosis and she calls it classroom 12. When she's having a moment, if she's experiencing an auditory hallucination, then she'll say, 'I've got to shut the door to classroom 12.' For me, it's my third-party voice and sometimes I have to block that out." (Jet – p. 8, 266-275)

> "So, when I went there, I felt really like welcomed. I felt really like at ease. I felt normal for a change, 'cause I felt as if I, I'm not the only one that's been through this, there's other people as well. And they deal with it differently, but at least I'm not on my own." (Nandi – pp. 12-13, 445-448)

Despite the differences between individual experience, there was an overall sense of connection felt for Jet and Nandi that was not felt with others in their social network. The ability to relate to specific experiences and diagnoses was significant for feeling "normal" and connected to other people. Being able to feel "normal for a change" suggests that with others who have not experienced unusual events, Nandi considers herself an outsider. George noticed

that it was “mainly people who have got their own mental health that I stayed in contact with” (p. 16, 583-584). For Nandi, having personal experience of unusual phenomena was the only way she truly understood that those diagnosed with a mental illness were able to “live normal lives” (p. 16, 561), suggesting that others who do not have these experiences may not have the ability to relate.

> “Schizophrenia’s something that I’ve just heard on TV or I’d heard on, you know, movies, and stuff like that. I don’t know anybody that has - now I do because I’ve engaged with people that engaged with the services - but prior to that, you know, there is nobody, there’s no friends or no family that can relate to me.” (Jet – p. 13, 462-466)

> “I don’t know too much about their opinions, they don’t know too much about mine. We sort of, I actually spoke about this in therapy, and I wrote them a letter [laughs], and I never got a proper response [laughs]. So, it’s one of them ones, but like… just to sort of write how I wanted to know what they... but [tuts] I never really got a proper response, so. I sort of left it at that. (George – p. 20, 708-716)

In the above quote, Jet also describes the inability for others without a similar diagnosis to relate to her, possibly stemming from a lack of information or misinformation within society and the media regarding psychosis. This highlights the significance of communicating with people who have shared experiences in order to feel a sense of belonging and connection. George displayed an eagerness to communicate with his family about their feelings towards him, however, he never received a satisfactory response. Later, George linked their lack of response to his culture rather than to the psychosis itself. He felt his culture had an impact on openness and communication from his family regarding mental health, with his experience being that “Asian families.. don’t really discuss things” (p. 6, 189-191). The importance of communication displayed itself strongly within George’s interview, and he felt clearly that this was key for individuals with psychosis.

> "Just engaging really, just being compassionate and engaging is the main thing. Just like being able to have those difficult conversations… Uh and being able to have a mature conversation, like maturity really." (George – p. 21, 746-748)

For him to feel emotional fulfilment, especially in relation to his family, communication was a requirement for George. Unlike other participants, he received this from close friends rather than those with shared experiences. Despite not having direct experience with psychosis, for connection, "reciprocity" was a necessary component of communication (p. 15, 542). The ability to share "little secrets that no one else knows" was important for him to connect within his friendships (p. 15, 539). An example of these "little secrets" can be understood through Jet's 'third-party voice' and her friend's 'classroom 12' when referring to auditory experiences. Here, it appears that connections are formed or maintained through shared experiences or insider knowledge.

The third theme highlights the significance of communication and how this can contribute to positive and negative feelings for participants. Fears of being judged or stigmatised by others outside of family and friends due to the perception of individuals with psychosis, as well as the way sense-making would be perceived, led to a lack of communication with others regarding experiences, resulting in social withdrawal and isolation for almost all participants. In relation to receiving their diagnosis, it was recognised that this was not communicated to them directly, rather knowledge of what they were being treated for was found coincidentally through documentation. Despite this, participants felt that being able to put a name to what they were going through allowed them to make sense of their experiences and supported the recovery process. With others who are also diagnosed with psychosis, some participants felt a sense of normality and belonging that they were not able to feel with others, with shared experiences and insider knowledge being key for communication and maintaining relationships. Although

this presented in different ways, throughout all three sub-themes, communication appeared to be the underlying factor necessary for a sense of inclusion, the ability to make sense of experiences, and forming connections with others.

6.3.4 Theme 4: The Effect of a Psychosis Diagnosis on Identity

The final theme relates to the impact a diagnosis of psychosis had on the participants, particularly in relation to the effect on identity. This theme explores the negative perception of a psychosis diagnosis, as viewed by both self and others, and the subsequent changing of identity for Christine, Keeley, and Nandi. For all participants except Nandi, the diagnosis also had an effect on whether or not they felt their testimony was believed by others.

4.1: Identity is changed as a result of being diagnosed with psychosis

In the process of gaining a diagnosis of psychosis, some participants felt they also lost their identity. For Keeley, the diagnosis was a turning point in life that "changed" her (p. 15, 549; p. 11, 400-401). She noted that in response to the change in identity she feels, friends around her also changed their perception of her, rather than the change occurring due to the psychosis itself. Regarding the change felt in others, she described her psychiatrist as understanding of her experience.

> "I remember my psychiatrist saying… I said, 'but I don't feel like the old me' [laughs]. And uh she says, 'no, you'll be a new you if you let yourself. You'll be a new you.'" (Keeley – p. 15, 550-553)

> "I did actually have a word with my psychiatrist and I said… well, we spoke more about my diagnosis about a month ago. And she said, 'don't let it define you. Because you're still Keeley.' So, she said, 'don't let it define you.' She said, 'don't, it's just a label.' She said, 'don't take it as anything more than that.'" (Keeley – p. 14, 508-513)

In the second quote, there was an attempt to make a distinction between diagnosis and identity, despite the first quote demonstrating a process of change occurring. This suggests that for Keeley, there was a sense of acceptance that was required during the diagnostic process in order for her to come to terms with her sense of self. The above quotes could also potentially indicate that whilst acceptance of a "new you" may be beneficial, this version of the 'you' is still anchored to your own self and identity, rather than being separate to it. For Christine, although she came to associate the diagnosis with herself in time, she also felt resigned to accepting this.

> "I suppose because their, well, doctor's diagnoses are generally quite reliable. Mm. Yeah. So, I don't know if there's any point trying to fight it because I know that it's happened now and it's probably on my medical records. So, [short laugh] it's going to stay there, so there's no point fighting it anymore." (Christine – p. 8, 289-295)

> "But I think now I'm starting to associate it with actually me, [laughs] more recently. But back then I wasn't at all. I just said that's what they say I had." (Christine – p. 8, 285-287)

Prior to this resignation, Christine made a point within her life to disassociate herself from the diagnosis, rejecting the label from the mental health professionals. In conversations with others, she "wouldn't say I had psychosis," but rather she would "make a point that that's what *they* said I had" (p. 8, 281-283). The use of "actually" where she describes associating the diagnosis with herself implies that prior to this point, the diagnosis had little to no part in the way she identified despite the association existing, although she now accepts this as part of herself. The impact of the power a health professional can have on identity within society was experienced by both Christine and Nandi.

> "It was more to my family, I think. So, I was still in the room, I don't think I was being very responsive. But that kind of made the senior psychologist more inclined

> to say that that's [psychosis] what I was experiencing to people who were listening." (Christine – p. 6, 198-201)
>
> "They'd treat me like a patient and I don't want to be treated like a patient." (Nandi – p. 19, 707-708)

In Christine's case, she felt "funnelled into what they already thought," as seen in the above quote (p. 7, 234). In her experience, any behaviour of hers was viewed in light of her diagnosis and treated as a symptom, potentially affecting her identity within society by fitting her into a mould of preconceived notions. For Nandi, the diagnosis was a negative experience that forced her into a role, where she felt others viewed her via a medical lens, perceiving her as a patient rather than a person. There is also an element of power imbalance, as for both, the diagnosis and the subsequent impact of this was unwanted, however neither had the ability to change their situations.

4.2: An individual's credibility is questionable based upon their diagnosis of psychosis

Apart from the effect on identity for the individuals themselves, the diagnosis also affected the way their feelings or behaviours were perceived or treated by others. For Jet and George, this perception of them as legitimate within society was experienced in different ways, with the former not being believed about her diagnosis based upon past behaviour and the latter not being taken seriously based upon his diagnosis.

> "I mean, they've [family] made up their opinion of me based on the facts that I've given them, I guess. And when I was in my twenties, I was a bit of a raver. I'd go out partying and I'd take drugs and I guess they think that I'm still that person and that I've made this up for attention." (Jet – pp. 16-17, 596-600)
>
> "If someone at uni was to sort of find out the full extent, it'd be like, 'woah.' They wouldn't take me seriously after that, I'm 100% sure of that, 'cause of how it goes. Like, I had it on my CV. Uh that I recovered, didn't get a job for months. Took it off, got one pretty quickly." (George – p. 17, 629-633)

In both cases their identity, either pre- or post-diagnosis, was understood to influence the way others viewed them, recognising that their perceived identity as someone with a diagnosis of psychosis had the ability to lead to dismissal of testimony and exclusion from others. In one example of this provided by Jet, with regards to another person's experience of psychosis, she stated, "she's a really clever woman and I believe what she's telling me" (p. 9, 306-307). Here, the perception of this person being "a really clever woman" seems important in believing her testimony. George's statement of this treatment of people with a diagnosis being "how it goes" indicates recognition of a social norm behind the stigma towards psychosis. Similarly, when it came to George presenting an idea within a university setting, he felt "a block to stop [others] delving into it if they know the history" of his psychosis (p. 24, 883-884). Within academia, where exploration of ideas are commonplace, he felt the diagnosis would cause others to change the way they respond to him in conversations, compared to those who do not know about his diagnosis. In addition to this, several examples were provided by Jet, George, Christine, and Keeley regarding not only dismissal, but also disbelief regarding their testimonies based upon their identity.

> "My partner gets a bit worried sometimes. He sometimes says, you know, 'are you sure? You're not hearing this, are you? You're not, you are well?" (Jet – p. 15, 535-537)

> "Even within family, like my parents recently said, 'well, we don't know whether we can believe anything you're saying.' They said that to me recently." (George – p. 24, 873-875)

> "I don't think my mum believes me as much when I tell her stuff. Because I've had like conspiracies before, they do wonder sometimes if they can trust me." (Keeley – p. 16, 562-564)

In the above quotes, participants identified how family members questioned their credibility based upon their experience with psychosis. In particular for Keeley, she links this back to her

previous “conspiracies,” suggesting that others may view her identity via the lens of her diagnosis and previous unusual experiences, affecting the belief they have in her testimony. This perception of her diagnosis, and the subsequent influence on her credibility, had a negative impact on her, resulting in feelings of frustration. In an example provided by Christine, her family expressed concern and alarm at her desire to volunteer for a year. Although gap years and volunteering are common experiences for young adults in society, this desire appeared to be viewed as another symptom of her psychosis, discounting her identity as an individual despite the diagnosis. Here, there may be a form of injustice at play, where people with psychosis are viewed as less credible or legitimate within society on the basis of their experiences with and diagnosis of psychosis.

The final theme highlights the way a diagnosis of psychosis impacted participants, in relation to the way they perceived their own identity, as well as the negative treatment they received from others. Participants described difficulties in recognising their own identity after a diagnosis, with others also changing their perceptions and viewing them through the lens of an individual with psychosis. In addition to this, the diagnosis played a role in the way others regarded their behaviours or testimonies. Participants felt that others displayed difficulties in trusting them or believing things they said, linking this back to their diagnosis and behaviour during previous unusual experiences. The impact of a diagnosis on their identity was perceived by participants as negative, stemming from the feeling of being funnelled into a mould due to the perception of them as less credible on the basis of their diagnosis.

6.4 Discussion

The present study draws on the lived experience of unusual phenomena for 5 individuals with a diagnosis of psychosis. The subsequent themes and sub-themes are reflective of the way in which sense was made of their experience, or developed through communication with professionals, as well as how participants felt they were treated by others pre- and post-diagnosis. All participants made sense of what they were experiencing by connecting the cause to real-life stressors such as trauma, with some also using a religious or cultural framework to make sense of this. In their perception of how they were treated by others, participants felt that those around them were monitors of society, observing for changes in 'normal' behaviour and determining their value as a member of society depending on their social and economic functioning or contribution. Communication was highlighted as an integral factor in three ways. First, a fear of being perceived negatively led participants to not disclose their experiences to others, resulting in social isolation and withdrawal. Second, with professionals, it was felt that the diagnosis was not actively communicated, however once participants knew what they were diagnosed with, they were able to make sense of their experiences. Third, with those who shared a similar diagnosis, participants felt a sense of connection and belonging they had not experienced with others. The diagnosis itself also led to changes in the way they perceived their own identity, as well as negatively affecting the level of credibility afforded to them by others.

6.4.1 The Process of Rationalisation

The first theme describes how unusual experiences were interpreted as resulting from real-life stressors, such as trauma or substance abuse. The initial period of lack of insight described

by George, and similarly experienced by Keeley and Jet, aligns with research that suggests the very nature of the experience makes them difficult to not only comprehend, but also to articulate to others (Leiviskä Deland, Karlsson, & Fatouros-Bergman, 2011; Ritunnano et al., 2022; Ruocchio, 1991). Therefore, it is possible that while these participants may have had their own way of understanding the experience at the time, this would have been difficult to describe during the interview. For Christine and Jet, and possibly others, through communication with professionals in EIS, the experience was perceived as the brain breaking down to cope with the difficulties of reality. In this way, the experience can be viewed as a meaningful psychosocial response to stress, which has previously been found to reduce distress and promote wellbeing and recovery (Steel et al., 2020). As suggested previously, it is possible that professional support with applying meaning to the experience allowed for the development of a coherent narrative, where participants were better able to make sense of their experience and articulate this (Noiriel et al., 2020).

In addition to connecting unusual experiences to real-life stressors, Christine and Nandi initially used religion or culture as a framework to make sense of the experience and aid in recovery. Despite supernatural elements, such as God and the devil, to facilitate understanding, Noiriel et al. (2020) suggests that it is the ability to apply meaning, regardless of whether this is rooted in paranormal interpretations, that allows individuals to make sense of what they are going through. This may imply that religion and culture play a significant role early on in the experience, being utilised as a framework of understanding that may offset any distress that develops for individuals who do not have any frame of reference through which sense can be made, or as participants in the present study describe, a lack of insight. With regards to previous research, findings were mixed, as although care coordinators were

perceived as influential in the sense-making process, for participants in the present study, personal frameworks of understanding the experience were invalidated (Harris, Collinson, & das Nair, 2012). For Christine specifically, she perceived a medical approach to be forced upon her by professionals, whilst Nandi described how her cultural interpretations were dismissed as false. In line with Borchers (2014), it is possible that in these cases the dominant medical model did not take into account subjective interpretations in the context of personal background. It has previously been recommended that the meaning individuals make of their experience should be situated in context and understood from their personal beliefs (Boydell et al., 2010; Saravanan et al., 2005). Additionally, Griswold, Del Regno, and Berger (2015) highlight how some 'hallucinations' relating to religion, either in content or interpretation, may be considered acceptable or even typical in certain groups. Therefore, it is necessary that a diagnosis of psychosis by a professional is considered in the context of the individual's cultural history, as opposed to invalidating their personal beliefs as false.

6.4.2 The Other's Role as a Monitor of Society

The second theme describes how others, such as family and friends, were perceived as watchful of participants, monitoring for changes in behaviour. The feeling of overprotection, as noted by Christine, has been highlighted by individuals with psychosis in previous studies (Pyle & Morrison, 2014; Wood et al., 2018), restricting growth and individuality (Gonzalez-Torrez et al., 2007). The watchful role of others has also been highlighted as a form of infantilisation for individuals with psychosis (Mora-Rios, Ortega-Ortega, & Natera, 2015), with any changes in behaviour interpreted as a result of the diagnosis (Gonzalez-Torrez et al., 2007). It is possible that these attempts at behavioural control are relative to control attributions

(Vasconcelos e Sa et al., 2017). Previous findings suggest that an interplay exists between attributional beliefs of family members and developed behaviours (Vasconcelos e Sa, Wearden, & Barrowclough, 2013). For relatives who perceive the individual with psychosis as capable of overcoming symptoms and associated behaviours, a critical attitude is more likely in order to restore previous functioning. For those who believe individuals are less capable of overcoming this, increased monitoring and controlling behaviours are likely to be exhibited (Vasconcelos e Sa, Wearden, & Barrowclough, 2013). This suggests that it is also imperative to acknowledge the beliefs of people around the individual with psychosis in order to go beyond the scope of simply educating others about the diagnosis, but also considering relatives' responses towards the individual in order to adjust their attributional stance (Crisp & Gleeson, 2009; Vasconcelos e Sa et al., 2017).

Participants also expressed how they felt their worth or value in society was dependent on their ability to function and contribute both socially and economically. Previous literature found that the monitoring role of others in relation to individuals with psychosis often kept them dependent on family, either economically or emotionally, due to the perception of them as incapable of looking after themselves (Gonzalez-Torrez et al., 2007; Rose et al., 2011). However, the opposite was found for Christine and Nandi in the present study, who both felt that others only valued them on the basis of whether they were able to function in or meaningfully contribute to society. According to Allman et al. (2018), significant contributions to both family and the community are possibly overlooked, and therefore unvalued, due to the focus on the individual's identity as a 'patient' or fear of losing a loved one to "madness" (p. 17). It is possible that Nandi's perception of her father comparing her to peers and viewing her as not achieving anything can be attributed to this fear of loss, both of a loved one to their

unusual experiences and of their potential future. Counteracting this 'perceptual filter' in operation, it has been recommended that others should be routinely asked about contributions by professionals after findings highlighted an increase in recognition of this as the interview progressed (Allman et al., 2018; Coldwell, Meddings, & Camic, 2011). This has the potential to reduce the participant's perception of being unvalued by others, as well as increase other's perceptions of individuals with psychosis as already holding value, regardless of economic contribution.

6.4.3 The Importance of Communication for Inclusion, Sense-Making, and Connection

The third theme highlighted how participants chose to not disclose their unusual experiences to others out of fear of the potential stigma they may face, leading to social withdrawal and isolation. Similar findings have been consistently found within past literature on psychosis and stigma (Griffiths et al., 2019; Noiriel et al., 2020; Wood et al., 2015), as well as within the analysis of the meta-ethnography in Chapter 3. As mentioned in the introduction, the findings can be understood in the context of the social identity theory (Tajfel et al., 1979), with knowledge of the stigma faced by marginalised groups leading to participants categorising themselves and identifying as a member of this group, resulting in the concealment of experiences and pre-emptively socially withdrawing to avoid discrimination. It has been previously suggested that targeting the root of the social isolation i.e. the perception of being stigmatised by others due to the negative connotations of the diagnosis, may be useful as a preventative measure through the use of social groups that promote acceptance and engagement (McIntyre et al., 2018). Indeed, within the present study, it was found that communication with peers with shared experiences was a positive experience for participants,

resulting in feelings of 'normality' and inclusion. In recent literature, peer support was deemed a meaningful source of support that destigmatised experiences of psychosis (Nguyen et al., 2022), with youth support groups being implemented into existing EIS (Hopkins et al., 2021). By providing access to these support networks early on in the process, it is possible that the perceived stigma and negative effects of social withdrawal may be reduced.

Regarding the importance of communication, participants also expressed how there was a lack of active discussion in the way that they learned about their diagnosis, finding this out through documentation as opposed to through a professional. It is key to note that this was highlighted as taking place prior to entering EIS, within hospitals and psychiatric centres. In fact, in line with past research (Harris, Collinson, & das Nair, 2012), EIS was perceived positively for most participants, supporting their understanding of what they were going through. Regarding the period prior to EIS, similar findings have been consistently identified in previous literature spanning the last few decades (Huurman et al., 2023; Lovell, 1995; Pitt et al., 2009). One of the main causes of disempowerment in one study was the passive discovery of the diagnosis i.e. finding this out second hand rather than it being communicated to them (Huurman et al., 2023). Even in cases where the diagnosis was directly disclosed, there was a lack of information provided to support their sense-making ability (Huurman et al., 2023), with 46% of the participants (n=13) in another qualitative study reporting the same (Lovell, 1995). Participants in the present study also noted that there was a delay in learning about their diagnosis, however, it has been suggested previously that appropriate timing of disclosing this information is essential, typically when the unusual experience is out of an acute phase, accompanied by documents informing individuals about what psychosis is (Huurman et al., 2023). Based on both past and present findings, it is possible that individuals with psychosis

would benefit from having their diagnosis actively communicated with them, as well as documented information that they can refer back to when necessary.

6.4.4 The Effect of a Psychosis Diagnosis on Identity

The final theme highlighted how receiving a diagnosis changed the way participants perceived their own identity. In a review of 17 studies including 447 participants diagnosed with psychosis, one major theme identified was a disruption to identity as a result of this (Ben-David & Kealy, 2020). Similarly, participants in the present study experienced a negative change to identity after being diagnosed, such as personal identity being replaced with the role of a patient. This can potentially be understood in the context of the social identity model of identity change (SIMIC). According to the SIMIC, the loss of membership to a social group results in a loss of access to psychological resources, leading to poorer mental health (Jetten et al., 2009). Through the lens of lost relationships, changes in identity can be perceived as a consequence of this (Conneely et al., 2021). For example, it had previously been found through a social identity approach that pivotal events can lead to perceptions of the self as gaining a new identity. The addition of this identity, for example, the role of a patient, may conflict or be viewed as incompatible with an individual's existing identity (Iyer et al., 2009). Literature has found that individuals with psychosis tend not to identify with the diagnosis and would rather distance themselves due to the negative connotations (Pitt et al., 2009). This suggests that changes to the way a diagnosis is perceived i.e. in a positive way, may serve to combat the negative effects on identity. In line with Keeley's care coordinator informing her that she can be a "new you if you let yourself" (p. 15, 553), the SIMIC also suggests that it is possibly the pivotal time that can be risky for the loss or gaining of identity as opposed to the change itself,

therefore, making it compatible with a positive understanding of change as personal growth (Conneely et al., 2021).

In addition to changes in identity, being labelled with a diagnosis also had an impact on the way participants felt they were treated by others, including dismissal of testimony and invalidation of credibility. The findings from the present study can be understood through the lens of epistemic injustice (Fricker, 2007). According to testimonial injustice, an individual's testimony is discredited on the basis of their identity, in this case, a diagnosis of psychosis. For much of the past literature, testimonial injustice has been identified in relation to mental health professionals and clinical practice (Kidd, Spencer, & Carel, 2023; Kious, Lewis, & Kim, 2023; Sanati & Kyratsous, 2015), however, findings from the present study suggest that this injustice can be extended outside of a clinical environment and be perpetrated by family or friends. Participants highlighted how family, partners, and peers expressed uncertainty about whether they could trust what participants are saying. Similar to George's fear that if his peers at university knew of his diagnosis, they would dismiss his ideas as lacking credibility, Kwong (2015) also notes that individuals with a diagnosis are often regarded as not having anything meaningful to contribute, and as such are not taken seriously. According to Kurs and Grinshpoon (2018), epistemic injustice can also be perpetrated in a social context, as found within the present study. Having a devalued social identity, as can be understood through stigma towards psychosis, may contribute to an individual's lack of willingness to participate in social scenarios where they would be expected to offer testimony or 'meaningful' discussions (Kurs & Grinshpoon, 2018). Despite much of the literature pointing to epistemic injustice within clinical settings, whilst Christine and Nandi may have experienced hermeneutical injustice during the sense-making process, no participants reported instances

of testimonial injustice within healthcare. Additionally, most participants experienced the opposite of hermeneutical injustice, whereby they were provided with the hermeneutical resources necessary to make sense of their experience and apply meaning to it. However, it is likely that this is due to recruitment of participants from EIS, which have previously been highlighted as a 'gold standard' level of care that is difficult to reproduce within other services (Lester et al., 2012).

6.4.5 Limitations

Aside from the similar limitations mentioned in Chapter 5 of a small sample size and a predominantly female sample of participants, one of the limitations of the present study is that all transcripts were coded by the researcher alone, as well as development of personal experiential themes and initial group experiential themes. However, in line with the recommendations to produce 'reliable' findings from the data (Noble & Smith, 2015), group experiential themes generated by the researcher were reviewed and further developed with the primary supervisor (APF) through regular meetings in order to reduce researcher bias. Similarly, the write up of these themes were also reviewed and revised by APF in order to ensure that all quotes and interpretations were demonstrative of participant's experiences at both an individual level and a group level.

Another potential limitation may derive from the development of the interview schedule. Despite being developed in collaboration with a philosopher (LB) and a clinical psychologist (APF), there is a possibility that the process of transforming the philosophical concept of epistemic injustice (Fricker, 2007) into empirical data may not be entirely comprehensive of the notion. However, the philosopher (LB) that supported the development of the interview

schedule has extensive experience in researching both epistemic injustice and psychosis. Additionally, all supervisors (APF, LB, and MB) have interdisciplinary experience of researching psychosis, and therefore, it is likely that the interview schedule was developed to a suitably appropriate standard in order to answer the research questions.

6.4.6 Clinical Implications

Within the present study, one of the key findings expressed across all participants was the way that their diagnosis was communicated to them, noting that this was a passive process as opposed to active. Seeman (2010) has previously noted how these settings require a specific protocol to improve the way information is shared. Based on past literature (Huurman et al., 2023), certain factors were noted as essential for the diagnostic discussions, including when, what, and how information is provided. One method that may be adapted to a mental health setting and improve the way information about the diagnosis is provided is the SPIKES protocol, a recommended guideline for delivering 'bad news' (Baile et al., 2000). The six steps involved in this process include: (i) setting up the interview, (ii) assessing the patient's perception, (iii) obtaining the patient's invitation, (iv) giving knowledge and information to the patient, (v) addressing the patient's emotions with empathic responses, and (vi) providing a strategy and summary of treatment options and future plans (Baile et al., 2000). Use of this protocol within mental healthcare settings as opposed to solely physical illnesses may provide a solution to the issues of when, what, and how information is provided. Despite the amendments that may need to be made to the protocol to make it suitable for a mental health context, for example, communication of diagnostic information over several sessions,

Huurman et al. (2023) highlights how the SPIKES protocol may be useful by allowing for a tailored approach to providing diagnostic information depending on the individual.

People around the individual with psychosis were also highlighted as playing a significant role, including family, friends, and peers, both in monitoring participant's behaviour but also in dismissing them as credible on the basis of their diagnosis. In line with past literature (Vasconcelos e Sa et al., 2017), findings from the present study also suggest that others exert a controlling nature that may be perceived as judgement and negative monitoring by the participant. Given the impact others appear to have on individuals with psychosis, it is imperative that close family members are also included in support programmes, with the individual's consent. A cognitive behavioural framework may be appropriate for tailored formulation of potentially challenging coping responses exhibited by family members (Crisp & Gleeson, 2009). Consistently within past research, the need for awareness of psychosis that destigmatises it has been recommended (Cairns, Read, & Murray, 2015; Joa et al., 2008), as well as highlighted within clinical practice guidelines (Addington, 2012; Murray, 2012). Additionally, a recent review from the family member's perspectives also highlighted their requirement for facilitated access to family interventions in order to support loved ones with psychosis (Estradé et al., 2023). As a minimum requirement, those closest to the individual should receive appropriate levels of information and targeted support in order to not only adapt any stigmatised perception of psychosis, but to also reduce the impact of this i.e. close monitoring of behaviour, negative judgement, and dismissal as invalid or not credible, on individuals with psychosis.

6.4.7 Future Research

The present study appears to have identified occurrences of epistemic injustice mostly outside of a clinical setting, specifically testimonial injustice (Fricker, 2007). Due to the scarcity of literature on epistemic injustice in a social context (Kurs & Grinshpoon, 2018), it is necessary for future research to investigate these epistemic inequalities specifically in social situations so that further understanding can be gained on how far this injustice extends. In terms of hermeneutical injustice specifically (Fricker, 2007), the present study found less occurrences of this than has been found in past literature (Kidd, Spencer, & Carel, 2023; Kious, Lewis, & Kim, 2023; Sanati & Kyratsous, 2015), however this is possibly due to the differences between recruitment settings, with EIS generally considered the highest standard of care for those with a diagnosis of psychosis (Lester et al., 2012). Therefore it may be useful for future research to explore the differences between two groups of individuals with a diagnosis, both within and outside of EIS settings. Additionally, a longitudinal study exploring how participants feel validated or invalidated at different points throughout their diagnostic journey may prove useful in identification of contributing factors to epistemic injustice, and subsequently how effects of this can be mitigated.

As highlighted in the clinical implications, there is yet to be empirical research surrounding the SPIKES protocol within a mental health context. Future research may benefit from exploring this as a potential option to communicate diagnoses effectively, as well as identifying further ways of actively communicating a psychosis diagnosis as opposed to passively. These guidelines should take into consideration when to provide information, what to provide, and how to provide this (Huurman et al., 2023). Additionally, it is recommended that future studies focus

on the lived experience of the diagnostic process for individuals at different stages in their psychosis, in order to identify the specific factors that may be needed depending on which stage the participants are in.

In conclusion, the present study identified four main themes that contribute to understandings of unusual experiences for those with a diagnosis of psychosis: the process of rationalisation, the other's role as a monitor of society, the importance of communication for inclusion, sense-making, and connection, and the effect of a psychosis diagnosis on identity. Although all participants made sense of their experience as connected to real-life stressors, the experience was also understood for some through religion or culture. People around the participants played a significant role in their lives, through monitoring their behaviour and dismissing them as lacking credibility due to their diagnosis. For most, the diagnosis allowed them to make sense of what they were going through, despite this not being communicated effectively, however it also had a negative effect on the way they perceived changes in their identity. This research provides insight into the lived experience of these individuals and suggests ways that information sharing can be improved.

Chapter 7

A MULTIPERSPECTIVE APPROACH TO EXPLORING EPISTEMIC INJUSTICE AMONGST NON-CLINICAL AND CLINICAL GROUPS WITH UNUSUAL EXPERIENCES

Abstract

Aim: The study aimed to compare how individuals both with (clinical) and without (non-clinical) a diagnosis make sense of their unusual experience and how they feel they are treated by others.

Method: The non-clinical group included six individuals (F=4, M=2) between the ages of 22 and 31, whilst the clinical group included five individuals (F=4, M=1) between the ages of 20 and 40. All participants were interviewed over Microsoft Teams. A multiperspectival IPA approach was utilised in order to compare findings from Chapters 5 and 6 of the thesis.

Results: Three themes emerged from the findings: (i) 'Connecting the experience to real-life stressors is important for those who are viewed as disconnected from reality;' (ii) 'Stigma is constructed within society and upheld by the authority of others;' and (iii) 'Testimonial injustice occurs in relation to the label, as opposed to the experience.' The themes outlined differences in external influence during the sense-making process, with some clinical participants experiencing hermeneutical injustice. Additionally, increased levels of stigma and changes in identity as a result of the diagnosis led to occurrences of testimonial injustice for

the clinical group, whilst the non-clinical group experienced both invalidation and validation of the unusual phenomena.

Conclusion: This study is the first of its kind to use a multiperspectival approach to provide insight into the lived experience of unusual phenomena and epistemic injustice, contributing empirically to the existing evidence base. Methods to combat epistemic injustice in both a clinical and social context have been discussed, in order to promote epistemic equality for marginalised individuals with a diagnosis of psychosis.

7.1 Introduction

7.1.1 Psychosis and Epistemic Injustice

A diagnosis of psychosis is typically characterised by an increased level of distress, as well as the need for professional support, in addition to the unusual experiences (Heriot-Maitland, Knight, & Peters, 2012). However, these experiences have also been known to occur in individuals without a medical diagnosis (Unterrassner et al., 2017), at an estimated prevalence of 5-10% in the general population as opposed to 0.7% for psychosis (Bosma et al., 2023). For people without a diagnosis, there is often a lack of distress meaning professional support is not always required (Boumans et al., 2017; Verdoux & van Os, 2002). The recognition of these psychotic-like phenomena currently favours a more dimensional approach within the literature that points to psychosis as being part of a continuum (Brett et al., 2007).

Research on psychosis has consistently highlighted stigma from others towards those with the diagnosis, with 87% of service users reporting incidences of discrimination (The Schizophrenia Commission, 2012; Wood et al., 2015). According to Corrigan, Kerr, and Knudsen's (2005) model, stigma-related processes were maintained via three significant

factors: stereotypes, prejudice, and discrimination. Occurring through wider society, the self, or interpersonal relationships, the 'stigma system' was found to be socially embedded (Wood et al., 2015). Studies have highlighted the internalisation of this by individuals with psychosis, suggesting that self-stigma is also at least partially developed by societal stigma (Vass et al., 2017). Both societal and internalised stigma can negatively impact the individual, ranging from internal distress to external structural inequalities, such as reduced opportunities to obtain employment or housing, and therefore a lack of ability for independence (Corrigan, Kerr, & Knudsen, 2005; Thornicroft et al., 2016). As such, it is imperative that research continually aims to understand and combat stigma towards psychosis, in order to reduce the negative effects of this on individuals.

