

**"At the time I didn't know what was going on, so  
they diagnosed me with schizophrenia".**

**The lived experience of being diagnosed with  
schizophrenia for people of Black African and/or  
Black Caribbean heritage: An Interpretative  
Phenomenological Analysis.**

**Abigail Gordon**

A thesis submitted in partial fulfilment of the requirements of the University of East London  
for the Professional Doctorate in Counselling Psychology

University of East London

September 2020

## **CONTENTS**

Acknowledgements .....	i
Dedication .....	ii
Abbreviations .....	iii
Quote from participant .....	iv
<b>Abstract</b> .....	<b>1</b>
<b>Introduction</b> .....	<b>2</b>
Research terminology .....	2
<b>Literature Review</b> .....	<b>5</b>
Overview .....	5
Literature search strategy .....	5
Definition of psychiatric diagnosis .....	5
The current context of diagnostic systems.....	6
Counselling psychology and psychiatric diagnosis .....	7
Advantages and disadvantages of using the diagnostic system .....	10
Definition of schizophrenia .....	11
Statistical research on the rates of schizophrenia .....	13
The bio-medical model of mental and emotional distress .....	13
Schizophrenia .....	14
Non-Western cultural explanations of psychosis .....	15
Psychiatric imperialism .....	15
African and African-Caribbean people in the mental health system in the UK ..	18
The lived experience .....	22
Relevance to counselling psychology and rationale .....	24
<b>Methodology</b> .....	<b>28</b>
Introduction .....	28
A qualitative approach .....	28
Epistemology .....	28
<b>Methodological framework</b> .....	<b>29</b>
Alternative methodologies .....	29
<b>Interpretative Phenomenological Analysis (IPA)</b> .....	<b>30</b>
<b>Design</b> .....	<b>30</b>
Sampling framework .....	31
Participant inclusion and exclusion criteria .....	32
Recruitment of participants .....	32
The participants .....	33
<b>Data collection</b> .....	<b>34</b>
Pilot interview .....	34
Procedure .....	34
Data collection .....	35
Transcribing the interviews .....	36
<b>Efforts to promote quality and validity in the research process</b> .....	<b>36</b>
<b>Ethical considerations</b> .....	<b>36</b>
Ethical approval .....	37
Ethical approach .....	37
<b>Analytic strategy and procedure</b> .....	<b>41</b>
Summary .....	42
<b>Analysis</b> .....	<b>43</b>
Introduction .....	43

Overview of super-ordinate themes .....	43
<b>Super-ordinate theme one: Schizophrenia is a social control.....</b>	<b>46</b>
Summary .....	56
<b>Super-ordinate theme two: Living with schizophrenia is a dynamic sentence.....</b>	<b>56</b>
Summary .....	65
<b>Super-ordinate theme three: “A spiritual dimension to this experience” .....</b>	<b>65</b>
Summary .....	70
<b>Super-ordinate theme four: Being Black with mental health issues .....</b>	<b>70</b>
Summary .....	74
<b>Discussion .....</b>	<b>75</b>
Introduction .....	75
<b>Schizophrenia is a form of social control.....</b>	<b>76</b>
<b>Living with schizophrenia is a dynamic sentence.....</b>	<b>80</b>
<b>“A spiritual dimension to this experience” .....</b>	<b>83</b>
<b>Being Black with mental health issues .....</b>	<b>84</b>
<b>The role of language and metaphors in IPA research .....</b>	<b>86</b>
<b>Limitations .....</b>	<b>87</b>
Limitations of IPA .....	87
Limitations of the current study .....	87
<b>Reflexivity .....</b>	<b>88</b>
<b>Implications for counselling psychology and other allied fields .....</b>	<b>90</b>
<b>Suggestions for further research .....</b>	<b>94</b>
<b>Conclusion .....</b>	<b>95</b>
<b>References .....</b>	<b>98</b>
<b>Appendices .....</b>	<b>131</b>
<b>Appendix 1</b> Ethics review decision letter .....	132
<b>Appendix 2</b> Request for title change to an ethics application .....	137
<b>Appendix 3a</b> Approval letter from service 1 .....	141
<b>Appendix 3b</b> Approval letter from service 2 .....	144
<b>Appendix 4</b> Example of research poster .....	146
<b>Appendix 5</b> Interview schedule .....	148
<b>Appendix 6</b> Example of participant information sheet .....	150
<b>Appendix 7</b> Consent form .....	155
<b>Appendix 8</b> Debriefing sheet service .....	157
<b>Appendix 9</b> Entry from my research journal .....	159
<b>Appendix 10</b> Example transcript of interview with Kwame .....	161
<b>Appendix 11</b> First case analysis – Marcie .....	164
<b>Appendix 12</b> Marcie’s initial list of themes .....	166
<b>Appendix 13</b> Picture of initial clustering of super-ordinate and sub-ordinate themes .....	170
<b>Appendix 14</b> Master table of super-ordinate themes and frequency .....	172
<b>Appendix 15</b> Efforts to promote quality and validity in the research process .....	174

## **Acknowledgements**

Firstly I would like to thank all of the eight participants: Peter, Sandra, Marcie, NSNG9, Glendora, Roy, Mary, Kwame and He-Man (pilot interview) who chose to take part in my research project. Without your engagement and participation the research would not have taken place.

I would like to thank my research supervisor Dr Claire Marshall for her interest in my research topic, support and critical guidance throughout the research journey.

I would like to thank Dr Pavlos Filippopoulos for his ongoing support. I would like to thank my family and friends who have been amazing over the last few years. I would like to specifically thank my sister Dawn, for her continuous support and being my personal cheerleader. You have witnessed the highs and the many lows on this path of becoming a counselling psychologist. To the One who loves unconditionally and brings peace to my soul. Thank you.

## **Dedication**

In loving memory of *Winston Harry Gordon* and *Clytie Jeanne Gordon*.

## Abbreviations

AESOP	Aetiology and Ethnicity in Schizophrenia and Other Psychoses
APA	American Psychiatric Association
APA	American Psychological Association
BAME	Black, Asian and Minority Ethnic
BME	Black and Minority Ethnic
BPS	British Psychological Society
CPN	Critical Psychiatry Network
DCoP	Department of Counselling Psychology
DCP	Department of Clinical Psychology
DSM	Diagnostic and Statistical Manual of Mental Disorders (Version 5)
HVN	Hearing Voices Network
ICD-11	International Statistical Classification of Diseases and Related Health Problems (Version 11)
ONS	Office for National Statistics
ISL	Inquiry into ‘Schizophrenia’ label
ISPS	International Society for Psychological and Social Approaches to Psychosis
NHS	National Health Service
NIMH	National Institute of Mental Health
UK	United Kingdom
WHO	World Health Organisation

*“...All I wanted is someone to talk to... and tell them about the voices in my head. So they call it schizophrenic. That’s what they call it. But even though they call it that, I just say “I hear voices, bad voices in my head”, but they call it schizophrenic”.*

(Glendora, participant)

## **Abstract**

Schizophrenia has long been a contested and controversial psychiatric diagnosis. Over the last six decades, research has consistently demonstrated that Black, Asian and Minority Ethnic (BAME), specifically people of Black African and/or Black Caribbean descent in the United Kingdom (UK) are more likely to face mental health inequalities and be diagnosed with schizophrenia in comparison to other ethnic groups (Fernando, 2002; 2008; 2010; Read & Dillon, 2013b; Nazroo, 2020). However there has been a paucity in research into the lived experience of receiving a diagnosis of schizophrenia. This research seeks to contribute to the field of counselling psychology and allied professions by exploring the lived experience of receiving a diagnosis of schizophrenia amongst this specific population. The phenomenon was investigated by adopting Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009). Semi-structured interviews were conducted with eight participants and subsequently analysed using IPA. The Six-Stages of Analysis was used (Smith et al., 2009) as a process of interacting with the data within an inductive and iterative cycle (Smith, 2007). The consisted of close interaction between the researcher and the text, using line-by-line analysis of each participant's transcribed interview (Smith et al., 2009). The findings revealed that participants were engaged in a range of meaning-making processes regarding their experiences relating to the diagnosis. Four super-ordinate themes emerged from the data: 'Schizophrenia is a form of social control', 'Living with schizophrenia is a dynamic sentence', "A spiritual dimension to this experience" and 'Being Black in the mental health system'. The findings highlighted that receiving a psychiatric diagnosis is not a static event located at one point in time. Rather it is a multifaceted process that is engaged with by the recipient on multiple levels beyond the diagnosis. The implications for Counselling Psychology and allied fields are reviewed, as well as limitations and suggestions for future research were discussed.



## **Introduction**

Mental health inequalities amongst Black African and Black Caribbean communities have been consistent in the mental health system in the United Kingdom for over six decades (Nazroo, 2020). Black African and Black Caribbean people are more likely to be diagnosed with schizophrenia (Thomas, 2014; NICE, 2014; Nazroo, 2020). African, African-Caribbean, and South Asian people are more likely to be detained under the Mental Health Act 2017 than White British people (Thomas, 2014). A diagnosis may increase access to further intervention and explanation of the mental distress (Hayne, 2003). However, a diagnosis can also be a source of labelling and social exclusion (Hayne, 2003; Pitt, Kilbride, Welford, Nothard & Morrison, 2009). Mental health policies in the UK also highlight the inequalities of African-Caribbean people with a diagnosis of psychosis and the pressing need for this inequality to be addressed (Department of Health [DoH], 2005; DoH, 2009 & DoH, 2011).

### **Research terminology**

The following terms were used within the research and will be defined in this section. The terms ‘western’, ‘west’, ‘non-western’ and are used in reference to culture and countries. Western countries and cultures are defined as those from Australasia, Europe, Americas and American-West. Non-western countries are those characterised as Central Asia, Far East, Middle East, Western Asian, North Africa and South Asia. Cultures within these countries are referred to as non-western or eastern cultures (Thompson & Hickey, 2005).

The term ‘psychosis’ is used to cover a set of related conditions including schizophrenia, schizo-affective disorder, schizophreniform disorder, delusional disorder, non-affective psychoses, and affective psychoses (National Collaborating Centre for Mental Health, 2014). The term ‘schizophrenia’ was introduced over 100 years ago and continues to be a primary diagnostic category for the experience of psychosis in Western psychiatry. The Critical Psychiatry Network (CPN) in the UK continues to call for the diagnosis to be eliminated, citing research evidence that supports the notion that it has no scientific basis, is harmful, and leads to stigma (CPN, 2011). Critics have argued that the concept of schizophrenia should be discarded as it is not an empirically reliable or valid scientific construct (Boyle, 1990; Bentall,

2003). Schizophrenia has been chosen as the explored phenomenon as Black African and Black Caribbean people have the highest incidence in comparison to other ethnicities (DoH, 2011; Thomas, 2014; NICE, 2014; Nazroo, 2020).

There are various terms to define the sample population for this research. The terminology includes 'Black, Asian & Minority Ethnic (BAME)', 'Black & Minority Ethnic' (BME), 'Black', 'Afro-Caribbean' and 'African-Caribbean'. With reference to my use of the terminology 'African' and 'African-Caribbean' in this research project, I used these terms to describe people who are: a) Black and born in the Caribbean or in Africa and living in the UK; b) Black and born in the UK and have parents or grandparents who were born in Africa and/or the Caribbean. When citing other literature, I have used the terminology that the author has chosen. However, within the text of the thesis, I have used 'Black African' and 'Black Caribbean' interchangeably with 'Black' because it defines the ethnicity of the sample of participants. The term 'Black' refers to a person with African ancestral roots; however, there is acknowledgement that the word potentially masks differences of heterogeneous cultures within African and Caribbean populations and it risks reinforcing racial stereotypes of these groups (Agyemang, Bhopal and Bruijnzeels, 2005).

Although Black individuals of African and Caribbean descent may share the experiences of slavery and colonisation; the communities may differ from each other in terms of customs, language, diet, migration history, and beliefs (Agyemang, Bhopal and Bruijnzeels, 2005). Reynolds (2004, p. 4) highlights that in official classification systems, African and Caribbean people "...tend to be collapsed into one ethnic group. Yet, although they share the same racial characteristics and phenotype, each of these groups are culturally and ethnically distinctive". Historians have noted that people of African descent have been present in Great Britain since the third century and the Black population grew in the 1500s (Olusoga, 2016; Fryer, 1984). The term 'Black' also has political connotations and it is frequently used to describe a shared experience for those who have experienced colonial or racist oppression by British colonialism (Afridi and Warmington, 2009). For example, Asian people may self-identify as being 'Black' because of the belief that their shared experience of racism prevails over cultural differences (Institute of Race Relations, 2014).

The participant group are referred to as ‘service users’ and ‘people with lived experience’. The term ‘service user’ can stir connotations of the individual being a passive recipient of mental health services and resources. In this thesis, the terms ‘service user’ and ‘person with lived experience’ are in reference to a more active and positive representation. For the purpose of the thesis, I will refer to ‘people with lived experience of schizophrenia’ to also denote people who have received a formal diagnosis of schizophrenia.