One form of discrimination that may explain the maintenance of stigma is epistemic injustice (Fricker, 2007), with studies researching the role of epistemic power imbalances potentially adding to the existing evidence base on stigma processes (Harris et al., 2022). The concept of epistemic injustice (Fricker, 2007), a type of discrimination concerning the undermining of individuals who belong to marginalised groups in their capacity as a knower, currently presents in two key forms: testimonial injustice and hermeneutical injustice. The former relates to dismissal of an individual's testimony on the basis of stereotypes held about their marginalised group, perceiving them to be less credible. Whereas, the latter refers to a lack of societal resources for marginalised groups that do not enable the individual to make sense of what they are experiencing (Fricker, 2007)[12]. Despite the concept previously being considered in relation to gender (Fricker, 2007) and race (Anderson, 2017), epistemic injustice

[12] For more information on epistemic injustice, see Chapter 2 of the thesis.

has increasingly been applied within the context of healthcare (Carel & Kidd, 2014), including in the assessment of delusions (Sanati & Kyratsous, 2015), psychiatry (Crichton, Carel, & Kidd, 2017), and illness (Kidd & Carel, 2017). In relation to people with a diagnosis of psychosis then, both stigma based on negative stereotypes, as well as structural power imbalances within healthcare settings, can contribute to the perpetration of testimonial and hermeneutical injustice, respectively (Carel & Kidd, 2014).

According to Gosselin (2019) and Wardrope (2015), the medicalisation of poor mental health can contribute to the injustices faced by people with psychosis, affording medical authorities a considerably high amount of epistemic privilege (Carel & Kidd, 2014). Previous qualitative research has highlighted how some clinicians appear to show little regard for the social and environmental context within which the unusual experiences occur, opting to solely focus on factors that fit their diagnostic criteria (Lovell, 1995). However, a diagnosis can also serve to support an individual's ability to make sense of their experience, suggesting that based on the person, this approach can either be perceived as a form of hermeneutical injustice or may provide the resources necessary for people to understand what they are going through. Sanati and Kyratsous (2015) suggest that a diagnosis of psychosis, particularly when experiences include delusional beliefs, may also result in other testimonies being perceived as false, due to the view of the individual as being unintelligible. This form of discrimination, also known as testimonial injustice, may be particularly prevalent towards individuals with psychosis due to the commonly held stereotypes towards the diagnosis.

Research comparing ways of making sense and treatment of others between clinical (individuals with a diagnosis of psychosis) and non-clinical (individuals with unusual

experiences without a diagnosis) groups is limited within the literature, specifically in relation to epistemic injustice. In one study comparing both groups (Heriot-Maitland, Knight, & Peters, 2012), non-clinical participants were thought to receive acceptance and validation from others with regards to their unusual experiences and were therefore better able to incorporate the experience into their personal and social lives. Despite both groups acknowledging the way in which others could invalidate their unusual experiences, only the clinical group experienced this invalidation (Heriot-Maitland, Knight, & Peters, 2012). Specifically focusing on epistemic injustice amongst clinical and non-clinical voice-hearers, Harris et al. (2022) found that both groups were at risk of facing testimonial and hermeneutical injustice, however, non-clinical voice hearers acknowledged access to a safe community where epistemic injustice was not present, preventing the internalisation of stigma possibly experienced by individuals with a diagnosis. Additionally, changes in identity, relationships, and power and position were experienced differently between the two groups, with the non-clinical group noting a positive shift, whilst the clinical group noted a negative shift (Harris et al., 2022).

7.1.2 Rationale and Aims

Research has highlighted how those with a diagnosis of psychosis may be likely to face testimonial and hermeneutical injustice (Carel & Kidd, 2014; Sanati and Kyratsous, 2015), particularly in relation to individuals experiencing similar phenomena without a diagnosis (Harris et al., 2022). Previous studies reflect a difference in the way clinical and non-clinical groups are able to make sense of their experience, as well as in the level of validation afforded by others in response to this (Heriot-Maitland, Knight, & Peters, 2012). Using the framework of epistemic injustice (Fricker, 2007), novel understanding of how stigma is formed and

maintained for individuals with psychosis through comparison with non-clinical groups can be added to the existing evidence base. Although this has recently been examined by Harris et al. (2022), the authors adopted a thematic approach to analysis and focused on the experiences of voice-hearers. It has previously been suggested that whilst thematic analysis can offer breadth, IPA offers depth of findings (Spiers & Riley, 2019). Given that the wider aims of the thesis were concerned with in-depth understanding of the lived experience for individuals with and without a diagnosis of psychosis, IPA was chosen as a more suitable method to uncovering instances of epistemic injustice. Therefore, the aims of the present study are twofold. First, to explore epistemic injustice more broadly amongst clinical and non-clinical groups with unusual experiences. Second, through the use of a multiperspectival IPA approach, to compare and contrast the in-depth understanding of lived experience already gained from both groups individually (see Chapters 5 and 6). Based upon the aims mentioned, the research questions are as follows:

(i) What are the similarities and differences in meaning-making processes between those with psychosis and those with unusual experiences?

(ii) What are the similarities and differences in perceived treatment from others between those with psychosis and those with unusual experiences?

(iii) Are individuals with psychosis more likely to experience epistemic injustice than those without a diagnosis?

7.2 Method

7.2.1 Design

The study was approved by the Surrey Research Ethics Committee (REC reference: 20/PR/0616; date 09/03/2021; Appendix 4) and the Health Research Authority (IRAS number: 286804; date 01/04/2021; Appendix 5). As the research was concerned with understanding the lived experience of people facing unusual occurrences, a multiperspectival, phenomenological[13] approach was utilised and data was collected via semi-structured interviews. This approach allowed for comparisons to be drawn between two directly related groups, the phenomenon of interest being unusual experiences. Adopting a critical realist epistemology, it was assumed through analysis that a 'real' world exists for each participant, however, this reality cannot be known by researchers with certainty.

7.2.2 Participants

The following chapter analyses the combined datasets of the previous two empirical chapters. Therefore, for detailed information on participant sampling and method of recruitment for both groups, see Chapters 5 and 6 of the thesis. A total of 11 participants were recruited and interviewed for the research (Table 7.1), five in the group with psychosis, and six in the group with unusual experiences. In order to protect the anonymity of participants and prevent potential identification, both ethnicity and diagnosis for the clinical group have been reported separately. Participant's ethnicities included: Indian, White British, Black British,

[13] For more discussion on the suitability of IPA to the study, see Chapter 4 (Methodology) of the thesis.

Black African, and Thai. Participant's diagnoses included: First-Episode Schizophrenia, Schizophrenia, Paranoid Schizophrenia, and Psychosis.

Table 7.1
Demographic details of participants

Group	Pseudonym	Age	Gender	Ethnicity
Non-Clinical	Madeline	27	Female	White
	Rayna	27	Female	Pakistani
	Zeke	22	Male	Mixed White and Black (Afro-Caribbean)
	Sara	29	Female	Pakistani
	Yusuf	29	Male	Pakistani
	Chloe	31	Female	Mixed White and Black (Caribbean)
Clinical	George	20	Male	
	Keeley	30	Female	
	Christine	25	Female	
	Nandi	25	Female	
	Jet	40	Female	

7.2.3 Data Collection

Data was collected via semi-structured interviews and conducted solely by the primary researcher. Interviews took place remotely via an online platform between November 2021 and January 2022 due to the Covid-19 pandemic, lasting between 22 and 84 minutes. Interviews were audio-recorded via a secure Dictaphone and transcribed within 2 weeks from the point of interview, during which time participants had the opportunity to withdraw their data from the study. After this point, recordings were deleted and transcripts were pseudo-anonymised so data could not be traced back to individual participants. For more detailed information on the process of data collection for both groups, see Chapters 5 and 6 of the thesis.

7.2.4 Data Analysis

A multiperspectival design (Larkin, Shaw, & Flowers, 2019) was used due to its ability to capture a certain phenomenon through the use of multiple perspectives. Exploring the perspectives of those with unusual experiences and those with a diagnosis of psychosis, this approach allows the researcher to go beyond the shared views of homogenous samples, extending to potentially more complex understandings of the phenomenon by analysing directly related groups. For more information on how the two groups were analysed individually, see the Data Analysis section within Chapter 5. At the point of the group experiential themes being created, conceptual overlaps, as well as conflicting perspectives across both groups were identified. These were then clustered into themes, with further analysis of potential paths of meaning or lines of argument across the datasets (Appendix 26). Finally, all individual transcripts were reviewed to ensure that all themes were reflected across all of the participants and that no significant experience was overlooked.

7.3 Results

Analysis of the data resulted in three themes, all of which were found to represent the views of both groups collectively, highlighting similarities and differences between viewpoints (Table 7.2). The themes reflect the main focus of the research relating to the participant's understanding of their experience and their subsequent treatment by others in relation to this. Each theme is explored below, illustrated with quotes from the participants, as well as researcher interpretation. In order to avoid repetition with Chapters 5 and 6, each theme will compare the findings more broadly, with some examples of more detailed comparisons between pairs of non-clinical and clinical participants.

Table 7.2
A table demonstrating which participant contributed to which theme.

Theme	Participants										
	Non-Clinical						Clinical				
	M	R	Z	S	Y	C	G	K	C	N	J
1: Connecting the experience to real-life stressors is important for those who are viewed as disconnected from reality	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
2: Stigma is constructed within society and upheld by the authority of others	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
3: Testimonial injustice occurs in relation to the label, as opposed to the experience	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓

7.3.1 Theme 1: Connecting the Experience to Real-Life Stressors Is Important For Those Who Are Viewed As Disconnected From Reality

The first theme relates to the way in which participants rationalised their experience as connected to or disconnected from reality. This differed between groups, with those without a diagnosis justifying their experience as unusual, whilst those with a diagnosis attempted to link their symptoms to real-life stressors. It is possible that this difference between groups may stem from the stigma of a diagnostic label, especially one that inherently suggests a break from reality, or from external influences such as mental health professionals.

Between the non-clinical and clinical participants, a clear difference of perspective emerged in relation to the way that sense is made of the unusual experience. For those in the non-clinical group, supernatural or spiritual explanations were most commonly cited, either through their perceived inability to rationalise the unusual experience or as a direct result of personal, cultural, and religious beliefs. Without meaning afforded to the experience by others, it is likely that individuals have more of an opportunity to explore their own worldviews and situate the experience within that context. Similarly, without a label and the attached stigma, there may be less concern over how others perceive both the experience and their explanation of it.

> "I don't even have any other justification as to why my laptop's flew off the chair. I couldn't say maybe it's this or maybe it's that, because it'll only make sense from my view that it would be the spirit world. Like, what else would have got the laptop off the chair or trying to just make him get out of the bed?" (Chloe, Non-Clinical Group – p. 16, 575-579)

> "I believe it is just the cannabis and the trauma, so two.. and there's the stress that comes along with that. All two, three of those factors sort of are what made it happen, to be honest." (George, Clinical Group – pp. 12-13, 444-447)

In contrast (as evident within the quotes above), for the clinical group, despite receiving a diagnosis that is commonly characterised as a break from reality, all participants rationalised their experience as connected to real-life stressors. Notably, although their understanding of the diagnosis contributed to sense-making, in questioning how they make sense of the unusual experience, no participant explicitly stated the label of their diagnosis. Rather, their descriptions were rooted in real-life stressors, with examples of childhood trauma, substance abuse, and stress frequently referred to. It is possible that participants are hesitant to refer to their diagnosis due to the perceived stigma from others in relation to the label. However, it may also suggest that there is an underlying importance for individuals with psychosis to connect their unusual experience with events in real life, in order to steer away from the perception of them as disconnected from reality.

In addition, a second option that presented itself throughout the analysis was the concept of change influenced by others. Despite clinical participants describing the initial period between the unusual experiences and hospitalisation / mental health services as a loss of insight, a key difference between the groups was the influence of an external perspective i.e. others who provided an explanation for the experience for the clinical group. Here, it is possible that the way individuals initially made sense of the event changed with outside input, a factor that was removed or less significant during the sense-making process for non-clinical participants.

Subsequently, the supernatural or spiritual beliefs retained by participants in the non-clinical group, may have been exchanged for real-life stressors in the clinical group. In a direct comparison between Yusuf and Nandi, who both held religious or cultural beliefs regarding their unusual experiences, only Nandi's understanding altered after communication with a mental health professional.

> "So, if I was to speak to someone who doesn't believe in this, they'll say, 100% probably diagnose me with some mental health issue, probably say I'm schizophrenic or anything like that. So, with them, it'll be a mental health issue but with me, thinking about why it's happened in our family, again you can't prove it and get evidence for it, but I'm 95-99% sure something may have been done, in terms of black magic or voodoo or something spiritually like that against our family." (Yusuf, Non-Clinical Group – p. 19, 680-689)

> "I felt as if the devil had come to me, he put demons inside my head, and that was what was causing me to become mentally unwell. And I also felt as if God was punishing me for my sins. But when I started to get counselling, my psychologist, she explained to me that it's nothing to do with religion. It's not a spiritual thing, it's a mental illness." (Nandi, Clinical Group – pp. 4-5, 141-148)

In the case of Yusuf, his religious beliefs taught to him during childhood provided a framework of understanding for his unusual experience, where he attributed the cause to Jinns, including possession, potentially as a result of negative supernatural activity from others. He also notes how mental health professionals would be likely to categorise his unusual experience as a "mental health issue," diagnosing him with a psychotic disorder. In the case of Nandi, her initial understanding of her experience was also rooted in the supernatural, stemming from her mother's South African cultural beliefs, despite her father also interpreting the experience as a mental health problem. However, Nandi's interpretation changed after contact with a psychologist, instead attributing the unusual experience to trauma and social isolation within childhood. It is evident here between the two cases that external influence is likely to have an effect on the sense made of the experience, but also that it was important for Nandi to not

simply accept a diagnosis of psychosis, but to instead connect this to real-life stressors. Whilst Yusuf and other non-clinical participants remained comfortable with accepting their supernatural interpretations, for Nandi and other clinical participants, there was an attempt to ground their unusual experience in trauma dealt with throughout life, after being diagnosed with a psychotic disorder.

It appears likely that this conflict of perspective is at least partially dependent upon the diagnosis that is afforded to some, and the subsequent meaning of the unusual experience that is provided by others. Without a diagnosis and explanation of the experience as being related to a mental health disorder, individuals appear to find their own way of sense-making, in a way that corroborates with their personal worldviews. For the non-clinical participants, rationalisations derived from individual personality type, for example, Madeline's creative personality type that lent itself to an overactive imagination, or through beliefs taught in childhood, such as Rayna, Sara, and Yusuf's Islamic belief in Jinns. Whereas for the clinical participants, a diagnosis provided an external rationalisation that they felt allowed them to make sense of their experience, rooting the cause in real-life stressors.

7.3.2 Theme 2: Stigma is Constructed Within Society and Upheld by the Authority of Others

The second theme relates to the significance of others in the individual's lives, particularly in relation to the construction and maintenance of stigma. For both groups, the fear of being perceived negatively by others due to the unusual experience led to concealment of this in order to avoid judgement. However, the other was experienced differently for both groups, with non-clinical participants finding positive use in the involvement of others in comparison to the clinical group who mostly perceived this as negative. Despite the usefulness highlighted

from the role of others, some non-clinical participants discussed reasons for how society may construct stigma towards people with psychosis.

For both the non-clinical and clinical participants, there was an overlap of consensus concerning the perceived role of others in their lives, with fear of judgement or lack of understanding being a primary concern. For all non-clinical participants except for Rayna, there was an expectation of being labelled as mentally ill by others, with genuine concerns relating to being diagnosed by Madeline and Yusuf. For clinical participants, fear related to judgement of the diagnosis itself, as well as the negative effect it had on functioning.

> "There's some stuff that I won't be able to tell them because our beliefs are different. I wouldn't, I wouldn't say it's changed our relationship, there's just certain things I wouldn't be able to, I wouldn't feel comfortable telling them, basically. Because of the experience I had and their reaction to it." (Sara, Non-Clinical Group – p. 18, 655-666)

> "I try to steer away from talking about my diagnosis or why I, why I can't work at the moment, you know. A common question from people is, 'oh, what do you do for a living?' You know, and then I'd go on to tell them that I'm on benefits. Then they want to know why I'm on benefits. 'Oh, because I had a breakdown.' 'Oh, what was your breakdown?' and all of this." (Jet, Clinical Group – p. 11, 374-379)

From the quotes above, the differences in the type of negative response expected is evident. For Sara, a response of disbelief from her atheist colleagues led to a decision of being selective over what she chose to share in the future. Whereas, for Jet, steering away from questions that may lead to the diagnosis afforded her a level of protection in what she could conceal. It is possible that it is not only the unusual experience that is stigmatised, but also the subsequent difficulties with working or socialising. This was a significant theme for Christine and Nandi, who perceived others as valuing their worth depending on their economic and

social contribution. For both groups, fear of stigma was present, however, these fears were multiplied for clinical participants, affecting multiple aspects of their lives.

Although fear from most participants regarding stigma was evident across both groups, there were some positives in the involvement of others noted by Madeline, who viewed them as useful for being able to test reality. Despite this role of the other as a monitor of what is real or 'normal' being considered protective for Madeline, for some non-clinical participants, this was experienced as a negative, authoritative monitoring. Here, a conflict of perspective emerged between the two groups, where the other as a monitor was experienced significantly differently.

> "I think other times it's been quite similar things, if I had seen something or heard something actually. You don't realise, you don't necessarily know it's not real, but you know it's not real by people in your environment because they'll go, "oh, there's nothing there," or maybe just something like that. You're like 'oh that's a bit unusual, why would somebody do that?' And then you actually realise that's something that you're just pursuing and not necessarily others." (Madeline, Non-Clinical Group – pp. 1-2, 30-36)

> "I think at that time they were just wanting to focus on my recovery, so being able to monitor me from home. And yeah, not do anything kind of different or drastic. Just keeping to a routine." (Christine, Clinical Group – p. 16, 574-580)

Comparing the cases of Madeline and Christine above, this monitoring by others was experienced negatively for Christine, however, positive effects were noted by Madeline. The differences in outlook may reflect the different stages participants are in with their unusual experiences. Without a diagnosis, others were able to positively monitor Madeline, ensuring that her experiences did not worsen and require professional support. This was also viewed as a way for her to bond with her partner and friends, perceiving this role as part of being a support network. However, for Christine who was already past that stage, the monitoring

centred around her behaviour in order to detect similar patterns during the point of intervention. Here, the monitoring by others, possibly as a result of the stigma already experienced, is perceived negatively.

Although Madeline noted the benefits of the role of others in her life, along with Chloe, she also highlights the difference between her unusual experience and experiences of others with a diagnosis of psychosis. Both attribute this to the impact others have in the way unusual experiences, especially ones with a diagnostic label, are perceived in society. Acknowledging her stance as coming from a social constructionist perspective, Madeline suggested that individuals lose the ability to make sense of what they are going through once a medical label is afforded to them, leading to a disconnect from the self and cementing the other's role as determining of an objective reality. Similarly, this view was held by Chloe, who described the impact society has on the perception of mental health, viewing it as something to be feared, and thus, stigmatised. The effect of others on an individual's identity was also highlighted by both, who believed that a label of psychosis meant an individual is first judged by this, dissimilar to undiagnosed individuals with unusual experiences who retained their identity in the eyes of others. Throughout this theme, the significance of others is demonstrated, through the fear of disclosing unusual experiences to them, the perception of their role as a monitor, as well as their involvement in the formation and maintenance of stigma.

7.3.3 Theme 3: Testimonial Injustice Occurs In Relation to the Label, as Opposed to the Experience

The final theme relates to the occurrence of epistemic injustice and the ways in which it was perpetrated against individuals. In the clinical group, participants faced testimonial injustice

from family and friends, compared to the non-clinical group who reported less instances of dismissal and invalidation. For non-clinical participants, the invalidation was based upon their role within their family as opposed to any perception of their identity as someone who experiences unusual phenomena. It can be assumed from this that a diagnosis of psychosis has a significant impact on identity, causing others to view the individual via a clinical lens, rather than as a person first.

A conflict of perspective was also identified between the non-clinical and clinical groups in relation to the credibility they were afforded from others after their unusual experiences. For most clinical participants, a shift in identity was experienced as a result of the diagnosis, with individuals feeling as if they were funnelled into the role of a patient. This feeling was further reinforced via professionals who were perceived as attributing non-clinical behaviours to the diagnosis. For example, in the case of Christine, her perception of determination towards her faith was replaced with the symptom of 'fixation', as well as her behaviour of sitting quietly amongst others and not listening being explained to her family as a symptom of psychosis. On the other hand, only one individual from the non-clinical group (Rayna) reported any change in the way others perceived their identity. However, the change reported was a shift in the opposite direction, where Rayna felt as though others viewed her as *special* for experiencing the supernatural element of their religion.

> "It sounds really weird, but like, you feel like you've just gone up in the ratings. Like, in the rank of like, 'oh yeah, she's experienced this thing, like, that makes her special in some sense.'" (Rayna, Non-Clinical Group – p. 15, 542-545)

> "My friends do look at me because I have changed a lot, It's changed me, I think. Like, being diagnosed, it has changed me." (Keeley, Clinical Group – p. 11, 400-401)

For Keeley, the diagnosis had a profound impact upon her identity, where she herself noticed an internal change. On the other hand, for Rayna, the unusual experience resulted in an external change of perception towards her, as opposed to any noticeable internal change in identity. Regarding their experiences however, both the non-clinical and clinical group experienced invalidation and validation, respectively. Whilst validation for the clinical group came via the form of acceptance with peers who also shared unusual experiences and a diagnosis of psychosis, for the non-clinical group, two participants experienced invalidation through their family. Based upon their role within the family as younger daughter and younger sibling, both Madeline and Rayna felt their experiences had been dismissed by parents and siblings.

Although both groups experienced instances of validation and invalidation, only the clinical group experienced a perceived lack of credibility directly in relation to their identity as an individual with psychosis. The validation of experiences within the non-clinical group was also acknowledged by them as being directly related to their identity. This suggests that whilst invalidation can occur, testimonial injustice, specifically as it relates to identity (see Chapter 2), occurred only in the clinical group. Given that this was not described in the non-clinical group, it may be that testimonial injustice occurs in relation to the diagnosis, as opposed to the unusual experience itself.

> "I feel like he listens because like I wouldn't just make up a lie and just, you know, come and tell you for jokes. But he knows I'm scared of that type of stuff. So, I think he believes me when I've said it." (Zeke, Non-Clinical Group – p. 7, 251-256)

> "I don't think my mum believes me as much when I tell her stuff. Because I've had like conspiracies before, they do wonder sometimes if they can trust me." (Keeley, Clinical Group – p. 16, 562-564)

Based on the quotes above, it may be seen how the perception of identity can play a role in the way credibility is affected and testimony is believed. For half of the non-clinical participants, it was felt that the people the experience was disclosed to had insight into who they are as an individual, therefore regarding their experiences as credible. Along with personality type, Madeline also suggests that a lack of prior mental health issues would influence others to perceive her experience as credible, implying that individuals with psychosis may lose this on the basis of their diagnosis. This concept was represented through Keeley, who believed that due to her past experiences of conspiracies, friends and family around her doubt her testimony. All clinical participants except Nandi provided examples of testimonial injustice occurring, suggesting that for this group, this specific form of stigma commonly exists in a social context.

Based upon the joint findings of both groups, a conflict of perspective can be seen regarding the reasons for which an experience is validated or invalidated. A positive or lack of change in identity following the unusual experience for non-clinical participants also results in a lack of change regarding their credibility. Hence, their identities as a serious person with a psychology background and no prior history of mental health problems (Madeline), a person afraid of the supernatural and who therefore would not lie about it (Zeke), and a truthful person whose personal life is deeply embedded in religion (Yusuf) remains intact and is perceived as legitimate, lending validation to their unusual experience. On the other hand, for clinical participants, it appears that a diagnosis of psychosis can result in both an internally experienced and externally perceived change in identity. This transformation from individual person to the role of a diagnosed patient who experiences unusual phenomena affects the

way credibility is perceived, leading to regular instances of invalidation and dismissal from others. Here, testimonial injustice has occurred.

7.4 Discussion

The present study draws on the lived experience of 6 individuals who experience unusual phenomena and 5 individuals with a diagnosis of psychosis. The subsequent themes are reflective of the similarities and differences between the non-clinical and clinical group in relation to their sense-making and perception of treatment from others. Clinical participants were found to ground their interpretation of what they were going through in real life stressors, in comparison to the non-clinical group who mostly adopted a supernatural frame of understanding through religious or personal beliefs. Additionally, whilst both groups concealed experiences due to fear of stigma from others, the non-clinical group perceived the involvement of others as a useful tool for reality testing. This differed from the clinical group who viewed this monitoring role as negative and unwanted. Unlike the non-clinical participants, shifts in identity for clinical participants led to instances of testimonial injustice. A positive or lack of change in identity meant that non-clinical participants were still perceived as legitimate by others with insight into their personality, lending credibility to them as an individual and validating their unusual experience.

7.4.1 Hermeneutical Injustice

In line with past research, it was identified that clinical participants linked their interpretations to life events or stressors, with little to no mention of the diagnosis as a way of explaining their experiences (Bergström et al., 2019). Throughout Chapter 6, the influence of mental health professionals on sense-making was discussed, highlighting the opposite of

hermeneutical injustice for most clinical participants due to its ability to provide participants with a way to make sense of their experience (Noiriel et al., 2020). However, within the first theme, in a direct comparison between Nandi (clinical) and Yusuf (non-clinical), the external influence of professionals on the participants sense-making process is made more apparent. For two clinical participants, the dismissal of their cultural and religious beliefs can be understood through the concept of hermeneutical injustice (Fricker, 2007). According to Hassall (2024), a psychiatric diagnosis that conflicts with previous self-narratives, as in the case of Christine's religious beliefs (see Chapter 6), puts individuals at risk of marginalisation through a dominant medical model. This dismissal of alternative interpretations belonging to participants, as well attribution of non-clinical behaviours to the diagnosis, reinforces the stigma and marginalisation experienced by individuals (Hassall, 2024; Lovell, 1995; Stanghellini, 2004). In comparison, non-clinical participants were all able to retain their personal beliefs and situate their experiences within the context of their own worldviews, without external influence changing their interpretation. Hermeneutical injustice was further demonstrated through the descriptions of changes in identity by clinical participants and feelings of being forced into the role of a patient. It is key to note however, that despite evidence of hermeneutical injustice (Fricker, 2007) taking place for some of the clinical participants, this was not the case for all.

7.4.2 Testimonial Injustice

The findings reflect existing research, with clinical participants experiencing testimonial injustice (Harris et al., 2022; Sanati & Kyratsous, 2015), and differences between non-clinical and clinical group's perceptions on responses from others. Understood through the concept

of testimonial injustice (Fricker, 2007), for non-clinical participants, the effect of the diagnosis on changes to perception of identity contributed to the way credibility and legitimacy of the individual as a knower was reduced, leading to dismissal or doubt from others regarding testimonies. Despite both groups experiencing stigma, clinical participants experienced a higher level of this (Heriot-Maitland, Knight, & Peters, 2012; Wood et al., 2015), particularly in relation to gaining a devalued social identity (Kurs & Grinshpoon, 2018). According to Harris et al. (2022), this could potentially be attributed to the existence of a safe and accepting community where non-clinical participants had the ability to socially connect and be perceived as an epistemic equal. The present findings lend support to this notion, as reference to close others who had insight into the participant's identity and validated their experiences were acknowledged by the non-clinical group. In comparison, except for shared experiences with peers who also had a diagnosis of psychosis, most of the clinical group made no such reference to validation via loved ones. Aligning with research by Kurs and Grinshpoon (2018), present findings also highlight the extension of epistemic injustice from clinical environments (Kidd, Spencer, & Carel, 2023) to social contexts.

7.4.3 Limitations

Similar to Chapter 6, one of the potential limitations of the present study is that the coding and development of themes generated through the multiperspective approach was conducted by the researcher alone. However, following the recommended guidelines to producing 'reliable' findings by Noble and Smith (2015), the researcher's primary supervisor (APF) regularly reviewed, further developed, and revised both the development and write up of themes in order to reduce researcher bias. All themes, quotes, and interpretations developed

in collaboration with APF are considered to be reflective of the lived experience of both non-clinical and clinical participants, at an individual and group level.

Despite the small number of participants in both groups, the sample is ethnically diverse allowing for greater representation of multiple perspectives. By comparing these perspectives between groups, it is possible that findings have been diluted, with some participant's voices not being represented as comprehensively as possible. However, a thorough, in-depth interpretative phenomenological analysis of each group has been conducted in Chapters 5 and 6, with a multiperspective approach (Larkin, Shaw, & Flowers, 2019) allowing for direct comparisons. Through these comparisons, the ability to produce novel, empirical findings that may have otherwise gone unnoticed became possible, significantly adding to the existing evidence base on epistemic injustice in psychosis. Additionally, as mentioned in Chapter 5, the concept of transferability is recognised as more appropriate than generalisability within qualitative research. Therefore, despite the small sample size, the detailed description of method within the thesis, as well as the presentation of in-depth analysis through multiple chapters, allows for evaluation of findings within other contexts (Stalmeijer, Brown, & O'Brien, 2024), thereby contributing to the literature on lived experience via quality and transferability, as opposed to generalisability.

7.4.4 Clinical Implications

The present study demonstrates the occurrence of epistemic injustice for individuals with a diagnosis of psychosis, suggesting that acknowledging and neutralising this specific form of stigma should be an aim going forward for mental health services in relation to psychosis. Despite the sense-making that a diagnosis afforded to most individuals, some of the clinical

participants still experienced the dismissal of their personal narratives and attribution of behaviour to symptoms of psychosis, suggesting that hermeneutical injustice still requires consideration. In line with the findings of a safe community accessible to only non-clinical participants, a similar space is needed for individuals with psychosis. Or at the very least, a space where they are not defined by one dominant narrative, but rather accepted as a person with multiple personal narratives. Harris et al. (2022) suggests that greater focus on listening to experiences has the potential to result in epistemic equality, whereby individuals narratives are believed and a range of sense-making frameworks are explored. Given that stigma has been highlighted at a structural level as opposed to individual, it is key for broader societal changes in the perception of psychosis, for example, via current and future anti-stigma campaigns that champion a biopsychosocial approach towards understanding.

Testimonial injustice was also highlighted as having occurred in a social context by family and friends as opposed to within a clinical context. This suggests a need for the inclusion of loved ones during the sense-making and recovery process, perhaps via support programmes, in order to combat stigmatised views of psychosis early on and reduce the behavioural control and testimonial injustice exhibited (Estradé et al., 2023). A substantial amount of information and education is required at a societal level to adapt beliefs already held regarding the diagnosis (Cairns, Read, & Murray, 2015). Through cognitive behavioural frameworks, it is possible that these challenging coping responses perpetrated by family and friends may be adapted to more appropriate, positive responses that support and suit the needs of the individual with psychosis (Crisp & Gleeson, 2009).

7.4.5 Future Research

The literature on epistemic injustice is scarce (Kurs & Grinshpoon, 2018), dominated by the consideration of epistemic injustice in clinical settings (Kidd, Spencer, & Carel, 2023; Sanati & Kyratsous, 2015). Therefore, it is necessary for future research to explore these inequalities in social settings, in relation to family and friends, in addition to mental health professionals. As the present study found instances of hermeneutical injustice in relation to sense-making in a minimal number of clinical participants, it is possible that this is due to the recruitment of individuals from EIS which is generally considered the 'gold standard' of care for those with a diagnosis of psychosis (Lester et al., 2012), as mentioned in Chapter 6. Future research should therefore focus on individuals at different stages of psychosis, recruited from different clinical settings, in order to identify factors contributing to epistemic injustice throughout the diagnostic journey. Given that the present study focused on psychosis and unusual experiences broadly, and as researched by Harris et al. (2022) in relation to voice-hearers specifically, there would also be additional benefit in separating out the unusual experiences, for example, those with visual experiences or persecutory worries, to determine whether the type of experience has an effect on the level of stigma perpetrated by others.

Although an aim of the present study was to explore instances of epistemic injustice, one novel finding was the dismissal and invalidation of experiences by family in the non-clinical group. As this related to the role of the participants within their family i.e. younger daughter and sister, it is possible that epistemic injustice occurs in different ways for people without a diagnosis, still in relation to the way their identity is perceived through family dynamics. It would therefore be interesting for future research to explore the way in which an individual's

identity, as it relates to their role within family, contributes to their ability to make sense of their unusual experiences.

In conclusion, the present study identified three main themes that contribute to understandings of epistemic injustice amongst non-clinical and clinical groups with unusual experiences: connecting the experience to real-life stressors is important for those who are viewed as disconnected from reality, that stigma is constructed within society and upheld by the authority of others, and how testimonial injustice occurs in relation to the label, as opposed to the experience. As far as the researcher is aware, this study is the first of its kind to use IPA, as well as a multiperspectival approach (Larkin, Shaw, & Flowers, 2019), to provide insight into the lived experience of unusual phenomena and epistemic injustice, contributing empirically to the existing evidence base.

Chapter 8

DISCUSSION

8.1 Aims of the Thesis

The rationale of the present thesis was to explore occurrences of testimonial and hermeneutical injustice amongst non-clinical and clinical groups with unusual experiences in an effort to contribute to the understanding of how epistemic injustice is formed and perpetrated against those with psychosis. Much of the past literature on epistemic injustice has been theoretical, with focus on clinical contexts such as healthcare and service user-professional relationships. Despite the recent shift in considering epistemic injustice in relation to psychosis specifically, studies have focused on individual experiences such as delusions (Sanati & Kyratsous, 2014) or voice hearing (Harris et al., 2022). In an effort to provide nuanced understanding on how epistemic injustice is utilised as a form of stigma towards individuals with psychosis, the present thesis aimed to understand the lived experience of individuals diagnosed with a schizophrenia spectrum disorder, as well as those who have unusual experiences without a medical diagnosis.