There is a dearth of research in which the experience and significance of receiving a psychiatric diagnosis is not considered (Howe, Tickle, & Brown, 2014; Nicholas, 2012; Harrison & Gill, 2010). In relation to the research topic, the voices of African and African-Caribbean people diagnosed with schizophrenia is explicitly absent, not only in the counselling psychology field, but also allied professionals. Working in multidisciplinary settings supporting clients with psychiatric diagnoses has increased my curiosity of how to work alongside diagnostic systems that are entrenched in the medical model, whilst holding the humanistic values of counselling psychology. I have long had an interest in schizophrenia and the impact on the Black community in the United Kingdom. I was interested in exploring the subjective accounts beyond the diagnosis. This research project is an opportunity for counselling psychologists and other allied helping professionals to increase their awareness and knowledge from a phenomenological perspective of the lived experience of a diagnosis of schizophrenia for people of Black African and/or Black Caribbean descent.

There are clear gaps in knowledge and qualitative research about the subjective experience for Black people with a diagnosis of schizophrenia. The intention is to build on the wealth of information provided by epidemiological studies. I sought to explore how participants construct the meaning of receiving a diagnosis of psychosis. I chose Interpretative Phenomenological Analysis (IPA) as a suitable methodology to explore the psychological processes of receiving a diagnosis (Osborn & Smith, 1998, p. 67). IPA was used to capture the richness of the participants’ lived experience and I applied a critical realist epistemological position (Fade, 2004). While I acknowledge that there is a reality of receiving a psychiatric diagnosis that is phenomenologically experienced, individuals experience the phenomenon with multiple truths depending on the meaning they assign to them.

## **Literature Review**

### **Overview**

The purpose of this chapter is to review the existing literature and research on receiving a diagnosis of schizophrenia for people of Black African and Black Caribbean descent. There appears to be a lack of research which centres on the subjective experience of this population living with schizophrenia. There is a further gap in the use of qualitative phenomenological research such as IPA. Therefore, my objective in this chapter is to present an overview of schizophrenia as a psychiatric diagnosis in relation to Black people in the UK. The chapter will also cover the relevance of the research topic to counselling psychology and end with the research question.

### **Literature search strategy**

Relevant literature was sought through website links such as ResearchGate and Google Scholar. An electronic database search was conducted on EBSCO and PsychInfo to obtain key papers, articles, and e-books. The preliminary search strategy was developed by identifying key words and combining them to develop and create new terms. Additional references were found through searching reference lists in the relevant sources.

### **Definition of psychiatric diagnosis**

The complex nature and the implication of receiving a mental psychiatric diagnosis has been the source of controversial debate for many years. Psychiatric diagnosis is, according to Segal, Corcoran, and Coughlin (2002, p. 13), “the identification and labelling of a psychiatric disorder by examination and analysis”. Psychiatric or mental disorders, according to *The Diagnostic and Statistical Manual of Mental Disorders (DSM-5<sup>th</sup> edition)* are defined as:

“A syndrome characterised by clinically significant disturbance in an individual’s cognition, emotion regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress or disability in social,

occupational, or other important activities”. (American Psychiatric Association (APA), 2013, p. 20).

The term ‘psychiatric diagnosis’ will be used interchangeably with ‘diagnosis’ throughout the thesis. Both terms are in line with the definition above. It is not my intention to argue the line of thought that science or scientific methods have no part to play in understanding schizophrenia. However, there is a robust evidence base to indicate that the present scientific basis of psychiatry is deeply inconsistent and flawed. Any type of diagnosis is essential to the practice of medicine and therefore it is vital to address the problems of diagnosis within the psychiatry system. In psychiatry, a diagnosis is ordinarily identified and located within the medical model. The medical model is the most universally used paradigm of treatment for schizophrenia (Beresford, 2005; Lightburn, 2005) and its proponents understand the phenomenon of schizophrenia through a framework of clinical categories and diagnostic guidelines, followed by medicalisation through medication.

### The current context of diagnostic systems

The Diagnostic and Statistical Manual of Mental Disorders (DSM-V) (APA, 2013) and the International Classification of Diseases (ICD-11) (World Health Organization (WHO), 2020) are diagnostic manuals which are based on the principle that mental distress can be divided into categories of medical disorders. The first edition of the DSM was published in 1952 and comprised 106 disorders. The current edition the DSM-V (fifth edition) contains over 400 types of ‘mental disorders’ (Johnstone, 2014). The DSM and ICD are the foundation of psychiatric practice (Guerin, 2017). Boyle & Johnstone (2014) points out that the fifth edition of the DSM has created concerns and criticisms from other psychiatrists, clinicians, and the wider public. One of the criticisms of the DSM-V is that new entries such as skin-picking (excoriation disorder) may just be a habit as opposed to a psychiatric illness (Newnes, 2014; Boyle & Johnstone, 2014). Children who have more than three tantrums a week for a year are at risk of being diagnosed with ‘disruptive mood dysregulation disorder’. Boyle and Johnstone (2014) claim that there is a danger that the new conditions will lead to the ever-increasing medicalisation of everyday life; where normal responses to everyday living are turned into illnesses and treated by medication. Medicalisation “privileges drugs as the default mode of treatment for most people in psychiatric services and diagnosis can set the scene for their misuse and overuse” (Johnstone and Boyle, 2018, p. 28).

Johnstone (2014) puts forward a strong argument that distressing and confusing thoughts, feelings, and behaviours should not be classed in the same way as the signs and symptoms of a physical disease process. She states that diagnosing a mental illness actually relies on subjective judgements about 'normal' behaviour in a particular context or culture. The suggestion that "psychiatric diagnoses are based on social and not medical judgement" is an interesting point of view (Johnstone, 2014, p. 32). The statement could be perceived as highly provocative to the psychiatry profession. However, earlier critics of the validity of psychiatric diagnosis contributed to the debate in the 1960s. Psychiatrists such as R. D. Laing (1964) and Thomas Szasz (1964) also argued that mental illness is a social and moral judgement and not a valid medical concept.

There are claims that the diagnostic manuals have become a profitable business. Greenberg (2013) asserts that the American Psychiatric Association made an estimated \$100 million a year from the DSM-V. Cosgrove and Krinsky (2012) state that over two-thirds of members of the DSM-V advisory task force have been shown to have links to pharmaceutical companies. This clearly seems to be a conflict of interest for the committee members. The pharmaceutical companies have a clear mandate in increasing both the number and range of diagnoses; this puts the independence of the committee into question (Johnstone, 2014).

### Counselling psychology and psychiatric diagnosis

In 1994, counselling psychology was officially recognised by the British Psychological Society as having a unique identity and philosophy of clinical practice (Corrie & Callahan, 2000; Bury & Strauss, 2006). The unique philosophy has been succinctly summarised by Bury and Strauss (2006, p.120):

"At its core, counselling psychology privileges respect for the personal, subjective experience of the client over and above notions of diagnosis, assessment and treatment, as well as the pursuit of innovative, phenomenological methods for understanding human experience. At the same time however, we find ourselves working within mental health teams and other health-care settings, where notions of "sickness" and the associated labels that go with the concept of mental illness prevail".

Thus, counselling psychology's philosophy is grounded within humanistic values whilst incorporating scientific philosophies such as positivism and empiricism (Strawbridge & Woolfe, 2010). This positivist philosophy is one that is shared with the medical model and its proponents view knowledge and fact as substantiated only when it is observable and measurable (Freeth, 2007a). The medical model views are in opposition to those held by proponents of the humanistic position in which, according to The Association for Humanistic Psychology in Britain (AHPb, 2013), it is impossible to categorise people into separate components; people have choices, and emphasis is placed on personal growth. These contrasting views have led to a debate within counselling psychology about how counselling psychologists are positioned on issues such as diagnosis (Bury & Strauss, 2006; Milton, 2012).

The concept of diagnosis is intrinsically connected to the medical model. Within the medical model, the process of diagnosing a mental health issue is parallel to diagnosing a physical health condition. The medical model infers that mental health difficulties are 'symptoms' of an 'illness' are positioned within the individual which will lead to a diagnosis and the application of a pharmaceutical, medical or psychological treatment (Strawbridge & Woolfe, 2003; Fletcher, 2012). The medical model is dominant within the NHS which has adopted a diagnostic way of thinking and working with people experiencing mental distress. Services in the NHS comply with NICE guidelines which "define the interventions that have the most positive impact on the 'symptoms' for each diagnosis" (Fletcher, 2012, p.2). Fletcher (2012, p.2) observes that the provision of mental health services are structured around diagnostic categories and psychological therapy and pharmaceutical interventions delivered within these services are "dictated by NICE guidelines" to be targeted towards particular symptoms of that diagnostic category as defined in the DSM-V (APA, 2013) or the ICD-11 (WHO, 2020).

In the scientist-practitioner model (Lane & Corrie, 2006), there is a balance of the tension between the humanistic value-base of counselling psychology and the medical model, which is the foremost approach in healthcare settings where psychology is embedded. The NHS is a common source of employment for counselling psychologists (Bor & du Plessis, 1997), where psychiatric classification is the dominant vehicle for thought and discussion about an individual's difficulties. With many psychologists employed by the NHS, the need to manage

the tension between holding the balance of the humanistic values of the counselling psychology field and working within the structural framework of the medical model may be unearthed.

Psychologists have also contributed to the debate about the usefulness and application of the DSM-V. The British Psychological Society (BPS) made an official statement in the form of a 26-page document to the American Psychiatric Association (APA) declaring that:

‘Clients and the general public are negatively affected by the continued and continuous medicalisation of their natural and normal responses to their experiences; responses which undoubtedly have distressing consequences which demand helping responses, but which do not reflect illnesses so much as normal individual variation’. (British Psychological Society, 2011, p. 2).

The Division of Clinical Psychology also issued an official statement about its standpoint on psychiatric diagnosis. The challenge was put forward for a paradigm shift towards a conceptual system that is no longer based on a disease model (Division of Clinical Psychology (DCP), 2013). The conveyed message reinforces that alternative non-medical ways of understanding mental distress must be established (Johnstone, 2014). The alternatives to working with psychiatric diagnosis consists of psychological formulation, voicing personal accounts, and reclaiming the narrative of the diagnosis experience (Johnstone, 2014). The DCP is possibly the nearest psychology branch to counselling psychology within the BPS. Counselling psychology also has its own unique division within the BPS, however, to date, it does not have a position statement on diagnosis. This may be somewhat surprising as working with diagnostic systems and clinicians who diagnose is an inherent part of our clinical practice.

Counselling psychology’s empirical literature in relation to diagnosis has so far been limited in the UK. The research focus has been on counselling psychologists’ experience of working with clients who have a psychiatric diagnosis (Davies, 2013; Weston, 2016; Dyson, 2016) and specifically, counselling psychologists’ experience of working with individuals diagnosed with schizophrenia (Larsson, 2011). Subsequently, in this thesis, I endeavour to build upon the knowledge base that currently exists about diagnosis in the field of counselling psychology.



### Advantages and disadvantages of using the diagnostic system

There are advantages in using the diagnostic system, for example having an established framework which can inform the practitioner of the relevant guidelines for treatment options. Diagnostic classification can also be beneficial to clients who have been struggling to understand distressing symptoms. The diagnosis can help to validate the client's experiences of isolation and help to recognise that they are connected to a wider group of people with the same diagnostic name (Fletcher, 2012).

Despite the advantages of the diagnostic system, there are concerns amongst practitioners, including counselling psychologists, about the challenges of working with a diagnostic framework. The notion that a diagnosis and the application of standardised therapies can target symptoms can lead to the incorrect assumption that this system allows for the accurate capturing of the needs of the individual. Atwood and Stolorow (1984) argue that enforcing a diagnosis and standardised treatment without acknowledging the impact, is likely to increase their emotional distress rather than decrease it and can force both the client and practitioner into a particular way of comprehending emotional distress. Fletcher (2012) appears to be presenting a possible paradox of the diagnostic system, both the client and the therapist cannot see how society and their own way of being have contributed to the development and reinforcement of the problem.

The impact of this paradox may lead to "heightened distress, repeat presentations and onward referrals" (Fletcher, 2012, p. 6). This could lead to frustration for both the therapist and the client. A client may access mental health services for decades not getting psychological needs met nor having a complete understanding of the contextual factors that may surround their diagnosis. The diagnostic system is well established and embedded in mental health services. It is unlikely that mental health services will completely stop working in a diagnostic way. The challenge for the counselling psychologist is to find the best way of getting the balance of working with a diagnostic system and working therapeutically towards the client's needs.