A review of the literature suggests that theoretically, hermeneutical injustice may occur through the medicalisation of mental health via a dominant medical model, leaving some individuals diagnosed with psychosis without the required hermeneutical resources to make sense of what they are experiencing (Gosselin, 2019; Wardrope, 2015). Based on their perceived lack of credibility due to the unusual phenomena experienced, for example, hallucinations or delusions, research also highlights how those with psychosis may be likely to

experience testimonial injustice (Hassall, 2024). In addition to this, findings from an empirical meta-ethnography (Chapter 3) reviewing qualitative literature on stigma towards psychosis also highlighted instances of epistemic injustice occurring throughout, supporting the need for further investigation on this concept. Therefore, the more specific aims of the empirical chapters that followed (5 and 6) focused on the way both non-clinical and clinical groups made sense of their unusual experiences, as well as the way people around them made sense of their experiences. Through this, any occurrences of hermeneutical injustice may possibly be identified. With regard to identifying instances of testimonial injustice, the second aim focused on the way participants were treated by those around them, exploring any differences pre- and post-experience. Finally, Chapter 7 aimed to compare and contrast the accounts of the non-clinical and clinical group in relation to their lived experience. Through this, it was expected that any similarities or differences between the groups would bring to light novel understandings of epistemic injustice.

8.2 Summary of Findings

8.2.1 The Experience of Stigma in People with Psychosis: A Meta-Ethnography (Chapter 3)

In Chapter 3, three main themes were developed from the synthesis: (i) 'Understanding Psychosis;' (ii) 'Other's Response;' and (iii) 'Own Response.' The first theme included three sub-themes: 'Lack of Understanding;' 'Psychosis in Comparison;' and 'A Sense of Ab / Normality.' The second theme included three sub-themes: 'Loss of Identity and Autonomy;' 'Epistemic Injustice;' and 'Social Exclusion.' The third and final theme included two sub-themes: 'Conceal and Withdraw;' and 'Difficulties Within Interpersonal Relationships.' All sub-themes contained a central concept of stigma, via the source of stigma, the experienced

stigma, and the response to stigma, in relation to people with a diagnosis of psychosis. The identification of epistemic injustice across the articles added to the existing theoretical literature on the philosophical concept, and highlighted the need for further investigation.

The meta-ethnography in Chapter 3 aimed to lay the foundation for the research conducted in the empirical chapters by first exploring whether epistemic injustice occurs within the relevant literature, in addition to the theoretical literature discussed in Chapter 2, in order to build upon it. As the findings within the meta-ethnography were key to highlighting incidences of epistemic injustice and guiding the later empirical chapters, the last search for articles was conducted prior to the data collection for Chapters 5 and 6. However, papers relevant to the review may have been published since this analysis was conducted and the chapter written. Following the systematic search strategy and eligibility criteria outlined in Chapter 3 (see sections 3.2.1 and 3.2.2), an additional two articles since the last search (02.11.2021) were identified for inclusion (Arboleya-Faedo et al., 2023; Commey, Ninnoni, & Ampofo, 2022) (see Appendix 27 for the PRISMA flowchart). Although much of the results sections across the two articles appear to show no significant differences to the themes and sub-themes developed in Chapter 3, neither study included any examples of hermeneutical or testimonial injustice.

8.2.2 Exploring Frameworks of Understanding and Meaning-Making Processes in People with Unusual Experiences (Chapter 5)

In Chapter 5, four main themes were developed: (i) 'Rationalising the experience as simply unusual;' (ii) 'Sense-making can be inherent or taught dependent on the individual;' (iii) 'The significance of the other in society;' and (iv) 'Legitimacy and validity of the unusual experience'. The themes outlined how participants felt the experience was not severe enough

as to cause distress or seek professional support, deeming it simply unusual, as well as making sense of their experience through supernatural beliefs or individual personality types. Participants described their fear of being perceived as mentally unwell, leading to concealment of the experience from others. The final theme highlighted ways in which the unusual experience was validated or invalidated by both the self and others.

8.2.3 Exploring Frameworks of Understanding and Meaning-Making Processes in People with Experiences of Psychosis (Chapter 6)

In Chapter 6, four main themes were developed: (i) 'The process of rationalisation;' (ii) 'The other's role as a monitor of society;' (iii) 'The importance of communication for inclusion, sense-making, and connection;' and (iv) 'The effect of a psychosis diagnosis on identity'. The themes outlined how all participants grounded their experience in real-life stressors, as well as religion and culture for some. Others played a significant role in participant's lives, through monitoring of behaviour and dismissing them as lacking credibility due to their diagnosis. For most, the diagnosis allowed them to make sense of what they were going through, despite this not being communicated effectively, however it also had a negative effect on the way changes in identity were perceived.

8.2.4 A Multiperspective Approach to Exploring Epistemic Injustice Amongst Clinical and Non-Clinical Groups With Unusual Experiences (Chapter 7)

In Chapter 7, three themes were developed from a multiperspectival analysis of the data collected from Chapters 5 and 6: (i) 'Connecting the experience to real-life stressors is important for those who are viewed as disconnected from reality;' (ii) 'Stigma is constructed within society and upheld by the authority of others;' and (iii) 'Testimonial injustice occurs in

relation to the label, as opposed to the experience.' The themes outlined differences in external influence during the sense-making process, with some clinical participants experiencing hermeneutical injustice. Additionally, increased levels of stigma and changes in identity as a result of the diagnosis led to occurrences of testimonial injustice for the clinical group, whilst the non-clinical group experienced both invalidation and validation of the unusual phenomena.

8.3 Limitations of the Thesis

Although the thesis presents a novel approach to understanding epistemic injustice in a social context[14] as it pertains to individuals with psychosis, as opposed to within a clinical context, there are several limitations that require consideration. It is possible that the difference between what was expected from the literature and what was experienced in the present thesis regarding hermeneutical injustice may be due to recruitment of a smaller sample size that opted in. It is likely that a larger sample may also include people who have a negative relationship with EIS, and so may report more incidences of epistemic injustice, but are therefore harder to reach. The sample population recruited for Chapters 5 and 6 represent individuals at only two stages: the first experiencing unusual phenomena without a diagnosis, and the second diagnosed with a schizophrenia spectrum disorder and receiving support from EIS for at least 1 year within the last 5 years. Given that the role of others in relation to stigma towards psychosis is well documented within past literature (Wood et al., 2015), as well as

[14] Although all incidences of epistemic injustice can be categorised as occurring within a social context, the term 'social context' used throughout this chapter will refer to the individual's family and friends, in order to highlight the difference to a clinical context with professionals.

how clinical services may influence the meaning made of experiences, a design that allowed for changes to be monitored at different stages of the diagnostic process may have provided a more nuanced understanding of epistemic injustice. Unlike testimonial injustice, hermeneutical injustice is inevitably difficult to detect. This is mainly due to collective social resources keeping the true meaning of experiences obscured from disadvantaged individuals, therefore, not making itself known as an injustice until after attempts to construct accurate meanings have been made (Fricker, 2007). Therefore, a cross-sectional design, for example, recruiting individuals pre-diagnosis, post-diagnosis within EIS, and post-EIS, or a longitudinal design with the same participants, may have been a suitable and more appropriate methodological design in order to identify instances of hermeneutical injustice specifically, as it is unlikely that individuals would be able to understand or articulate whether they have experienced this or not early on in services. With regards to the current design then, it may have been beneficial to split the clinical group between those who have recently used EIS (within the past year) and those who have used it for a longer period of time (a minimum of 5 years since using EIS).

Recruitment of non-clinical participants relied on self-reported experiences based on a screening questionnaire designed by the primary researcher (Appendix 9), whilst clinical participants were recruited via their care co-ordinator within an EIS. With both groups, an interview schedule (Appendices L and V) designed by the researcher was utilised. Another potential limitation of the present thesis then was the reliance on individuals to accurately report the nature of their experiences, as well as articulate the meaning made of these experiences, assuming they have the hermeneutical resources to do this. In consideration of

this, for the clinical group, it may have been beneficial to use validated tools in conjunction with the interview schedule, such as The Scale for the Assessment of Positive Symptoms (Andreason, 1984) or The Positive and Negative Syndrome Scale (Kay, Fiszbein, & Opler, 1987), in order to facilitate discussion and understanding of experiences. However, it is also possible that the use of multiple methods to collect data from participants may be time-consuming, leading to further issues such as participant fatigue. Conducting the interview on two separate occasions may also have led to the problem of retaining participant interest in the research. As the thesis aims to adopt a phenomenological approach to meaning making throughout, it could be considered that the use of validated tools itself perpetrates hermeneutical injustice, assuming that interpretation of the participant's experience can be categorised by the scales.

Although the thesis utilised a phenomenological approach to understanding the lived experience of the target populations, the notion of epistemic injustice itself has yet to be operationalised. Much of the literature regarding epistemic injustice is theoretical in nature, and subsequently, a universal understanding of the philosophical concept for use within empirical research is absent. Given that the empirical chapters within the present thesis were a novel endeavour as they aimed to operationalise epistemic injustice, it is possible that the interview schedule may have required further development in order to reach a comprehensive understanding of the concept in action. In comparison to one other study that has attempted to ask individuals about their experiences surrounding epistemic injustice (Harris et al., 2022), there were significant similarities between both interview schedules (p. 951; Appendix 22), in relation to questions regarding changes in relationships with others and how participants made sense of what they were going through. This lends support to the way

the philosophical concept of epistemic injustice was operationalised for the purpose of empirical research within the present thesis. To approach a universal understanding, a larger-scale survey or questionnaire amongst individuals diagnosed with a schizophrenia spectrum disorder across the United Kingdom may be required in future, in order to determine the common features of epistemic injustice. Phenomenological research can then continue to build upon a wider understanding of the concept, as opposed to solely theoretical literature.

Another potential limitation of the present thesis is recruitment of individuals with broad unusual experiences in both the non-clinical and clinical groups. It is possible that specific experiences, such as delusions or voice-hearing, may influence the way sense is made by individuals or how they are treated by others. For example, delusions have previously been perceived as a prime example of irrationality. Sanati and Kyratsous (2015) argue that this perception can be extended across the individual's beliefs more generally, labelling the person as irrational. Testimonial injustice can then be perpetrated when the individual is viewed by others as lacking credibility. Delusions may also evoke a sense of meaning or order for the diagnosed individual that the dominant medical model may not account for (Ritunnano & Bortolotti, 2022; Ritunnano et al., 2022), therefore potentially leading to instances of hermeneutical injustice. On the other hand, for voice-hearers, epistemic injustice was demonstrated through shifts in identity (feeling reduced to a label), relationships with others (stigma and marginalisation), and power and position within society (at the bottom of the social ladder in relation to hopes and future goals) (Harris et al., 2022). This highlights how specific experiences can influence the way epistemic injustice is experienced. Within the present thesis, differences between individual experiences were not examined, but rather

epistemic injustice in psychosis was explored more broadly. While this allows for more general patterns and themes to be identified and explored in people with experiences of unusual perceptual phenomena (with and without diagnoses) it is possible that certain nuance regarding specific aspects of the concept may not be identified. It would be appropriate for future research to continue exploring epistemic injustice amongst both those with unusual experiences and individuals diagnosed with psychosis, separated into specific experiences, for example, delusions, voice-hearing, and hallucinations, in order to gain knowledge on similarities and differences between groups.

Both the non-clinical group and the clinical group within the thesis were disproportionate in relation to recruitment of different genders, mostly leaning on the experiences of female participants in both. In the non-clinical group, there were 33.33% of male participants (2 out of 6), and 20% of male participants (1 out of 5) in the clinical group. Unfortunately, two individuals who declined to participate due to unavailability in the non-clinical group were both male. Also noted by Yehya et al. (2022), the views of these individuals would have contributed to more balance amongst the sample. In comprehensive reviews examining gender differences in psychosis, it was found that social functioning was better in females, along with better remission and lower relapse rates (Carter et al., 2022; Ochoa et al., 2012). In another study, the general public were found to be more likely to socially reject a male with psychosis than a female (Cheung et al., 2018). Based on this, although no specific gender differences were identified in the present thesis due to small sample sizes and a reduced number of male participants, it is possible that differences in the way epistemic injustice is perpetrated may exist between genders. The finding that males with psychosis exhibit poorer

social functioning (Carter et al., 2022; Ochoa et al., 2012) and higher social rejection (Cheung et al., 2018) may suggest that they may be more likely to experience epistemic injustice, in part due to changes in perception of social role or identity by self and others; the significance of which in relation to the concept (Fricker, 2007) has been highlighted throughout the present thesis (see Chapters 5, 6, and 7). Therefore, future research that focuses on recruiting male participants and exploring gender differences in incidences of epistemic injustice is warranted.

8.4 Contribution of the Thesis to the Literature

The findings from the empirical chapters reported in the current thesis add to the literature on the way epistemic injustice is perpetrated against those with psychosis. According to Fricker's (2007) concept of epistemic injustice, individuals experience prejudice on the basis of their identity, for example, gender, race, or mental health difficulties, and are discriminated against in their capacity as a knower. This form of stigma is perpetrated in two ways, via hermeneutical injustice and testimonial injustice (Fricker, 2007). The former denotes that there is a lack of collective resources within society that means individuals may struggle to make sense of certain experiences. On the other hand, testimonial injustice suggests that based on negative and prejudicial stereotypes, an individual's credibility is undermined in their capacity as a knower. Both hermeneutical and testimonial injustice then can be understood as occurring only in response to an individual's identity, leading to an absence of resources to make sense of experiences and dismissal of testimony due to a perceived lack of credibility.

On the basis of identity, epistemic injustice can extend across a range of populations, including those experiencing difficulties with poor mental health (Crichton, Carel, & Kidd,

2017; Gosselin, 2019; Wardrope, 2015). The research reviewed in Chapter 2 supports this notion, highlighting how a dominant medical model can serve to overshadow any personal frameworks of understanding individuals may have about their experiences (Carel & Kidd, 2014; Gosselin, 2019), as well as how those with experiences characterised as delusions, hallucinations, or voice hearing can lead to dismissal of credibility in their capacity as a knower (Hassall, 2024; Sanati & Kyratsous, 2014). However, very little research has examined this concept empirically. The present thesis addressed this gap in the literature by exploring the occurrence of this in individuals with psychosis. Additionally, the thesis also researched this in individuals who experience unusual phenomena without a diagnosis, comparing non-clinical and clinical groups to identify nuances in understanding the way epistemic injustice is formed. As it stands, no previous research has examined this broadly within the literature on psychosis, with only one study examining epistemic injustice amongst non-clinical and clinical voice hearers specifically (Harris et al., 2022).

Broadly speaking, the findings presented in the current thesis support the existence of epistemic injustice against individuals diagnosed with a schizophrenia spectrum disorder, suggesting that they are especially vulnerable in comparison to their non-clinical counterparts. Although the present thesis focused on the diagnosis as the point of difference, it is key to note that the groups are likely to differ in more than just this. For those diagnosed with psychosis, it is possible that they also differ from the non-clinical group with regard to their level of distress, cognitive function, and social network, amongst other factors. Additionally, it is difficult to disentangle the influence of the diagnosis on any occurrences of epistemic injustice from any intersectional vulnerabilities that participants may have. However, many of the examples provided by participants within Chapter 6 (i.e., people with a schizophrenia-

spectrum diagnosis) suggested that they perceived the dismissal of their credibility in their capacity as a knower as being directly influenced by the diagnosis as well as behaviour during previous unusual experiences, such as in subtheme 4.2. Whereas, for participants in Chapter 5 (i.e., people who had unusual experiences but without a clinical diagnosis of psychosis), stronger reference was made to role within family with regard to invalidation of experience. Therefore, given that both groups experience unusual phenomena, but only the clinical group noted being disbelieved about their testimony, as well as difficulty with the sense-making process for some participants, it may be proposed that, at least partly, epistemic injustice was perpetrated in relation to the clinical group's identity as individuals with a diagnosis of psychosis. Findings align with Fricker's (2007) description of the philosophical concept, with the present thesis highlighting its formation through empirical research on psychosis.

8.4.1 Hermeneutical Injustice and Psychosis

It has previously been suggested that due to the adoption of a medical framework as a primary method of understanding unusual experiences, hermeneutical injustice may occur as individual's personal, social, and cultural or religious contexts are not taken into account during the meaning-making process (Hassall, 2024; Lovell, 1995). Findings from the present thesis were mixed with regards to hermeneutical injustice specifically. The meta-ethnography conducted in Chapter 3 highlighted how a medical approach was experienced negatively by individuals and dominated explanations of unusual experiences within past literature, heavily focusing on diagnosis and medication, as well as the representation of behaviours as symptoms (Rose et al., 2011; Wood et al., 2018). In comparison, findings from Chapter 6 suggested that the majority of participants in the clinical group viewed their diagnosis

positively in terms of the understanding it afforded them regarding their experiences. This is in line with one of the critiques against hermeneutical injustice presented in Chapter 2, whereby a diagnosis can be a useful tool for some and serve to enlighten the meaning they make (Crichton, Carel, & Kidd, 2017; Kikkert et al., 2006; Patel et al., 2010).

One similarity found between Chapters 3 and 6 was the lack of information provided to individuals regarding psychosis, as well as a lack of timely and active communication of it prior to entering EIS (Howe, Tickle, & Brown, 2014; Gonzalez-Torrez et al., 2007), leaving participants without the hermeneutical resources necessary to make sense of their experiences. This is in line with past literature that suggests EIS adopts a recovery-focused approach and supports individuals with the sense-making process (Harris, Collinson, & das Nair, 2012). Therefore, whilst it can be considered from the present thesis that a diagnosis can be a positive tool for the meaning-making process, there is a need for this to be actively communicated to the individuals, rather than through the passive and sometimes accidental discovery on documentation as discussed by participants within Chapter 6. It also suggests that to maximise the utility of this process, information is provided that can best provide hermeneutical resources necessary for participants to gain a full understanding of what they are experiencing. It is also imperative to consider the difference between 'imposing' a diagnosis on an individual versus 'offering' one. From Chapter 6, it can be seen how for Christine especially the diagnosis was perceived as something she felt resigned to accept due to the medical authority of professionals. Whilst a diagnosis can offer an opportunity to make sense of complex phenomena, imposing it on service users may alienate them from any personal narratives and process of sense-making, thus creating the injustice. Through the 'offering' of a diagnosis, as also considered by Hassall (2024), individuals may be able to

integrate this into any existing hermeneutical frameworks, in turn facilitating personal agency and minimising alienation.

For some participants in Chapter 6, mental health professionals within EIS were perceived as dismissive of cultural and religious beliefs that were initially used to make sense of the experience. It is possible that this can be attributed to a concept closer to the definition of wilful hermeneutical ignorance (Pohlhaus, 2012), which argues that, as opposed to Fricker's (2007) concept of hermeneutical injustice that suggests there are no collective resources within society for marginalised individuals to make sense of what they are going through, resources do exist but are unrecognised by dominantly situated knowers. Rather than their identity as someone with a diagnosis however, this may occur in relation to their identity as an ethnic minority in the UK or as a religious individual. In this case then, for the participants in the clinical group, it is possible that the hermeneutical resources available to them from other aspects of their lives were dismissed and invalidated by professionals who were not members of that social group, for example, of South African descent. Although this notion has not been identified within previous literature, it is possible that several aspects of identity may affect one situation. For example, being a religious, black female with a diagnosis of psychosis may mean that epistemic injustice is occurring at several different levels (e.g. religion, race, gender, and/or diagnosis) as opposed to just one level. However, this theory warrants further research in the future. As it stands, through the inadequate sharing of information for most participants as well as the dismissal of personal contexts for some, the findings from Chapters 6 and 7 align with the research presented in Chapters 2 and 3, suggesting that hermeneutical injustice is experienced by those with a diagnosis of psychosis, leading to difficulties in understanding not only the unusual experience, but also the diagnosis itself.

8.4.2 Testimonial Injustice and Psychosis

Previous literature suggests that due to their diagnosis and perceived identity as a patient, individuals with psychosis are at risk of experiencing testimonial injustice. According to Hassall (2024), those with psychosis are viewed as unreliable reporters and as lacking credibility on the basis of unusual experiences they have had in the past. Findings from Chapters 3, 6, and 7 lend support to this. In Chapter 3, participants from the reviewed literature felt their testimonies were frequently discredited by professionals, as well as misattribution of unrelated experiences to psychosis (Pyle & Morrison, 2014; Wood et al., 2018). For example, one quote in the meta-ethnography described how mental health professionals disregarded a participant's report of body pain (due to the psychosis diagnosis), later discovering that the individual was afflicted with kidney stones (Gonzalez-Torrez et al., 2007). Examples of testimonial injustice were provided throughout interviews with participants in Chapter 6, however these incidents involved family and friends as opposed to mental health professionals as identified within Chapters 2 and 3. In fact, no instances of testimonial injustice were reported that involved care coordinators within EIS. Rather, a novel finding of the present thesis in comparison to the literature, testimonial injustice occurred within a social context as opposed to a clinical one for participants from the clinical group. Epistemic injustice has only been explored in very limited research, especially in relation to a social context (Harris et al., 2022; Kurs & Grinshpoon, 2018), with findings from the current thesis being the first to explore this broadly within psychosis.

In line with research in Chapter 2 (Conneely et al., 2021), clinical participants expressed feelings of being forced into the role of a patient. This also supported the role of identity

change in relation to epistemic injustice (Fricker, 2007). In comparisons of both clinical and non-clinical groups, Chapter 7 highlighted how both forms of epistemic injustice occur in relation to the diagnosis itself as opposed to the unusual experience. For example, non-clinical participants described no instances of testimonial injustice, rather relationships with others remained unchanged. On the other hand, for clinical participants, relationships with partners, family, and friends were associated with distrust and the concern of testimonies being a symptom of psychosis on the basis of the diagnosis. Therefore, findings from the present thesis support the notion that a diagnosis leads to a perceived change in identity, therefore leading to instances of testimonial injustice (Lakeman, 2010). Testimonial smothering (Dotson, 2011), one of the ways testimonial injustice presents itself, was not found to occur within Chapter 6. However, this is also indicative of the overall findings within the empirical chapters that suggested epistemic injustice occurred in a social context as opposed to a clinical one. For non-clinical participants, despite not experiencing invalidation to a similar degree as clinical participants, findings from Chapter 5 highlighted how the fear of being stigmatised by others still persisted, especially due to the negative connotation of 'crazy' associated with unusual experiences. Findings from the present thesis broadly align with the literature reviewed in Chapters 2 and 3, specifically in relation to testimonial injustice and partly in relation to hermeneutical injustice.

8.5 Clinical Implications of the Thesis

The current thesis supports the experience of epistemic injustice (Fricker, 2007) in the lives people with a diagnosis of psychosis rather than people who report unusual perceptual experiences without a diagnosis of psychosis. Through comparisons between a non-clinical

and a clinical sample of participants with unusual experiences, it was possible to highlight significant differences that could possibly be attributed to a diagnosis of psychosis and subsequent changes in identity. Although hermeneutical injustice did not occur to the extent expected in relation to the literature reviewed within Chapters 2 and 3, and the empirical chapters within the present thesis suggested that epistemic injustice occurred mostly in a social context rather than a clinical context, the findings still appear to have significant clinical implications.

8.5.1 Communication of the Diagnosis

Findings from Chapter 6 suggest that inadequate sharing of information regarding the diagnosis contributed to the experience of hermeneutical injustice, leaving individuals with psychosis without the hermeneutical resources necessary to make full sense of what they were going through. Clinical participants described how the diagnosis was communicated late to them, often passively through accidental viewing of documentation rather than through active and open discussion. One way of improving this issue, as discussed within Chapter 6, is to develop or adapt a protocol that assists with information-sharing and diagnostic discussions. Indeed, one method that could possibly be adapted to make it suitable for a mental health context is the SPIKES protocol (Baile et al., 2000) that aims to share knowledge and information with the service user but also address their emotions with empathetic responses, providing hope for the future through a strategy and summary of treatment options. This has also been supported in the literature by Hassall (2024), who suggests that the provision of a diagnosis should be accompanied with explanations that it is descriptive of

the unusual experience as opposed to being an explanation for it, with full recovery being a possible and attainable goal for the future.

As mentioned previously, there should also be consideration around 'offering' a diagnosis as opposed to 'imposing' it on service users. It is necessary that this discussion takes place in as timely a manner as possible in order to not leave individuals without the hermeneutical resources needed to make sense of their experience or allow them the space to integrate this into their personal frameworks of understanding. Findings from the present thesis support previous literature that suggests information-sharing regarding the diagnosis requires significant attention (Farooq, Green, & Singh, 2019). There is a clear need for professional bodies to develop guidelines and implement change, with focus on the timeliness of providing the diagnosis, as well as avenues of communication. Online resources as a method of sharing information may be a suitable approach, with previous literature suggesting that mental health mobile technology may be well received by individuals with psychosis (Aref-Adib et al., 2016). However, given that this would require funds or access to laptops or mobiles by individuals, focus could be placed on providing in-person information sessions, utilising online resources as an additional source of information, potentially offered in stages so as not to overwhelm individuals (Hill, Wilson, & Stanley, 2023). It is necessary that clinicians ensure information has been understood at each stage and a space in which open dialogue can occur without judgement has been provided to service users so that any concerns can be alleviated.

8.5.2 An Epistemically Open Space

For many participants in Chapter 6, the diagnosis itself afforded a way of making sense of experiences they previously noted as having no insight into. However, some participants

experienced dismissal of personal interpretations for what they were going through, leading to perceived changes in identity and feelings of being funnelled into the role of a patient. The data presented in Chapter 5 offers support to the previous literature that suggests individuals with unusual experiences appear less distressed than their clinical counterparts, making sense of what they are going through by utilising personal, cultural, or religious frameworks (Pigeon-Gagné et al., 2022; Yehya et al., 2022). However, findings from Chapter 7 suggest that whilst non-clinical participants have an open space to discuss these interpretations, either with family or friends, no such opportunity was identified for clinical participants. Additionally, the data presented in Chapter 6 also aligns with previous reviews within Chapters 2 and 3, suggesting that individuals with psychosis are more likely to develop a coherent narrative and apply meaning to their experiences through the support of a professional (Noiriel et al., 2020).

As stated by Drożdżowicz (2021), the onus is on mental health professionals to solicit testimonies regarding unusual experiences from the individual in order to prevent epistemic losses. Therefore, it may be helpful for service users to be provided with an open space that affords them epistemic autonomy and authority (Gosselin, 2019). Despite the limited time clinicians typically have with service users, as well as the potential difficulties with implementation, strategies could be put in place to challenge the issue of epistemic injustice. For example, simply listening to individual's experiences and interpretations has been suggested as a potential method of leaning towards epistemic equality (Harris et al., 2022; Lakeman, 2010). Hassall (2024) suggests a case-formulation approach may be a viable way of facilitating the clinician-service user relationship, in order to construct a collaborative and shared understanding of unusual experiences. This would allow for the necessary epistemically open space, where individuals can focus on meaning-making processes and

formation of personal, coherent narratives. Indeed, alternative ways to conceptualise psychosis have been identified through review of the past literature in Chapters 2 and 3, and it is possible that these conceptualisations may provide hermeneutical resources to marginalised individuals that do not necessarily subscribe them to a pre-existing medical framework (Oakland & Berry, 2015; Tate, 2019). Given that the findings in Chapter 6 suggest alternative explanations may centre around cultural or religious frameworks of understanding, further support, for example, through religious leaders, may be useful in order to address spiritual needs (Cullinan et al., 2024).

8.5.3 Perception of Credibility

Chapter 7 highlighted how stigma was expected from others in both the non-clinical and clinical groups, however only the clinical group experienced this. In relation to the unusual experience itself, despite both groups experiencing some invalidation, only the clinical group's invalidation appeared to occur as a result of previous unusual experiences, diminishing the perception of the individual's credibility. Additionally, participants in Chapter 5 also experienced validation from others that clinical participants did not experience, except with peers who share a similar diagnosis. Findings suggest that those with psychosis are likely to experience testimonial injustice, especially within a social context. As previously discussed within Chapters 5 and 6, there is a need for the destigmatisation of psychosis and unusual experiences at a structural level in order to reduce negative perceptions of diminished credibility. As a start point, increasing knowledge and awareness could be targeted towards partners, family, and friends, for example, through anti-stigma campaigns.

The use of a phenomenological toolkit developed for primarily for use within clinical contexts (Carel & Kidd, 2014), may be beneficial if adapted for use within social support sessions. Through this, loved ones of service users may learn how to suspend any pre-existing attitude towards the experiences and understand the effect of the unusual experience or diagnosis on the individual. Additionally, the use of the toolkit within an open, epistemic space may mean people can be supported to construct a self-concept that is different to the diagnostic identity found within Chapter 6 (Tekin, 2011). Changing the perception to self and identity may limit any internalisation of stigma, reducing the harms perpetrated by epistemic injustice. However, it would be necessary for such perception to change for those around the individual also, in order to avoid the occurrence of epistemic injustice in the first place. Whilst working directly with clinicians or support groups that provide information sessions for family and friends in order to destigmatise the diagnosis, general public perception may change through increased knowledge on interpretations of experiences that move towards a more psychosocial understanding. Though difficult to destigmatise psychosis at a societal level, continued work on this is vital in order to improve perceptions of credibility and reduce the harms of testimonial injustice.

8.6 Conclusion

In summary, the current thesis has presented findings that offer support for the occurrence of epistemic injustice (Fricker, 2007) amongst individuals who experience psychosis. Furthermore, the data suggests that there are differences between non-clinical and clinical groups, whereby undiagnosed individuals with unusual experiences do not experience epistemic injustice, lending support to the notion that both hermeneutical and testimonial

injustice occurs in relation to perceived identity i.e. the identity of a diagnosed or 'mentally ill' person (Hassall, 2024), rather than the unusual experience itself. Non-clinical participants were able to rationalise their unusual experiences as simply unusual, deeming them not problematic enough as to require professional support, also making sense of them as relative to the supernatural or individual personality types. In comparison, clinical participants rooted their interpretations in real-life stressors as a result of communication with care coordinators, as well as religion and culture for some, although these latter interpretations were overshadowed by the diagnosis. Despite poor information-sharing surrounding this, the diagnosis was experienced as a useful tool to make sense of unusual experiences for the clinical group. For both groups, others played a significant role, however this displayed itself in different ways. Whilst both groups experienced fear of being perceived as ill, leading to concealment in some cases, only the clinical group experienced this stigma through the monitoring of behaviour and dismissal of testimony as lacking credibility based on the diagnosis. Invalidation from others regarding the unusual phenomena was also experienced in the non-clinical group, however validation regarding interpretation also occurred.

Taken together, the findings presented in the thesis highlight how hermeneutical injustice occurred within the clinical group through poor timeliness and information-sharing surrounding the diagnosis, as well as the dismissal of religious and cultural interpretations for some. In addition, testimonial injustice was also associated with perceived changes in identity and subsequent lack of credibility afforded to clinical participants, leading to dismissal of testimony. Conversely, non-clinical participants were able to make sense of their unusual experiences according to their personal, religious, and cultural worldviews, as well as experiencing validation regarding their experiences or interpretations from others. Due to the

limitations of the methodology (i.e. a limited number of population samples), as well as the difficulty in detecting hermeneutical injustice in comparison to testimonial injustice, it is unclear how personal interpretations of the clinical group may have developed pre- and post-contact with EIS. Given that participants with psychosis within the present thesis were recruited at different points within their journey post-EIS, the influence of the diagnostic process on changes to the meaning-making processes cannot be determined. Further research that utilises either a longitudinal approach or a cross-sectional design with an increased number of groups at different stages may be useful for highlighting the key factors involved in the perpetration of hermeneutical injustice.

The approach used in the present thesis has attempted to place individuals with a diagnosis of psychosis back into a position where unusual experiences can be understood through their own personal interpretation of it. Given that the focus is on exploring instances of epistemic injustice, it was of significant importance to utilise a careful and considered approach to the terminology used throughout the thesis, in order to appreciate the lived experience of both those with unusual experiences and those with a diagnosis in the context of their personal and social worlds, as opposed to focusing on specific 'symptoms.' It is hoped that the understanding derived from this approach will lead to greater focus on the significance of the individual and their personal worldviews throughout the diagnostic process, as well as contribute to reducing the perpetration and harm of epistemic injustice.