Limitations have been revealed in using psychiatric diagnosis with non-Western cultures (Owusu-Bempah & Howitt, 2000). Judgements surrounding diagnosis seem to be based on the differences in cultural norms. There has been controversy around psychiatric diagnosis since

the 1960s when psychiatrists R. D. Laing and Thomas Szasz proclaimed that schizophrenia was an invalid category and the concept of mental illness was meaningless (Laing, 1960; Szasz, 1964; Johnstone, 2008). The criteria for psychiatric diagnoses have been critiqued for being based on social and cultural norms which are “dressed up as medical ones” (Johnstone, 2008, p. 9). The use of phrases in the DSM-V such as ‘bizarre beliefs’ ...that the person’s culture would regard as totally implausible and ‘odd beliefs ...inconsistent with cultural norms’ (American Psychiatric Association [APA], 2013) seems to fit with Johnstone’s (2008) argument. An example of a social problem categorised as a medical illness include the diagnosis of ‘drapetomania’, which was assigned to slaves in nineteenth-century America for having the inexplicable urge to run away from plantations (Fernando, 2002). This demonstrates the perverse use of diagnoses that was endorsed by psychiatry as a form of social control. There were substantial financial implications for the loss of slaves, perceived as lucrative commodity.

It has been argued that the classification system for psychiatric diagnosis does not meet the basic scientific requirements of reliability and validity (Bentall, 2003; Bentall & Beck, 2004; Boyle, 1990; Johnstone, 2008). It can be difficult to shift or eliminate a psychiatric diagnosis once a person is labelled (Read, 2013). The CPN in the UK concedes that the diagnosis of psychosis or schizophrenia does not have a scientific grounding and is harmful and stigmatising to the recipient (CPN, 2011). Fernando (2017) stipulates that the history of psychiatry’s need to diagnose mental ‘illnesses’ is interlinked with the desire to exercise power and control over people. Despite the drawbacks of diagnosis and the medical model perspective, the use of diagnosis and medical interventions are widespread.

### Definition of schizophrenia

In modern times, schizophrenia is synonymously referred to as psychosis. Psychosis is described as perceiving or interpreting reality in a very different way to other people (MIND, n.d.). An example of psychosis includes hearing voices. Psychosis is linked to a number of mental health conditions including schizophrenia, bipolar disorder, personality disorder, drug-induced psychosis, and postpartum psychosis (MIND, n.d.). Psychosis usually refers to an experience and considered to be a symptom of the aforementioned mental health problems and not a diagnosis itself (MIND, n.d.).

In Western mental health, a diagnosis of schizophrenia is dependent on one or more key ‘positive symptoms’, including delusions, hallucinations, disorganised thinking and disorganised behaviour (Morris, 2017). The ‘negative symptoms’ relate to a loss of ability and enjoyment in life, such as poor hygiene or reduced range of emotions (APA, 2013; Morris, 2017). Pitt et al. (2009) postulate that there are positive and negative aspects to receiving a mental health diagnosis. The researchers interviewed service users who stated that positive aspects of receiving a diagnosis include “naming the problem” and “providing a means of access to appropriate help and support” (Pitt et al., 2009, p. 421). However, there are also limitations to receiving a mental health diagnosis, such as labelling and increased social exclusion (Hayne, 2003; Pitt et al., 2009).

Schizophrenia remains a challenging experience to conceptualise and does not seem to have one particular cause. Geekie and Read (2009, p. 112) have managed to categorise the many theories of psychosis into 11 categories, namely, the ‘biological’, ‘stress-vulnerability’, ‘existential’, ‘spiritual’, ‘neuropsychological’, and ‘psychological’ approaches. Since the mid-nineteenth century, conceptualising schizophrenia has remained a challenging task (Bentall, 2003). Both Krapelin and Bleuler are considered to be the founding founders of the psychiatric system. Emil Krapelin (1856-1926) defined schizophrenia as ‘dementia praecox’ – a severe and interminable disease progressing from mental deterioration to early death. Kraepelin’s pessimistic view of schizophrenia predicated that death is the only outcome from a diagnosis of schizophrenia. However, there has been a shift as the theoretical frameworks of schizophrenia have evolved. Research has shown that people can and do recover from schizophrenia (Thornicroft & Tansella, 2003; Williams, 2012).

There are a number of misconceptions relating to psychosis and schizophrenia. A commonly held view is that there is a heightened chance of violence, even though the risk from people with psychosis and schizophrenia is substantially small (Morris, 2017). People with mental health issues are amongst the most stigmatised groups in society, with those diagnosed with schizophrenia at the end of the spectrum (Morris, 2017). The Inquiry into the ‘Schizophrenia’ Label (ISL, 2012) was an independent inquiry in which the schizophrenia label was examined in the United Kingdom. The researchers surveyed over 500 people diagnosed with schizophrenia and found that over 80% believed the diagnosis is damaging and dangerous to them. Jenkins and Carpenter-Song (2009) researched the subjective experience of stigma

connected to schizophrenia-related conditions. The authors found that 96% of participants reported an awareness of stigma pervading their daily life. Cechnicki, Angermeyer and Bielanska (2011) found that the most shared experience of stigma is related to the feeling of rejection by other people. This is particularly profound, particularly with the identification that even the anticipation of a negative response or discrimination can lead to individuals avoiding engaging with aspects of life and therefore enhance their sense of isolation (Farrelly et al., 2014).

### Statistical research on the rates of schizophrenia

The Adult Psychiatric Morbidity Survey (National Centre for Social Research and Department of Health Sciences University of Leicester, 2014) gathers the prevalence and incidence of mental health disorders on the adult population of England. The age group with the highest prevalence of schizophrenia for both women and men was the group between 35 and 44 years of age. The data shows a higher prevalence of schizophrenia in Black men (3.2%) than men from other ethnicities. The researchers found that 'psychotic disorder' did not vary significantly among ethnic groups for women. Research has shown that men under the age of 45 were found to have twice the rate of schizophrenia than women, but there was no difference in its incidence after this age. The rate of schizophrenia was found to be significantly higher in Black Caribbean and Black African migrants and their descendants, compared with the baseline population (NICE, 2014). There has been a vast amount of research demonstrating higher rates of psychosis among BME populations in the UK, particularly in people from Black Caribbean and Black African backgrounds (Coid et al., 2008; Kirkbride et al., 2012). However, there are limitations to simply investigating the rates of psychosis without attempting to understand the context, cultural differences, and social and political factors.

### The bio-medical model of mental and emotional distress

In 2018, 70.9 million prescriptions for anti-depressants were issued in England, compared with 36 million in 2008 (NHS Digital, 2019). The number of prescriptions for anti-depressants in England has almost doubled in the past decade and has been steadily increasing year on year, with 64.7 million prescribed in 2016 and 67.5 million issued in 2017 (NHS Digital, 2019). Prescription on this astronomical scale indicates the dominance of the medical model which requires a medicalised response for 'conditions' such as depression and schizophrenia. Read and Dillon (2013, p. 394) argue that the medical model can wedge a distance between people

who have “suffered the worst of what we humans can do to one another”. Medicalising human distress in the form of an ‘illness’ can result in encouraging fear and rejection of the person rather than listening to their story. Milton (2010) posits that the medical model is a significant factor that increasingly pathologises human distress and everyday life. It is not surprising that the majority of people who are diagnosed with ‘schizophrenia’ do not disclose it to others (Ucok et al., 2012). The researchers also found that ‘anticipated discrimination’ was common amongst people diagnosed with schizophrenia (Ucok et al., 2012).

### Schizophrenia

In recent years there has been an international paradigm shift to move away from the term schizophrenia because of the associated “stigma, poor reliability and validity” (Read & Dillon, 2013, p. 401). Key organisations including the Schizophrenia Fellowship (in the UK and New Zealand) have removed the term from their name, becoming Rethink Mental Illness (UK) and Supporting Families (New Zealand) (Trenchard & Read, 2012; Read & Dillon, 2013). Another dynamic movement is the Hearing Voices Network which has established groups across the globe, providing support for those who hear voices and/or have visions. There are almost 200 groups in the UK; 91 in England and 34 in London ([Hearing Voices Network, n.d.](#)). The founders maintain that hearing voices is a response to distressing life experiences and can be attended to in ways that do not depend on psychotropic medication (Ferguson, 2017).

The notion of schizophrenia has long been challenged and critiqued. Laing (1960) was able to provide rational explanations for what otherwise would be considered meaningless psychotic behaviour. Laing (1960) argued that this behaviour could be understood as a reasonable response to current or past life events or circumstances. An alternative paradigm has been introduced to understand mental distress within a trauma, dissociation, attachment, and neuroscience framework (Dillon, Johnstone & Longden, 2014). On the basis of empirical evidence, researchers have suggested that there is a strong causal connection between childhood trauma and psychosis later in life (Bentall, 2003; Read, van Os, Morrison & Ross, 2005; Bebbington, 2009; Skehan, Larkin & Read, 2012; Read & Mayne, 2017). Specific ‘symptoms’ of schizophrenia such as hallucinations are strongly related to childhood abuse and neglect, along with other mental health issues (Read, 2013). Bentall (2003) also refutes the arguments of the biomedical approach regarding the difference in brain structure of those who

are diagnosed with schizophrenia. He argues that trauma and adversity affect brain structure. This does not mean that all adverse events in childhood lead to mental distress, however, they may lead to a vulnerability to mental health issues later in life. Along with recognising psychosocial factors such as early life experience, poverty, and other inequalities, the interaction between brain functioning and our environments is also recognised in the alternative paradigm.

### Non-Western cultural explanations of psychosis

Fernando (2009) posits that there are cultures which tend to view distress relationally. For example, South Asian communities consider the mind, body, and spirit as one, instead of as separate entities as in the common Western view. Fernando (2017) stresses that the medical model and psychiatry take global precedence over all possible explanations of human distress. He highlights that there are many inequalities in the mental health service. BME people are more likely to be diagnosed as being “schizophrenic”, “sectioned under the Mental Health Act”, “held by Police under the Mental Health Act for observation”, “transferred to locked wards” and “not referred for Talking Therapies” (Fernando 2017, p. 94). In the 1980s and 1990s, psychiatric research on Black and Asian communities was primarily centred on the numbers that yielded from epidemiological surveys (Fernando, 2017). Fernando (2017) criticises epidemiological studies in this topic area because they do not lead to further knowledge about the causes for this over-representation or contain suggestions on how clinical practice can be improved. He goes further to say that epidemiological studies do not challenge the “traditional diagnostic categorisation” (Fernando, 2017, p. 101) by remaining within the medical framework and therefore reducing the possibilities of increasing our understanding of human experience. In relation to the proposed research, using IPA will allow a contribution to the knowledge base of understanding the lived experience of receiving a diagnosis of psychosis and the meaning that is attributed to receiving the diagnosis.

### Psychiatric imperialism

Psychiatry has been criticised for being a system that colonises (Mills, 2013) by naming people’s experiences in alienating terms that deny personal meanings and experience. Distributing diagnostic names position people in need of psychiatric care (Johnstone, 2000;

Mills, 2012). The globalisation of mental health and psychiatry is “the imposition of western values, customs and practices on non-western cultures” (Thomas et.al, 2005, pp. 27-28). Whereas Patel and Prince (2010, p. 1976) define global mental health as an “area of study, research and practice that places a priority on improving mental health and achieving equity in mental health for all people worldwide”. Fernando (2010, p. 113) critiques the global mental health as “psychiatric imperialism”.

The inequalities and overrepresentation of Black people in mental health services can be perceived as the perpetual legacy of colonial history (Fitzpatrick, Kumar, Nkansa-Dwamena & Thorne, 2014). To explore the notion of the globalisation of mental health and the impact of postcolonialism on Black people, the historical text of ‘Black Skin, White Masks’ by Frantz Fanon has to be considered. The book was written in French and published in 1952; the first English translation followed in 1967. Black Skin, White Masks was the first text to investigate the psychology of colonialism. Fanon examines how colonialism is internalised by the people who are colonised, how an inferiority complex is integrated, and the ways that Black people end up emulating their oppressors. Although the phenomenologist Merleau-Ponty did not delve into the issue of race, Fanon, a student of Merleau-Ponty, saw that his approach made it possible to philosophically extend his exploration to the lived experience of Black people (Hudis, 2015).

Thomas (2013, p.117) postulates that the lasting consequence of colonisation is the “colonised mind”. Thomas (2013, p.120) goes further to describe this as ‘disorders of empire’ which are both “contextual and relational, affecting both colonised and coloniser”. One of the lasting effects of colonisation is projecting a superior ideal onto anyone who may represent the coloniser and rejecting other people who may represent the people who were colonised, even if one’s identity is closer to the colonised. Thomas (2013, p.121) refers to this process as being “internally colonised”. This concept is similar to ‘internal racism’ which Pyke (2010, p.567) defines as ‘White racism that is internalized by the non-White group or individual and is directed inward toward the self or the group’. Pyke (2010, p. 553) reiterates that as with all forms of racism, internalised racism is not the result of an individual “psychological defect” and therefore ‘blame’ or the ‘problem’ of internalised racism is not attributed or located in the individual.