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Appendix 1
Breakdown of Quality Appraisal

Paper	Theoretical Approach		Participants	Study Design	Data Collection	Validity			Analysis				Ethics
	Is the qualitative approach chosen appropriate for the study?	Is the study clear in what it seeks to do?	Do participants have a clinical diagnosis of a primarily psychotic disorder?	How defensible / rigorous is the research design / method?	How well was the data collection carried out?	Is the context clearly described?	Were the methods reliable?	Is the role of the researcher clearly described?	Are the data 'rich'?	Is the analysis sufficiently rigorous and reliable?	Are the findings convincing ?	Are the conclusions adequate?	How clear and coherent is the reporting of ethical considerations?
Knight, Wykes & Hayward (2003)	✓ Suitable approach used to fulfil the aims of the research.	✓ Clear aim and rationale for the study is provided in the introduction. ✓ Appropriate discussion of relevant literature.	? States that participants have a clinical diagnosis but need more information i.e. ICD / DSM.	✓ Sufficiently rigorous. ✓ Clear description of sample and method of data collection with rationale provided. × No mention of sampling method.	✓ Method of data collection described well. ✓ Information included on the duration of interviews and content of interviews. ✓ Clear reporting of recording of	✓ Relevant information regarding participants was provided. × No mention of where the interviews took place. × No reporting of potential bias of setting.	? One method of data collection used. ✓ Method of data collection used is appropriate to fulfil the aims of the study.	× The role of the researcher i.e. reflexivity, is not discussed. × No mention of how the research was explained and presented to participants. × Researcher's positionality has not	✓ Context can be derived from the data. ✓ Detailed analysis provides insight into participant's experience. ? Differences in experiences between participants have been explored, however,	✓ Clear description of method of data analysis with cited literature as justification. ✓ Detail provided about how the method of analysis led to creation of themes. ✓ Transcription carried out by	✓ Themes are clearly presented in a logical manner. ✓ Extracts from original data included. ✓ Data appropriately referenced. ✓ Findings are credible in relation to the aims of the study.	✓ Links between data, interpretation, and conclusions are adequate. ? One of the conclusions mentioned is not completely supported / prevalent enough in the analysis. ? One limitation of IPA discussed	× Granting of ethical approval by a committee has not been stated. ✓ Some mention of informed consent and anonymity of participants within the method section.

					interviews. ✓ Rationale provided for interview schedule used.			been stated.	the authors do not state how many participants contributed to which interpretations.	more than one person. ✓ Themes were assessed by an independent researcher. × No mention of how any discrepancies were handled.		and discounted. ✓ Implications of the research are clearly defined.	
Gonzalez-Torrez et al. (2007)	✓ Suitable approach used to fulfil the aims of the research.	✓ Clear aim and rationale for the study is provided in the introduction. ✓ Appropriate discussion of relevant literature.	? States that participants have a clinical diagnosis but need more information i.e. ICD / DSM.	✓ Sufficiently rigorous. ✓ Clear description of sample / sampling method and method of data collection with rationale provided.	✓ Method of data collection described well, with rationale provided for the way in which the focus groups were carried out. interviews. ✓ Clear reporting of recording	✓ Relevant information regarding participants was provided. ✓ Mention of the atmosphere the authors wanted to create for participants. × No mention of where the	✓ Method of data collection used is appropriate to fulfil the aims of the study. ? One method of data collection used.	✓ Mention of who approached the participants for the research. ✓ The role the researchers took during the focus groups is discussed. × The role of the researcher i.e. reflexivity,	✓ Context can be derived from the data. ✓ Analysis provides insight into participant's experience. × Differences in experiences between participants have not been explored.	✓ Clear description of data analysis. ✓ Detail provided about how the method of analysis led to creation of themes. ✓ Mention of discrepancies and how they were handled.	✓ Themes are clearly presented in a logical manner. ✓ Extracts from original data included. ✓ Data appropriately referenced. ✓ Findings are credible in relation to the aims of the study.	✓ Links between data, interpretation, and conclusions are adequate. ✓ Limitations of the study have been discussed. ✓ Implications of the research are clearly defined.	× Granting of ethical approval by a committee has not been stated. ✓ Some mention of informed consent within the method section.

					of interviews. ? Information given on the content and structure of focus groups, although duration of focus groups was not stated.	interviews took place.		is not discussed. × Researcher's positionality has not been stated.		× Themes were not assessed by an independent researcher. × No mention of who or how many researchers transcribed the recordings.			
Jenkins & Carpenter-Song (2009)	✓ Suitable approach used to fulfil the aims of the research.	✓ Clear research questions and rationale for the study is provided in the introduction. ✓ Appropriate discussion of relevant literature.	✓ States that participants have a clinical diagnosis assessed through the Structured Clinical Interview for DSM-IV.	✓ Sufficiently rigorous. ✓ Clear description of sample / sampling method and method of data collection with rationale provided.	✓ Method of data collection described well. ✓ Information included on the amount and duration of interviews. ✓ Content of measure	✓ Relevant information regarding participants was provided. × No mention of where the interviews took place. × No reporting of potential bias of setting.	✓ Method of data collection used is appropriate to fulfil the aims of the study. ✓ Multiple methods of data collection used.	× The role of the researcher i.e. reflexivity, is not discussed. × Researcher's positionality has not been stated. ✓ Mention of how the participants were recruited	✓ Context can be derived from the data. ✓ Detailed description of the participants whose quotes were used. ✓ Detailed analysis provides insight into participant's	✓ Clear description of method of data analysis. ✓ Detail provided about how the method of analysis led to creation of themes. ✓ Mention of which researchers transcribe	✓ Themes are clearly presented in a logical manner. ✓ Extracts from original data included. ✓ Data appropriately referenced. ✓ Findings are credible in relation to	✓ Links between data, interpretation, and conclusions are adequate. × Limitations of the study have not been discussed. ? Implications of the research have been	× Granting of ethical approval by a committee has not been stated. ✓Some ethical consideration mentioned e.g. informed consent.

					described well. ✓ Rationale provided for the measure used.			for the research.	experience. ? Differences in experiences have been explored, however, the authors do not state how many participants contributed to which interpretations.	d the recordings. ✓ Mention of discrepancies and how they were handled. × Themes were not assessed by an independent researcher.	the aims of the study.	discussed a little.	
Loga-nathan & Murthy (2011)	✓ Suitable approach used to fulfil the aims of the research.	✓ Clear aim and rationale for the study is provided in the introduction. ✓ Appropriate discussion of relevant literature.	✓ States that participants have a clinical diagnosis according to International Classification of Disease (ICD-10).	✓ Clear description of sample and method of data collection. × No mention of sampling method. × No rationale / justification provided.	✓ Method of data collection described well. ✓ Content of measure described well. × No information given on the duration of	✓ Relevant information regarding participants was provided. × No mention of where the interviews took place. × No reporting of potential	✓ Method of data collection used is appropriate to fulfil the aims of the study. ? One method of data collection used.	✓ The role of the researcher i.e. reflexivity, is discussed throughout. × Researcher's positionality has not been stated.	✓ Context can be derived from the data. ✓ Analysis provides insight into participant's experience. ? Differences in experiences have	✓ Clear description of method of data analysis. ✓ Mention of discrepancies and how they were handled. ✓ Use of triangulation. ✓ Mention of which	✓ Themes are clearly presented in a logical manner. ✓ Extracts from original data included. ✓ Data appropriately referenced. ✓ Findings are	✓ Links between data, interpretation, and conclusions are adequate. ✓ Limitations of the study have been discussed. ✓ Implications of the research	✓ Granting of ethical approval by a committee has been stated. × No ethical consideration within the method section e.g.

					interviews. ✓ Rationale provided for the measure used.	bias of setting.		× No mention of how the research was explained and presented to participants.	been explored, however, the authors do not state how many participants contributed to which interpretations.	researchers transcribed the recordings.	credible in relation to the aims of the study.	have been discussed.	informed consent / anonymity.
Rose et al. (2011)	✓ Suitable approach used to fulfil the aims of the research.	✓ Clear aim and rationale for the study is provided in the introduction. ✓ Use of hypotheses is suitable for thematic analysis. ✓ Appropriate discussion of relevant literature.	? States that participants have a clinical diagnosis but need more information i.e. ICD / DSM.	✓ Clear description of sample and method of data collection. × No mention of sampling method. ✓ Rationale / justification for sample is provided.	✓ Content of measure described well. ? Method of data collection described well, but no information given on the duration of interviews. ✓ Rationale provided for the measure used.	✓ Relevant information regarding participants was provided. × No mention of where the interviews took place. × No reporting of potential bias of setting.	✓ Method of data collection used is appropriate to fulfil the aims of the study. ✓ Multiple methods of data collection used.	× The role of the researcher i.e. reflexivity, is not discussed. × No mention of how the research was explained and presented to participants. × Researcher's positionality has not	✓ Context can be derived from the data. ✓ Analysis provides insight into participant's experience. ? Differences in experiences have been explored, however, the authors do not state how many	✓ Clear description of data analysis. ✓ Mention of discrepancies and how they were handled. ? Themes were not assessed by an independent researcher however; one researcher was a mental health	✓ Themes are clearly presented in a logical manner. ✓ Extracts from original data included. ✓ Data appropriately referenced. ✓ Findings are credible in relation to the aims of the study.	✓ Links between data, interpretation, and conclusions are adequate. ✓ Limitations of the study have been discussed. × Implications of the research have not been discussed.	× Granting of ethical approval by a committee has not been stated. × No ethical consideration within the method section e.g. informed consent / anonymity.

								been stated.	participants contributed to which interpretations.	service user.			
Howe, Tickle & Brown (2014)	✓ Suitable approach used to fulfil the aims of the research.	✓ Clear aim and rationale for the study is provided in the introduction. ? Minimal discussion of relevant literature.	? States that participants have a clinical diagnosis but need more information i.e. ICD / DSM.	✓ Clear description of sample and method of data collection. × No mention of sampling method. × No rationale / justification provided.	× Content of interview not described. ✓ Method of data collection described with information on the duration of interviews. × No rationale provided for the measure used.	✓ Relevant information regarding participants was provided. × No mention of where the interviews took place. × No reporting of potential bias of setting.	✓ Method of data collection used is appropriate to fulfil the aims of the study. ? One method of data collection used.	? The role of the researcher i.e. reflexivity, is mentioned vaguely. × No mention of how the research was explained and presented to participants. ✓ Researcher's positionality has been stated.	✓ Context can be derived from the data. ✓ Analysis provides insight into participant's experience. ✓ Differences in experiences have been explored with mention of how many participants contributed to which interpretations.	✓ Clear description of method of data analysis. × No mention of discrepancies or how they were handled. × Themes were not assessed by an independent researcher. × No mention of who or how many researchers transcribed the recordings / conducted the analysis.	✓ Themes are clearly presented in a logical manner. ✓ Extracts from original data included. ✓ Data appropriately referenced. ✓ Findings are credible in relation to the aims of the study.	✓ Links between data, interpretation, and conclusions are adequate. ? Minimal discussion of limitations of the study. ✓ Implications of the research have been discussed.	✓ Granting of ethical approval by a committee has been stated. ✓Some ethical consideration mentioned e.g. informed consent.

Pyle & Morrison (2014)	✓ Suitable approach used to fulfil the aims of the research.	? Rationale for the study is provided in the introduction., but the aims have not been made clear. ? Some discussion of relevant literature.	✓ States that participants have either an ICD-10 Schizophrenia Spectrum diagnosis or meet entry criteria for Early Intervention in Psychosis Services.	✓ Clear description of sample and method of data collection. × No mention of sampling method. ✓ Rationale / justification for sample size provided.	✓ Content of interview described well. ✓ Method of data collection described with information on the duration of interviews. ✓ Rationale provided for the method of data collection used.	✓ Relevant information regarding participants was provided. × No mention of where the interviews took place. × No reporting of potential bias of setting.	✓ Method of data collection used is appropriate to fulfil the aims of the study. ? One method of data collection used.	✓ The role of the researcher i.e. reflexivity, is discussed. × No mention of how the research was explained and presented to participants. × Researcher's positionality has not been stated.	✓ Context can be derived from the data. ✓ Analysis provides insight into participant's experience. ? Differences in experiences have been explored, however, the authors do not state how many participants contributed to which interpretations.	✓ Clear description of method of data analysis. × No mention of discrepancies or how they were handled. × Themes were not assessed by an independent researcher. ✓ Mention of which researchers transcribed the recordings / conducted the analysis.	✓ Themes are clearly presented in a logical manner. ✓ Extracts from original data included. ✓ Data appropriately referenced. ✓ Findings are credible in relation to the aims of the study.	✓ Links between data, interpretation, and conclusions are adequate. ✓ Limitations of the study have been discussed. ✓ Implications of the research have been discussed.	✓ Granting of ethical approval by a committee has been stated. ✓Some ethical consideration mentioned e.g. anonymity.

Mora-Rios, Ortega-Ortega & Natera (2015)	✓ Suitable approach used to fulfil the aims of the research.	✓ Clear aim and rationale for the study is provided in the introduction. ✓ Appropriate discussion of relevant literature.	✓ States that participants have a clinical diagnosis according to ICD-10 or the DSM-IV-TR.	✓ Clear description of sample and method of data collection. ✓ Clear description of sampling method. × No rationale / justification provided.	✓ Content of interview described well. ✓ Method of data collection described with information on the duration of interviews. ✓ Rationale provided for the method of data collection used.	✓ Relevant information regarding participants was provided. ✓ Authors state where the interviews took place. ✓ Authors provide justification for the setting used.	✓ Method of data collection used is appropriate to fulfil the aims of the study. ? One method of data collection used.	× The role of the researcher i.e. reflexivity, is not discussed. ✓ Authors describe how the research was explained and presented to participants. × Researcher's positionality has not been stated.	✓ Context can be derived from the data. ✓ Analysis provides insight into participant's experience. ✓ Differences in experiences have been explored with mention of how many participants contributed to which interpretations.	✓ Clear description of method of data analysis with rationale. ✓ Mention of discrepancies or how they were handled. × Themes were not assessed by an independent researcher. ✓ Mention of which researchers conducted the interviews / analysis.	✓ Themes are clearly presented in a logical manner. ✓ Extracts from original data included. × Data not appropriately referenced. ✓ Findings are credible in relation to the aims of the study.	✓ Links between data, interpretation, and conclusions are adequate. ✓ Limitations of the study have been discussed. ✓ Implications of the research have been discussed.	✓ Granting of ethical approval by a committee has been stated. ✓Some ethical consideration mentioned e.g. anonymity.
Paul (2016)	✓ Suitable approach used to fulfil the aims of the research.	✓ Clear aim and rationale for the study is provided in the introduction.	✓ States that participants have a clinical diagnosis according to ICD-10.	✓ Clear description of sample and method of data collection. ✓ Clear description	✓ Content of interview described well. ✓ Method of data collection described	✓ Relevant information regarding participants was provided.	✓ Method of data collection used is appropriate to fulfil the aims of the study.	? The role of the researcher i.e. reflexivity, is mentioned briefly in	✓ Context can be derived from the data. ✓ Analysis provides insight into participant	✓ Clear description of method of data analysis with rationale. ✓ Mention of	✓ Themes are clearly presented in a logical manner. ? Minimal extracts from original	✓ Links between data, interpretation, and conclusions are adequate.	✓ Granting of ethical approval by a committee has been stated.

		✓ Appropriate discussion of relevant literature.		of sampling method. ✓ Rationale / justification for sampling method is provided.	with information on the number of interviews. ✓ Rationale provided for the method of data collection used.	✓ Authors state where the interviews took place. × No reporting of potential bias of setting.	? One method of data collection used.	the discussion. ✓ Authors describe how the research was explained and presented to participants. × Researcher's positionality has not been stated.	's experience. ✓ Differences in experiences have been explored with mention of how many participants contributed to which interpretations.	agreement on themes and use of member-checking. ✓ Mention of which researchers transcribed the interviews / conducted the analysis. ✓ Detail provided about how the method of analysis led to creation of themes.	data included. × Data not appropriately referenced. ✓ Findings are credible in relation to the aims of the study.	? Minimal limitations of the study have been discussed. ✓ Implications of the research have been discussed.	✓ Ethical consideration mentioned e.g. anonymity.
Wood et al. (2018)	✓ Suitable approach used to fulfil the aims of the research.	✓ Clear aim and rationale for the study is provided in the introduction. ✓ Appropriate	✓ States that participants have a clinical diagnosis according to ICD-10.	✓ Clear description of sample and method of data collection. ✓ Clear description of sampling method. × No rationale /	✓ Content of interview described well. ✓ Method of data collection described with information on the	✓ Relevant information regarding participants was provided. ✓ Authors state where the	✓ Method of data collection used is appropriate to fulfil the aims of the study. ? One method of data	× The role of the researcher i.e. reflexivity, is not discussed. × Authors do not describe how the research	✓ Context can be derived from the data. ✓ Analysis provides insight into participant's experience.	✓ Clear description of method of data analysis with rationale. ✓ Mention of agreement on themes and use of	✓ Themes are clearly presented in a logical manner. ✓ Extracts from original data included. ✓ Data appropriat	✓ Links between data, interpretation, and conclusions are adequate. ✓ Limitations of the study	✓ Granting of ethical approval by a committee has been stated. ✓ Ethical consideration

		discussion of relevant literature.		justification for sampling method is provided.	duration of interviews. ✓ Rationale provided for the method of data collection used.	interviews took place. × No reporting of potential bias of setting.	collection used.	was explained and presented to participants. ✓ Researcher's positionality has been stated.	? Differences in experiences have not been explored. ✓ Mention of how many participants contributed to which interpretations.	triangulation. ✓ Mention of which researchers conducted the analysis. ✓ Detail provided about how the method of analysis led to creation of themes.	ely referenced. ✓ Findings are credible in relation to the aims of the study.	have been discussed. ✓ Implications of the research have been discussed	mentioned e.g. informed consent.
Yen, Huang & Chien (2020)	✓ Suitable approach used to fulfil the aims of the research.	✓ Clear aim and rationale for the study is provided in the introduction. ✓ Appropriate discussion of relevant literature.	? States that participants have a clinical diagnosis but need more information i.e. ICD / DSM.	✓ Clear description of sample and method of data collection. ✓ Clear description of sampling method. ✓ Rationale / justification for sampling method is provided.	× Content of interview has not been described. ✓ Method of data collection described with information on the duration of interviews. ✓ Rationale	✓ Relevant information regarding participants was provided. ? Authors vaguely mention where the interviews took place. × No reporting of potential	✓ Method of data collection used is appropriate to fulfil the aims of the study. ✓ Multiple methods of data collection used.	× The role of the researcher i.e. reflexivity, is not discussed. × Authors do not describe how the research was explained and presented to participants.	✓ Context can be derived from the data. ✓ Analysis provides insight into participant's experience. ? Differences in experiences have been explored,	✓ Clear description of method of data analysis. ✓ Detail provided about how the method of analysis led to creation of themes. × No mention of discrepancies or how	✓ Themes are clearly presented in a logical manner. ✓ Extracts from original data included. ✓ Data appropriately referenced. ✓ Findings are credible in relation to	✓ Links between data, interpretation, and conclusions are adequate. ? Minimal limitations of the study have been discussed. ✓ Implications of the research have been discussed	✓ Granting of ethical approval by a committee has been stated. ✓ Ethical consideration mentioned e.g. anonymity.

					provided for the method of data collection used.	bias of setting.		× Researcher's positionality has not been stated.	however, the authors do not state how many participants contributed to which interpretations.	they were handled. × Themes were not assessed by an independent researcher.	the aims of the study.		
Vyas, Wood, & McPherson (2021)	✓ Suitable approach used to fulfil the aims of the research.	✓ Clear aim and rationale for the study is provided in the introduction. ✓ Appropriate discussion of relevant literature.	? States that participants are under the care of an Early Intervention in Psychosis service but need more information i.e. diagnosis / ICD / DSM.	✓ Clear description of sample and method of data collection. ✓ Clear description of sampling method. × No rationale / justification for sampling method is provided.	✓ Content of interview described well. ✓ Method of data collection described with information on the duration of interviews. × No rationale provided for the measure used.	✓ Relevant information regarding participants was provided. ✓ Authors state where the interviews took place. × No reporting of potential bias of setting.	✓ Method of data collection used is appropriate to fulfil the aims of the study. ? One method of data collection used.	✓ The role of the researcher i.e. reflexivity, has been discussed. ✓ Authors describe how the research was explained and presented to participants. ✓ Researcher's positionality has been stated.	✓ Context can be derived from the data. ✓ Analysis provides insight into participant's experience. ? Differences in experiences have not been explored. ✓ Mention of how many participants contributed to which	✓ Clear description of method of data analysis. × No rationale provided for method of data analysis. ✓ Mention of agreement on themes and of which researchers conducted the analysis. ✓ Detail provided about how	✓ Themes are clearly presented in a logical manner. ✓ Extracts from original data included. ✓ Data appropriately referenced. ✓ Findings are credible in relation to the aims of the study.	✓ Links between data, interpretation, and conclusions are adequate. ? Limitations of the study have been discussed. ✓ Implications of the research have been discussed	✓ Granting of ethical approval by a committee has been stated. ✓ Ethical consideration mentioned e.g. informed consent.

									interpretations.	the method of analysis led to creation of themes. × Themes were not assessed by an independent researcher.			

Appendix 2

Example of Initial Data Extraction Table

Category / Concept	**Gonzalez-Torrez et al. (2007)**
Theme 1: Mental illness vs. lack of willpower	Behaviour related to illness is misattributed as a lack of willpower by others - accused of laziness and drama. Failure to understand behaviour is illness-related. **''The psychologist... told me that my illness was there because I had invented it... the family doctor... didn't believe what I had, that I was ill... he said that I was asking for sick leave because I didn't want to work..''**
Theme 2: Prejudice related to dangerousness	Others show fear due to the stereotype of danger surrounding mentally ill people. **''I took the elevator and my neighbor was leaving and she was frightened. She always gets frightened.''** Perceived by professionals as trouble-causers **''(at the Psychiatric Hospital) we were told that the coffee machine wouldn't last long because certain aggressive people would break it."** **''The media... as soon as something happens... someone gets killed... it was a mentally disturbed person who had schizophrenia''**
Theme 3: Over-protection-infantilization	Close social network over-protects patient (e.g. by hiding sensitive information) - restricts individuality and personal growth. **''Only because I'm getting up early in the morning... they start to say you're becoming a little like this, you're beginning to do that. Because of my illness, my family thought I couldn't do anything on my own and so they did everything for me.''**
Theme 4: Daily social discrimination	In many areas of daily life, patients are treated differently when people are aware of their condition (e.g. at work / house-hunting / shopping) **''I sell my watercolours and they use me: they barter with me, they lower the price, they lower me by taunting me and saying 'that guy is crazy'"**

Theme 5: Discrimination in health care	Felt they were not believed by professionals. Seriousness of somatic symptoms were underestimated. Felt they were viewed as passive in the decision-making process. **''Until they discovered what I have (kidney stones), they didn't listen to me, it was all due to nerves, whenever I said my stomach ached, this side ached, it was nerves…''**
Theme 6: Descendants	Due to the genetic component of schizophrenia, patients were mistreated when they mentioned having kids by both family and professionals. **''You mention to the psychiatrist that you want to have a child and he says 'no, that's not possible, don't even think of it'.''** **''My mother had my (fallopian) tubes tied. I was under legal age; they did it to me when I was 17''**
Theme 7: Avoidance-social isolation	Socially isolate to cope with both the actual and perceived stigma, as well as their own prejudices. **"I don't have any friends because I left them all''**

Appendix 3

Data Extraction and Initial Concepts – Example of Theme 1: Understanding Psychosis (Sub-theme 1: Lack of Understanding)

Paper	Theme 1: Understanding Psychosis (Sub-theme 1: Lack of Understanding)
Knight, Wykes & Hayward (2003)	Predominantly negative attitudes from others to understanding psychosis. **"People don't understand. I mean, they'll say, is it split personality or something basic like that."** *Quotes provided do not necessarily support the author's interpretation of negative attitudes. More indicative of a lack of understanding / misunderstanding what psychosis is.* Experience as both perpetrator and victim of stigmatising attitude, accentuating self-stigma. **"I didn't know too much about mental illness. [break] And I think that my attitude before OK, has, is perhaps caused some sort of friction on myself, in terms of healing myself."** *Own lack of knowledge / understanding about mental illness prior to dx affects their current self. The kind of attitude held prior to dx isn't mentioned, although the current friction suggests it's a negative one.*
Gonzalez-Torrez et al. (2007)	Behaviour related to illness is misattributed as a lack of willpower by others - accused of being lazy and overdramatic. ''**The psychologist... told me that my illness was there because I had invented it… the family doctor... didn't believe what I had, that I was ill… he said that I was asking for sick leave because I didn't want to work..''** *Discrepancies in understanding - failure to understand behaviour is related to the dx. Not believing that the dx exists.* Others show fear due to the stereotype of danger surrounding mentally ill people. **''I took the elevator and my neighbour was leaving and she was frightened. She always gets frightened.'' Perceived by professionals as trouble-causers ''(at the Psychiatric Hospital) we were told that the coffee machine wouldn't last long because certain aggressive people would break it" - views that are reinforced by the media. ''The media... as soon as something happens... someone gets killed... it was a mentally disturbed person who had schizophrenia.''** *Participants felt that it was the negative portrayals of schizophrenia in the media that maintains the prejudices / negative stereotypes held by others. The main stereotype being 'dangerous' and 'aggressive.' "Certain aggressive people" - groups individuals together and negatively labels them due to dx.*
Jenkins & Carpenter-	Lack of comprehension about the illness. **"And it really blows a lot of people away when I tell them about that. That my family really doesn't care. They expect me to function as though I don't have schizophrenia. They never want to talk about it. They never want to**

Song (2009)	**discuss it. They never bring it up. It's like they want me to be normal, even though I have this illness. I -it bothered me a lot. I used to be jealous, I know some people where their families are really close, you know, and I don't have that."** *Lack of familial closeness due to dx. View dx as abnormal. Lack of understanding about the effect the illness can have on the person. Avoiding mentioning it / almost pretending it doesn't exist.* Most people uneducated about medication use. **"I removed myself from her life for months because that's where I drew the line. She said umm, I told her about somebody who was in bed for about fourteen years with chronic fatigue and she said that's because they wanted to be. And I said something about, 'well you know my psych drugs make me tired too.' Which I think they do . . . She said 'Well you need to get off those! Well I just didn't speak to her for months and months, because I thought somebody with an attitude like that, uh uh . . ."** *Behaviour related to medication is misattributed as laziness. Lack of understanding led to withdrawal.* Portrayal of mentally ill as prone to violence / unpredictable. **"I think there's a tendency, everyone assumes, you know, the mentally ill that I'm a danger to society. I'm more a danger to myself than anyone else." "People are ignorant when it comes to mental illness. All they see is someone on the news that someone felt threatened and took an assault rifle and started shooting people. Because he didn't take his medication, that's what they see."** *Dx associated with the medical approach. Medical approach / medication is viewed as the correct method of treatment. Without medication, person is viewed as dangerous by others. Ignorance about mental illness - understanding / knowledge of mental illness comes from the news. which often portrays violence.*
Loganathan & Murthy (2011)	
Rose et al. (2011)	Others didn't understand person's behaviour. Assumed and expected violence. Misunderstood the cause of their illness e.g. attributing it to laziness / political beliefs. **"It does show you just how even the informed middle classes, even you (interviewer), know about mental illness. Everybody knows very little about it. Because most of the publicity is negative, about violence and so on. There's no information for people, is there? And also they don't like talking about it."** *Lack of information for others about the illness. People actively avoid learning / talking about it - treat it like something taboo. Even people who think they know about it e.g. interviewer, doesn't really understand it - perhaps true understanding can only come from experience?* **"It does show you just how even the informed middle classes, even you (interviewer), know about mental illness. Everybody knows very little about it. Because most of the publicity is negative, about violence and so on. There's no information for people, is there? And also**

	they don't like talking about it." *Negative portrayal of people with psychosis as violent, maintains negative stereotype of danger / aggression associated with the dx.*
Howe, Tickle & Brown (2014)	Avoiding the term schizophrenia leads to lack of understanding. Lack of knowledge perceived from both family and professionals. **"I feel doctors sit back and they don't know . . . they might give you a diagnosis of schizophrenia . . . they think it's some kind of chemical imbalance in the brain . . . but they can't explain it."** *Focus on the biological approach - participant feels that even professionals don't really understand the dx they're giving out. [Avoiding the label can be perceived as a lack of understanding, leading to hermeneutical injustice.]* Stigma is reinforced by media. **"It's really bad information . . . because everything you watch on television, if there's [a murder] and that the person has always suffered from [schizophrenia] for a number of years, they always seem to say that."** *Maintenance of negative stereotypes of schizophrenia i.e. violence / danger. Schizophrenia is brought up almost as the cause of the murder, in this case.*
Pyle & Morrison (2014)	Concerns of being stereotyped by others because of dx e.g. someone to be feared / unpredictable. **"If you mention that you have had psychosis then they think you are some kind of axe murderer or serial killer or something like that rather than being ... kind of someone that has run into difficulties in their life, that they have a stress based illness so to speak.."** Also a source of amusement for others with a lack of understanding. **"You see people who will say ... walk about quite like normal people will walk around with T-Shirts that have "I hear voices and they don't like you" and it's like ... oh my god it is not funny."** *Discrepancies in understanding. Participant adopts a stress-based approach to the illness. Others maintain negative stereotypes of people with psychosis as dangerous / violent. There is a lack of understanding portrayed by others through jokes they make - no understanding of the effect on someone who experiences auditory hallucinations and the effect this can have on them.* Media is a primary source of education about psychosis for public and it portrays negative stereotypes, especially violence. **"A lot of people are not educated about schizophrenia, so they read in the paper "schizophrenic has killed somebody" and in their mind they are thinking schizophrenia is really bad."** *Portrays people with psychosis as violent. Public education about psychosis comes from the media - they're only learning about the negative things people have done and are associating it with the label as a whole.* Absence of positive images in the media. **"You read in the papers all the time "oh this guy just got out of hospital and he went and killed 3 people" or whatever, you know what I mean? You read about it all of the time. I mean you don't see people … a story in the paper saying, "Peter had a mental health problem for 12 months and he is all better now and he is living happily ever after and met someone and is doing a lot more with his son and doing great", you don't see that in the Sun or the News of the World, it's all grim and bad news**

	and it's all the bad side of mental health." *No representation of the good side of mental health. The media doesn't show the "normality" of people with psychosis. Treats them as different - also a form of inequality.*
Mora-Rios, Ortega-Ortega & Natera (2015)	Media was a major source of social exclusion through the reinforcement of negative stereotypes. No supporting quote provided.
Paul (2016)	
Wood et al. (2018)	Lack of understanding about cause and maintenance of dx - contributes to the ongoing stigma. **"I remember in the community that people don't understand their illness. They don't understand so they will think that they are a highly, highly dangerous person"** People w/dx may not understand it fully themselves. Staff don't understand either. **"Yes, they [ward staff] said it's all in your head. In no terms like that, it's all in your head."** *Discrepancies in understanding - participants view this as a lack of understanding by others, including self. Professionals adopt a bio approach i.e. it's all in your head - doesn't help participants feel like staff understand what they are experiencing. Others have a negative understanding of what the dx is e.g. having psychosis makes you dangerous.* Media are the main perpetrators of negative stereotypes of schizophrenia as dangerous and unpredictable. Seen as crazy / abnormal / failure. **"People just have that one view that schizophrenics are highly dangerous and murderers!"** *Quote provided doesn't necessarily support the author's interpretation i.e. no mention of media. Although the "one view" may be in reference to this.* Experienced stereotyping by family and friends - maintained by portrayal in media. **"I've had friends that have seen me in that way, I'm a schizophrenia, schizophrenic so must be a murderer. A friend did see me in that way." "Most people just follow what's in the media and is only a few people in the minority who can see where you're coming from and see your story."** *People's understanding of schizophrenia comes from the media - constant portrayal of negative stereotypes means people, including friends and family, will view schizophrenia in a negative way. Perception of person can change after dx of schizophrenia.*

Yen, Huang & Chien (2020)	Experienced no support from family, instead experienced misunderstanding and discrimination. **"My family views me as trash. They call me trash… They complain that I cannot work to earn a living even though I am physically healthy."** *Lack of understanding demonstrated in the quote - family doesn't understand why the participant can't work even though they are physically healthy. Don't understand that a mental illness is / can be as difficult as a physical illness.* Media reinforces negative stereotype of schizophrenia as terrifying - increases self-stigma. **"The newspapers, magazines, etc. tend to stigmatize mental illness and schizophrenia. I hear of patients with schizophrenia committing homicide… I read a news article yesterday that said that a patient with schizophrenia was harassing neighbors. The neighbors could only sleep three hours per day. There was also news about a patient with mental illness harassing neighbors by crying out, ringing doorbells, and banging on doors. The media tends to describe us as destroyers, troublemakers, murderers, or people who do strange and crazy things."** *Negative representation of people with schizophrenia in the media as dangerous / aggressive / violent. Absence of positive representation. Treats them as different to everyone else.*
Vyas, Wood, & McPherson (2021)	Participants noted that psychosis experiences were associated with harmful stereotypes. For example, they described a concept within South-Asian communities where a person could "catch" or be infected by psychosis if they were near them. Participants felt that South-Asian communities consequently distanced themselves from those seen negatively and "othered" within the community to avoid contagion. **"I remember when I was out of hospital I wasn't really in the right state of mind, the way I was acting and stuff like that, they wanted to keep their distance and stuff. I remember trying to sit next to my relatives and they literally got up and moved a couple of spaces away from me. That was bad, I got quite numb after." "Not everyone in the community are open-minded towards mental health problems . . . some people just say you're going 'coo-coo' and think they'll get it off you." "They think that people who hear voices or see things are automatically going to attack them . . . . "** *Cultural beliefs and myths surrounding what psychosis is – incorrect view of it being infectious. Avoiding people with psychosis for fear of catching something.*

Appendix 4

Ethical approval by the Surrey Research Ethics Committee

NHS
Health Research Authority

London - Surrey Research Ethics Committee
Nottingham Centre
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

09 March 2021

Dr Andrew Fox - Academic Supervisor
University of Birmingham
52 Pritchatts Road
Edgbaston
Birmingham
B15 2TT

Dear Dr Fox

Study title:	**Exploring frameworks of understanding and meaning-making processes in experiences of psychosis: a qualitative cross-sectional study**
REC reference:	**20/PR/0616**
Protocol number:	**ERN_20-1008**
IRAS project ID:	**286804**

Thank you for your letter of 24 February 2021, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair (Chrissie Lawson) and Lead Reviewer (Hayley-Jo Grafton.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above

research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Further guidance on registration is available at:
https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:
https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at:
https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at
https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Social Media Advert - Non-Clinical]	1.0	22 October 2020
Copies of materials calling attention of potential participants to the research [Posters - Non-clinical]	2.0	24 February 2021
Covering letter on headed paper [Cover Letter]		02 July 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of insurance]		17 September 2020
GP/consultant information sheets or letters [Letter to Care Co-ordinator]	1.0	04 August 2020
Interview schedules or topic guides for participants [Interview Schedule]	4.0	20 July 2020
Interview schedules or topic guides for participants [Interview Schedule - Non-Clinical]	1.0	20 July 2020
IRAS Application Form [IRAS_Form_09102020]		09 October 2020
Letter from sponsor [Letter from sponsor]		17 September 2020
Other [REC Letter - Unfavourable Opinion]		29 June 2020
Other [Delegation Log]	1.0	28 July 2020
Other [Risk Protocol]	1.0	14 July 2020
Other [Screening - Non-Clinical]	1.0	02 July 2020
Other [Support Services]	2.0	04 February 2020
Other [Demographic Details]	3.0	02 July 2020
Other [Demographic Details - Non-Clinical]	1.0	20 July 2020
Other [Further evidence of insurance]		01 August 2020
Other [PANSS]	1.0	21 October 2020
Other [Ethical Review]	1.0	24 February 2021
Other [Evidence of Safeguarding Adults Training]		07 December 2020
Participant consent form [Consent Form]	5.0	24 February 2021
Participant consent form [Consent Form - Non-Clinical]	2.0	24 February 2021
Participant information sheet (PIS) [PIS]	6.0	24 February 2021
Participant information sheet (PIS) [PIS - Non-Clinical]	2.0	24 February 2021
Research protocol or project proposal [Protocol]	3.0	24 February 2021

Summary CV for Chief Investigator (CI) [CI CV]		10 February 2020
Summary CV for student [CV]		14 February 2020
Summary CV for supervisor (student research) [CV (Lisa)]		03 September 2020
Summary CV for supervisor (student research) [CV (Matthew)]		04 September 2020
Summary CV for supervisor (student research) [CV (Andy)]		21 October 2020

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:
https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 286804 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



Mrs Chrissie Lawson
Chair

Email: surrey.rec@hra.nhs.uk

Enclosures: After ethical review – guidance for researchers

Copy to: Dr Birgit Whitman

Lead Nation: approvals@hra.nhs.uk

Appendix 5
Ethical approval by the Health Research Authority

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

N/ADr. Andrew Fox
Academic Supervisor
University of Birmingham
52 Pritchatts Road
Edgbaston
Birmingham
B15 2TTN/A

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

01 April 2021

Dear N/ADr. FoxN/A

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Exploring frameworks of understanding and meaning-making processes in experiences of psychosis: a qualitative cross-sectional study**
IRAS project ID:	**286804**
Protocol number:	**ERN_20-1008**
REC reference:	**20/PR/0616**
Sponsor	**University of Birmingham**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report

(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **286804**. Please quote this on all correspondence.