The process of internalised racism maybe underpinned by an unconscious element. In her study ‘The Psychology of Racism’, Robin Johnson (Johnson & Holloway-Friesen, 2011) emphasises that internalised racism involves both "conscious and unconscious acceptance of a racial hierarchy” in which White people are consistently positioned above non-White people. Internalised racism is the manifestation of racist attitudes and stereotypes towards themselves and other people from the same ethnic group. Johnson and Holloway-Friesen (2011) go further to state that internalised racism is one of the common forms of racism that people fail to acknowledge. Davids (2011) presents a psychoanalytical framework for internalised racism, in which he depicts historical patterns of racial oppression internalised by people of all ethnicities which manifests in interpersonal relationships, organisations, and systems. This dynamic can be closely linked to the systemic challenges presented by the theme of internalised racism. There is a dynamic between ‘self’ and a racialised ‘other’ which serves to hold experiences that a person does not wish to own. The rejected parts of self and identity may be expressed through anxieties about race and difference. The literature review yielded little research on internalised racism and mental health. The predominate focus of research on racism seems to cover institutionalised racism and the mental health of BME people (McKenzie & Bhui, 2007; Bradby, 2010; Fernando, 2017; Nazroo, Bhui, & Rhodes, 2020). Institutional racism is defined as:

“The collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture, or ethnic origin. This can be seen or detected in processes, attitudes, and behaviour that amount to discrimination through unwitting prejudice, ignorance, thoughtlessness, and racist stereotyping which disadvantages people in ethnic minority groups” (Macpherson, 1999, p. 49).

McKenzie & Bhui (2007, p. 650) refute that “once the existence of institutional racism in mental health care is accepted, progress can be made to understand and tackle the causes of racial disparities”. An example of addressing institutional racism in mental health care on a systemic level is ‘Delivering Race Equality in Mental Health Care’ (DoH, 2005), which was a five-year action plan for addressing equality and discrimination in mental health services in England for all BME people including those of Irish or Mediterranean origin and east European migrants. The action plan was a government response to the recommendations made by the



inquiry into the death of David Bennett, a Black man diagnosed with schizophrenia who died following being restrained by five nurses.

### African and African-Caribbean people in the mental health system in the UK

According to the 2011 Census (Office for National Statistics [ONS], 2018) the total population of England and Wales was 56.1 million and 86.0% of the population was White. Asian ethnic groups made up the second-largest percentage of the population (at 7.5%), followed by Black ethnic groups (at 3.3%), Mixed/Multiple ethnic groups (at 2.2%) and Other ethnic groups (at 1.0%). Despite Black people making up 3% of the total population of England and Wales, this ethnic group is over-represented in mental health services and inequalities in mental health have been evidenced (Nazroo, 2020). The over-representation of ethnic minority people in the UK receiving psychiatric diagnoses is particularly concerning (Rees et al., 2016; NHS Digital, 2019).

The incidence of schizophrenia for Black Caribbean people in the UK has been identified as amongst the highest in the world (Bourque, van der Ven, & Malla, 2011; Kirkbride et al., 2012; Tortelli et al., 2015) and is not replicated in Black populations in Caribbean countries (Bhugra et al., 1996; Hickling & Rodgers-Johnson, 1995; Mahy, Mallett, Leff, & Bhugra, 1999). Incidence is the 'rate of occurrence of new cases of a given event or condition (e.g. a disorder, disease, symptom, or injury) in a particular population in a given period (APA, n.d.). There are a range of inequalities that are key factors affecting the mental health of Black African and Black Caribbean people. Black populations are more likely to experience poverty, have poorer educational outcomes, higher unemployment, and contact with the criminal justice system than other ethnic groups (Equality and Human Rights Commission, 2016; Memon, Taylor, Mohebati, Sundin, Cooper, Scanlon & de Visser, 2016; Lammy, 2017; Cabinet Office, 2018; Powell, Francis-Devine & Foley, 2020).

A family history of migration and personal experience of migration from one country to another is likely to increase the likelihood of the development of psychosis (Fernando, 2009; Fernando, 2010) and has been considered as a risk factor for being diagnosed with schizophrenia (Bhugra, 2000; Bhugra & Jones, 2001; Cantor-Graae & Selten, 2014). The significant number of

diagnoses in schizophrenia have been observed in second-generation people who have originally migrated to the UK from Africa or the Caribbean (Tortelli et al., 2015).

Published statistical data demonstrate that there is a significant difference for a diagnosis of schizophrenia for Black people. The latest Adult Psychiatric Morbidity Survey in 2014 (McManus, Bebbington, Jenkins, & Brugha, 2016) found that Black men (3.2%) were more likely than Asian men (1.3%) and White men (0.3%) to experience a psychotic disorder in the last year of the survey being conducted. There was no significant variation found between women of different ethnic groups. The risk of being diagnosed with schizophrenia in Black Caribbean groups is estimated to be nearly seven times higher than in the White population (Fearon et al., 2006). In 2017 and 2018, detention rates under the Mental Health Act 2017 were four times higher for people in the 'Black' or 'Black British' (288.7 detentions per 100,000) population groups than those in the 'White' group (71.8 detentions per 100,000 population) (NHS Digital, 2018). This is supported by the Count Me in Census, in which information is collected on inpatient care, where higher than average admission and detention rates for Black groups were found every year from 2006 to 2010 (Care Quality Commission, 2010). The research indicates that there is a consistent trend for people from the Black population to have a higher rate of schizophrenia and psychosis in comparison to other ethnic groups.

The literature review revealed that there is a significant gap regarding studies of the subjective experience of receiving a diagnosis of schizophrenia for African and African-Caribbean people. The vast majority of studies in this research area are epidemiological and therefore use quantitative methods. A key study in this research topic area is a case-control study conducted in London and Nottingham, UK for a 2-year period and in Bristol, UK for a 9-month period. Case-control studies "compare people with the disease of interest (cases) to people without the disease (controls) and look for differences in past exposure to possible causes of the disease" (Carr, Unwin & Pless-Mullooli, 1997, p. 64). The Aetiology and Ethnicity in Schizophrenia and Other Psychoses (AESOP) study (Fearon et al., 2006) was funded by the UK Medical Research Council. The primary aim of the study was the investigation of the high rates of schizophrenia and other psychoses in African-Caribbean people from the UK and an examination of the aetiology of psychosis. The inclusion criteria stated that participants had to be 16-65 years old, experiencing their first episode of psychosis, and have had no previous

contact with mental health services for psychosis. Recruitment took place over a two-year period, 592 cases and 412 controls were recruited. The AESOP study measured the incidence of schizophrenia and other psychoses which occurred in a defined time period (Bowling, 2009). The researchers confirmed a significantly higher incidence of schizophrenia at nine times higher in African-Caribbean people [IRR 9.1 (6.6-12.6)] compared to six times higher in Black Africans [IRR 5.8 (3.9-8.4)]. The incidence rate was higher in comparison to the White British baseline population (Morgan et al., 2006). Other findings revealed that the incidence rate of 'White other', 'Asian', 'Mixed', and 'Other' were also higher than the White baseline population. The results also showed that the incidence of psychosis varied between the geographical areas covered in the study. The follow-up study tested the hypotheses at eight to 12 years after the original study. The second phase of the AESOP study is referred to as AESOP-10. AESOP-10 is a 10-year follow-up study of a cohort of 412 participants from the original study who were contacted and re-interviewed.

To date, the AESOP study and the AESOP-10 are the largest studies investigating the incidence of schizophrenia and psychosis amongst African and Caribbean people conducted in the UK. The results are in line with previous research findings, indicating that African-Caribbean and Black African people are the ethnic groups who most frequently receive a diagnosis of psychosis or schizophrenia. However, the study is not without its limitations. A potential limitation of the study is measuring the presence of schizophrenia or psychosis through the incidence rate at the time of first presentation to services. The researchers of the AESOP study (Fearon et al., 2006, p.1548 ) have noted that there is a possibility that the "incidence rates calculated on the basis of first presentation to services may not correspond exactly to the true incidence of psychosis in any community at any given time". The incidence rates were dependent on individuals who accessed mental health services and may not be a true reflection of people who have experiences which would be defined as schizophrenia or psychosis within a diagnostic framework in the community.

The researchers have stated that they reduced potential diagnostic bias by reporting the diagnosis by "consensus" and "blind to ethnicity" to reduce the chances of diagnosis-bias amongst ethnic groups (Fearon et al., 2006, p. 43). However, it is not stated how the consensus was obtained or who the consensus was sought with, whether with the participants or other

researchers. Interviewing participants during their first episode of psychosis when they may feel vulnerable could be considered unethical. The researchers do not state whether there were contingency plans in place should the participants become distressed during the study. Participants may also have felt coerced to take part in the study because recruitment took place at the first point of reference for treatment. Although there are advantages to the use of case-control studies such as being relatively cheap and swift to conduct because researchers start with people with the health condition, rather than people who will develop the health condition (Carr, Unwin & Pless-Mulloli, 1997); case-control studies are also prone to different types of bias. Firstly, information bias which arises from the process used to collect information in the study (Carr, Unwin & Pless-Mulloli, 1997). Secondly, the recruitment and comparison of cases and controls can be affected through selection bias.

Epidemiology studies such as the AESOP study have been criticised for assuming that ‘diseases’ such as schizophrenia, can solely be defined through the use of medical or psychiatric classification (Bowling, 2009). Epidemiology can be defined as “the study of the distribution and determinants of disease frequency in human populations” (Bruce et al., 2006, p. 6). In epidemiology, data is examined by looking at the causes and risk factors of disease in the population (Bowling, 2009). Observing schizophrenia as a disease places this research within the Western medical model. Although the researchers do not state their epistemological stance, the nature of the study would fit within the positivist paradigm. In the deductive approach, the researcher is permitted to start with a hypothesis and then test the validity of the hypothesis (Bruce et al., 2008). In epidemiological studies, there is an emphasis on empiricism, the study of “observable phenomena by scientific methods, detailed observation and accurate measurement” (Bruce et al., 2008, p. 3).

Investigating the presence of schizophrenia in new cases who present at mental health services does not broaden our knowledge about schizophrenia as a phenomenon, the lived experience of receiving a diagnosis of schizophrenia, or the meaning that individuals attribute to receiving this diagnosis. At present, there are a number of gaps in research regarding the meaning-making of a diagnosis of schizophrenia. There is limited qualitative research in which the researchers explore the experience of receiving a diagnosis of schizophrenia for an African or African-Caribbean person.

There are limited studies where researchers look at the impact of receiving a psychiatric diagnosis from a service user perspective (Pitt et al., 2009; Howe, Tickle, & Brown, 2014). Pitt et al. (2009) conducted a user-led qualitative study in the UK. The aim of the researchers was to explore the impact of diagnosis on people who experience psychosis from a service-user perspective. Two service users conducted the research and were supervised by two clinical psychologists. Eight participants were recruited; six were White British and two participants were African-Caribbean. Six of the participants were men and two were women. Some participants received more than one diagnosis. The data was analysed using IPA and findings were yielded that were similar to those of Howe, Tickle, and Brown (2014). Some of the participants experienced receiving a diagnosis in a 'positive' manner. Diagnosis gave a route to access not only medication but also psychological therapies such as cognitive behavioural therapy.

Diagnosis was also perceived as a means to legitimise the experience of mental distress and also understanding from family and friends. However, participants also reported diagnosis being a strong cause of disempowerment. Some participants stated that the diagnosis was not disclosed to them and they only found out second-hand. The research also confirmed that the predominance of the biomedical model and medication as the sole treatment could be disempowering to service users. The researchers classed the Black participants as 'African-Caribbean' and did not clarify or take into account the differences between the ethnic groups. For example, someone can be Black and born in the UK, however, their family may originate from Africa or the Caribbean. The researchers reported that the African-Caribbean participants disclosed that a 'lack of understanding and awareness about cultural difference' left them feeling disempowered (Pitt et al., 2009, p. 421). This is the only reference about ethnicity made by the authors. This demonstrates the gap of qualitative research exploring both diagnosis and ethnicity.

### The lived experience

A lived experience can be defined as a "person's awareness and comprehension of both internal and external stimuli. This concerns what is occurring internally or within the surrounding environment. It involves the capacity to think, feel and perceive what *is* happening and what

*has happened*” (Morris, 2017, p. 3). Experiences are unique and significant to the individual. It is important for healthcare practitioners to engage with the internal world of those with lived experiences of mental health issues (Morris, 2017). Exploring the lived experience of schizophrenia permits the reader and practitioner an opportunity to understand the contextual information of the participant’s personal experiences of the diagnosis. Specifically for counselling psychologists and other allied health professionals, investigating the lived experience of schizophrenia opportunity will be given to understand the meaning attributed to schizophrenia and also contribute to developing an awareness of the ‘felt-sense’ of living with the diagnosis.

There is value and necessity of learning about the lived experiences of mental health and IPA studies have contributed to knowledge in the mental health field (Larkin & Thompson, 2012). The value of exploring the subjective experience is also evident even in differentiated approaches of IPA (van Manen, 1990). It is only the service user who can truly convey and contextualise what it feels like to live with schizophrenia. Increased awareness about the lived experience and meaning-making of schizophrenia can encourage us to reframe our own internal framework of psychiatric diagnoses and support these individuals effectively. The absence of investigating lived experiences of a psychiatric diagnosis infers that personal meaning is not important. Johnstone (2008, p. 13) postulates that the “personal impact and meaning” of psychiatric diagnosis is less explored in research. It is incredulous to believe that receiving a psychiatric diagnosis would not have an impact on an individual. Removing the meaning of a psychiatric diagnosis leaves a void in the knowledge and practice in the counselling, psychology, and psychotherapy arenas.

Excluding the subjective experience of Black African and Black Caribbean people with a mental health diagnosis means that their voices are effectively silenced. This is a strange paradox because within the mental health field the ‘patient’ or service user is meant to be at the centre of their care through interventions such as being assessed, receiving a diagnosis, and treatment. Therefore, excluding the subjective experience means that their personal experience and understanding of the diagnosis is not explored. Fernando (2017) states that at the point of his book going to print, he was unaware of any published studies in professional journals in which the researchers investigate the subjective experience of African and African-Caribbean people or their opinions about diagnosis and treatment. Exploring the lived experience of

schizophrenia is important because it acknowledges the importance of the client's understanding of their experience of psychosis and schizophrenia and encourages "ethically sound clinical practice", allowing the client to be the "author" of their own story (Geekie & Read, 2009, p. 28).

### Relevance to counselling psychology and rationale

The objective of the current research is to explore the subjective experience of receiving a diagnosis of schizophrenia through the use of IPA (Smith, 2004). This is supported by Geekie and Read (2009), who argue that to understand mental health without acknowledging or incorporating the subjective lived experience is an impossible and fateful task.

Exploring the lived experience of schizophrenia amongst people of Black African and Black Caribbean heritage fits with national clinical guidelines. The National Institute for Health and Care Excellence's ([NICE], 2014) guidance on 'Psychosis and schizophrenia in adults: prevention and management' states that:

"Mental health services should work with local voluntary Black, Asian and minority ethnic groups to jointly ensure that culturally appropriate psychological and psychosocial treatment, consistent with this guideline and delivered by competent practitioners, is provided to people from diverse ethnic and cultural backgrounds" (NICE, 2014, p. 11).

'Delivering Race Equality in Mental Health Care' (DoH, 2009) contains recommendations for the need to generate knowledge about psychosis for ethnic minority groups, including the exploration of service users' views. The first version of 'Psychosis and Schizophrenia' (BPS, 2014) was heavily criticised for excluding issues such as the "over-representation" of Black people diagnosed with schizophrenia (Fernando, 2017, p.165) and any meaningful engagement between the subject matters of ethnicity, psychology, and schizophrenia (Kalathil & Faulkner, 2015). There is limited information about culture or diversity in the revised publication on 'Psychosis and Schizophrenia' (BPS, 2017). It is suggested in the report that psychologists are encouraged to "move beyond the medical model" and respect non-medicalised views about the causes of psychosis (BPS, 2017, p.103). However, the report does not contain any suggestions

how we can work with people with a non-Westernised view of their psychosis and schizophrenia. This reinforces the gap in literature regarding the subjective experiences of people from culturally diverse communities and the lack of knowledge about their experiences with schizophrenia in the field of psychology.

Cooper and McLeod (2007, p.136) refer to pluralism as an “ethical and political commitment to respecting, valuing and being inclusive towards otherness: other worldviews and respectful to our clients”. As a field, counselling psychology is a context in which the interaction with a pluralistic world is encouraged, where we can accept the enriching influence of other genders, faiths and cultures without having to withstand against them (Milton, 2010). Milton (2010, p.8) goes on further to say that those who actively participate in the “messiness” of difference are not always in comfortable territory. Although we are encouraged as practitioners to actively engage with the ‘other’ and ‘otherness’, this invitation does not come without its challenges.

In a report on psychotic experiences by the BPS (BPS, 2014a), it is recommended that service users should be recognised as experts on their own experiences. Working with a client who has a psychiatric diagnosis may be an example of the tension and challenges that counselling psychologists can face. The nature of the counselling psychology training in the UK is that it has a focus on a pluralistic approach, where practitioners study and work with more than one modality. This approach reinforces to the practitioner that ‘one approach does not fit all’. Counselling psychologists focus on the wellbeing of a person, promoting a relational stance rather than psychopathology. Essential factors such as contextual, social, and political factors are inseparable from one’s sense of self and psychological distress (Woolfe et al., 2007). The authors demand a standpoint beyond the positivist epistemological approach to the medical model, incorporating the individual’s experiences with the world. The field of counselling psychology provides an alternative philosophical underpinning – a paradigm shift in view of human nature and distress.

The pluralistic stance extends to the research aspect of counselling psychology. A pluralist view of research can ‘open psychological therapy to scientific advancement’ regardless of the underlying assumptions (Rafalin, 2010, p.48). In 2005, the BPS identified the scientist-practitioner model as a core component of research and clinical work in counselling



psychology. The scientist-practitioner model has been heralded as the ‘cornerstone of counselling psychology identity’ in the UK (Rafalin, 2010, p.42). Other than the doctoral research being a mandatory element in the professional doctorate in counselling psychology training, conducting research is an opportunity to engage with the ‘otherness’ of the client and bring awareness to the counselling psychology community.

Remarkably, there is a paucity in the literature of counselling psychology exploring the impact of receiving a psychiatric diagnosis (Johnstone, 2014; Howe et al., 2014). Johnstone (2014) highlights that due to the powerful influence of psychiatric diagnosis, it is crucial that we listen to the accounts of those who have been psychiatrically diagnosed. Howe et al. (2014) found that there is a need to address the process of giving a diagnosis. Evidence is indicative of the diagnosis of schizophrenia being an extremely powerful factor in a person’s wellbeing. It can have an adverse effect on a person’s self-identity and be a source of labelling and social exclusion (Vellenga & Christenson, 1994; Dickerson, Sommerville, Origoni, Ringel, & Parente, 2002). The significance of exploring the experience of receiving a diagnosis remains absent within psychiatry and mental health services (Howe et al., 2014) and the counselling psychology field.

Other studies situated within the proposed research area use a qualitative design with a sample of professionals such as counselling or clinical psychologists and therefore researchers obtain the psychologist’s ‘expert’ view on schizophrenia. The current research in clinical and counselling psychology is from the clinician’s perspective. To date, the literature review has yielded studies that mainly come from an etic stance. Etic knowledge is derived from someone who does not directly experience the phenomenon (Eckensberger 2014). In contrast, it is my intention in the proposed research to approach the topic from an emic perspective; where knowledge comes from the subjective and first-person account of the phenomenon. There is clearly a significant gap in counselling psychologists engaging in the subjective experience and meaning-making of receiving a diagnosis of schizophrenia on an empirical level. There is a gap in the literature of investigations of the meaning of a diagnosis of schizophrenia in which phenomenological methodology such as IPA is used.

It was found through carrying out the literature search for this study that there are unpublished theses on the broad area of receiving a psychiatric diagnosis. Some of these examples include looking at the meaning and constructs of mental health and diagnosis through the lens of counselling psychologists and psychotherapists using IPA (Vassiliou, 2016), using grounded theory (Larsson, 2011; Davies, 2013), or looking through the lens of clinical psychologists (Nicholas, 2012). To date, the current research in clinical and counselling psychology is primarily located from the clinician's perspective. There is clearly a significant gap in counselling psychologists engaging in the subjective experience and meaning-making of receiving a diagnosis of schizophrenia on an empirical level and specifically using IPA methodology. The literature search yielded unpublished theses on the participant population: understanding the meaning-making of voice-hearing for African-Caribbean men using narrative analysis (Minchin, 2016) and exploring Black African service users' experiences of recovery from mental illness using IPA (Tuffour, 2017). However, there appears to be limited knowledge about the subjective experience for people of Black African and Black Caribbean descent living with the diagnosis of schizophrenia or the meaning they attribute to receiving the diagnosis.

### Research question

The literature review has led me to the following research question:

What is the lived experience of receiving a diagnosis of schizophrenia for people of Black African and/or Black Caribbean heritage?

## **Methodology**

### **Introduction**

In the following chapter the methodological and epistemological position adopted in this study will be considered. The rationale for the particular qualitative methodology selected, namely IPA will be outlined. Sections on *Participants, Recruitment, Procedure* and the ethical considerations for the research will be presented. The chapter will conclude with the *Analytic strategy and procedure* that was undertaken.

### **A qualitative approach**

As a Counselling Psychologist in training, I have an interest in exploring the meaning-making involved in human experience. I was, therefore, drawn to qualitative approaches to research. Such methods attend to lived-experience and so I felt this group of perspectives to be most compatible with my research interests. The literature review highlighted that much of the existing research into this phenomenon is from a quantitative perspective. Quantitative research can facilitate an investigation of causal relationships or provide an understanding of *what* is happening regarding, for example, the effects of medication or treatment (Twigg, 2015). However, quantitative methods can only study what is observable. In the case of this study, arguably such methods would not therefore, offer the tools to understand the deeper meaning that individuals may attribute to receiving a diagnosis. For this reason, a quantitative perspective was considered inappropriate to fully address the research question. A qualitative approach to exploring the subjective experience of a diagnosis addressed the identified gap in the literature regarding how people of African and Caribbean descent view a given diagnosis of schizophrenia. Quantitative methodologies have produced general statistical accounts of the diagnosis of schizophrenia. Such accounts arguably lack the depth and richness that qualitative research can offer in relation to exploring the lived experience of a phenomenon.

### **Epistemology**

Epistemology has been defined as a “branch of philosophy concerned with the theory of knowledge” (Willig, 2013, p.4). According to Willig (2008; 2013), it is key for the researcher to identify their epistemological position before choosing a methodology. Methodology and epistemology are interdependent, it is not possible to consider the methodology without first

considering the underpinning epistemology. The current research was adopted by a critical realist stance. The critical realist paradigm does not seek to find one truth but instead an account of the phenomenon that is grounded in the words of the participants (Pringle, Drummond, McLafferty, & Hendry, 2011). The emphasis is on how and what meaning is made from experiences rather than trying to quantify and measure its frequency. In this study, participants were asked to reflect upon their subjective experiences. Each account was considered in the participant's individual context. There was no attempt to discover one truth but multiple truths, with the aim of identify both the participants' and the researcher's interpretations of events (Willig, 2008).

### **Methodological framework**

#### Alternative methodologies

There are a range of qualitative approaches to research, informed by different ontological and epistemological underpinnings (Willig, 2008). Other qualitative methodologies such as Grounded Theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990) and Narrative Analysis were considered in terms of their appropriateness for addressing the research question.

Grounded Theory focuses on the study of social processes within particular contexts (Willig, 2013). Grounded Theory consists of systematic guidelines for gathering, integrating and analysing qualitative data in order to construct emergent theory (Charmaz, 2006). Grounded Theory is characterised by the researcher's simultaneous movement between both data collection and analysis, with the aim of grounding the analysis in the data (Willig, 2013). Although Grounded Theory can answer questions concerning subjective experiences, the aims of theory generation in Grounded Theory were seen as incongruent with this study's aim. This research aimed to explore the participants' individual experiences of receiving a diagnosis of schizophrenia rather than generate or construct theory. As this study was designed to explore the participants' subjective experiences of receiving a diagnosis of schizophrenia, Grounded Theory was not considered an appropriate research methodology.

Narrative Analysis was also considered as a possible methodology. Narrative Analysis looks at the content of experiences, how narratives are constructed and why the stories are told. This type of analysis is concerned with how people sequentially connect events and make them meaningful to the listener (Riessman, 1993). *Stories* are situated within a social and cultural

context on a micro and macro level (Braun & Clarke, 2015). Narrative Analysis is similar to IPA in that it is concerned with how people make sense of the world (Murray, 2003). A narrative can be defined as “an organized interpretation of a sequence of event [which] involves attributing agency to the characters in the narrative and inferring causal links between the events” (Murray, 2003, p.113). Narratives share six features: settings, characters, initiating events, attempts, consequences and reactions (McAdams, 1993). Willig (2013) highlights that narratives are considered an essential aspect of meaning-making in narrative analysis. The focus of the research here was not language and the structure of words and therefore Narrative Analysis was also eliminated as an appropriate methodology.

Interpretative Phenomenological Analysis (IPA, Smith, Flowers & Larkin, 2009) was deemed to be the most fitting methodology as it focuses on individual experiences and gaining an understanding of a particular phenomenon. This methodology permits an idiographic examination of receiving a diagnosis of schizophrenia ‘case by case’ and the exploration of the ways that participants make sense of this phenomenon (Smith, et al., 2009). Approaching this research project using the inductive approach key to IPA has allowed me to grapple with this topic with sensitivity and curiosity. In addition, such an approach fosters an engagement with the subject matter that is led by the participants. This is important because it has the potential to address possible power imbalances in the research process.