Yours sincerely,
Natasha Bridgeman

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Dr Birgit Whitman*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed belo

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Social Media Advert - Non-Clinical]	1.0	22 October 2020
Copies of materials calling attention of potential participants to the research [Posters - Non-clinical]	2.0	24 February 2021
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Other [PIC Agreement - FTB]	1.0	27 July 2020
Other [PIC Agreement - BSMHFT]	1.0	27 July 2020
Other [Further evidence of insurance]		01 August 2020
Other [PANSS]	1.0	21 October 2020
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Summary CV for supervisor (student research) [CV (Matthew)]		04 September 2020
Summary CV for supervisor (student research) [CV (Andy)]		21 October 2020

IRAS project ID	286804

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
NHS involvement is limited to undertaking PIC activity.	PIC activities should not commence until a PIC Agreement is in place. HRA and HCRW recommend use of the standard Participating NHS Organisation to PIC agreement available here.	HRA and HCRW recommend use of the standard Participating NHS Organisation to PIC agreement, available here .	No external study funding has been sought.	The Chief Investigator is responsible for all study activities including PIC activity	No Honorary Research Contracts, Letters of Access or pre-engagement checks are expected for local staff employed by the participating NHS organisations. Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix 6

Recruitment Poster for the Non-Clinical Group



Appendix 7

Social Media Advert for the Non-Clinical Group

Social Media Advert for Non-Clinical Group

Have you had an unusual experience before?

If you are over the age of 18 and have not had a diagnosis of a psychiatric or neurological condition, then we want to hear from you!

To check your eligibility and take part in research where we explore these experiences with you in an interview, then please contact [redacted] for more information.

Appendix 8

Participant Information Sheet for the Non-Clinical Group

EXPLORING FRAMEWORKS OF UNDERSTANDING IN CLINICAL AND NON-CLINICAL POPULATIONS

PARTICIPANT INFORMATION SHEET – NON-CLINICAL

We would like to invite you to take part in this study on exploring frameworks of understanding in clinical and non-clinical populations. Please read this information sheet carefully before you decide whether you would like to take part in the study. This information sheet contains information about why the study is being conducted and what your participation would involve. This study has been reviewed by the Surrey NHS Research Ethics Committee. If you have any questions or require any further information please do not hesitate to contact the researcher, Aneela Khan, at [redacted]

AIM AND PURPOSE OF THE STUDY

The study aims to develop a better understanding of the experiences of people who have unusual experiences without a psychiatric diagnosis. During the interview, we will ask you about how you understand and make sense of these experiences, particularly the similarities and differences between your way of understanding what you have been experiencing and other's ways of understanding what you are experiencing. The study will help the research team to understand the different types of experiences people without a psychiatric diagnosis have, and how others in their lives respond to these experiences. Once the data has been collected, it will be written up as part of a PhD in Psychology. The research will also be submitted for publication in academic journals.

WHAT WILL THE STUDY INVOLVE?

After reading through the Participant Information Sheet, you will have the opportunity to ask any questions about the study and have these answered to your satisfaction. If you decide you would like to take part in the study, you will be invited to take part in an interview at a time convenient to you. The interview will take place face-to-face at the University of Birmingham or online via Microsoft Teams. If the interview takes place in person, you will be reimbursed for any travel costs incurred as a result of participation.

At this meeting, you will first be asked to sign two copies of the consent form. One copy will stay with you and one copy will stay with the researcher. If the interview is being conducted remotely, the researcher will email you the consent form to fill out and sign. You will then email

the completed consent form back to the researcher as evidence of consent, also keeping a copy for yourself. The interview will then take place. The researcher will have a list of possible questions to ask you, however, these are only a guide. If there are any questions you do not wish to answer, then you do not have to answer them. You can stop the interview at any point without providing a reason. This will be audio-recorded.

The entire interview will take between one to two hours, but there is no minimum time required of you. Once the interview has finished, it will be typed up and anonymised with no identifying information to ensure what you say cannot be traced back to you. Anonymous quotes from the interview will be included in write-ups from the research.

ARE THERE ANY RISKS THAT PARTICIPANTS MIGHT FACE?

You may find it upsetting to recount past experiences of any difficulties you may have faced. If this happens, please let the researcher know, during or after the study. You will be able to take breaks during the interview at any point or reschedule for another time without providing a reason. The researcher will provide you with a list of appropriate support services that you can access following the study, if you wish to.

CONSENT: DO I NEED TO TAKE PART?

No, you do not need to take part in this study. It is your choice whether you would like to take part or not. If you choose to take part, you will be asked to sign a consent form, which will be given to you at the time of interview. If the interview is online, the researcher will send you the consent form to sign and return via email.

CONFIDENTIALITY

We will need to use information from you for this research project. This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly.

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you after 2 weeks following the interview.

All data collected during the study will be anonymised and stored securely so that only the research team and approved others at the University of Birmingham will have access to the

data. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. If at any point we are concerned about your safety or the safety of others because of something you have discussed with us, we may need to discuss this with others (e.g. your GP) to try to ensure the safety of you and others. However, the researcher would always attempt to talk to you first before doing this.

WHERE WILL THE DATA BE STORED?

All data collected during the study will be kept in locked or password-protected storage at the University of Birmingham that only the research team will have access to. All personal and identifying information (e.g. your name, contact details) will be stored separately from the audio recordings and transcripts so that you cannot be identified. No identifiable data will be shared with other organisations (unless we are worried about safety of you or others, see above) or published in any reports. All data will be handled in accordance with the Data Protection Act 2018. Audio-recordings of the interview will be destroyed as soon as transcription has taken place. Once the research is complete, all personal contact information (e.g. email address / contact number) will be destroyed.

WITHDRAWAL: WHAT IF I WANT TO LEAVE THE STUDY?

You can stop being part of the study at any time, without giving a reason. If at any point during the interview you have any concerns about what you have said, the researcher can remove those sections during transcription. You can also withdraw certain statements or sections from the interview by contacting the researcher after the interview has taken place. You will have up to two weeks from the date of your interview to indicate your withdrawal from the study. After this date, your personal details will no longer be linked to the data collected as part of the study. Therefore, we will no longer be able to trace the transcript of the interview back to you and withdraw you from the study.

WHO IS INVOLVED IN ORGANISING THIS RESEARCH?

This research study is organised and conducted by Aneela Khan, as part of her University of Birmingham PhD in Psychology programme. This research is supervised by Dr Andrew Fox ([redacted]), Professor Lisa Bortolotti ([redacted]), and Professor Matthew Broome ([redacted]).

WHAT IF THERE IS A PROBLEM?

The University has in force a Public Liability Policy and/or Clinical Trials policy which provides cover for claims for "negligent harm" and the activities here are included within that coverage. If you would like to complain about any aspect of the study, please contact Aneela Khan's supervisors: Dr Andrew Fox ([redacted]uk), Professor Lisa Bortolotti ([redacted]), or Professor Matthew Broome ([redacted]). Additionally, if you wish to make a formal complaint to someone not involved in the research please contact the Head of School, School of Psychology, University of Birmingham, B15 2TT, or by email at hos.psychology@contacts.bham.ac.uk.

THANK YOU

Appendix 9

Screening Questionnaire for the Non-Clinical Group

EXPLORING FRAMEWORKS OF UNDERSTANDING IN CLINICAL AND NON-CLINICAL POPULATIONS

Screening Questions for Non-Clinical Group

(Delete as appropriate)

1. Have you ever received a diagnosis of a psychiatric condition? Yes/No

2. Have you had at least one unusual experience in the last 5 years? Yes/No

3. Did your unusual experience occur whilst you were under the influence of alcohol, medication, or drugs? Yes/No

4. Did your unusual experience occur whilst you were waking up or falling asleep? Yes/No

5. Did your unusual experience occur whilst you were conscious? Yes/No

Appendix 10

Consent Form for the Non-Clinical Group

EXPLORING FRAMEWORKS OF UNDERSTANDING IN CLINICAL AND NON-CLINICAL POPULATIONS

CONSENT FORM – NON-CLINICAL

Participants will keep one copy of the completed consent form and the participant information sheet. The researcher will keep one copy of the completed consent form in their site file.

Please put your initials in each box if you consent to the statement next to it.

1. I confirm that I have read and understood the participant information sheet titled 'exploring frameworks of understanding in clinical and non-clinical populations.' I confirm that I have had the opportunity to consider the information and ask questions that have been answered to my satisfaction. ☐

2. I agree to my interview being audio-recorded and I understand that this recording will be backed up on a password-protected secure university drive that only the research team will have access to. ☐

3. I understand that my participation is completely voluntary and that I am free to withdraw part of or all of my data up until two weeks after the date of my interview without providing a reason and without being penalised in any way. ☐

4. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham to ensure that the analysis is a fair representation of the data. Parts of the data may also be made available to people outside of the research team (e.g. my GP) but only if there are concerns about myself or others coming to harm. Only the Chief Investigator and Postgraduate Researcher will have access to my consent form and demographic details. ☐

5. I understand that direct quotes from my interview may be published in any write-up of the data, and used for training purposes, but that my name will not be attributed to any such quotes. ☐

6. I agree to take part in the research study. ☐

Print Name:

Participant signature: Date:

Researcher Name:

Researcher Signature: Date:

Appendix 11

Demographic Details Form for the Non-Clinical Group

EXPLORING FRAMEWORKS OF UNDERSTANDING IN CLINICAL AND NON-CLINICAL POPULATIONS

DEMOGRAPHIC DETAILS – NON-CLINICAL

Unique Identifier:

Age:

Gender:

Ethnicity:

Occupation:

Pseudonym:

Appendix 12

Interview Schedule for the Non-Clinical Group

EXPLORING FRAMEWORKS OF UNDERSTANDING IN CLINICAL AND NON-CLINICAL POPULATIONS

INTERVIEW SCHEDULE – NON-CLINICAL

At the start of the interview, thank the participant for agreeing to take part and ask if they are still happy to go ahead with being audio-recorded. Make sure they have a physical copy of the Participant Information Sheet and have signed the consent forms. Remind them that it is completely fine if they would like to take a break at any point or stop the interview and they don't have to provide a reason for either. Inform the participant that if they are asked a question that they do not wish to answer, they should let me know and we will move on to the next question.

- **Is there anything you would like to ask or discuss before we begin?**

INTERVIEW

- **Could you tell me about the unusual experience/s you have had?**
  - Possible prompts: What happened? When did it happen? What was going on at the time? How did that feel? What thoughts were you having? Did you ever feel like you needed to talk to someone about it e.g. GP? [Elicit description of the experience]

- **How did you understand or make sense of what you were experiencing?**
  - Possible prompts: What did you think was happening? Why do you think that was happening? How did it feel when it happened? How do you feel about it now talking about it?

- **Have you ever spoken to other people that have had unusual experiences?**
  - Possible prompts: What was their experience? Did you ever talk to them about your experience? What was their response to your interpretation / way of understanding? How did that feel? How do you feel about it now talking about it? Were their experiences different to yours? How did they make sense of their experiences? What do you think about their interpretations of their experience?

- **Have you ever spoken to family/friends/acquaintances about your experience?**
  - Possible prompts: Why / why not? What was their response to your experience? What was their response to your interpretation / way of understanding? How did

they explain it? Were their explanations of it similar to yours? What was that like? How did you feel? What did you do? How do you feel about it now talking about it?

- **Has your understanding of your experience changed in any way since hearing other's interpretations?**
  - Possible prompts: What do you think happened now? How do you feel about it now? *If there are changes,* why do you think your understanding of your experience has changed?

- **How would you describe your relationship with the people you told about the experience? How do you get on with them?**
  - Possible prompts: Do you feel they listen to you? Could you give me an example? What kind of things do you do and talk about? Could you give me an example? How is that?

- **Have you noticed any changes in the way people talk with you since your experience?**
  - Possible prompts: Ask about people who were told about the experience. Could you give me an example? Do you think their perception of you changed? How did you feel? What did you do? *Note to think about belief* – do people believe them? What was it that made you feel you were not believed [words/phrases used – body language e.g. lack of eye contact, eye rolling, doubtful look, lack of interest]? How do you feel other respond to contributions you make to conversations?

- **When you interact with the people we've discussed today, how do you feel?**
  - Possible prompts: What do they do that is helpful / unhelpful? Has it affected you? In what way? What affected you? Could you give me an example of the effect it had? What was that like? How did you feel? What did you do? How do you feel about it now talking about it?

Appendix 13

Risk Protocol

RISK PROTOCOL

Confidentiality limits must be stated at the beginning of all interviews to ensure any disclosures of risk will allow the researcher to pass this information on to the appropriate body.

ALL participants should be provided with a list of support services at the end of the interview, regardless of whether they are at risk to self, at risk to others, or at risk from others. This includes participants that have not made any disclosures of risk.

If a participant makes any disclosures concerning risk to self, risk to others, or risk from others, the following procedure will be followed.

The researcher must inform the Chief Investigator of any participants who make disclosures of risk to self, risk to others, or risk from others.

If the researcher is concerned about risk, then stop the audio recording.

RISK TO SELF

Ask if any ideas of risk to self are passing thoughts/feelings or if they have a more concrete plan.

Note: Do not use dismissive terminology i.e. ask, "is it a passing thought or feeling?" NOT "is it *just* a passing thought or feeling?"

The researcher must make note of what the specific thought(s) are. This should ideally be via writing down specific quotations directly from the participant rather than paraphrasing. Let participant know what you are making notes of.

If it is a passing thought/feeling: The researcher must check if there have ever been times it has become more than a passing thought/feeling.

If NO: Continue with the interview if the participant is happy to do so.

Note: Even passing thoughts/feelings of causing risk to self should be passed on to the participant's care team. This can be done after the interview.

If YES: Continue below.

If it is ever more than a passing thought/feeling or if they have a plan:

- **Ask for details of their plan.**
  - Do they know how they would cause risk to self?
  - Do they have a plan to carry this out at some point?
  - Do they have the means to go through with their plan?
  - Have they decided when they will carry out their plan?

- **Ask about protective factors.**
  - Is there anything preventing them from carrying out their plan?

- What is keeping them safe at present?

Note: Reaffirm participant's protective factors and highlight/be encouraging about these factors with them.

- **Ask if they are in touch with clinical services (if unknown).**
  - **IF YES:** Ask if their care team are aware that they have been having these feelings. The researcher must reiterate that they have a duty of care to ensure that they are safe and discuss what the participant has told them with their care team.
  - **IF THE RESEARCHER DOES NOT HAVE THE DETAILS OF THEIR CLINICAL SERVICES:** Ask if the participant will provide the researcher with these details.
  - **IF THE PARTICIPANT IS NOT IN CONTACT WITH CLINICAL SERVICES:**

Ask if they will provide us with their doctor's details. The participant should be encouraged to speak to their doctor about how they have been feeling. The researcher should inform the participant that they will contact their doctor to let them know how the participant has been feeling.

If the participant states that they refuse to speak to their doctor or pass on their details to the researcher, they should be encouraged to speak to their doctor if they feel able and to speak to one of the support services listed.

IF THE PARTICIPANT IS IMMINENTLY SUICIDAL (i.e. the researcher has strong reason to think that the participant is in danger of causing risk to self if immediate support is not received):

Alert the Chief Investigator and then contact the participant's care team whilst the participant is still at the interview site to take advice on the best course of action. If the care team cannot be contacted, call the emergency services on 999 and stay with them until they are under the care of clinical staff. If the researcher feels the level of risk to the participant is significant but not enough for A&E, and if the participant's care team cannot be contacted, call the FTB crisis team on: 0300 300 0099 or the BSMHFT crisis team on: 0121 262 3555.

If interviews are conducted remotely, ask the participant if there is someone currently with them and encourage them to go to A&E. If the participant is unable to get to A&E themselves, ask them for their address and let them know you will contact the emergency services. Contact both the Chief Investigator and the participant's care team to alert them to the situation. If the researcher feels the level of risk to the participant is significant but not enough for A&E, and if the participant's care team cannot be contacted, encourage them to call the FTB crisis team on: 0300 300 0099 or the BSMHFT crisis team on: 0121 262 3555.

IF THE PARTICIPANT IS NOT IMMINENTLY SUICIDAL BUT THEY DO HAVE A PLAN:

If known or if details have been provided, the researcher should attempt to contact their care team before the participant leaves. If the researcher is unable to get in touch with their care team during this time, further attempts at contact should be made once the participant leaves. For participants without a clinical service, the researcher should make them aware that their doctor will be contacted and updated about their presenting risk. Participants without a care team/doctor's details should be provided with details of FTB and BSMHFT services and encouraged to use these. Ask the participant if they are happy to continue the interview.

RISK TO OR FROM OTHERS

In either case of risk to others or risk from others:

- Contact both the Chief Investigator and the participant's care team / doctor (if known) to update them on the disclosure.

In the instance of risk to others:

- Obtain as much information as possible.
- The researcher must inform the participant that they have a duty to pass this information on to the appropriate service i.e. care team / doctor / police.
- If the risk concerns children, the researcher must contact the designated Senior Child Protection Officer (SCPO) at the University of Birmingham i.e. the Director of Legal Services, Carolyn Pike, on: 0121 414 3916, or her secretary via email: legalservices@contacts.bham.ac.uk.
- If the risk concerns domestic abuse, the researcher must report this to the police via the non-emergency line i.e. 101.

In the instance of risk from others:

- Establish what kind of danger the participant is in.
- Obtain information about the history of the danger, including any injuries obtained.
- Establish whether the participant is in current contact with the individual causing risk and to what extent i.e. is the participant living with the individual?
- Establish if the individual causing risk has access to vulnerable people e.g. working with children.
- Call either 101 or 999 for emergency services, depending on the current level of risk.

Appendix 14
Support Services Document

SUPPORT SERVICES

High quality recovery based services to adults in the Midlands.
17 Graham Street, Hockley, Birmingham B32 2BA
Phone: 0121 6088001
email: [redacted]
web: birminghammind.org

Confidential support for people experiencing feelings of distress or despair.
Phone: 116 123 (24-hour helpline)
Website: www.samaritans.org.uk

Emotional support, information and guidance for people affected by mental illness.
Phone: 0300 304 7000
Text-care: comfort and care via text message, sent when the person needs it most: www.sane.org.uk/textcare
Peer support forum: www.sane.org.uk/supportforum
Website: www.sane.org.uk/support

City centre drop-in service for mental health based in Digbeth (21, Birmingham B5 6BJ).
Phone: 0300 300 0099
Website: https://www.forwardthinkingbirmingham.org.uk/services/13-pause

Appendix 15

Vignettes for Participants in the Non-Clinical Group

Madeline

Madeline has had multiple unusual experiences across her lifetime, typically rationalising them as events that occur during periods of vulnerability, stress, lack of sleep, and poor mental health in general. These are all deemed as normal and mundane, except for one that occurred in the absence of her usual background context, therefore making it unusual and bizarre. Madeline's overarching explanation is a preternatural one: the idea that unusual things happen that do have a, as yet unknown, logical and rational reason. Despite her own reasoning, she maintains and accepts that individuals have several explanatory models for one experience.

Madeline's friends and partner are her support network, whereby she feels comfortable enough to open up, trusting them to monitor the situation for potential progression. Reality testing often occurs with her support network, where she is able to determine what is and is not real. Perceived negative responses and lack of support in other areas of her life lead to concealment of the unusual experiences. She has concerns about burdening family with her experiences, partly due to the negative context of the experience which she would also have to reveal, and also in part due to worries they have over other family members with diagnosed mental and physical illnesses. Although she believes a hierarchy exists for how bad an experience is (i.e. cancer at the top), she does not believe her experience to fall within this hierarchy, deeming it a neutral experience that can be rationalised.

Rayna

Rayna has had one unusual experience that she initially rationalised as sleep paralysis as it occurred whilst she was in bed. However, her interactions with others who had experienced sleep paralysis led to her ruling this out as a possible reason for the event due to the fact that it is likely to occur whilst falling asleep or waking up, maintaining that she was doing neither. This then led to religious interpretations of the event, with beliefs around the supernatural being taught from childhood. Environmental factors also contributed to the religious rationalisation, as she lived opposite a park and nature was synonymous with the home of Jinns according to her religion of Islam. Despite her belief in the supernatural, Rayna felt that this belief was not solely influenced by her religion, but that due to her open-minded personality, she would naturally be more inclined to question the existence of non-human beings.

She had concerns over sharing her experience with her older sister due to an expectation of her dismissing it on the basis of her being the younger sibling and possibly exaggerating the event. However, with others in the family, such as her aunts, Rayna felt she had been deemed special in a way for having gone through a supernatural experience that was taught to them as part of their religion growing up. Although she mentions she had not disclosed the experience to others, she felt that non-Muslims would interpret her experience as sleep paralysis due to her being in bed at the time it occurred, whilst other Muslims would interpret it similarly to her and perceive the cause as related to Jinns. In addition to this, Rayna felt that

unusual experiences would be difficult for others to understand unless they had personally experienced it, as they would have no frame of reference for the rationalisation process. There were fears over requesting professional support for the experience as she expected doctors would diagnose her with a disorder and provide medication as a treatment option.

Zeke

Zeke has had one unusual experience that has left him with long-lasting, negative impacts, both psychologically and behaviourally. Often throughout the interview, Zeke commented upon his lack of understanding as to why the unusual experience occurred, however, his use of language suggests he is inclined towards a supernatural understanding of the event. He experiences more intense fear than usual when engaging with supernatural-based media and avoids this as much as possible. Due to the proximity of the unusual experience, he no longer feels safe in his home, except for when he is in his bedroom. Specific situational contexts similar to the one when the unusual experience occurred have left Zeke with intense fear and frequent reflection when alone at night. He maintains that he does not know whether or not he believes in the supernatural, but avoids supernatural-related objects / media to be on the safe side.

Zeke avoids discussion of unusual experiences, whether that be his own or others, only disclosing to friends when he can pass it off light-heartedly as something to laugh at. He fears that serious discussion of the topic will induce negative emotions later when he is at home alone and validate his experience by grounding it in reality. His friends listen to and validate him, keeping in mind his comfort levels based upon what they already know about his "scared" personality. Zeke avoids disclosing to the family he lives with as they have different beliefs on the supernatural and may view him as "crazy" or lying about the experience. He also believes medical professionals would view him as "crazy" and would not accept any other understanding of his experience if it is not a medical one, leading to a lack of disclosing.

Sara

Sara had multiple unusual experiences, all of which occurred with other people present who were of the same religion as her and also shared similar interpretations for the experience. As a Muslim, she viewed these unusual occurrences as a result of Jinn activity, as was taught to her in her childhood. With some of the experiences taking place whilst on a holiday in a rural / semi-rural area, Sara linked the nature around her as a place where Jinns live and are therefore, more active. When another member of her family had an unusual experience, Sara attempted to rationalise this and suggested that her family member may have been dreaming or that the knocking that could be heard may be a result of loud neighbours. However, whilst rationalising this to her sister in law, she then encountered her own unusual experience whereby she felt a physical rush through her body, which her family and friends interpreted as a fearful reaction to what her sister in law had disclosed to her. Her own experience afforded credibility to her sister in law's experience, and Sara maintained that the cause of the event was supernatural in nature, despite what family stated.

Sara felt that those who shared the same religion as her would have similar interpretations to her, despite her family attempting to rationalise the unusual experience as having a non-

supernatural cause. In this particular instance, Sara believes that her family did not interpret the experience as Jinn related due to both her and her sister in law experiencing the event separately. Given that her family believed her previous unusual experiences to be Jinn related whilst she was on holiday with friends, this suggests that for her family, credibility is afforded to an experience if others are also there to experience it. Sara's friends, who also share her faith, disclosed their own experiences to her, interpreting the event as related to Jinns. She also believed that those who did not share her faith would instead make sense of her experience as her being deluded. In disclosing her unusual experiences to her atheist coworkers, Sara noted how she felt they perceived her as crazy and did not believe her testimony, leading her to feel uncomfortable with sharing anything similar with them again.

Yusuf

Yusuf and his family have faced several unusual experiences over the 6 years, both interpreting the experience as related to Jinns due to their belief in the religion of Islam. Although Yusuf makes sense of the 'what is happening?' in terms of Jinns, he also offers insight into the 'why is this happening?,' in relation to his usual experience. During the times over the years that the experiences occur, Yusuf views this as a positive check-in from God, for him to determine where he might be going off track in his life, for example, not praying enough or not praying correctly. He believes that these unusual experiences, along with his job of supporting others through charity in war-torn countries, keep him in line and that hardship helps him avoid doing other bad things in life.

Yusuf notes that he would only disclose these unusual experiences to others who share the same faith as they would be more likely to understand and interpret the event the way he does. In disclosing the experience with his Muslim employer, he states that he was met with understanding and afforded time off work to recover from the experience. He also notes that from people of the same religion, he would only disclose to those who he felt he was close to and who knew him as a person. Yusuf felt that he would be less inclined to share his experiences with people who were not of a similar faith to him, especially not to mental health professionals, as they would most likely diagnose him with schizophrenia or try to section him.

Chloe

Unusual experiences were common for Chloe, and she tended to view these as a positive source of guidance and comfort, after being unable to rationalise the event as a natural occurrence initially. This then led to spirituality and a spirit world as a way for her to make sense of the experiences. She felt comforted by the occurrences and felt that something was looking out for her, particularly when she uncovered that her partner had been cheating on her around the same time that he went through an unusual experience in her home that he perceived as negative, both emotionally and within his culture. However, Chloe also notes that despite her belief in the spiritual world, not all events are due to this and that some experiences have a non-spiritual basis, for example, pipes making noises in the house.

Chloe acknowledges that there are several ways that two people may perceive the same event, and that whilst others may view her experience as having a rational explanation, her

own experiences led to the conclusion of the cause being spiritual in nature. In terms of her family, Chloe's mum believed in her interpretation after having her own unusual experience in Chloe's home, whilst she believes her son and father would rationalise the events as non-spiritual and as being coincidental. In terms of people who don't share her interpretation, Chloe feels she would be unlikely to disclose her experiences due to fear of being perceived as mentally ill. She discusses what she believes is the current stance of society towards those diagnosed with a psychotic disorder, and states that they are viewed as a label first rather than a person. She also believes that presentation of other behaviours as identified via assessments, for example, preoccupation, may be the difference between those with unusual experiences and those with a diagnosis.