### **Interpretative Phenomenological Analysis (IPA)**

Three core concepts underpin IPA: phenomenology, hermeneutics and idiography (Smith et al., 2009). IPA involves a detailed examination of each participant’s lived experience (Smith & Osborn, 2015). Smith & Osborn (2015) highlight that the objective of IPA is to explore personal experience and individual subjective accounts of a given phenomenon. IPA incorporates the philosophy of phenomenology. A key phenomenologist is Heidegger and his focus on meaning-making and the human inter-subjective relatedness to the world (Smith et al., 2009).

As a researcher, I have an active role in the research process (Smith & Eatough, 2007). The term ‘double hermeneutic’ refers to a two-stage process of interpretation. The double hermeneutic cycle consists of each participant trying to make sense of phenomenon and their experience and the researcher, in turn, attempts to make sense of the participant’s meaning-

making and interprets this information (Smith & Osborn, 2008). Through the position of engaging with a participant's account, a researcher may gain access to their inner world allowing them to attempt to understand the experience being recounted. The double hermeneutic recognised in IPA is similar to the clinical interaction between a therapist and client. The client attempts to make meaning out of their life experiences and the therapist may facilitate this process with an interpretation (according to the theoretical framework within which they are working).

Finally, IPA is idiographic as demonstrated on two levels. Firstly the in-depth analysis of each case must be methodical and systematic. Secondly, an IPA researcher seeks to comprehend the nuances of lived experiences from the perspectives of particular people in particular contexts and is committed to the thorough examination of each individual case. The aim of the research presented here was to gain an in-depth understanding of the participants' subjective experiences of receiving the diagnosis of schizophrenia. IPA was therefore deemed an appropriate methodology (Smith & Osborn, 2008).

## **Design**

### **Sampling framework**

The objective of IPA is to look at the “detail about the perceptions and understanding of this particular group rather than prematurely make more general claims” (Smith and Osborn, 2008, p.55). Accordingly, the participant sample was not intended to be representative of the sample population. Furthermore, it has been suggested that an appropriate number of participants for professional doctoral research is between four and ten (Smith, Flowers and Larkin, 2012). In line with these recommendations, this study focused on a relatively small number of participants.

Purposive sampling, by which participants are selected according to the criteria specified in the research question, is a common form of data collection in IPA studies (Willig, 2013). IPA studies aim to recruit a homogeneous sample of participants and purposive sampling aids in this objective. Smith, Flowers and Larkin (2012) indicate that there is a degree of flexibility regarding how a sample may be considered homogenous and so the level of homogeneity varies between studies. In the current study, homogeneity was that all participants received a diagnosis of schizophrenia. Another shared characteristic was that all

participants self-identified as being Black and of African and/or Caribbean descent. The inclusion criteria helped to facilitate and maintain the homogeneity of the sample.

#### Participant inclusion and exclusion criteria

The inclusion criteria specified a sample which consisted of Black men and women of African and/or Caribbean descent who identified as having a diagnosis of schizophrenia. All individuals were aged over 18 years old. One of the inclusion requirements was that the person must have received a diagnosis of schizophrenia at least two years prior to participation. The reasoning behind this was that a person with *psychosis* is considered to be outside a crisis period between two and five years after diagnosis (NICE, 2014). The exclusion criteria stipulated that participants did not have a current substance use problem or psychotic experience that required psychiatric inpatient admission. This was to help ensure their ability to consent to, and participate in, the study. The managers at both services, assigned one staff member the responsibility of liaising with the participants when needed. This process helped to simplify the communication with the participants. The allocated workers at both of the services provided an informal screening process to ensure that individuals met the inclusion criteria and were available after the interviews should the participants need to talk about the effects of the interview. This ensured that the participants were supported throughout the entire research process.

A total of nine participants (including one who participated in the pilot study) were recruited.

#### Recruitment of participants

My intention was to recruit all of the participants from one service. At the first site, I completed five interviews (four men and one woman) including the pilot interview. However, due to an organisational change, I was unable to complete the recruitment at the first site. I continued the research at another community mental health service. The two sites had shared characteristics, they were both community services offering the specific provision of mental health support to local people of African and/or Caribbean descent. Both were located in London within the voluntary sector. I recruited an additional four participants at the second site. At the end of the recruitment phase, there was almost an equal number of men and women participating in the research (five men and four women).

### The participants

In Table 1, participant demographics are presented. Mary was the only participant who received her diagnosis outside of the United Kingdom. Peter and Marcie have both received two diagnoses related to schizophrenia. Three of the participants wanted to have their real names printed in the thesis and the remaining six' are pseudonyms.

Table 1: Participant demographics and details of diagnosis.

Name	Age	Ethnicity	Diagnosis	Time since receiving diagnosis (years)
He-Man (Pilot)	58	Black Caribbean	Schizophrenia	36-37
Peter	50	Black African Nigerian	Schizophrenia  "Psychosis aggravated"	19  15
NSNG9	40	Black British	Paranoid Schizophrenia	17
Kwame	41	Black African Ghanaian	Schizophrenia	16
Mary	62	Black African	Paranoid Schizophrenia  (Received diagnosis in Nigeria)	39
Glendora	58	Black Caribbean	Schizophrenia	30+
Marcie	63	Black Caribbean	Schizophrenia  Paranoid Schizophrenia	20  12
Sandra	57	Black Caribbean	Schizophrenia	19
Roy	56	Black British	Schizophrenia	30+



## **Data Collection**

### **Pilot interview**

The pilot interview was conducted with a male participant. At the end of the interview, he was asked to feedback about his experience of the interview process. The pilot study was an opportunity to practice my skills as an interviewer and bracket my experience as a trainee counselling psychologist in relation to asking further questions.

As a result of the pilot interview, all of the original interview questions remained. In addition, I added some phenomenological probes to the Interview schedule to aid the interview process e.g. *can you tell me a bit more about that?* I also noted that it had been useful to repeat the last few words spoken by the participant as this opened up the dialogue. To ensure that I remained reflexive, I made regular notes in my reflexive journal. Data from the pilot interview was not used in the main analysis, however, it was formative in helping to draft the final interview schedule and the literature review.

### **Procedure**

Interviews were conducted in private rooms at the two services. I provided bottles of water for the participants and considered how the seats were arranged to ensure that participant and researcher were comfortable.

At the beginning of each interview, I welcomed and thanked the participant for taking part in my research project. I reminded each participant of the research topic and informed them of the purpose of the interview. I discussed the inclusion criteria and went through the information sheet (Appendix 6). All of the participants were given the information sheet prior to the interview. This helped the participant to understand the nature of the research and also gave them an opportunity to consider any questions that they might want to bring to the interview.

My interview introduction was consciously crafted to create space for the participants to speak about personal and sensitive experiences. I told the participants that they could have a brief break if they wished. I informed them that I had nine questions to ask, however, the interview was led by the participants' responses. I also informed them that they had the right to pause or stop the interview process and indicated the approximate time that the interview would take. I also checked whether the participants had any questions for me. Once the participants

understood the aim of the research and what participation entailed signed the consent form (Appendix 7). I then recorded basic demographics such as ethnicity, age, diagnosis and when they received the diagnosis. Participants were provided with a paper copy of both the information sheet and consent form.

At the end of the interview, each participant was asked: “How have you experienced the interview?”. This question is referred to as a “clean-up” question which Braun and Clarke (2013, p.81) suggest may generate useful unforeseen data. Such questions allow the participant to speak about aspects of their experience which may not have been covered. The use of a clean-up question also demonstrates that each participant was actively consulted as to what they believed was relevant and significant regarding the diagnosis. In addition, the clean-up question helped to address a possible power imbalance between interviewer and participant. Participants were informed as to when the interviews were coming to a close, for example, “...We have two questions left...”. This helped to prepare the participants for the cumulation of the interview.

### Data collection

Semi-structured interviews are an effective way to collect data in IPA research (Braun and Clarke, 2013; Finlay, 2011; Smith et al., 2009; Willig, 2008; Smith and Osborn, 2008). They permit the collection of in-depth data and allow stories and personal experiences about the phenomenon to be shared. A semi-structured interview schedule (Appendix 5) was developed to facilitate a process by which participants could discuss their lived experience openly. All questions were open-ended. The sequence of the interview questions was flexible to ensure that the dialogue focused on the participants’ meaning-making (Kvale, 1996). Use of prompts during the interview was incorporated to invite participants to expand upon their answers (Braun and Clarke, 2013). It has been recommended that a good interviewer-participant relationship influences participants’ self-disclosure and the depth of the experiences that they may be willing to reveal (Braun and Clarke, 2013; Knox and Burkard, 2009). Hence, a conscious effort was made to build a good rapport with possible participants in the communal areas of the community projects and continued throughout the interview process.

The interviews were approached with ethical negotiation and sensitivity. The qualities fostered in IPA such as taking a non-judgmental attitude, flexibility, patience, empathy and responsiveness (Finlay, 2011; Eatough and Smith, 2006; Smith et al., 2009) were employed.

This helped to capture the richness and complexity of the participants' meaning-making. After interviewing eight participants, it was felt that a sufficient depth and breadth of data had been obtained. It was felt that data saturation had been somewhat attained as the narratives by the various participants had become repetitive (Fusch and Ness, 2015).

### Transcribing the interviews

Smith et al. (2009) recommend that researchers do their own transcribing as this allows for full immersion in the data, accordingly I transcribed all of the interviews myself. The interviews were transcribed verbatim, however, aspects of language such as the exact length of silences or pauses were not transcribed as the central aim of IPA is to interpret the meaning of the content (Smith et al., 2009). A reflexive diary was kept to record my initial thoughts and comments during transcription and playback of the audio-recordings. This later proved useful during data interpretations. Transcriptions were stored securely and audio-recordings were saved on an encrypted-USB stick. The shortest interview lasted approximately forty minutes and the longest interview lasted for two hours.

### **Efforts to promote quality and validity in the research process**

Please read Appendix 15 for a detailed description on endeavoured efforts to incorporate quality and validity in the research process using Yardley's criteria (Yardley, 2000, 2007).

### Ethical Considerations

This section covers my responsibilities as a researcher and a counselling psychologist in training working within an ethical framework. *Working ethically and legally* is a core standard (Standard 3) that must be achieved for all counselling psychologists (BPS, 2019). The BPS (2019) further stipulate in Standard 3 that all research involving human participants must be conducted in line with the BPS Code of Human Research Ethics (2014b).

Ethics has been defined as the "science of morality or of duty" (Palmer-Barnes & Murdin, 2001, p.2). Ethics pertaining to research can be defined as the "moral principles guiding research from its inception through to completion and publication of results" (BPS, 2014b). Ethics is at the core of counselling psychology practice (Olsen, 2010) and precedes how we

relate to the other. This is evident in all aspects of clinical practice with clients, in supervisory relationships and not least, ethics is imperative in research.

### Ethical approval

Ethical approval was granted from the University of East London School of Psychology Ethics Committee before data collection commenced (Appendix 1). I obtained an official letter from the manager of each service that I intended to recruit from, evidence that I was granted permission to carry out the research at their facility (Appendices 3a and 3b).

### Ethical approach

The ethical considerations for this research were guided by the University of East London's Code of Good Practice in Research Guide (2014), the British Psychological Society's Professional Codes of Ethics (BPS, 2018, 2009) and the Code of Human Research Ethics (BPS, 2014b). The key ethical points I will cover in this section are *informed consent*, *anonymity*, *interpretation* and *self-care as a researcher*.

Informed consent is as essential research as it is in psychological therapy (Olsen, 2010). During this study, informed consent was seen as a continuous process that was sought from the participant throughout the entire research endeavour. Informed consent involved ensuring that the participant fully understood the reasons for the study and the nature of what taking part involved. Participants were informed of the right to withdraw both before and during the interview. Participants evidenced that they understood the expectations of the researcher by signing the consent form (Appendix 7).

At the end of the interview, each participant was asked about their experience of the interview process. This was intended to provide space to reflect and the opportunity to communicate any feedback if they wished. It was also designed to minimise any imbalance of power between participant and researcher.

Participants were given a debriefing sheet (Appendix 8) and made aware of the options available should they need additional support as a result of taking part in the study. Initially, participants were reminded to speak to their keyworkers at their respective services. They were also given the contact number for the Samaritans, a twenty-four-hour phoneline offering

support to emotionally distressed people. if necessary, participants were encouraged to go to their local Accident and Emergency department. Finally, participants were given the telephone number of the relevant out-of-hours urgent advice-line for mental health service users. The telephone numbers given were situated in the London Borough where the services were located.