Appendix 16

Complete Example of Personal Experiential Themes and Subthemes for Madeline

1. PRIORITISING OTHERS OVER HERSELF AND HER EXPERIENCES
1.1 DOWNPLAYING THE EXPERIENCE AVOIDS BURDENING LOVED ONES
Concerned she would burden parents with her UE – p6, 214 – 218 *I would never talk to my parents about it 'cause I know they would really worry and they really worry about my sister so it's not a... unless I was going somewhere with the conversation or I was really worried about myself, I wouldn't want to worry them unnecessarily.*
Chooses to prioritise others over self and questions whether it's to her own detriment – p14, 519 – 523 *I'm sort of reflecting on now after this conversation of, 'how often do I put myself um first or others first? Do I put other people's wellbeing before my own? Um and when that could be potentially harmful and when should it, should I actually, if I need to um draw more attention to myself, if I feel that's necessary.'*
Downplays UE as an occasional event to avoid burdening others – p6, 198 - 200 *That's not something I would um want to burden him with and worry about, when I feel that it's not a... like an issue, it's just a, just kind of a fleeting thing.*
Downplays other areas of her life to protect other's feelings – p6, 205 – 208 *I do think I tend to underplay to the people in my life how much I work and how much random stuff I do. Um so, I think talking about those kind of things then people would worry*
Avoids conversations about UE to keep others comfortable – p3, 97 – 103 / p6, 187 - 190 *But then when I noticed that the way he reacted I was like, 'oh right, I know that I am seeing something that he is not seeing' so I kind of didn't dwell on it. Um he also gets spooked really easily [laughs], like he hates creepy things. Um so I was like, 'oh no, I don't want to draw this out.'* *I think 'cause it was a like at night and he, yeah, he can't handle like horror films or anything like that, so he - he gets creeped out so I can't really, 'cause I know I'll scare him.*

2. LEGITIMACY AND VALIDATION OF THE UNUSUAL EXPERIENCE CHANGES DEPENDING UPON FAMILY, FRIENDS, AND SOCIETY GENERALLY
2.1 THE UNUSUAL EXPERIENCE IS VALIDATED BY OTHERS ON THE BASIS OF BACKGROUND / IDENTITY
Opens up with friends who also share their UE's and validate each other's interpretation – p5, 177 - 183 *I don't think there's one explanation to different things. I think it can mean different things to different people, so yeah. When we have these conversations its quite like open and I'll be like, 'oh, this is the stuff I think,' and then, I think through my psychology background, people think, 'oh okay, that makes sense that you just think of it in terms of brains and um perceptions and things that happen around you.'*
Partner shares her understanding of her UE – p6, 203 - 205 *I think he'd see it more as like the result of stress and not necessarily clinical but more like oh, maybe me overworking myself and not sleeping enough um, I'm taking on too much*
Her and her UE is viewed as legitimate on the basis of an absence of previous mental health problems (not treated differently – example of testimonial injustice not occurring) – p8, 291 - 297 *I-I think people... with me can, even though I think I can be a jokey person, see me as quite like a serious um person with my work and stuff as well. So if they kind of, I don't think they wou-they would say it to me or treat me any differently. I think they would just kind of accept it and accept that it was sort of legitimate and because I've-I've not had any um issues um around then. I don't think it was brought up as like, 'oh, this is, that was sort of the start of maybe a mental breakdown.'*
2.2 THE UNUSUAL EXPERIENCE IS VIEWED AS LESS LEGITIMATE THAN UNIVERSALLY KNOWN ILLNESSES
Some are wary of those with UE's – p8, 259 - 262 *But then there might also be people who don't have it and it's so out of their comfort zone, they might feel quite uncomfortable and really unsure how to react or what it means and how to have a conversation about it*
Cancer is universally understood as a negative experience and treated as legitimate, unlike UE – p15, 553 - 556

Yeah, um, it's obviously really.. i-it's really harder 'cause I think with the way with cancer, at least there's so much, like if you say you have cancer, people take it seriously right away. Kind of universally understood for how horrendous it is and how hard it is
2.3 LACK OF VALIDATION FROM FAMILY GENERALLY LEADS TO UNUSUAL EXPERIENCES BEING DISMISSED AND INVALIDATED
Family are generally sceptical of her based on her identity / role within the family dynamics – p10, 358 - 361 *They always saw me as the kind of youngest one, and so in conversations, I feel as though sometimes when I bring up stuff, um it-it's almost as if they doubt me and I don't think they understand the work I do 'cause they're not in... research, so I think it confuses them and I think sometimes as well my parents um weren't as privileged as I've been growing up. Um they came kind of from working class backgrounds and had to fight really hard so I-I think there's also sometimes some insecurities there over the opportunities they've had versus the opportunities I've had and because of how they see me in the family dynamic*
She is not viewed seriously in her family or validated by them – p10, 366 - 368 *In conversations as well, I think they, they maybe don't take me as seriously as I want to be taken and as I feel I deserve to be.*
Lack of recognition for her achievements in her family – p11, 373 - 375 *I-I think they also, they don't get the kind of academic achievements, they don't get what it means if you publish a paper, if you're asked to write a book. They just go, "oh okay, is that paid?"*
Dad would rationalise UE via a frustrating response of her exaggerating – p9, 310 - 317 *Um I think my dad, he doesn't really talk about feelings or do things in that direction [laughs]. Um he's also... um particularly like, math-maths and physics. He would, and he always likes to like joke, which pisses me off, about that I exaggerate things. And I think he would be like, "oh you're exaggerating, you didn't see anything." I think he would be the one who would be like, "oh no, it was a rainy night, it was fine. There's nothing wrong with you."*
Dismissing / not believing UE contributes to the stigma surrounding conversations on mental health – p8, 280 - 286 *But I think also people sometimes have the explanation of, 'oh, you must have just mistaken it. You must have not seen somebody. You know, it's like dark at night, raining, it's not the best visibility kind of thing.' So, I think you also have some people who would go the other way of being like, 'oh, you saw nothing,' and like not believing you that what you experienced is what you experienced, which I think can also be a, a tricky [laughs] but interesting barrier to that sort of conversation.*
Concern of lack of belief from family leads to shutting down any potential discussion – p9, 319 - 326 *Or "there's not- and there's nothing- it didn't happen." I think he would be that direction. Which I think my brother would be as well, he's more like my dad [laughs]. Um yeah, it doesn't make me feel like I want to open up or have that conversation with them.*

3. THE OTHER PLAYS A SIGNIFICANT ROLE IN DETERMING THE UNDERSTANDING OF UNUSUAL EXPERIENCES AND THE IMPACT THIS HAS ON A PERSON
3.1 SOCIETY'S RESPONSE TO MENTAL HEALTH GENERALLY HAS AN IMPACT ON THE WAY UNUSUAL EXPERIENCES ARE VIEWED
Society plays a big role in determining feelings about the UE and the impact it has on you – p14, 516 - 518 *I think people's reactions are quite funny of how, how much that can determine how you feel, like can make you feel more isolated and lonely or more supported and grateful.*
Society can be a useful sounding board for identifying a "normal" UE and a clinical one – p13, 482 - 487 *Um.. I think people, if-if you're judgemental or make your own kind of conclusions, that's not very helpful because that might just be you're trying to explore what this means, I think you're, so talking about it can help because it sort of helps you reflect on, 'was this like a, a dangerous unusual um experience or like a, a normal unusual experience'*
Society has medicalised mental health / experiences, leading to avoidance and withdrawal – p8, 262 - 270 *We've made mental health... kind of, pathologisation of mental health, but we've really alienated ourself from health and from our minds and from our bodies, and um w-while I obviously agree with a lot of the clinical definitions and having medication, I don't think that's everything to it. So actually, sometimes people can feel so uncomfortable about talking about mental health um that it's sort of counterproductive as well, because you should be able to talk about different experiences of low and high moments of mental health.*

Unhelpful to hijack a conversation about UE to disclose own experience, even if well-intentioned – p14, 489 - 496

People mean really well by this, but I think sometimes when people then jump in with their own experiences, um which can be great to share, but then maybe have you finished talking about your own ones? Like sort of, if they right away, and I think that's where you-you li-realise the-when you do kind of training on mental health stuff and learning kind of support, the difference between um having a conversation versus actively listening of like, 'are you giving that person space to talk about what they want to talk about? Are you jumping in and making it about yourself?'

Use of medical terms for her UE e.g. paranoid / hallucinate (clinical approach embedded in society) – p3, 42 – 44 / 85 – 86

I have been drugged before um and I had really severe hallucinations um where other people wouldn't have any / Those wouldn't last as long, but then it does start to affect- because then you get paranoid.

3.2 FRIENDS ARE USEFUL FOR DETERMINING WHICH EXPERIENCES ARE REAL AND NOT REAL

Others are significant for determining reality – p2 - 3, 69 - 72

I think it's also really hard because you don't know, how do you know what's real or not real because it all seems real to you. So one of the few times is-is when it comes up in conversation and other people don't see it or hear it.

Reality testing – p1 - 2, 30 - 36

I think other times um…it's been quite similar things, if I had seen something or heard something actually. You don't realise, you don't necessarily know uh it's not real, but you know it's not real by people in your environment because they'll go, "oh, there's nothing there," or maybe just something like that, you're like 'oh that's a bit unusual, why would somebody do that?' And then you actually.. realise that's something that you're just pursuing and not necessarily others.

Social reality testing with partner – p1, 21 - 24

Um, but I remark, I s-I mentioned it to my partner being like, "what on earth is that person doing? Are they okay?" Um and he was just like, "what are you talking about? There is nobody there, I can't see anyone."

Acceptance of partner's response confirming UE – p3, 97 - 99

But then when I noticed that the way he reacted I was like, 'oh right, I know that I am seeing something that he is not seeing' so I kind of didn't dwell on it.

3.3 A SUPPORT NETWORK INVOLVES MONITORING THE POTENTIAL PROGRESSION OF EXPERIENCES AND SHARING EXPERIENCES WITH FRIENDS

Friends play a protective role in monitoring the situation for potential progression – p7, 229 - 234

So actually opening up about that and then, maybe also just that person realising, 'oh, this is happening in your life. This is something just to keep an eye on. Is this just a… a set experience or is this an actual regular thing that needs to be um worrying?' So I think it's almost kind of a bonding thing within friends.

Friends would recognise if she needed support – p13, 458 - 461

If I do ever need anything, I know if-if I were ever in a situation where I would be worrying about stuff, I know there's people around me who would pick up on it and be there for me and support me, which is.. nice to know, and I realise how privileged I am to have that.

A judgement-free zone is necessary for open communication – p13, 477 - 479

And yeah, just making, creating a sort of safe space that if the person does ever feel vulnerable or in a bad way, that they can speak to you again about it.

Friends are her support network – p17, 608 - 610

I think the-they're just lovely people and they're just very like, 'oh okay, that's interesting,' and then you begin talking about it and um there for you

More support from friends and partner than family – p13, 449 - 456

Um I think you realise… it's amazing with friends, like the people you make, who are supportive, like I think. I love my family, my parents are wonderful… um and as complicated as my sister is, I do still have love for her and my brothers are so wonderful. Um but they have their, their flaws, and I'm lucky to have friends who are such great people, who can kind of be there for me when maybe that's not in the character of my um family, and my partner who… he's super. I feel very lucky to have him in my life and to be such a strong support network as well.

The ability to find humour in the UE via shared experiences balances out strange feelings – p7, 234 - 244

And the friends in particular that I was thinking about were the ones who were really there for me when I was… um at my worst and had kind of bad, bad, going through some bad stuff, so they're people I feel really comfortable with being vulnerable and open and they're also.. I think also sometimes with the, talking about

it in the sense of like spirituality or spookiness, I think people, it-it can almost be a, done in quite like a humourful way. I think there's such a-like, a nice balance there of um sharing experiences but, you know, so… um joking about yourself if it's in an appropriate setting obviously. Not making fun of each other, but like bringing kind of humour to how bizarre it can be to be human and experience different things.

3.4 PERCEIVED NEGATIVE RESPONSE FROM FAMILY LEADS TO NOT DISCLOSING THE EXPERIENCE

Expected negative response leads to concealment of UE from family – p12, 428 - 435

I mean I don't-I don't see my experience that way, so I think that's why I so-w-, it's just, it was a very, yeah… um, non-descript unusual experience, but the consequences of sharing it would be [29:16 – 29:17 unintelligible], I think with my family. It would be like… I don't think it would be a productive conversation to have with my family [laughs].

Expects less support from family due to how mundane the UE is and the lack of impact it has – p12, 417 - 426

I think also, um… with my family moving around to different countries and jobs my parents have done, uh that they, they've seen extreme poverty and extreme violence in different setting. And my mum used to work in like hostage negotiation type stuff and um things surrounding terrorism and stuff like that so, I-I think when you've seen so much like violence and bad stuff it's then when you see more minor bad stuff, it's really, you have a different perspective, and you can be less sens-sensitive to actually, for other people

Different perceptions of UE: problem (family) vs potential problem (friends / partner / her) – p13, 466 - 470

Even things like I was saying with my mum, like she would do it in a very loving way, but she would um.. sort of jump to problem-solving and solutions, even though like in this situation it would be, 'oh, I-I know I'm not unwell, it was just an odd experience, but maybe something we keep an eye on.'

4. A HIERARCHY OF NEGATIVE EXPERIENCES EXISTS AND UNUSUAL EXPERIENCES ARE NOT SITUATED WITHIN THIS HIERARCHY

4.1 A HIERARCHY OF BAD EXPERIENCES EXIST, WITH UNIVERSALLY UNDERSTOOD PHYSICAL ILLNESSES E.G. CANCER RECEIVING THE MOST FOCUS, FOLLOWED BY DIAGNOSED MENTAL ILLNESSES

A hierarchy of bad experiences exist – p12, 421 - 424

I-I think when you've seen so much like violence and bad stuff it's then when you see more minor bad stuff, it's really…you have a different perspective.

The priority she places on others with illnesses makes it hard for her to disclose her UE – p15, 527 – 529

I think when you have a, um… an unwell family member and you're going through something, it's quite difficult to then say, 'oh, also I need sort of love and support.'

Within society, there's more focus and support for higher levels of bad i.e. cancer, than lower levels i.e. UE – p15, 538 - 545

When Chernobyl hit but, um their children have now had cancer, so like two-year olds having cancer and stuff like that, even though we didn't have a history of that before, but it's just that kind of group that lived in that village… um at the time, so I think they're um, I struggle a bit with them. They're very like righteous and annoying as a group, so now nothing can be as b-, obviously you feel really horrendous for them, um but they've been doing okay with chemo. Um but then, it can't, you can't talk about anything else because they've had such a h-awful time and that's kind of the focus.

Mental illness is permanent in comparison to physical illnesses that have treatments – p15, 553- 563

Yeah, um, it's obviously really.. i-it's really harder 'cause I think with the way with cancer, at least there's so much, like if you say you have cancer, people take it seriously right away. Kind of universally understood for how horrendous it is and how hard it is, um but least there's treatments in place. I mean, they're awful and so chemical, but at least there-there can be a-a cure or something that can happen, even though you might go back. While mental health, you're just also on really toxic medication, like my sister, um and there is no - that's you for life, there's no, there's no way you'll ever be over it, and so I think that i-it's quite hard, they're two different things. Like one might take your life immediately, while the other one maybe at some stage and you're kind of living with it.

Physical illnesses are less complex to understand than UE / mental illnesses – p16, 574 - 582

I don't think my experience is a negative experience, while I think obviously cancer and um severe mental illness is a negative experience, even though you might be able to draw out some… positive reflections and outcomes from it um… yeah I-I think it's more… maybe the stuff around it that can be complicated. Um… while I think yeah, something with cancer is quite clear cut, you have this growth, this tumour, that's what's hurting

you. Mental health, my sister, can be so many, can be experiences that she's had that I don't even know about that's confounded and made it difficult.
Regardless of hierarchy, the impact of a UE is unique and relative to each person – p12, 425 - 426 *For other people, even though their things on a magnitude of shitty um might not be as extreme, but it's still real and can still be hurtful.*
4.2 WITHIN THE HIERARCHY, MENTAL HEALTH EXISTS ON A CONTINUUM AND UNUSUAL EXPERIENCES MAY SHIFT BETWEEN BOTH ENDS
Mental health exists on a continuum – p8, 268 - 270 *You should be able to talk about different experiences of low and high moments of mental health.*
Live connection between experiences and diagnoses that can shift – p7, 228 - 229 *I-I'm kind of a firm believer that you can experience um maybe like symptoms of mental illness without actually necessarily having um it.*
4.3 THE UNUSUAL EXPERIENCE IS SITUATED WITHIN A NEGATIVE CONTEXT BUT IN ITSELF IS NEUTRAL, THEREFORE NOT EXISTING WITHIN THE HIERARCHY OF BAD EXPERIENCES
UE is neutral and not within the hierarchy of bad for her – p16, 563 - 566 *I think for me with the unusual experience, I don't see necessarily as a bad experience. I-I don't... I think in a, it's not, I think it's a neutral experience.*
The UE is a neutral experience situated within a negative context – p16, 574 - 578 *I don't think my experience is a negative experience, while I think obviously cancer and um severe mental illness is a negative experience, even though you might be able to draw out some... positive reflections and outcomes from it um... yeah I-I think it's more... maybe the stuff around it that can be complicated.*
UE is ordinary to her, but exists within a wider negative context that's difficult to share – p12, 437 - 445 *Yeah. I-I think also for me, even things like saying like, 'oh, I've had it with.. when I've been like drugged by people in clubs and stuff,' I-I don't think.. that's also a whole conversation about... experiencing being drugged in clubs and um those kind of like, violence and things like that, and I think those are conversations I've also not really had with my family and things that I know would hurt them as well and they wouldn't want to... hear about and it's sort of in the past and not something I feel necessary talking about. So, it's a kind of, you know, the incident itself is very unremarkable, but it's sort of confounded in a bigger complex net and situation of things.*
Difficulty disclosing UE due to the lack of impact it has on her – p15, 546 - 547 *So, I think any... if you brought up stuff that's not... at that level, i-i-it's kind of not worth bringing up.*
Experience is mundane in comparison to a severe, clinical experience that's disruptive – p2, 59 - 67 *But it-I think the funny thing is, I remember thinking, obviously with doing some stuff in psychology, you think about that and you're like, 'oh right, is this like a clinical um worrying thing,' but it's so anti-climactic that I know will sometimes be-I just see like you're on a street and I see a person there but they're not doing anything, they're just like another person so it's not anything. It's not a very exciting...'something' that is happening, it doesn't really disrupt um any bit of my d-day*
Reluctant to think too much about UE to keep it mundane and ordinary – p5, 172 - 174 *I've never really, I don't think I've ever really dwelled on it because I don't want that to be a sort of a-a big, a big thing*

5. UNUSUAL EXPERIENCES AND THEIR MEANINGS ARE DEPENDANT UPON THE INDIVIDUAL, BUT THE COMMONALITY OF EXPERIENCES ALLOW FOR CONNECTION WITH OTHERS
5.1 CERTAIN PERSONALITY TYPES E.G. CREATIVES, ARE PREDISPOSED TO EXPERIENCING UNUSUAL EVENTS, ESPECIALLY WITHIN CERTAIN CIRCUMSTANCES
People have a predisposition to unusual experiences – p2, 40 - 47 *I just know that I am the kind of person that I think is more likely to be um inclined to that. Um even things like when I, I don't-don't like taking drugs but I have been drugged before um and I had really severe hallucinations um where other people wouldn't have any, so I feel like my mind is more inclined.*
Predisposed to experiencing UE so avoids things that put her in that position i.e. drugs – p3, 106 - 110 *I think I'm aware of it that I-I know myself, like I don't use drugs because I know I'm really susceptible to things and under drugs I get really scary hallucinatio-or like, I don't know if hallucinations the right word, um and when I'm sleep deprived, so I try to take kind of behaviours that I know I don't put myself in that situation*

UE is a negative result potentially caused by personality type – p4 – 5, 143 - 148 *I've always been inherently quite like a-a creative person and I have a really strong imagination and I've always had that as a child and I can really immerse myself into my own world, so I think... while that gives me lots of really wonderful b-benefits to have a mind like that, I think sometimes the side effect is that it can have weird experiences 'cause of the way my mind might be able to work and imagine things*
Behaviour change as a result of UE's negative impact – p2, 48 - 51 *I know even within drug usage, it's a reason for me to be-find them really off-putting, that for me it's really easy in-when you shouldn't have hallucinations or any kind of things during drug usage, appears as that I will*
5.2 INDIVIDUAL INTERESTS AND WAYS OF VIEWING THE WORLD AFFECT THE UNDERSTANDING APPLIED TO UNUSUAL EXPERIENCES
Sense-making is dependent upon the individual, even within shared cultures / communities – p17, 616 - 620 *'Cause the people that, in that immediate scenario that are all told about... um... the majority being kind of like White Northern Central European, and even within that there's kind of one sort of very similar culture, people all have such different explanations of it, which I think is super interesting*
Different worldviews within the same family (individual vs collective) – p17 - 18, 631 - 643 *I think it's such a funny one of like, I-I really enjoy thinking about like, how do we view the world and think about the world in like the way and I-m-I'm very much a kind of, on the [laughs] the constructivist side of life, that I think we construct our own reality to an extent. Like I think there is a, there is a reality but we also... do construct it in many different ways and I think it's so funny that like my dad, who's very much like maths, physics, a boomer, um works in like the business world, he has such a like different take on... the world than I would have uh which is also just really interesting 'cause I'm his daughter and I have a very close relationship with him and I always spent more time with my dad than my mum probably, um and that I have such a different worldview to them and I, yeah, I don't know where I picked it up or why I think the way I do [laughs].*
Others make sense of her UE based on their own personal background / interests – p8, 277 - 279 *Um I think they were more, they were like somebody who really likes like horror films and ghost stories, so I think they were more kind of, in that direction of like, 'oh, it must have been like a... a kind of ghost-esque story.'*
Personal beliefs and worldviews affect the way you rationalise the UE and the impact it has on you – p18, 648 - 649 [Question on how she thinks constructing reality (her worldview) plays a role in understanding unusual experiences] *Yeah, I think for me, it kind of helped, 'cause I wasn't freaked out, because I was like, 'oh, I don't believe in ghosts'*
There can be multiple ways to explain one UE – p17, 611 - 616 *Actually how do you, it's-when you have something so weird that you don't know... that you can have so many different explanatory models to it and it's-it probably one of those ones where, without realising, there's so many different people who ha-would have such strongly different ways of looking at it, even within the same culture*
Her worldview does not allow for a negative impact from the UE – p18, 652 - 658 *If you think in a purely rational world and you're having a so-called irrational experience, then that's also terrifying because your whole meaning of the world... is shook and has been changed. But if you think like me, that the world is just a little bit unpredictable and kind of made up by your own mind, then it makes sense that you might have like a glitch or that your mind sometimes comes up with its own thing and it doesn't necessarily have to be good or bad, it's just what it is*
5.3 UNUSUAL EXPERIENCES ARE COMMONLY SHARED AND ALLOW FOR FEELINGS OF BEING CONNECT TO THE SELF, THE OTHER, AND THE WORLD
UE's are shared experiences that allow for connection to others – p14, 503 - 505 *Uh i-it's r-really good, I mean, I know that I can speak to them about anything if I need to and also then experiences that they've shared with me as well, so kind of, you realise you're not alone*
The UE acts as a natural check-in as to her mental wellbeing – p16, 571 - 573 *Um but I think it also makes me very in tune with my body, of understanding how do I take care of my mind and my brain and when am I at my worst and when am I at my best and appreciating um my body*
Questions reality but still feels connected to it – p2 – 3, 67 - 71 *I don't think it makes me feel like I have a, not a grasp on reality, so it's just a, a very occasional thing that's happened a handful of times in my life. Um but yeah, I think it's also really hard because you don't know, how do you know what's real or not real because it all seems real to you*

Shared experiences provides connection to the world and others – p14, 510 - 512 *That's a kind of nice human bonding experience and then you also realise, I mean in history, how many times did people have unusual experiences um throughout time and, yeah. I think it makes you feel connected*

6. WHAT MAKES THE UNUSUAL EXPERIENCE 'UNUSUAL' IS THE INABILITY TO RATIONALISE IT
6.1 THE UNUSUAL EXPERIENCE IS RATIONALISED VIA SITUATIONAL CONTEXTS AND BIOLOGICAL PROCESSES
Previous experiences rationalised by vulnerability so feel less unusual (positive impact of sense-making) – p2, 54 - 59 *That one was a bit unusual versus other times have been, when I've been really stressed or um kind of when bad things or some difficult things have happened in life and-and then they, it tend-I noticed that I started to see things or hear things that other people necessarily weren't*
Rationalises the UE through science / biological process – p4, 136 - 140 *I'm such a- intense believer in forms of science that I think it's just uh sometimes the normal reaction from the brain to sometimes be processing things and the way we dream, we don't quite understand how that works. So even sometimes to me would make sense that it could happen while we're awake that we experience unusual things*
Rationalisation / shrugging off – p1, 13 - 21 *Um and it was kinda like they were just like walking on the motorway and they didn't ha-they were like holding an umbrella but didn't have their umbrella up, so I was just kind of like what. It just looked really strange for the setting to be obviously walking on a motorway um which, doesn't feel particularly normal and also in like the pouring rain to be holding an umbrella but not holding an umbrella up. Um but then I was kinda like 'oh, it's probably just somebody who's got lost and that's where they're walking.'*
Rationalisation: context of vulnerability and stress when UE occurs – p2, 38 - 40 *Um not, not super common but obviously a bit more, um I know they-they tend to happen when I'm quite stressed, so it'll be in times of, where I have a lot going on um that I'll-I'll be more vulnerable*
Rationalises that her UE is not grounded in reality – p16, 567 - 569 *I don't think I'd describe it as a positive experience, but it's sort of a, 'oh right, okay, my brain can do that. My brain can just... see stuff, imagine stuff that isn't there.'*
6.2 THE INABILITY TO APPLY SITUATIONAL EXPLANATIONS TO THE EXPERIENCE LED TO IT FEELING UNUSUAL
Lack of rationalisation made this experience unusual – p2, 51 - 54 *Um but yeah, those-in that setting, it wasn't anything. I wasn't sleeping, I wasn't under any drugs. It was just a normal day and I just saw it. And I don't even remember whether it was a... it was just a very average day so it's just a bit, that one was a bit unusual*
Lack of context to rationalise leads to otherwise mundane experience feeling odd – p5, 155 - 158 *I think it's quite funny that my one that stood out to me was just, there wasn't any, anything that I can think of why it would happen, that the person that I saw wasn't anybody I knew, it was just, just kind of there, it was so uneventful [laughs], and so uninteresting actually, as a situation [laughs]*
No prelude (no build-up) – p1, 6 - 11 *I was tryna think of like...one in particular and um I think for me it was this-this one time I was driving um with my partner and it was like a-really kind of like rainy night and we were driving on a sort of motor-a motorway road, it wasn't like fully dark yet. Um and we were just talking, just like a really normal average day, and then I just remember like seeing on the road, on the motorway, somebody walking*
Emphasis on the ordinariness of the UE and lack of context / rationalisation making it odd – p3, 95 - 97 *That's the one time I could think of when it was so or-such an ordinary day. It didn't really feel like oh I was sleep-deprived or I'd been drugged or anything, so it was a bit surprising*
Juxtaposition of UE feeling both strange and normal – p5, 150 - 154 *Um, I think it's quite bizarre 'cause you sort of go, 'oh, what does it, what does it mean and is it something that should be... um... should be worrying.' Um but I think of it more as, I don't know, I think that's why your research is really interesting of how do you differentiate kind of just the, a normal odd experience from a experience that somebody needs further support from*
6.3 WITHIN THE SPECTRUM OF MEANING-MAKING, THERE ARE PRETERNATURAL AND SUPERNATURAL EXPLANATIONS FOR THE EXPERIENCE

There's a shared human experience of preternatural phenomena i.e. UE – p5, 166 - 168 *I feel like a lot of people actually have… ex-unusual experiences like that that they can't explain that have just sort of happened and… um I think th-the brain can be a wonderful thing but also very perplexing thing*
Differences in understanding the UE between the West (preternatural) and the East (Supernatural) – p17, 621 - 625 *Um is-I-I do wonder if you'd have.. yeah, I'm tryna think of my friends… um from different countries, so a few from um kind of South Africa, Namibia, and China and things like that, India um, how they would perceive it as well and I think that you might have more religious explanations or sort of spiritual explanations*
Supernatural understandings of the UE may have a more negative impact on the person – p18, 649 - 652 *So I think if you-if you believed in ghosts, then it's so understandable that you might be really paranoid and scared because… what does this mean if this spirit is here or this ghost is here*
Accepts that there are several frameworks of understanding, including supernatural ones – p4, 130 - 134 *People who-who might be religious or spiritual would kind of talk about it in a sense of um maybe it's a ghost or um God or God speaking to them in a different way, but for me I definitely don't-I don't feel that. I can understand why people would think that way*
Preternatural beliefs – p4, 140 - 142 *I think, you know, there's so much about how we perceive the world and understand the world that we don't understand in terms of colours and imaginations*
Rationalises UE as preternatural – p14, 505 - 509 *Other people have unusual experiences exactly, probably quite a normal phenomena of being a human being that sometimes we experience things that are maybe not um… explainable in that minute. I'm sure there are rational explanations for different things but we might not have the knowledge to understand it*

7. POTENTIAL CLINICAL ASSOCIATIONS WITH THE UNUSUAL EXPERIENCE
7.1 CONCERNS SURROUND FAMILY AND SOCIETY ASSOCIATING UNUSUAL EXPERIENCES WITH A MEDICAL DIAGNOSIS / APPROACH, LEADING TO AVOIDANCE OF THE TOPIC
Avoids disclosing due to potential association with disorder based on family history – p6, 207 - 214 *Um so, I think talking about those kind of things then people would worry, and my, um my sister has a um diagnosis of bipolar but potentially um other illnesses, and I have a really difficult relationship with her, and other family members who clearly have, I think would potentially be diagnosed with… various things who didn't um, I think that's then always a worry when you know people and your family*
Concern that society / GP would label her experiences as severe and clinical – p4, 110 - 115 *Um so-so bringing it up I'm like, 'oh, I don't really want that to be something that people associate with me,' cause I don't see it at a stage of it being clinically bad but I don't know if other people would. [08:19 – 08:20 unintelligible] I don't know if I went to my GP and mention it, how they would feel about me, whether they would be concerned or not*
Avoiding disclosing UE to GP due to labelling and clinical association – p4, 118 - 122 *So when I was…when I had any kind of unusual experiences um when I was uh r-really unwell, I'd, had seen um a counselling mandate for-from work, I had to see a GP, um but I didn't specifically mention that. I think I was a bit cautious to open up too much because I didn't, I didn't really want that to be a kind of a-a label or further thing*
Concern that others may view UE as a medical issue – p13, 472 - 477 *Uh so actually listening to the person about how they're experiencing it themselves, like often people will, y-you know your body and your mind and um if you're saying, 'actually, I'm okay. I-It was just a.. unusual experience, it's nothing to worry about. We don't need to like drag me to the hospital, to a GP, um it's okay.' So, I think those, listening is probably… um the big one*
Mum would have immediate medical concerns regarding UE if disclosed – p9, 306 - 308 *I think my mum would be really worried, she's really worried about my sister. Um I think she would be super concerned and would want to take me to a hospital right away*
Concern that loved one's response may be via a clinical lens e.g. mental health – p6, 196 - 198 *So, I think if there's something like that, um I know he would worry about me, whether I was okay and whether I'm in a bad place, if my mental health's in a bad place*
The ability to rationalise the UE disregards the need for clinical treatment – p4, 122 - 124 *I felt like it was a, more like a one-off experience, or something that had an explanation versus something that was severe and clinical*

Appendix 17

Complete Example of Group Experiential Theme 1 (Non-Clinical Group)

6. WHAT MAKES THE UNUSUAL EXPERIENCE 'UNUSUAL' IS THE INABILITY TO RATIONALISE IT
6.1 THE UNUSUAL EXPERIENCE IS RATIONALISED VIA SITUATIONAL CONTEXTS AND BIOLOGICAL PROCESSES
Previous experiences rationalised by vulnerability so feel less unusual (positive impact of sense-making) – p2, 54 - 59 *That one was a bit unusual versus other times have been, when I've been really stressed or um kind of when bad things or some difficult things have happened in life and-and then they, it tend-I noticed that I started to see things or hear things that other people necessarily weren't*
Rationalises the UE through science / biological process – p4, 136 - 140 *I'm such a- intense believer in forms of science that I think it's just uh sometimes the normal reaction from the brain to sometimes be processing things and the way we dream, we don't quite understand how that works. So even sometimes to me would make sense that it could happen while we're awake that we experience unusual things*
Rationalisation / shrugging off despite initial unusualness – p1, 13 - 21 *Um and it was kinda like they were just like walking on the motorway and they didn't ha-they were like holding an umbrella but didn't have their umbrella up, so I was just kind of like what. It just looked really strange for the setting to be obviously walking on a motorway um which, doesn't feel particularly normal and also in like the pouring rain to be holding an umbrella but not holding an umbrella up. Um but then I was kinda like 'oh, it's probably just somebody who's got lost and that's where they're walking.'*
Rationalisation: context of vulnerability and stress when UE occurs – p2, 38 - 40 *Um not, not super common but obviously a bit more, um I know they-they tend to happen when I'm quite stressed, so it'll be in times of, where I have a lot going on um that I'll-I'll be more vulnerable*
Rationalises that her UE is not grounded in reality – p16, 567 - 569 *I don't think I'd describe it as a positive experience, but it's sort of a, 'oh right, okay, my brain can do that. My brain can just… see stuff, imagine stuff that isn't there.'*
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6.3 WITHIN THE SPECTRUM OF MEANING-MAKING, THERE ARE PRETERNATURAL AND SUPERNATURAL EXPLANATIONS FOR THE EXPERIENCE
There's a shared human experience of preternatural phenomena i.e. UE – p5, 166 - 168

I feel like a lot of people actually have… ex-unusual experiences like that that they can't explain that have just sort of happened and… um I think th-the brain can be a wonderful thing but also very perplexing thing
Differences in understanding the UE between the West (preternatural) and the East (Supernatural) – p17, 621 - 625 *Um is-I-I do wonder if you'd have.. yeah, I'm tryna think of my friends… um from different countries, so a few from um kind of South Africa, Namibia, and China and things like that, India um, how they would perceive it as well and I think that you might have more religious explanations or sort of spiritual explanations*
Supernatural understandings of the UE may have a more negative impact on the person – p18, 649 - 652 *So I think if you-if you believed in ghosts, then it's so understandable that you might be really paranoid and scared because… what does this mean if this spirit is here or this ghost is here*
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Preternatural beliefs – p4, 140 - 142 *I think, you know, there's so much about how we perceive the world and understand the world that we don't understand in terms of colours and imaginations*
Rationalises UE as preternatural – p14, 505 - 509 *Other people have unusual experiences exactly, probably quite a normal phenomena of being a human being that sometimes we experience things that are maybe not um… explainable in that minute. I'm sure there are rational explanations for different things but we might not have the knowledge to understand it*

2. JUSTIFYING OWN UE AS UNUSUAL WHILST RATIONALISING OTHER'S UE AS USUAL
2.1 JUSTIFYING THE EXPERIENCE AS UNUSUAL AND NOT HAVING A RATIONAL EXPLANATION
Justification process to rule out rational explanations – p5, 155 – 161 *I fe-, I definitely feel like it's more because I wasn't scared enough to be feeling lightheaded. And I wasn't unwell or anything or I ain't got, I-I haven't got any health conditions or nothing. So, for that, for randomly to happen to me when I'm standing by the door, and my sister in laws just told me that the door was knocking, it w-, I, like I said, I've heard worse, like the whispering and whatnot and the door turning, and if I wasn't that scared then, I doubt this happened to me out of fear.*
Justifying her experience as unusual – p6, 196 – 198 *And the fact that it was footsteps and all three of us heard it from upstairs and then the dishes clattering. They had no cottages around us and whatnot, so that was o-, I'd say the scariest experience I've had.*
Justifying that the experience was unusual and not a normal reaction to fear – p2, 45 – 49 *I-I felt like, um it wasn't, um is that I felt like that was sort of unusual for it to happen to me, because I've heard voices before seen stuff before and I've never felt that rush through my body and this story was just my sister in law telling me she's heard knocks on the door and I felt that rush through my body, so I felt like it was something more to it, if you know what I mean?*
Justifying experience as unusual and not having a rational explanation – p11, 388 – 395 *She straight away thought it was a Jinn, 100%. She was like, 'I know for a fact there was something knocking on my bedroom door.' She-she-she said, 'if I was half asleep, it's a different story, or if I was like, you know, um not well, different story. She goes, 'I was sitting up and the knocking was happening.' She goes, 'there's no chance that it's the neighbour when I could hear my door knocking.' And they were knocking the way I would knock the door. So, when I normally would knock three times, but it knocked three times and then it carried on knocking slowly.*
Justifying the physical symptoms as part of the UE and not a reaction to fear – p13, 467 – 483 *So, I felt uh my blood rushing through my body and felt weak, so I was like, 'I need to lie down.' And as I lay down, I could hear myself breathing heavily. Uh I felt it when like um I've been in pain, like when I've hit my head or you know, uh um um got my fingers trapped in the door. And then like, you know, you can't get your breath back, and your blood's rushing and you need to lie down. So, just when I've been in like physical pain, that-that's it. Probably like two, three times in my lifetime. Uh I-I honestly felt like I was standing by the door, and something was, maybe rushed past me or through me. Uh I can't explain it and I don't know for-for certain if it's true, but I do know that I wasn't scared enough to be feeling weak at that point.*
2.2 INITIAL REACTION TO ANOTHER'S UE IS TO RATIONALISE THE EXPERIENCE

Dismissal of each other's disclosed UE's – p3, 69 – 77 *And uh we both heard it and we both went quiet, and then we were like, 'what the hell was that?' There was no, we went in the room. And then the n-, we told our friends the next day, they thought, 'ah, it's nothing,' 'cause there'd been something that dropped of a drawer or whatnot. Uh then the next day, my friend who was sleeping closest to the door, the doorknob turned and she shouted my name, but I was, um what's it called? I ignored her 'cause I thought she wanted to have a chat, but she told me the doorknob turned. And I-I did hear that, but I thought it was her doing it, like playing with the doorknob.*
Tendency to rationalise UEs that are not experienced by herself directly – p8, 266 – 271 *So, with the other experiences um obviously, I heard it myself, like the pearl, the door, the whispering, and footsteps. And even though it was scary um but the experience I had with my sister in law, when she told me she heard knocking, obviously I was like, 'ah, it could be anything.' You know, you make excuses maybe with next door neighbours or maybe you're dreaming or whatnot, even though she was awake.*
Rationalising other person's UE – p1, 20 – 22 *And she goes, 'someone just knocked my door.' And I-I was like, 'are you sure? Like, were you awake when this happened or maybe, you know, you were dreaming?'*
Initial reaction is to rationalise UE – p10, 335 – 338 *I was messaging the group saying, 'you're lying, you're probably making food yourself or whatnot.' But my two friends upstairs, they did believe that, they believed 'em straight away that something's going on, but I didn't believe 'em. For that reason, we didn't go check it out.*
Initial response to another's UE is to look for rational explanations – p4, 108 – 118 *And uh then um, they said to us meet us halfway down the stairs so we can check out what the noise is. And I said to my other friend, 'they're lying. Like, they obviously want us to come down to help them cook or do something or they'll wanna jump out at us, try and scare us.' So, I says to my mate, 'ignore 'em. They-they're just joking about, it's them in the kitchen.' And uh so, we ignored it and um uh, later on, we'd hear them walking upstairs, 'cause they used to go out on the balcony for fresh air or whatnot. So, in the middle of the night, we heard footsteps walking upstairs and whispering, and I said to my friend, I said to my friend that, 'see, if there was something downstairs, they wouldn't be walking up the stairs, like you know, coming on to the balcony.'*
Initial reaction is to rationalise other's UEs – p14, 504 – 508 *Uh one of my friends experienced, she saw someone in her back garden in the night. And uh, yeah, and I go, 'maybe it was a shadow.' She goes, 'no, it was a lady dressed in black' in her back garden.*

1. JUSTIFYING THE UE AS A SPIRITUAL EXPERIENCE IN THE ABSENCE OF RATIONAL EXPLANATIONS
1.1 ATTEMPTS TO RATIONALISE THE UE
Initial attempt to always look for rational explanation – p2, 35 – 37 *But it did freak me out, I'm not gonna lie. 'Cause I was like, 'woah, that is a big laptop, at no point could have that, no windows are open, it ain't that windy outside even if it was.'*
Trying to rationalise the UE – p9, 331 – 335 *Um well, I had, I've got mine in my fire-, not my f-, it's, there's not a fire there, but there's like a fire opening bit. So, I've got um the card in that bit. So, I walked into the lounge and it just fell over. So, I just looked and I thought, 'oh, how would have that fell over?' Like, it just don't make sense. Again, there's no windows open, my son's at school.*
Trying to rationalise UE – p1, 26 – 30 *So, me and my partner at the time was lying on the settee, and my laptop was actually on the other sofa and it was up against the pillow. And because it's a heavy one, it's not like it could have just flopped down or whatever. So, we were just watching television anyway and then all of a sudden, the laptop was literally thrown onto my floor.*
Trying to rationalise UE – p1, 13 – 21 *And I remember putting my cotton buds on the bath rack and it was the Johnson's baby ones. And I remember the lid was definitely firmly on it, 'cause I just um got my son ready, and then I was in the living room with my son's dad and I heard a noise. So, I thought, 'oh, I wonder what that is.' So, I went into the hallway and the lid of the cotton bud lid, tub sorry, was thrown onto the bathroom floor and there would have been no way*

possible that it would have been able to have fallen off. Not from the distance that, where the cotton buds itself were, if that makes sense?
1.2 THE INABILITY TO RATIONALISE LEADS TO SPIRITUALITY AS A WAY OF SENSE-MAKING
Recurring UEs negate the chance of coincidence – p7, 239 – 243 *Um 'cause it was a coincidence every single t-, if it happened just the once, you could look at it and think, 'okay, it's just whatever.' But because it was when he was at mine all the time, um I could literally put you on the-, not now, 'cause we don't speak, at the time, I coulda put you on the phone to him and he coulda said it himself.*
Pattern and repetitive occurrence of UE negates the chance of it being a coincidence – p13, 446 – 464 *And I seen the mirror hour on my dashboard on my clock. And it came up and I was like, 'oh, this is um, there's a mirror hour.' I says uh, 'I'm gonna have to look that up.' [laughs] I'm basically talking to myself, but talking to my son. And I turned around and he's like looking at me like, 'oh God,' like sort of thing. 'She's off on one again.' [laughs] And he's like, 'mum, you know the-the time's just changed. It's like, it's like it's a coincidence, you just looked.' But when it happens to ya loads and loads and loads and loads, there's only so many coincidences that can happen in life. It's like.. you can look at your clock and it just turns to say 11:11, for example. Those things can probably be a co-coincidence. But then when you look later on and it's 12:12, and it's 13:13, it isn't that I'm being mindful to man it, like watch the clock. Because I definitely ain't. Um but I notice these things.*
Spiritual activity is the accepted explanation in the absence of rationalisation – p16, 574 – 579 *But it could, d'you know what, it could generally just be, I don't, I don't even know, I don't even have any of the justification as to why my laptop's flew off the chair. I couldn't say maybe it's this or maybe it's that, because I could, it-it'll only make sense form my view that it would be the spirit world. Like, what else would have got the laptop off the chair or trying to just make him get out of the bed?*
Inability to rationalise leads to spiritual understanding – p3, 70 – 74 *I remember I just got a new lightbulb in my hallway, and it literally just, few days later, just started flickering on and off. And I thought, 'that's not normal. Like, it's a brand new lightbulb.' And then, it happened a few like other times and then it stopped. So, I knew it wasn't a fault with the lightbulb and I know it's more spiritual.*
The ability to rationalise some experiences and not others leads to spirituality as a way of sense-making – p15, 519 – 532 *So, you can, again you can look at it as maybe it's your floorboards, maybe it's your-your, the loft or the pipes for the heating or whatever, you just. It could well be that. Sometimes, you can differentiate between, 'okay, that sounds, that's like my pipes because the-the heater's cooling down. Oh, that's the boiler.' So, when you live in a property, you kind of identify certain noises as, like I say, that's the cooker or whatever. Um but when you know there's nothing on at all, and the heater's, the heating's not been on, so therefore, the pipes don't need to cool down, and you hear certain noises, it is a bit, 'oh, okay,' sort of thing. 'What is that?' Which does make you think, it's not to say all the time it's spiritual related, but sometimes it is obvious that it is, if that makes sense.*
Accurate knowledge of other experiences lends validity to psychic's interpretation – p3, 99 – 102 *Um and I had a dog pass away. Um few years, well, over four years ago now. And when she was walking to my house, um she literally turned round and said, 'oh, can you close this door before we go into the reading because there's a little brown dog running around my by feet.'*
Using the Other to test sense-making – p3, 85 – 97 *I literally just ignore it, but my son actually talks in his sleep and he has for years. So, when I had that lady come to my house to do the reading, she actually said um, she says, 'I'm picking up that your son's very gifted and just to let you know, when he's asleep, he's talking to spirits.' So, I was like, 'cause I didn't talk to her, I didn't engage in a way 'cause it was my first ever reading, I didn't know if I wanna give anything away. So, I was just like, 'oh okay, oh okay.' And it wasn't 'til after when the reading finished, I says to her, I says, 'that makes sense,' I says, 'because I can't ever understand what my son's saying.' I says like, 'I'll even pause my tele or whatever to listen to what he's saying, but I can't make ends meet as to what he was actually like, sentence, I can't like understand what he's saying.' Um so, it has always made me think ,'oh, what is he doing?' But the lady said he's speaking to the spirits in the house.*
No pushback or alternative explanations offered as to her beliefs – p17, 625 – 629

No, because no-one's really challenged me on it. No-one's really said, 'well, have you thought about this or have you done this or have you-?' No-one's ever said anything like that to me. So, I haven't, whereas, the positive ones, it's-it's different, because it's just back and forth positive conversation. No-one's really challenged me on it, so no.

3. UNDERSTANDING THE UE
3.1 ATTEMPTS TO RATIONALISE THE UE
Trying to rationalise the UE – p1, 27 – 31 *And I've just stopped, and I've thought, 'shall I go upstairs, or shall I just leave, sh-or shall I, you know, go and check it out?' I've gone in the living room, I'm looking around the living room, nobody's in here. I turn the tele off and I've done a whole lap around the downside area of my house just to double check that nobody's here*
Rationalisation of UE / brushing off – p1, 9 – 12 *I can hear this breathing sensation almost coming from behind me. But all that's behind me is my living room door, then the living room's there, so there's nothing behind me. So obviously my first instinct's to look back, nothing's there, I carry on eating.*
Rationalisation – p2, 55 – 56 *I thi- at first, I'm just tryna keep my cool, so I'm like, 'oh, it's just a sound, that it could come from anywhere, maybe an open window or something'*
Still wants to rationalise with logic – p2, 47 – 48 *So like I al-, like I, the only thing I think in my head is there must be a reasonable explanation for it*
Lack of rationalisation causes negative impact – p9, 301 – 303 *[gulps] I think it's beca-because, you know, I don't have that deeper understanding of like, what could be happening or what it could be, it's like, I feel powerless.*
3.2 LEANS TOWARDS A SUPERNATURAL EXPLANATION DESPITE ATTEMPTING TO MAINTAIN A NEUTRAL POSITION
On the fence with his beliefs, but still avoids supernatural-related things to be on the safe side – p6, 194 – 199 *You see, and I- I've still try and maintain that like I don't necessarily believe or not believe but like I wouldn't, I wouldn't go near like a church late at night or a cemetery or anywhere scary. I would never read like-like-like some kind of spell or curse, I'd never say Bloody Mary in the mirror, like anything to do with paranormal stuff, even down to like a haunted house. I really don't want any part of it. Like I can't be around that stuff.*
Supernatural understandings of UE – p2 – 3, 66 – 70 *[Exhales]. So, at first I'm thinking, 'ooh, you know, it's okay, it'll stop in a second, this is just something that's happening,' and after a bit I'm like, 'no, there is something downstairs and it definitely knows I'm here.' And especially, it was when I, when that tele's come on as I'm going upstairs, that's when I'm like, 'there's something knows I'm down here'*
Lack of logical rationalisation leads to supernatural fears – p3, 73 – 77 *See, I-I still try and maintain that there was a reasonable explanation for- it's like I don't have that though, so it's like a-all I can say is that something... I felt like something was there, especially when I was um when I was sitting down and I first felt that breath, 'cause that felt like it was right in my ear, like somebody's just breathing in my ear right next to me*
On the fence with supernatural understandings and predisposition – p2, 40 – 47 *But I think the thing is, it's like, I'd never say, oh you know, like I believe in ghosts or like, you know, I'm susceptible to hearing them things, but I'd never say I don't believe either like. I sit on the fence, just in case I say I don't believe, then one really tries to come out and...and like have a go.*
Supernatural concerns – p2, 57 – 59 *But then after about 5 minutes, that's when I don't feel okay and I feel like something could pop out behind me at any, like at any moment, like so it was a bit panicky.*
Accepts that he lacks understanding, but leans towards the supernatural – p3, 81 – 87 *See, I-I try and leave it down to like, you know, I-I don't really have the understanding or maybe.. of whatever this thing was, like I-I, maybe I can't understand, maybe I can't like grasp... what it wanted or-or-or why it was there, but I just kn-, I-I just felt like it was there. I don't know it was there, but I really felt like something was there. Like that's like the only like experience of like of that kind of nature that I've had, so that's why I felt like i-it must have been there.*

The presence / absence of a UE is dependent upon his response to the first one – p6, 212 – 215
Say if I would have just stayed down there or like, if I wouldn't have turned the tele off or didn't do anything wrong or didn't do it all right and that's why nothing's happened since then.

Appendix 18
Letter to the Care Co-ordinator for the Clinical Group

Dr Andrew P. Fox
Chief Investigator
52 Pritchatts Road
University of Birmingham
Edgbaston
Birmingham
B15 2TT

[DD/MM/YYYY]

Dear [name of care co-ordinator],

I am writing to inform you that your patient, [name of participant], has consented to taking part in the following study:

Exploring Frameworks of Understanding in Clinical and Non-Clinical Populations.

Please feel free to get in touch if you have any concerns about [name of participant]'s capacity to consent throughout the study. Please note that [name of participant] can only be withdrawn from the study up to two weeks from the date of the interview, by which time their data will not be able to be traced back to them. The research team will get in contact with you if they deem there to be a significant level of risk to [name of participant] or others.

Yours sincerely,



Dr Andrew P. Fox
Chief Investigator

Tel: 0121 414 2752
Email: [redacted]

Appendix 19

Participant Information Sheet for the Clinical Group

EXPLORING FRAMEWORKS OF UNDERSTANDING AND MEANING-MAKING PROCESSES IN EXPERIENCES OF PSYCHOSIS

PARTICIPANT INFORMATION SHEET

We would like to invite you to take part in this study on exploring frameworks of understanding in experiences of psychosis. Please read this information sheet carefully before you decide whether you would like to take part in the study. This information sheet contains information about why the study is being conducted and what your participation would involve. This study has been reviewed by the Surrey NHS Research Ethics Committee. If you have any questions or require any further information please do not hesitate to contact the researcher, Aneela Khan, at [redacted]

AIM AND PURPOSE OF THE STUDY

The study aims to develop a better understanding of the experiences of people diagnosed with a schizophrenia spectrum disorder, specifically their experiences of using mental health services. During the interview, we will ask you about your time with these services, particularly the similarities and differences between your way of understanding what you have been experiencing and your teams' way of understanding what you are experiencing. The study will help the research team to understand the different types of experiences people using mental health services have, and how others in their lives respond to these experiences. Once the data has been collected, it will be written up as part of a PhD in Psychology. The research will also be submitted for publication in academic journals.

WHAT WILL THE STUDY INVOLVE?

After reading through the Participant Information Sheet, you will have the opportunity to ask any questions about the study and have these answered to your satisfaction. If you decide you would like to take part in the study, you will be invited to take part in an interview at a time convenient to you. The interview will take place face-to-face at the University of Birmingham or online via Microsoft Teams. If the interview takes place in person, you will be reimbursed for any travel costs incurred as a result of participation.

At this meeting, you will first be asked to sign three copies of the consent form. One copy will stay with you, one copy will be given to your care co-ordinator, and one copy will stay with the researcher. If the interview takes place online, the researcher will read out each point on the

consent form, to which you will say whether you agree to the statement or not. You will then be asked to say your full name in confirmation of consent which will be added to the form by the researcher. The consent process will be witnessed by the Chief Investigator and will be countersigned by them as evidence of consent being obtained. The consent form will be kept by the research team, with one copy emailed to you and one copy emailed to your care co-ordinator. The interview will then take place in two parts. For the first part, the researcher will have a list of possible questions to ask you, however, these are only a guide. If there are any questions you do not wish to answer, then you do not have to answer them. You can stop the interview at any point without providing a reason. This section of the interview will be audio-recorded.

The second part of the interview will involve answering questions from the Positive and Negative Syndrome Scale (PANSS); a measure that aims to assess the severity of experiences and symptoms. At the time of the interview, the PANSS will be used to better understand your experiences within the past week specifically. Not all questions will apply to you, and as with the first interview, you are not required to answer any questions you do not wish to. This section of the interview will not be audio-recorded.

The entire interview will take between two to three hours, but there is no minimum time required of you. Once the interview has finished, the first part will be typed up and anonymised with no identifying information to ensure what you say cannot be traced back to you. Anonymous quotes from the first part of the interview will be included in write-ups from the research. The second part of the interview will not be audio-recorded nor typed up and so no quotes will be included in write-ups from the research. Instead, this part will provide the researcher with a summary of your experiences and any difficulties (such as symptoms) and this will be used to inform the research but will remain anonymous.

ARE THERE ANY RISKS THAT PARTICIPANTS MIGHT FACE?

You may find it upsetting to recount past experiences of any difficulties you may have faced. If this happens, please let the researcher know, during or after the study. You will be able to take breaks during the interview at any point or reschedule for another time without providing a reason. The researcher will provide you with a list of appropriate support services that you can access following the study, if you wish to.

CONSENT: DO I NEED TO TAKE PART?

No, you do not need to take part in this study. It is your choice whether you would like to take part or not. If you choose to take part, you will be asked to sign a consent form, which will be given to you at the time of interview. If the interview takes place online, you will be asked to consent to a series of statements which will be read out to you at the time of interview. If your care team informs us that you are no longer able to consent whilst taking part, you will be withdrawn from the study. Data already collected with consent will be kept and no new data will be collected.

CONFIDENTIALITY

We will need to use information from you and from your care team, if applicable, for this research project. This information will include your name, contact details, and diagnosis. People will use this information to do the research or to check your records to make sure that the research is being done properly.

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you after 2 weeks following the interview.

All data collected during the study will be anonymised and stored securely so that only the research team and approved others at the University of Birmingham will have access to the data. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Your care co-ordinator will know that you have chosen to take part in the study, however, they will not be aware of anything you say to the researcher, except in cases of risk. If at any point we are concerned about your safety or the safety of others because of something you have discussed with us, we may need to discuss this with others (e.g. your NHS clinical team) to try to ensure the safety of you and others. However, the researcher would always attempt to talk to you first before doing this. You can find out more about how we use your information at www.hra.nhs.uk/information-about-patients/.

WHERE WILL THE DATA BE STORED?

All data collected during the study will be kept in locked or password-protected storage at the University of Birmingham that only the research team will have access to. All personal and

identifying information (e.g. your name, contact details) will be stored separately from the audio recordings and transcripts so that you cannot be identified. No identifiable data will be shared with other organisations (unless we are worried about safety of you or others, see above) or published in any reports. All data will be handled in accordance with the Data Protection Act 2018. Audio-recordings of the interview will be destroyed as soon as transcription has taken place. Once the research is complete, all personal contact information (e.g. email address / contact number) will be destroyed.

WITHDRAWAL: WHAT IF I WANT TO LEAVE THE STUDY?

You can stop being part of the study at any time, without giving a reason. If at any point during the interview you have any concerns about what you have said, the researcher can remove those sections during transcription. You can also withdraw certain statements or sections from the interview by contacting the researcher after the interview has taken place. You will have up to two weeks from the date of your interview to indicate your withdrawal from the study. After this date, your personal details will no longer be linked to the data collected as part of the study. Therefore, we will no longer be able to trace the transcript of the interview back to you and withdraw you from the study.

WHO IS INVOLVED IN ORGANISING THIS RESEARCH?

This research study is organised and conducted by Aneela Khan, as part of her University of Birmingham PhD in Psychology programme. This research is supervised by Dr Andrew Fox ([redacted]), Professor Lisa Bortolotti [redacted]), and Professor Matthew Broome ([redacted]).

WHAT IF THERE IS A PROBLEM?

The University has in force a Public Liability Policy and/or Clinical Trials policy which provides cover for claims for "negligent harm" and the activities here are included within that coverage. If you would like to complain about any aspect of the study, please contact Aneela Khan's supervisors: Dr Andrew Fox ([redacted]), Professor Lisa Bortolotti ([redacted]k), or Professor Matthew Broome ([redacted]
Additionally, if you wish to make a formal complaint to someone not involved in the research please contact the Head of School, School of Psychology, University of Birmingham, B15 2TT, or by email at hos.psychology@contacts.bham.ac.uk.

THANK YOU

Appendix 20

Consent Form for the Clinical Group

EXPLORING FRAMEWORKS OF UNDERSTANDING AND MEANING-MAKING PROCESSES IN EXPERIENCES OF PSYCHOSIS

CONSENT FORM

Participants will keep one copy of the completed consent form and the participant information sheet. The researcher will keep one copy of the completed consent form in their site file.

Please put your initials in each box if you consent to the statement next to it.

1. I confirm that I have read and understood the participant information sheet titled 'exploring frameworks of understanding and meaning-making processes in experiences of psychosis.' I confirm that I have had the opportunity to consider the information and ask questions that have been answered to my satisfaction. ☐

2. I give my permission to the researcher to inform my care co-ordinator that I have chosen to take part in this study. ☐

3. I agree to the first part of my interview being audio-recorded and I understand that this recording will be backed up on a password-protected secure university drive that only the research team will have access to. ☐

4. I understand that my participation is completely voluntary and that I am free to withdraw part of or all of my data up until two weeks after the date of my interview without providing a reason and without being penalised in any way. ☐

5. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham to ensure that the analysis is a fair representation of the data. Parts of the data may also be made available to people outside of the research team (e.g. NHS team responsible for me) but only if there are concerns about myself or others coming to harm. Only the Chief Investigator and Postgraduate Researcher will have access to my consent form and demographic details. ☐

6. I understand that direct quotes from the first part of my interview may be published in any write-up of the data, and used for training purposes, but that my name will not be attributed to any such quotes. ☐

7. I agree to take part in the research study. ☐

Print Name:	Participant signature:	Date:
Researcher Name:	Researcher Signature:	Date:
Lead Supervisor Name:	Lead Supervisor Signature:	Date:

Appendix 21

Demographic Details Form for the Clinical Group

EXPLORING FRAMEWORKS OF UNDERSTANDING IN CLINICAL AND NON-CLINICAL POPULATIONS

DEMOGRAPHIC DETAILS

Unique Identifier: ……

Age: ……

Gender: ……

Ethnicity: ……

Length of time in Early Intervention Service: ……

Access to any mental health services prior to EIS: ……

Pseudonym: ……

Appendix 22

Interview Schedule for the Clinical Group

EXPLORING FRAMEWORKS OF UNDERSTANDING IN CLINICAL AND NON-CLINICAL POPULATIONS

INTERVIEW SCHEDULE

At the start of the interview, thank the participant for agreeing to take part and ask if they are still happy to go ahead with being audio-recorded. Make sure they have a physical copy of the Participant Information Sheet and have signed the consent forms. Remind them that it is completely fine if they would like to take a break at any point or stop the interview and they don't have to provide a reason for either. Inform the participant that if they are asked a question that they do not wish to answer, they should let me know and we will move on to the next question.

Note: This semi-structured interview schedule aims to cover the areas below. Prompts are completely optional. Questions will naturally overlap, so if you feel a question has already been answered, then this can be skipped, so as not to unnecessarily burden participants.

- **Is there anything you would like to ask or discuss before we begin?**

INTERVIEW

- **Could you tell me about how you first came to receive services from a mental health team?**
  - Possible prompts: Was this with Early Intervention or somewhere different [explore]? What led up to you seeing someone? How did you get the help that you are receiving now? What was going on at the time? What changes were you noticing? How did that feel? What thoughts were you having? [Elicit description of the symptomatic experiences]

- **How did you understand or make sense of what you were experiencing?**
  - Possible prompts: What did you think was happening? Why do you think that was happening? How did it feel when the changes began? How do you feel about it now talking about it?

- **When you saw the mental health team, what was their explanation of what you were experiencing [use their language re: psychotic symptoms]?**
  - Possible prompts: Which team / who in the team? How do you feel about their interpretation / way of understanding things [their language re: psychotic symptoms]? Explore similarity / differences. [*If they mention the medical*

approach/medical terminology, ask what they think about this approach to understanding experiences?] What was their response to your interpretation / way of understanding? How do you feel about it now talking about it?

- **Have you ever spoken to other people that have experienced the same things as you?**
  - Possible prompts: Did you ever talk to them about your experiences of [use their language re: psychotic symptoms]? What was their response to your interpretation / way of understanding? How did that feel? How do you feel about it now talking about it? Were their experiences different to yours? How did they make sense of their experiences? What do you think about their interpretations of their experience?

- **Have you ever spoken to anyone else about your experiences?**
  - Possible prompts: Did you tell people (friends/family/acquaintances)? Why / why not? Do they know about your use of services? What was their response to your interpretation / way of understanding? How did they explain it? Were their explanations of it similar to yours? What was that like? How did you feel? What did you do? How do you feel about it now talking about it? Did you tell anybody who doesn't know about your use of services? What was their response to your interpretation / way of understanding? How did they explain it? Were their explanations of it similar to yours?

- **Do you still experience [use their language re: psychotic symptoms] now? Has it changed in any way? How do you make sense of these things you experience now?**
  - Possible prompts: What do you think is happening now? How do you feel about it now? *If there are changes,* why do you think your understanding of your experience has changed?

- **How would you describe your relationship with the mental health team? How do you get on with them?**
  - Possible prompts: Do you feel they listen to you? Could you give me an example? Are there times when you see the team and you don't talk about the 'schizophrenia [or their language]'? What kind of things do you do and talk about? Could you give me an example? How is that? Have there been times you have wanted to talk about something other than the 'schizophrenia [or their language]'?

- **Have you ever asked your mental health team for information about [diagnosis: use their terms]? How did that go?**
  - Possible prompts: Could you give me an example? What was that like? How do you feel about their response to the information you've asked for? How do you feel about it now talking about it? What do you think about the information you have been given so far in the services?

- **Have you noticed any changes in the way people talk with you since using mental health services?**
  - Possible prompts: Ask about people outside of services (family/friends/colleagues). Could you give me an example? When did you notice that change? Why do you think their perception changed? What was that like? How did you feel? What did you do? *Note to think about belief* – do people believe them? About what – 'symptoms' or non- 'symptom' experiences? What was it that made you feel you were not believed [words/phrases used – body language e.g. lack of eye contact, eye rolling, doubtful look, lack of interest]? How do you feel other respond to contributions you make to conversations?

- **When you interact with the people we've discussed today (clinician/care team/other service users etc.) how do you feel?**
  - Possible prompts: What do they do that is helpful / unhelpful? Has it affected you? In what way? What affected you? Could you give me an example of the effect it had? What was that like? How did you feel? What did you do? How do you feel about it now talking about it?

Appendix 23

Vignettes for Participants in the Clinical Group

George

George's experiences began as what he describes "nutjob behaviour" and was associated with violence during that period of his life. Although the experience felt normal and real to him at the beginning, his hospital stay, initiated by his parents, brought awareness to something being wrong. This insight was difficult to keep in the beginning and he experienced new symptoms that he was not aware of before, attributing this to over-exposure to other patients with mental health issues during his hospital stay and sharing delusions during his "sponge state." He accepts the medical diagnosis of psychosis and studies the literature to keep up to date on information regarding it, however he notes that he was not informed of his diagnosis via conversation, but was only ever given a leaflet on it. He believes the psychosis was triggered by trauma he had experienced in his past, as well as from stress and substance use.

Regarding others in his life, George has a trusting and positive relationship with his EIS care coordinator. He also has some close friends in his life that he is able to open up to and be there for as well. He feels emotionally unfulfilled by the lack of communication with his parents and attributes their "three word answers" to the Asian culture they were raised in. He states that he lost many of his acquaintances that he kept on social media during his hospital stay, causing feelings of isolation and loneliness. He also describes instances of testimonial injustice, where he feels he was not / would not be taken seriously when others know of his diagnosis. This form of epistemic injustice was also present with family members who still have issues trusting or believing what he's saying based on his diagnosis and past symptoms.

Keeley

Keeley's experiences began a couple of weeks before her family took her to hospital. These experiences were inherently negative, with voices telling her not to trust those around her, that people on the television were talking negatively about her, and that the roof would cave in. This experience was terrifying for her and she often commented on how scary that period of her life was, speaking to her mother about it when she was unable to cope. Once in hospital, she was able to make sense of her experience after a while, initially thinking she was in prison due to the area and the windows in the doors. The diagnosis of schizophrenia was not discussed with her, instead she came across the diagnosis on her ward round document.

Keeley has a strong relationship with her EIS team, where she feels able to discuss anything, even daily situations unrelated to the diagnosis. She finds everybody in her team supportive and the medication especially useful. She expressed concerns to her care coordinator regarding not feeling like her old self, and was subsequently told that if she wanted to, she could become a new person, and that she is still herself regardless of the diagnosis. She feels she can share her experiences and relate to those who also experience the same symptoms, as well as share the same understanding of psychosis as a coping mechanism for stress on the brain. Her friends and family are her support network, however, she did feel that some of the

people close to her have changed the way they converse with her as a result of her change in identity, and not necessarily due to the diagnosis itself.

Christine

Christine described her experience as a positive one, where she felt guided by God to do "the right thing," e.g. volunteering / becoming 'fixated' on doing certain things. She felt she did not have psychosis in the way it was described to her i.e. auditory and visual hallucinations, however, she did feel resigned to accept psychosis as the reason for her experiences. Her trigger for psychosis was explained to her by her care coordinator as a way to cope with her expectations of life and work after university not matching up to reality. She felt that many of her 'normal' behaviours were classified as symptoms by her care coordinator and she was funnelled into a diagnosis.

Christine noticed that she tended not to open up about her diagnosis to others, with concerns of her diagnosis dehumanising her in society. She felt she had to prove herself as a functioning member of society in order to remove the stigma of the label and be viewed as a valid person. However, she had a positive and trusting relationship with her EIS team and close friends responded with more sympathy to her diagnosis than when she simply stated that she was "unwell." She encountered instances of testimonial injustice from family, where she felt they were overprotective and she had to walk on eggshells around them as they viewed her behaviours and wants as linked to her previous symptoms.

Nandi

Nandi's experiences included voices telling her to self-harm and become disabled, and harm her family, also informing her that she would be judged negatively in society for being disabled. She rationalised her experience in several ways: i) a religious interpretation of God punishing her for her sins and demons putting the voices in her head; ii) over exposure when working with individuals with mental health issues; and iii) the psychological impact of life stresses and isolation during her teenage years by both family and friends. Due to her mother's culture being a part of South Africa, she had a strong belief in the cultural way of explaining and treating experiences. After 5 months of praying in South Africa did not help her recovery, her white father decided things were "enough" and she needed to receive medical help from a GP. She feels that the diagnosis helped her make sense of her experience and medication helped her recover, which prayer alone would not have done. However, she does not believe religious and medical treatment are mutually exclusive and suggests that prayer played a role in her recovery too, as well as her connection with God.

Nandi had several fears consisting of fear of judgement by others and family. For this reason she chooses to conceal her diagnosis from wider society. She felt her parents were overprotective whilst she was a teenager, isolating her from other peers. She describes significant tensions within the family home at the beginning of her symptoms until she moved out, with anger over medication having to be used and her being unable to go to work and function the way other her age were. Although she felt others in society had the ability to strip her of her identity and force her into the role of a patient, she maintained a close and trusting relationship with her EIS team. She felt able to open up to them and described her

experience of receiving information on the diagnosis as a positive one, with regular group sessions allowing for learning, connection and shared experiences with other service users, and non-judgemental support.

Jet

Jet describes her experience as feeling real initially and believing there was a connection to childhood trauma involving abuse by an uncle. She believed others were talking about her, leading to what she describes as bad behaviour e.g. walking into other's apartments to see why they were speaking about her, and used reality testing with others as a way to determine what was and was not real. Her symptoms were triggered by a police report she made regarding her uncle and cutting contact with family who did not believe her childhood trauma. As she used to take drugs, people around her deemed her behaviour to be drug related. Once in services, she describes how she was never informed of her diagnosis and instead saw it on a piece of paper. However, the diagnosis made sense to her and allowed her to make sense of her experiences. She has a positive relationship with her EIS team and feels validated and understood by them, leading to feelings of relief.

Jet experiences testimonial injustice and disbelief in general areas of her life. Specific to the diagnosis, her partner questions her behaviour and questions whether she's experiencing symptoms. More generally, people around her believe she is lying about the diagnosis in itself and is using it as a cover for her behaviour when she is on drugs. Similarly, when communicating with a worker from the DWP, she also felt her diagnosis was not believed and that instead she was being treated as if she was lying in order to benefit from society. Lack of belief and validation from others in society caused feelings of loneliness and could potentially trigger symptoms. She steers away from questions that could lead to discussion of the diagnosis and conceals this for both her own sake and the other's sake e.g. it being a hard thing for them to deal with. However, she can relate to others with similar experiences and feels connected to them.