Participants' confidentiality was upheld following the Data Protection Act 2018 and the BPS Code of Ethics and Conduct (BPS, 2009). For example, the code invites psychologists to "Record, process, and store confidential information in a fashion designed to avoid inadvertent disclosure" (BPS, 2009, p.11). To protect each participant's right to anonymity and confidentiality, all identifying data in the transcripts were anonymised and references to specific geographical locations were omitted. The first names of the participants were replaced with pseudonyms. Three of the participants requested to have their first names printed in the thesis and any future publications. All interviews were audio-recorded and recordings saved onto an encrypted-USB stick (BPS, 2014b). All identifying information such as signed consent forms were locked away separately from the research data. At the point of writing, all documentation saved digitally remains password-protected. Following GDPR guidelines (ICO, 2018) the transcripts will be kept for five years in a lockable cabinet and then destroyed. The audio-recordings were deleted following the completion of the transcriptions.

Smith et al. (2009, p.205) postulate that "interpretation in IPA is a form of *amplification* or *illumination* of meaning, which is cued or sparked by a close engagement with the data, and which requires creativity, reflection and critical awareness for its full development". Interpretation is indeed central to IPA and therefore while conducting this research it was important to reflect upon the associated ethical implications.

I recognised the power that interpreting another person's experience could give me as a researcher. In a clinical environment, it is common for a psychologist to interpret the experiences of their client to some degree depending on the theoretical modality. Interpretation in this context appears to be different to interpretation in research, primarily because, in a clinical setting, the client is present and able to engage with the interpretation and adjust it if they feel that it is inaccurate. In a research setting, the participant is not present and interpretations are made retrospectively using the recording of the interview and the transcript.

It could be argued that this form of interpreting imposes the view of the researcher onto the participant's experience without allowing the participant to interact with these interpretations.

Willig (2012, p.56) has identified three key strategies to address ethical concerns in interpreting data. These include 1. Keeping the research question in mind and being modest regarding what the research can reveal 2. Ensuring that the participant's voice is not lost and 3. Remaining open to alternative interpretations (Willig, 2012, p.56). Smith et al. (2009) make it clear that while the researcher interprets the data through the hermeneutic circle, the participant is the expert of their own experience. IPA guidelines also make it clear that interpretations should always be grounded in the words of the participant and be able to be followed back to the original data (Smith et al., 2009). This guideline was at the forefront of my mind while I was analysing the participants' data.

The intention was not to intentionally cause harm to participants, however, asking individuals to reflect on their experiences of schizophrenia may cause some distress. To ensure the safety of both participants and researcher, the interviews took place in a room at the service during its opening hours. This permitted the interview to take place with minimal interruption. Conducting the interviews at the service also provided a support mechanism to participants during and after the interview process.

A lot of consideration and thought went into making the room comfortable for both the researcher and the participant. For example, arranging the seats in a way that both individuals could be seen clearly whilst respecting personal space. My experience of being a therapist influenced my level of sensitivity in creating the right atmosphere for the interviews to take place. My clinical experience allowed me to be well placed to support participants should they become distressed during the interview and then signpost to their allocated worker if necessary. During the introduction of each interview, participants were told that they could have break during the interview should they feel they need to. None of the participants took a break during the interview.

It was important to consider the impact of the interview upon myself as a researcher. I sought support from my therapist and research supervisor when attempting to reflect on how the interviews affected me. The use of the research journal was paramount in charting all aspects

of the research process in a reflective manner (Appendix 9). I wrote in my reflexive diary at the end of each interview engaging with and recording my emotional responses and my rationale for decisions that had been taken.

### **Analytic strategy and procedure**

The analytic strategy implemented Smith et al. (2009)'s suggestions for IPA data analysis. IPA involves interpretation of the transcribed data, rather than a complete description of the participants' accounts. The process of analysis involves interacting within an inductive and iterative cycle (Smith, 2007) signifying that the researcher must bracket their own preconceptions and repeatedly return to the source of the data when making interpretations. This involves close interaction between the researcher and the text, using line-by-line analysis of each participant's transcribed interview (Smith et al., 2009). The aim is to achieve an interchange between the researcher and the data, in order to understand and interpret what it might mean for a participant to have particular experiences in a particular context (Smith et al., 2009). The analysis sought to encapsulate the individual degrees of both individual and collective experience, demonstrating areas of both convergence and divergence in the data (Smith, 2011).

Smith et al. (2009)'s Six-Stages of Analysis was followed to identify shared themes that encapsulate the participant's lived experience of a diagnosis of schizophrenia. The transcribed interview data was analysed in line with these steps. Appendix 11 provides an audit trail of my first analysis of Marcie's interview.

Stage 1- During the first stage of analysis, I replayed the interview and re-read the first transcript meticulously several times. Given IPA's principle of idiography, Smith et al. (2009) suggest analysing one case in detail before moving onto the next. Each reading has the potential to produce new revelations and I was able to become even more familiar with the data. Whilst listening to the recording, I used this as an opportunity to reflect on how the participant engaged in the interview and how I experienced the interview. Notes were taken of initial thoughts and observations of the transcript, in order to bracket these off and remain close to the data.

Stage 2 – The second stage consisted of participating in a close line-by-line examination of the text. Identified exploratory themes were recorded in the right margin of the text (Smith et al., 2009). I noted any content that seemed significant or interesting and these annotations were made in the right-hand margin of the transcript. These comments were either descriptive, linguistic or interpretive. At this stage, interpretations should come from an iterative process



of description followed by interpretation established in the original data. This process was carried out for the entire first transcript.

Stage 3 – The third stage covered the formation of the clustering themes into emergent themes based on their possible links with other sub-ordinate themes (Smith et al., 2009). This stage involved returning to the transcript with a fresh outlook to check whether new themes would emerge and using the left side of the table to note the emergent themes (Smith et al., 2009).

Stage 4 – A chronological list of the emergent themes was compiled and connections were made between them grouping certain themes together. Once emergent themes were grouped together, I compiled a summary table which was then used to identify the ‘subordinate’ themes and the ‘superordinate’ themes that emerged. These were recorded along with the page and line reference, to enable examples of each theme to be found within the transcript at a later time.

Stage 5 – involved repeating the entire process above for the remaining seven transcripts. This required bracketing of my ideas and acquired notions from the previous transcript(s). Therefore reducing the chances of being influenced by another transcript and treating each transcript as unique (Smith et al., 2009).

Stage 6 - included looking for patterns across each transcript and integrating them into a table of superordinate and subordinate themes grounded in the participant’s data (See Table 1) (Smith et al., 2009).

## **Summary**

This chapter has presented a description of the method used in this research project. The processes of recruiting the participants, the ethical approach, interviewing and analysing the participants’ personal experiences were also discussed. The process of data collection and analysis were presented with constant review and evaluation of my actions as a reflexive researcher. In the next chapter, an analysis of the data is presented.

## Analysis

### Introduction

The analytic strategy from the previous chapter was implemented at the analysis stage. This chapter will explore the themes and quotations from the transcripts have been included in the body of the text to understand and maintain sensitivity to the context of data (Smith et al., 2009). Participant quotations are presented in an italic font in order to discern them from the main text of the chapter and the researcher's voice. This reflects IPA's double hermeneutic stance as a researcher attempting to make sense of another person making sense of their own personal experience (Smith, 2004). I acknowledge that the interpretations of the emergent themes are only one possible perspective and do not cover all aspects of the participants' subjective experiences of being diagnosed schizophrenia. Themes were selected on the basis of their relevance to the research question: 'What is the lived experience of receiving a diagnosis of schizophrenia for people of Black African and/or Black Caribbean heritage?'

### Overview of super-ordinate themes

Four super-ordinate themes and fourteen sub-ordinate themes (See Table 1 below) emerged from data analysis and illustrated participants' experiences of living with schizophrenia. The first super-ordinate theme, 'Schizophrenia is a form of social control', captures the participants' definition and understanding of what schizophrenia means to them personally. It also highlights the extent that participants believe that the diagnosis has been imposed on them.

The second super-ordinate theme, 'Living with schizophrenia is a dynamic sentence' captures participants' journeys through receiving their diagnosis and how that diagnosis impacted themselves and the people around them.

The third super-ordinate theme, "A spiritual dimension to this experience", portrays participants' search for further meaning to their lived experiences of schizophrenia within a spiritual framework.

The fourth super-ordinate theme, ‘Being Black with mental health issues’, encapsulates the importance that being Black has on the participants’ identity as well as the impact of racism. Both of these core aspects are underpinned within the lived experience of schizophrenia.

**Table 2: Summary of super-ordinate themes and sub-ordinate themes**

<b>Super-ordinate themes</b>	<b>Sub-ordinate themes</b>
Schizophrenia is a form of social control	<i>The fear of being rejected and stigmatised</i>  <i>“Aberration”: Departure from what is ‘normal’</i>  <i>An imposed label</i>
Living with schizophrenia is a dynamic sentence	Medicalised interventions of control  <i>Being “dismissed” by others</i>  <i>Accepting a new identity</i>  <i>“I tell the psychiatry, there’s nothing with me”</i>
“A spiritual dimension to this experience”	<i>“Only God knows ...”</i>  <i>“A shamanic experience”</i>  <i>Christianity and faith in God</i>  <i>Battle between good and evil</i>
Being Black with mental health issues	<i>Racism and being othered</i>

	<p><i>“Black people need something behind them to pull them in the right line”</i></p> <p><i>“I’ve always known my history, I’ve always loved my Black Skin” Cultural pride</i></p>
--	---

Table 3 portrays the presence of the superordinate themes in the individual transcripts and whether the super-ordinate theme was present in over half of the sample. NSNG9 was a pseudonym chosen by a male participant. The participant stated that the name is connected to the Congolese culture.

**Table 3: Master table of super-ordinate themes and frequency**

<b>Participant</b>	<b>Schizophrenia is a form of social control</b>	<b>Living with schizophrenia is a dynamic sentence</b>	<b>“A spiritual dimension to this experience”</b>	<b>Being Black with mental health issues</b>
Marcie	Yes	Yes	Yes	Yes
Kwame	Yes	Yes	No	No
NSNG9	Yes	Yes	Yes	Yes
Roy	Yes	Yes	No	Yes
Glendora	Yes	Yes	Yes	Yes
Sandra	Yes	Yes	Yes	No
Mary	Yes	Yes	Yes	No
Peter	Yes	Yes	No	No
<b>Theme present in half of sample</b>	Yes	Yes	Yes	Yes

### Key symbols in transcript extracts

[...] denotes an omission of text

... denotes a pause

### **Super-ordinate theme one: Schizophrenia is a form of social control**

Many of the participants recalled accounts of being misunderstood and the fear of being stigmatised if relatives, friends, and their social circle knew that they were diagnosed with schizophrenia. Participants were not given a definition of schizophrenia. Instead, they were asked the first question on the interview schedule (Appendix 5): “In your own words, what is schizophrenia?” This allowed the participants to share their understanding and meaning-making of schizophrenia and the effects of living with the diagnosis.

### **Sub-ordinate theme one: The fear of being rejected and stigmatised**

*Marcie: I think there's a certain image on us...everybody looks at you in a particular way. I don't know if they cast the camouflage on us for people to think "oh I thought you were suffering from a mental illness" or something like that. It's affected, I think it...I know it's affected my life. It's affecting my future...they said to me "would you like your job back..?" I said no, reason...I do not want any of the clients to say, come back reporting me for hitting them and abusing them. (Page 1)*

Marcie states that the diagnosis has impacted and continues to impact her life. This is reinforced by the repetition of using the word “affect” in both the past and present tense. There is a pressing concern that is expressed, as Marcie considers how she is perceived by others. Marcie specifically believes that schizophrenia has affected her employment opportunities. She declined the offer of returning to her job due to a concern that her clients would accuse her of attacking them if they found that she was a “schizophrenic”. Marcie highlights that she is at risk of being accused of being violent to others through being stigmatised by others. She highlights a familiar stereotype that people with schizophrenia are violent and are likely to cause harm to others. She refers to “us” which infers that her experiences are not isolated but shared amongst those with the diagnosis. Phrases such as “certain image on us” and “cast the camouflage on us” sounds like intentional behaviour by those in the mental health system.

Marcie uses an interesting metaphor of “*cast the camouflage on us*” which seems paradoxical. The purpose of camouflage is to blend or disguise one’s self. However, the camouflage that Marcie seems to refer to draws attention to the person and makes them stand out for having a “*mental illness*”. Marcie does not want to stand out but the “*camouflage*” in the form of the diagnosis has been “cast” on her by psychiatrists and psychologists and covers who she is and therefore no longer seen by others.

*NSNG9: ..most of the time I was worried about what other people thought in the earlier years I was worried about what other people thought. (Page 13).*

NSNG9 recalls that during the initial stages of receiving the diagnosis, he was concerned about what other people thought about him having schizophrenia. The level of this worry is demonstrated in the repetition. NSNG9 has made various transitions with the diagnosis from being concerned about what his family and friends thought about his diagnosis to embracing his experiences as a spiritual journey.