Appendix 24

Complete Example of Personal Experiential Themes, Themes, and Subthemes for Christine

1. THE OTHER AS A MONITOR OF SOCIETY
1. THE OTHER IS SIGNIFICANT FOR MONITORING BEHAVIOUR AND DETERMINING NORMALITY
The Other is significant for determining normality – p1, 6-11 *People um, in my family for exam-example, they uh started noticing a change in my behaviour. Um I was not um able to kind of sit in the same place uh for-for any extended period of time, uh more than a few minutes, I suppose. Um I would be talking um about things that were a bit, [tuts] kind of a bit um, a bit disturbing, I suppose, to them.*
Inability to function is a sign of something wrong in society – p1, 13-17 *Um yeah, I wasn't able to work very much. So, it goes back to where I was saying I wasn't able to sit for very long and concentrate on one thing. Um yeah, I think those are the first, the first signs. Oh and um eating as well. I, I wasn't really eating much at that time.*
Others determine what is normal and not normal in society – p16, 572-580 *But they were just advising against it…Because I think at that time they were just wanting to focus on my recovery, so uh being able to monitor me from home. And yeah, not do anything kind of different or drastic. Just keeping to a routine.*
The Other monitors behaviour and judges what is normal and abnormal via a medical lens – p12, 415-422 *So, this would have been on the tail end of me being unwell. Um so, if I was to ever [sighs] um, do anything that was a bit out of the ordinary or be insistent on something, then they would kind of be triggered and start asking more questions and say, 'you know you used to be like this,' et cetera, and-and, 'you know the symptoms of psychosis are this and this is how you're behaving,' kind of thing, to-to line them up basically. So, that's, it's not really conversation, it's to bring it up, yeah*
Monitoring by the Other causes behaviour changes – p13, 447-452 *It-it's, it is like walking on egg-eggshells around them. So, I'm aware that they, they're literally kind of hanging on my every word [laughs]. Um and watching my behaviour. Uh just to kind of see if there's anything that I say that could link me back to that uh that season in my life.*
Overprotection and infantilisation as a way for the Other to monitor behaviour – p12, 438-441 *Um a bit um [tuts] kind of, uh what's the word now? A bit in cotton wool, like wrapped in cotton wool, protected and-and shielded.*
1.2 HAVE TO PROVE YOURSELF AS A FUNCTIONING MEMBER OF SOCIETY TO BE TAKEN AS A PERSON AND NOT A DIAGNOSIS
The Other monitoring behaviour dehumanises and strips her of her identity – p12, 437 *I-I felt funnelled again into the diagnosis. Uh less human*
Have to prove yourself as a functioning member of society to be taken as a valid, legitimate person instead of as a diagnosis – p13, 473-481 *I think that now that time has gone on a little bit and I've proven that I'm able to go back to work, I can be reliable at work, uh take care of myself and be in charge of where I move to and things um consistently. I think things are starting to get back to normal. Uh so, I'm able to present an idea and for it to be taken seriously rather than uh taken and s-something to be um dissected and investigated. Um and-and maybe labelled as something to do with a symptom. So, it's just taken now, it's just taken as um an idea.*
Has to prove herself as a functioning member of society to be considered valid by the Other and not viewed as a diagnosis – p14, 500-504 *I do feel like I have to control my behaviour. Like, to still show that I'm, I'm not that anymore. Um that I'm well, if you want. Um and I really hate that phrase [laughs]. Uh but, yeah, just-just to-to say that um I'm valid on my own now, that I don't need to be associated with that, and I'm still able to-to make a valid contribution*
The Other's perception of someone who is labelled with a diagnosis is dehumanising and strips you of your identity – p6, 216-219 *I'm very aware that anyone who has a label um, everyone sees them through that label. So, I didn't feel from that point um very um, like human, to say it like that. It-it's a bit harsh to say it like that, but I-I just felt like I was my um diagnosis and that's it*

2. EIS (THOSE WHO UNDERSTAND) VS OTHERS (WIDER SOCIETY = THOSE WHO DON'T)
2.1 RELATIONSHIP WITH EIS WAS POSITIVE AND SUPPORTIVE
Able to discuss anything with EIS – p10, 368-369 *Um thinking back to it, it kind of feels like a relief to be able to talk about something different for a bit*
Positive, supportive relationship with EIS team – p10, 351-362 *Um I've left the services now, but that was recently. Um so, whereas, in the beginning, I was quite sceptical. I think now I'm more likely to be able to go to them in, w-when I'm having any kind of concern, whether it's a big concern or a small one. I'm more likely to be able to-to go to them now. From my own point of view, like. Um so, they al-, they've always been there and they've said from the beginning that uh, th-they'll be help, there to help, and they have and so I've built up trust with them, uh and, I, and can say that I'm more likely to now.*
Conversations unrelated to diagnosis can help build trust between coordinator and patient – p11, 371-381 *Um and I feel like they-they understand that and so, from, differently from, speaking about my care coordinator, that's-that's what she would do. Um a lot of the time, just-just make normal conversation. Um but-but then also cover the bases that I think she would have been um told to or uh from her practice, that she would have to cover as well. Like, how are you doing at work? Are you eating? Are you sleeping? Um are you doing anything in your free time or what are you doing? Those kind of questions. But then uh, as-as you kind of build up that relationship and those things are out of the way, then you-you've got time to talk as well*
2.2 CONCEALING DIAGNOSIS FROM OTHERS FOR THEIR SAKE AND OWN SAKE
Concerns around discussing experience due to the negative effects on others – p11, 399-400 *No. I don't think i would want to bring it up for them, because I know that it was quite a painful time for them*
Concealing diagnosis from others, but accepting medical interpretation – p9, 324-328 *So, the first time I think I probably would have said something like, 'I was unwell for a year and a half.' Um 'I was absentminded for a year and a half, like I was um out of work for a year and a half,' but I wouldn't specifically say why*
Others are more wary and change the way they communicate after diagnosis – p14, 484-492 *Um even people who I could clearly see that had been talking to my family members um, and then they've-they've obviously told my-my friends or the people around me that this is going on, they're kind of uh tiptoeing around me. Most of them, not all of them. It is isolating. I-I just wanted to have a normal conversation. And I deserve to ha-, I'd find myself rolling my eyes a lot at their uh responses or lack of.*
Doesn't open up about experiences to others – p7, 237-256 *It's more like um, we-we kind of both knew that we had psychosis and that was about it. We didn't really talk about it at all…They knew I'd been through, through the services and um I've, I've had uh support and things like that, but I, I don't really speak about my specific experiences.*
Difficulty from others in knowing how to respond to experiences – p8, 264-271 *Um it was more of a, more of a point of listening. Um so, it's hard to know, I-I get it, It's hard to know that, uh what to say in that, that scenario. So, they didn't really give much um much response, but their response was questions. Um… I think more to do with how I felt about that or how I am now. Um… how it kind of, how long I was, I was unwell for. Um yeah. I think those are the only questions that I can think that they asked, like specifically*

3. EPISTEMIC INJUSTICE
3.1 TESTIMONIAL AND HERMENEUTICAL INJUSTICE BY EIS AND SOCIETY
Information in healthcare is delayed – potentially hermeneutical injustice – p5, 156-160 *It was in the sessions, quite, quite late on. Maybe… um, I think about four months, I wanna say, four months. But my-my perspective on sort of time during that time was quite off. Uh but yeah, I think it was quite late on.*
Concerns over common behaviour based on diagnosis – example of testimonial injustice – p12, 426-434 *Um when, I think when um I wanted to focus on volunteering for an extended period of time. Like, I think it was a year or something and I was having a discussion with them. Um and they were saying, 'well, you-you*

can't really do that because you need to um have a living, you need to earn a living first,' and they were suggesting that that's kind of not a uh a well mindset to be thinking from. And I was kind of saying, 'yeah, but I-I've got these reasons and I really want to do it and I feel led to it and I'm trying to put my foot down here because this is what I want to do.' Um and they were kind of a bit concerned and a bit alarmed.
Experience is moulded to fit into preconceived diagnosis – p7, 234 *like I was, I was being funnelled into what they already thought*
Any unusual behaviour is all attributed to the diagnosis – p6, 198-201 *Um it was more to my family, I think. So, I was still in the room, I don't think I was being very responsive. But uh that kind of made, made the uh doctor psycholo-senior psychologist um more, more inclined to say that that's what I was experiencing to people who were listening*
Explanation / defending own interpretation is viewed as another symptom – potentially epistemic injustice – p7, 224-232 *Mm so, they would ask me. Um I-I think I relayed it as-as much as I could, as accurately as I could. Um but yeah, because, because I was so insistent on everything else, um and I was also insistent that I wasn't unwell, then I guess that they kind of saw that as uh as a symptom. That I was um, I forgot what they call it, that-that-that specific uh line of symptom, but um like, I was fixated or whatever you want to call it. Um so, I guess that was another symptom of psychosis in their um their-their eyes.*
Specific interpretations (medical) can be forced on to the individual by the Other – p6, 187-193 *Um I remember o-, they were quite insistent or suggesting that I-I had um [tuts] hallucinations and voices, but I can't say that I had the p-, the-the hallucinations and voices in the way that they were describing it. Um I couldn't say that, but I think from my behaviour, they must have thought that that's what I was experiencing. But I-I don't think I did*
3.2 DIFFERENTIATING SELF FROM IDENTITY HAS NO EFFECT ON THE WAY YOU ARE PERCEIVED
Making a point to disassociate self from diagnosis – p8, 281-283 *I said that I was uh diagnosed with psychosis. So, I wouldn't say I had psychosis, it was more, it was always to make a point that that's what they said I had*
Association with label can increase with time – p8, 285-287 *But I think now I'm starting to associate it with actually me [laughs] more recently. But then, back then I wasn't at all, I just said um, that's what they say I had*
Resigned to the power of a medical diagnosis – p8, 289-295 *Um I suppose because their, well, docs, doctor's diagnoses are generally quite reliable. Mm. Yeah. So, I-I don't know if there's any point trying to fight it because um I know that it's happened now and it's probably on my medical records. So, [short laugh] it's gonna stay there, so there's-there's no point fighting it anymore*

4. RATIONALISING THE EXPERIENCE
4.1 THERE IS A NEED BY OTHERS TO RATIONALISE THE EXPERIENCE AND GROUND IT IN REALITY
Others look for explanations to rationalise experience – p8, 274-278 *They just were keen to find out what my thoughts on that was and they would ask me um or-or prompt me to say where that came from. Whether it was caused.*
EIS was a well-rounded, holistic approach to interpretation – p9, 299-308 *I suppose I can only speak from my instance, but I think [sighs], given how thorough the process was, how much time they took over it and um speaking to people around me as well, I think it was quite holistic. Those who were able to see my, my behaviours um all hours of the day and in different s-scenarios and circumstances as well, where they couldn't be present to see it themselves. So, it's like eyewitness accounts, things like that.*
Insistence upon rationalising experience by others – p5, 144-148 *They-they just spoke about uni basically…Uh i-it kind of came across, well, came out through uh my um sessions with them. Uh so, that was something constant that they kept asking me about. Um.. yeah, so that came up a lot*
Experience is rationalised by the Other as grounded in reality – p4, 126-135 *they um kept referring back to university. Um I think what the impression I got was that they think it was me, to do with being um isolated for, for a-a long time. Um and then suddenly being thrown back into the world. Uh so, like being isolated at university, uh used to one set of things, and then being thrown out into-into the life and life not going exactly how it was regimented in university. Um and then I kind of got stressed and*

overwhelmed. Wasn't able to deal with it and then that happened, so. I think that's-that's what they were trying to get at
Immediate response from others to her behaviour was to see a medical professional – p11, 404-407 *Um I remember my family saying that um in conversation with other people that they knew in, if you-if you um have experience with mental health um, whether through work or personally, uh they were saying to get me in to a specialist*
Family intervened quickly with a medical approach to her behaviour – p2, 35-40 *Um I'm not sure who stepped in, but all of a sudden, I just knew that one of the, well, my-my care coordinator, who was my care coordinator, um I was introduced to her for the first time. Um and then, after that various members of-of the rest of the team. Um so, senior psychologists and um mental specialist, people like that. Um yeah, so that was, that was in uh, I think was a short time.*
4.2 INTERPRETATIONS ARE NOT FIXED AND ARE SUBJECTIVE
Different subjective ways of viewing the experience means it's a matter of perspective i.e. fixated vs determined – p1, 23-32 *Um being fixed on uh pleasing, pleasing God in a specific way. Um like, I, I have to do this and I have to do that and um not really giving myself a choice in that. Things like that… So, I just thought I was doing the right thing and kind of following what I knew was right um and nothing could-could sway me from doing the "right thing," in inverted commas [laughs]. Um it, yeah, I-I didn't feel any different really. I just felt really determined and really driven and to me, it seemed like a, quite a positive thing*
Interpretations are not rigid and they can change in time – p6, 187 *Um looking back, I think it was quite accurate*
There is a perception of psychosis and its symptoms that she can't relate to – p6, 206-210 *Um… the-the, from my memory, I don't remember having any kind of hallucinations at all. Um I was present-minded, like I was, I was in the moment, I knew um that what I was experiencing was definitely reality. There wasn't any kind of uh weird sightings or-or a dre-, um hallucinations. Like, I knew that it was 100% um how it was at the time*
4.3 RATIONALISES EXPERIENCE AS A POSITIVE WAY OF COPING IN AN UNPREDICTABLE WORLD
Disconnect between expectations of life and reality can trigger unusual experiences – p3, 73-81 *Uh I think because, I know now that it was because I wasn't really um getting the answers that I knew I needed um back then. So, I was fresh out of university and kind of things weren't going as expected. I had expected to be in a job um straight away. Um and expected to be in the job that I wanted exactly. Uh whereas, it took me, I think about a year and a half, to get a job. Maybe two years. And, and it wasn't anything to do with what I wanted to do. Um and I know now that I was pretty much, kind of giving up on my whole ideas and of-of like things that I knew, how life worked, if that makes sense*
The experience can be a positive thing and take away from the ambiguity in the world – p3, 96-98 *It-it was a rush. It was a real rush. Um so, it, in a way it was quite fulfilling. Like, I knew what I had to do, I did it, and there was no in-between. Like, I, it was instant gratification really*
The experience was positive and isn't necessarily harmful to the person – p2, 64-70 *Um I just thought I had yes, fixed views, but in the right direction. Um like I said, I didn't think that there was anything or much wrong at all. Um I-I just felt that I knew what I needed to do and was just carrying it out. And really focused on that*
The experience can be a way of coping in an unpredictable world – p3, 83-85 *I was kind of giving up on um life in a way and opting for something that I knew was a failsafe, which was my faith. Um which I still stand by*

Appendix 25

Complete Example of Group Experiential Theme 1 (Clinical Group)

2. MAKING SENSE OF EXPERIENCE VIA RESEARCH AND ROOTING IT IN REALITY
2.1 RATIONALISES EXPERIENCE AS LINKED TO TRAUMA AND SUBSTANCE USE
Finding own ways to understand experience – p13, 454-458 *It's-it's like, there are periods obviously of loss of insight and then comin' out of hospital, there was no insight for.. a good few months. Umm but yeah, when in the terms, in the times of insight it was just sort of, for me, research, research, research. To read up as much as I can about it. Learn as much as I can and just whatever I can do to recover*
Repressed traumas express themselves as symptoms – p4, 131-134 *So, if you ask me, if you could ask me about it and it, I'd-I'd just have no idea what you were on about. Uh so those sort of things came out through, so it was an expression, almost an expression of the subconscious where they was sort of there, they came through and expressed*
Links trauma to triggering of symptoms - 5, 154-158 *I just sort of, I'll give this as an example, so it had been happening, psychologically speaking, over a long time, that sort of thing, and mixed with trauma, so I would see a lot of violence and that sort of thing, a lot of uh psychological gaslighting, that sort of thing. All those things were a-a while and then sort of culminated in that uh..*
Understands his experience as relative to past traumas – p4, 124-127 *...the trauma, past traumas really sort of wrapped up and got entangled and became messed with and it was often past traumas that, was sort of past at the time so, that hadn't been really come out and been explored.*
The internal monologue disconnects from reality and interacts with symptoms instead – p5/6, 174-186 *it's sort of you unable to think properly. So the actual internal monologue is completely disrupted and I'm not sure, I haven't read much of the literature, but um that's like a really crucial thing is that the thought process is not, does not take place because the internal monologue is disconnected from normality, or whatever the proper word is for it. So it's so disconnected from that, that it just revolves around the symptoms and responding to them and-and like getting stuck on them. So, there's definitely an aspect where a symptom will happen and then for the next ten minutes, you'll be sort of stuck on it and that is the thoughts that are going on instead of a normal internal monologue like, 'oh, what shall I have for dinner? What-what's uh what's on the TV? Oh, this girl,' that sort of thing. But instead of that, it would just be revolving around those positive symptoms.*
Makes sense of his experience as being caused by trauma, stress, and substance use – p12/13, 444-447 *Uh I believe it is just the cannabis and the trauma, so two.. and there's the stress that comes along with that. All two, three of those factors um sort of are what ha-, made it happen, to be honest*

4. RATIONALISING THE EXPERIENCE
4.1 THERE IS A NEED BY OTHERS TO RATIONALISE THE EXPERIENCE AND GROUND IT IN REALITY
Others look for explanations to rationalise experience – p8, 274-278 *They just were keen to find out what my thoughts on that was and they would ask me um or-or prompt me to say where that came from. Whether it was caused.*
EIS was a well-rounded, holistic approach to interpretation – p9, 299-308 *I suppose I can only speak from my instance, but I think [sighs], given how thorough the process was, how much time they took over it and um speaking to people around me as well, I think it was quite holistic. Those who were able to see my, my behaviours um all hours of the day and in different s-scenarios and circumstances as well, where they couldn't be present to see it themselves. So, it's like eyewitness accounts, things like that.*
Insistence upon rationalising experience by others – p5, 144-148 *They-they just spoke about uni basically...Uh i-it kind of came across, well, came out through uh my um sessions with them. Uh so, that was something constant that they kept asking me about. Um.. yeah, so that came up a lot*

Experience is rationalised by the Other as grounded in reality – p4, 126-135 *they um kept referring back to university. Um I think what the impression I got was that they think it was me, to do with being um isolated for, for a-a long time. Um and then suddenly being thrown back into the world. Uh so, like being isolated at university, uh used to one set of things, and then being thrown out into-into the life and life not going exactly how it was regimented in university. Um and then I kind of got stressed and overwhelmed. Wasn't able to deal with it and then that happened, so. I think that's-that's what they were trying to get at*
Immediate response from others to her behaviour was to see a medical professional – p11, 404-407 *Um I remember my family saying that um in conversation with other people that they knew in, if you-if you um have experience with mental health um, whether through work or personally, uh they were saying to get me in to a specialist*
Family intervened quickly with a medical approach to her behaviour – p2, 35-40 *Um I'm not sure who stepped in, but all of a sudden, I just knew that one of the, well, my-my care coordinator, who was my care coordinator, um I was introduced to her for the first time. Um and then, after that various members of-of the rest of the team. Um so, senior psychologists and um mental specialist, people like that. Um yeah, so that was, that was in uh, I think was a short time.*
4.2 INTERPRETATIONS ARE NOT FIXED AND ARE SUBJECTIVE
Different subjective ways of viewing the experience means it's a matter of perspective i.e. fixated vs determined – p1, 23-32 *Um being fixed on uh pleasing, pleasing God in a specific way. Um like, I, I have to do this and I have to do that and um not really giving myself a choice in that. Things like that… So, I just thought I was doing the right thing and kind of following what I knew was right um and nothing could-could sway me from doing the "right thing," in inverted commas [laughs]. Um it, yeah, I-I didn't feel any different really. I just felt really determined and really driven and to me, it seemed like a, quite a positive thing*
Interpretations are not rigid and they can change in time – p6, 187 *Um looking back, I think it was quite accurate*
There is a perception of psychosis and its symptoms that she can't relate to – p6, 206-210 *Um… the-the, from my memory, I don't remember having any kind of hallucinations at all. Um I was present-minded, like I was, I was in the moment, I knew um that what I was experiencing was definitely reality. There wasn't any kind of uh weird sightings or-or a dre-, um hallucinations. Like, I knew that it was 100% um how it was at the time*
4.3 RATIONALISES EXPERIENCE AS A POSITIVE WAY OF COPING IN AN UNPREDICTABLE WORLD
Disconnect between expectations of life and reality can trigger unusual experiences – p3, 73-81 *Uh I think because, I know now that it was because I wasn't really um getting the answers that I knew I needed um back then. So, I was fresh out of university and kind of things weren't going as expected. I had expected to be in a job um straight away. Um and expected to be in the job that I wanted exactly. Uh whereas, it took me, I think about a year and a half, to get a job. Maybe two years. And, and it wasn't anything to do with what I wanted to do. Um and I know now that I was pretty much, kind of giving up on my whole ideas and of-of like things that I knew, how life worked, if that makes sense*
The experience can be a positive thing and take away from the ambiguity in the world – p3, 96-98 *It-it was a rush. It was a real rush. Um so, it, in a way it was quite fulfilling. Like, I knew what I had to do, I did it, and there was no in-between. Like, I, it was instant gratification really*
The experience was positive and isn't necessarily harmful to the person – p2, 64-70 *Um I just thought I had yes, fixed views, but in the right direction. Um like I said, I didn't think that there was anything or much wrong at all. Um I-I just felt that I knew what I needed to do and was just carrying it out. And really focused on that*
The experience can be a way of coping in an unpredictable world – p3, 83-85 *I was kind of giving up on um life in a way and opting for something that I knew was a failsafe, which was my faith. Um which I still stand by*

1. MAKING SENSE OF EXPERIENCES
1.1 SENSE MAKING AND TREATMENT IS DEPENDENT UPON INDIVIDUAL CULTURE / BELIEFS

Religious interpretation considered but not well understood – p4, 126, 131 *I didn't understand why it was happening to me. Uh I thought that it had to do with the devil. I thought that the devil had put demons inside me and that was causing me to have a breakdown*.
Different cultures have their own way of interpreting experiences and removing the problem – p5, 162-167 *Yeah if, yeah if they believe it is a spiritual thing, what they do is they-they pray for you a lot. So, they do a lot of praying, but they don't go to the doctors to get the help because they don't think that it's an illness. They think that it's got to do with the devil*
Culture and upbringing has an effect on beliefs regarding unusual experiences and treatment – p5, 173-179 *So, because my mum, my mum's Black South African and my father's White British. So, with my mum, she believed that it was a spiritual thing. With my dad, he knew that it was a mental illness. So, what happened is my mum got me to get some, got people to pray for me, from my country. And then on the other side, my dad, he took me to the GPs and got me help*
Different cultures provide different ways of making sense of experience - p18, 644-649 *Yeah, my mum understood and uh my mum's side of the family, they all understood. But my dad's family, side of the family, they're White British, so um they-they-they knew that it was a mental illness. But because of my mum's side of the family, um I was a bit unsure, I was a bit 50/50. Like, a part of me thought um it's spiritual, another part of me thought it's a m-, psy-, it's a mental illness*
Type of treatment is dependent on individual beliefs / culture – p12, 417-425 *Um I think it's important to follow religion. Um the people in South Africa, they still believe that it's got to do with the devil and the demons. They've, they still believe that and they're the reasons why I believed that at the start before I got help. So, they still stick to that, they still believe that it's got to do with the devil and it's a spiritual thing, and you can only get better if you get prayers, and that's all that you need, and you don't need to go to the doctors. And like, a lot of the time in South Africa, when someone's unwell, they go, they go, they go to the priest first , before they go to the hospital and get help*
Cultural beliefs and medical treatment does not have to be mutually exclusive – p12, 430-434 *I believe that sometimes prayer doesn't always work. Sometimes you need to actually go to the doctors and you need to take the medication and that's-that's the way that you can recover. But in my culture, they just believe that it's a, it's a spiritual thing*
Medical treatment was a second option to religious treatment – p21, 751-753 *And when I got back, my dad was like, 'right, she needs to go to the GP now. Because this is getting out of hand.' And so we went to the GP, and um now, I'm here*
Attempted to recover from experience using religious treatment as a first resort – p20, 746-749 *Well, what happened was, my mum sent me to South Africa for about five months. So, I could, I could get all the prayers and that*
Religious treatment is also essential for her recovery – p20, 738-741 *Um I pray every day. Um my mum prays for me. Um yeah. And I feel as if being close to God is another reason why I've been able to recover*
Religious treatment was not enough to treat experience – medical treatment was a second option – p21, 768-777 *What happened there was I was sent to the [tuts], I was sent to the, in my culture we have what you call um traditional healers. So, what they do is that they're praying, praying, praying like non-stop for you. And the traditional healer said that it's a spiritual thing and it's got to do with demons and it's got to do with the devil. And um yeah, that's what they said. And I had-, my mum had to pay them money to pray for me, 'cause well, they charge money and that, the-the traditional healers, so you have to pay them to help you. So, I spent about five months there, and then for non-stop, they were just praying and praying and praying. And then I came back to the UK, and then my dad said, 'right, it's time that she goes to a GP now*
Religion is still significant in her life, even if medical support is needed instead of prayers – p12, 415-417 *Um I think prayer is important. It's important to be close to God. Not just when you're unwell, but whe-, really just in general. Its important to have a relationship with God*.
Believes in both own religious interpretation and medical interpretation towards treating experience – p21, 780-786

I think that, I think that it's 50/50 with my point of view. It's 50/50 because 50% there were, one of the reasons why I recovered as quickly as I have is because of the prayers. And then 50% is because of the medication. So, I'm in between really

1.2 TRYING TO FIND ANY WAY TO MAKE SENSE OF THE EXPERIENCE (SOCIETY / OTHER MENTAL ILLNESS / RELIGIOUS / MEDICAL)

Interpreted experience as due to over-exposure to poor mental health from others – p2, 53-60

Uh I volunteered there for about a year and whilst volu-volunteering at the [redacted: mental health service], I wasn't, I got involved with uh people that were um suffering from mental health problems. And at that st-, and I think maybe that had an um an-an impact on me. It had an-an affect on my mental hea-, on my mental health. I'm not saying that I blame the patients that I worked with for my own mental health problems, but I think that's when it began

Experience of working within mental health and observing patients contributed to negative understanding of psychosis – p16, 571-582

Um basically, when I was volunteering at the [redacted: mental health service] in [redacted: area], um some of the patients were very aggressive towards the staff. So, I think that was one of the reasons why I had that opinion. And some of them would stay in uh hospital for a while, and I thought that maybe if you're going to hospital, you have to stay in hospital for the rest of your life. I didn't know that you can recover and you can go back home and-and get your life back on track. I didn't know that. I never knew that, but when I went, started to get help, I started to learn a lot about my mental health. Not just about my mental health, but about different kinds of mental health problems as well

Interprets experience as rooted in reality – past traumas caused negative experience – p3/4, 97-119

I think it was happening because I've had some really bad experiences in my life. Um I got bullied at secondary school really badly. Um 'cause what happened was, I went to, how do I put this? Basically, I went to secondary school in [redacted: area], and like, all the kids knew each other from primary school. They'd all gone to the same primary school, they'd been to secondary school, they had already formed their friendships. Whilst me, I went to school in [redacted: area], I went to a primary school in [redacted: area], and then my family moved into [redacted: area] and then I was in secondary school in [redacted: area]. So, I didn't really know anyone. So, I didn't have any friends, but I did try to make them. But they just, they wasn't interested in making friends with me, they didn't want anything to do with me, because they already had their friendships. Do you know what I mean? And then, so like, I was singled out a lot of times. Like, for example during P.E. I was always the last one to get chosen, um and lessons where people had to be in groups, I was always the last one to be chosen. At lunchtimes, I'd always sit alone, no one would wanna engage with me, no one would wanna sit with me. People would pick on me because of the colour of my skin, 'cause I'm black. Um people would just like, they were very judging

1. RATIONALISING EXPERIENCE AS GROUNDED IN REALITY

1. RATIONALISES EXPERIENCE AS CONNECTED TO TRAUMA

Experience explained as stress from past trauma – p5/6, 181-184

I didn't know much about psychosis at the time. Um I just, it was explained to me that due to the trauma that I'd experienced and reliving that trauma when I'd gone to the police station, um that that could have triggered off um sort of the early warning signs.

Made sense of experience as related to trauma in her past – p1, 25-27

I thought that I um, I-I thought I was hearing and seeing things um that were related around a trauma that I'd-I'd experienced as a child. Um so, what I was hearing and seeing, I thought it was true.

Rationalising the behaviour as drug-related – p7. 230-234

It was hard because I couldn't explain to people what was going on and the people closest to me thought that it was drug-related, you know. And at the time, I was taking a copious amount of-of drugs at the time, I'll eb honest with you. Um and so, I used to go to a drug and alcohol service.

Accepting any explanation as long as it's a way for her to understand the experience – p5, 165-166

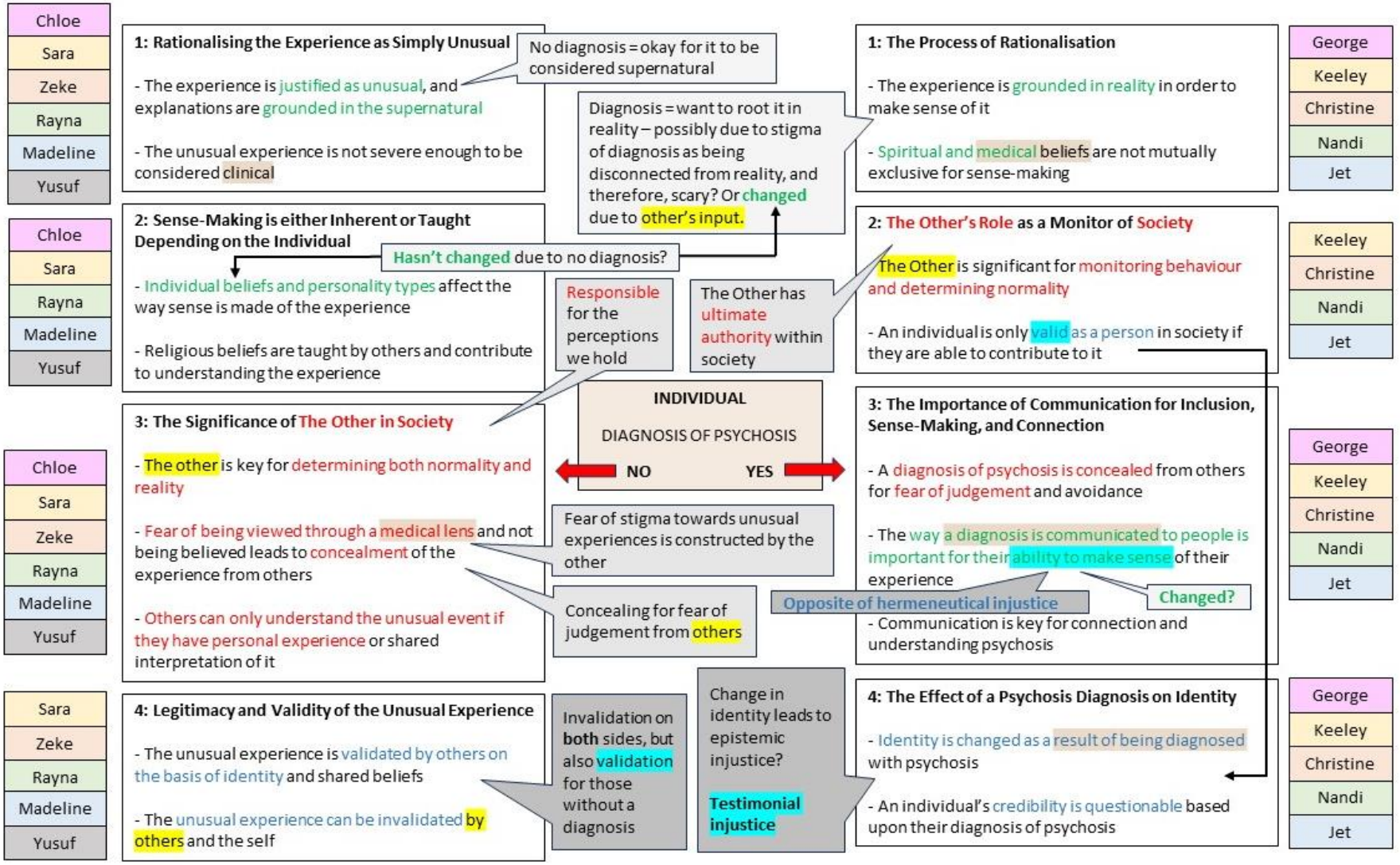
Um I didn't wanna believe it. But I had to because it was the only explanation to what was happening around me.

Made sense of experience as triggered by recounting past trauma (brain is the reason) – p17, 627-630

But it has, it has taken its toll on me and by going to the police, just brought something else up to the surface. You know, in my brain
Rationalising the experience as grounded in reality makes it feel real – p3, 78-79 *Because it was all focused around the-the trauma that I'd been through as a child, um that's why I thought, that's why I thought it was real*
1.2 OTHERS RATIONALISE EXPERIENCE AS GROUNDED IN REALITY
Experience interpreted by others as stress and grounded in reality – p4, 143-144 *She, she explained to me that I was, this is, I was extremely stressed. Um and she'd asked me about my past.*
Others rationalise their experience in the same way – psychosis is triggered by reality – p9, 301-303 *My friend uh, uh the one who calls it classroom 12, um she went through some traumatic stuff in her life and she believes that that was the trigger for psychosis she experienced.*
Others rationalise experience as substance use based upon what they know about her – p10, 357-358 *they just thought I was, I was either high on drugs or just like having a moment, you know.*

Appendix 26

Analysis of Datasets For the Multiperspective Approach



Appendix 27

Prisma Flowchart for Search Strategy