*Kwame: I keep it confidential at the church. I don't disclose it. It's only relatives or friends I might disclose it, but not...it's minimal it's not much, it's minimal (Page 12).*

Some participants found that the only way to manage the possibility of being stigmatised and/or rejected by others was not to tell them that he was diagnosed with schizophrenia. Kwame states that he keeps his diagnosis a secret from the people at church and has made a decision not to disclose it to them. By keeping the disclosure to a “*minimal*” Kwame has restricted this information to certain friends and family members. Kwame’s interview happened to be one of the shortest. During the interview I got the sense that Kwame did not want to speak about aspects of the diagnosis and started to focus on his current achievements and hopes for the future.

*Peter: Stigma in, in terms of uh schizophrenia and psychosis are very, very negative, uh both in society and one has to be very careful, depression is much more, ah accepted in uh[...] the society...the wider society sees mental health not only as some kind of a threat, but it doesn't see mental health as an illness, it sees it more as a threat that needs containing. It doesn't really...there isn't empathy it's not as forthcoming. Empathy*

*is...there's greater for cancer, there's great empathy for people with broken legs, but schizophrenia no-no [...]. I'm getting quite clear in the warning about the penalties, uh that the stigma will incur...(Page 2)*

Peter indicates that when a person says they have depression, they face less stigma from society than when they disclose a diagnosis of schizophrenia. He makes a distinction between people with a physical condition or a mental “*illness*” such as depression in contrast with schizophrenia, stating that there is a greater empathy for someone with a physical illness. The inference is that people with depression also receive greater empathy. The societal response to schizophrenia is one of containment penalty that is inflicted on the individual. The person who is defined as ‘schizophrenic’ must be contained because of the thoughts and behaviour that appear to be outside of societal norms. Rather than receiving an empathic response Peter believes that people living with schizophrenia are in fact punished. The personal responsibility for the diagnosis seems to be located within the individual.

Interviewer: What would you say the penalties are?

*Peter: The penalties are in mental health terms are very clear, are very clear, yet even practitioners cannot generally see them. If you are sitting in the mental health ward...If you are sitting in the mental health ward. Those people who are schizophrenic and others, they will be suffering from forms of depression... The people who will be suffering from depression, in general, there is an acceptance...it is a slow acceptance to be happening for about 30 years, is that they will get better. [...].the unspoken agreements people have between themselves and how societies work that way. The people who are schizophrenic, there is an acceptance between them.... (Page 2-3).*

*Peter: My family members have never, have never had access to the question of schizophrenia.[..] No, it is not for them to know [...].All I've ever informed them about is that I'm depressed...(Page 12).*

The penalties of having schizophrenia seem to be fatalistic in comparison to depression where there is an acceptance and higher chance of recovery. Peter suggests there is a myriad of “*unspoken agreements*” about the nature of schizophrenia between mental health professionals and people with schizophrenia; between society and people with schizophrenia; amongst people living with schizophrenia and finally the agreement within the individual. The

agreement perpetuates the stigma about how people with schizophrenia are viewed. Even mental health practitioners are unable to see the collusion and complexity of how stigma is maintained. However there is an acceptance and understanding of the diagnosis amongst the people living with schizophrenia that the very nature of having schizophrenia means that they stand out from others in society. Peter highlights that over the last three decades, society has increasingly accepted depression and therefore is accepted by external forces. It is interesting that Peter states that the perception of depression has changed over the last 30 years because this also marks when he received the diagnosis. There is a deep sense of shame connected to schizophrenia and it has become easier for Peter to say that he has depression.

*Peter: For many years my view has been that people in schizophrenia, they're outsiders and they have complied with this thinking because I do. (Page 32).*

Similar to Marcie, Peter's use of "they" reveals an 'us versus them' scenario where people living with schizophrenia are not accepted but rejected and seen as an outsider group to the mainstream. Being "*in schizophrenia*" is the antithesis of being outside. For Peter there is a sense that he has resigned himself to the notion that he is both inside of the phenomenon and yet outside of the mainstream. The concept of an insider group and outsider group or the ingroup/outgroup effect (Billig & Tajfel, 1973) is built on the premise that the members of each group will see the other group members as a form of 'other'.

Many participants recalled accounts of being misunderstood as well as the fear of being stigmatised if relatives, friends and their social circle knew that they were diagnosed with schizophrenia.

### **Sub-ordinate theme two: "Aberration" - Departure from what is 'normal'**

*Marcie: It must be there because I'm seeing it and sometimes I can describe what I see. So whether it's um.. seen in a different space, different dimension, or if whether it's an aberration, I don't know what it is. (Page 1).*

Marcie stated that at times she sees things that other people cannot see. Aberration is defined as a departure from what is normal. A departure from what is normal can be viewed in line



with displaying behaviour that moves away from everyday societal norms. It can also be seen as moving away or elevation to an existential or transcendental place. She is certain that what she sees is real because she has seen it with her eyes, although she queries whether she is seeing through a “*different dimension*”, eluding to another spiritual realm or psychic gifting.

*Mary: My eyes, my ears that's reality. I know the voices are talking but I know it's not, it's not real anymore and before I used to think it was real. (Page 10).*

*Mary: (Sighs) Hearing, well for me personally, it's hearing things no one else can hear which was a bit frightening in the beginning, yeah, until you realise that oh this is not happening, it's not real. (Page 16).*

There is an interplay between what is deemed as reality and non-reality. Mary highlights that if she sees or hears something through her physical senses then there must be some truth in it. Other people including mental health professionals are used as the benchmark for these experiences. If someone else is not experiencing what she is, then it cannot be true. Participants describe experiences where their senses are fully engaged in activities that mainstream society would consider to be out of the ordinary. Mary describes being frightened of hearing things that no one else can hear. However, over time she concludes that she hears the voices talking but no longer believes that they are real.

*NSNG9: I think the evidence shows that a lot more people experience erm hearing voices not necessary the visual hallucinations but hearing voices anyway but they're not necessarily diagnosed as schizophrenic or having any kind of psychosis as such and think that everybody experiences it sometime in their life, but they may not realise it. I think it's very very normal. I've heard people who have had the same experience as me, say that it's an abnormal experience. It's not abnormal to experience but I think more and more, I think it's probably a very, very normal...I think probably everybody goes through it..(Page 15).*

However, NSNG9 normalises voice-hearing as happening to people who have not been diagnosed with schizophrenia and explains that it could be a common phenomenon. NSNG9 highlights that his personal experiences of hearing voices and “visual hallucinations” are not

a departure from what is considered normal despite those who have similar experiences characterise them as “abnormal” . The repetition that voice-hearing is “very, very normal” and something that “everybody experiences” or “goes through” reinforces that NSNG9 has normalised his experiences and does not consider his experiences to be any different to the wider population.

*NSNG9: ...There was one incident where I was slamming a chair into a restaurant into a restaurant, this is one of the tasks that my voices were telling me to do. I had to throw the chair at this...er...I think it was a coffee house or restaurant and I was picked up by the police then. This was in broad daylight and the police picked me up then and I was ..I assumed that they were to section me (Page 4).*

Hearing other voices in addition to one’s own voice or that of someone who is physically present can be described as both a unique and challenging experience. Those participants who still hear voices recall incidents where the voices gave commands that had to be obeyed, regardless of the possible consequences. NSNG9 relays an incident in which the voices gave him a set of tasks he had to complete. Obedience to the task resulted in the police being called and NSNG9 being arrested for causing criminal damage. NSNG9 presents his voices as omnipotent; an all-powerful presence that must be obeyed by the hearer.

Interviewer: ..In your own words what is schizophrenia?

*Sandra: Well, it’s an illness, that you hear voices. [Hmm]..It’s voices in your head, but it sounds really loud like, like a tannoy voice [Hmm] [...] it’s come across like it’s been tannoyed, erm out in the air and anybody could hear it, but you, you feel as though everybody can hear it but you...deep down they don’t hear it, only you hear it.(Page 1).*

Sandra’s meaning-making of schizophrenia is that it is an illness of hearing voices. Sandra’s account suggests that the voices are dominating and all-encompassing, leaving the hearer with little space. She experiences the voices as aggressive. Referring to the voices as a “tannoy voice” infers that their volume is amplified in Sandra’s head. The word “tannoy” has connotations of an instruction or command that is about to be announced. People generally stand to attention when an announcement is made through a tannoy. The voices are so loud

that Sandra contemplates that everyone else can also hear the voices, however she acknowledges her own conclusion that she is the only one who can hear the “tannoy voice”. It almost sounds like a wishful plea that others should be able to hear the loud “tannoy voice” and the sadness that remains when Sandra realises that she is isolated in this experience.

*Glendora: ...I don't know why because all I wanted is somebody to talk to, like I am talking to you and tell them about the voices in my head. So they call it 'schizophrenic'. That's what they call it. But even though they call it that I just say "I hear voices, bad voices in my head", but they call it 'schizophrenic'.*

Interviewer: Do you feel that you have schizophrenia?

*Glendora: Well that's what they call the voice. I don't label it as schizophrenic [...]*

Interviewer: Would you prefer me to call it ‘voice-hearing’ rather than schizophrenia?

*Glendora: Yeah (Page 8).*

Glendora seems to express despair at being diagnosed with schizophrenia, a “label” that she neither identifies with nor agrees with. The numerous repetition of “they call it”.

*Glendora: ...sometimes 10 people talking to you at the same time, get very confused (Page 1).*

Many of the participants presented a multiplicity of voices. Glendora explains how confusing it can be to hear up to 10 voices talking at the same time giving various instructions such as to “harm yourself”, “walk naked on the street” (Glendora, page 1).

*Mary: Yep, so the second time the voices came and the second time they came I was a bit more knowledgeable. So, I would refuse to do the things I was told to do, I was hearing them and it was very distressing it made me very depressed. So, er, I was given medication of course and that was a pattern and then the voices left (Page 2).*

During her interview, Mary asked me whether I “minded” her talking about her voice-hearing experiences (“Do you mind if I tell you about the voices?” Page 3). I responded that this was absolutely fine. On reflection, Mary’s question was possibly enquiring whether she can entrust her inner thoughts and experiences as the researcher. Perhaps she is not used to having a safe

space where she can speak about the voices without judgement. Once verbal permission was given, Mary gave a further detailed account of her voice-hearing encounters. Mary was 23 years old when she received her diagnosis in Nigeria, which is also where she initially started hearing voices. The second time Mary heard voices she felt more knowledgeable and prepared to manage the distressing experience. At times it seemed that she was able to resist the overpowering presence and commands of the voices. She also implies that the medication was a contributory factor to eliminating the voices.

*Mary: There's a leader the head of the voices who is conducting all the various activities...that he says he wants to do on me and other people...probably two and then the other voices are like his under...underboys. Underboys, like they are under his command... "Oh, yeah, we are going to do it really, really bad for Mary" and then that's how many voices let me see, the head voice, the head voice and then about three other voices that are obeying the head voice's commands, and then I have the pleasant voices. [Mmm] One of the voices is Jesus and one of the er voices is erm...that I hear angels talking to me [Okay]. Saying "don't worry. You know that God is with you. God is fighting for you. He will protect you". The same thing Jesus says so that cheers me up. [That cheers you up]. That cheers me up. (Page 5).*

Mary presents a hierarchical structure to the multiple voices that she hears; there is a leader of the voices who instructs at least other two voices. The voices predominately seem to be male. Mary describes a scenario where the voices are threatening her. The word "underboys" conjures imagery of a military-type operation can be seen as the foot soldiers that carry out the instructions. Mary is a Christian and seems to get a lot of reassurance that there are "pleasant voices" in the form of God, Jesus and angels who are defending her against the "unpleasant", "nasty voices".

*Mary: The voices tell me that they hate me and they are going to ruin my life, they are going to spoil my life and that they are going to make me run mad. You know things like they're going to rape me and they are going to do this and they are going to do that and it's incessant at my flat at nights. [...] Morning time is normally quiet. [...] Afternoon is not too bad, but at night-time, it gets urgh, incessant. What I end up doing is to shut them*

*out I put on, well I might put on the radio in the, in the...when I'm... when I want to go to bed and because they're so incessant. I put in earplugs. (Page 3).*

Mary has identified a pattern with the presence of the voices. The “unpleasant voices” are present during the night, she is not likely to hear the voices in the morning. The repetition of the word “incessant” gives the reader a sense of the distress experienced by Mary due to the relentless attack and harassment from the voices threatening to cause her harm. Mary equates schizophrenia with hearing voices and the meaning she attributes is that schizophrenia is going to “spoil” her life and “make” her “run mad”. Her vivid description of the content from the voices sounds traumatising, stating that they want to sexually violate her is perhaps metaphorical of the level of violation that has already taken place. The voices are invading and violating her mind, her home and her life; this is a continuation of the military analogy.

*Kwame: They've disappeared. Since 2002 I haven't heard any. (Page 10).*

Participants depicted a range in the presence and the permanency of the voices. Kwame stated that he no longer hears voices.

### **Sub-ordinate theme three: An imposed label**

*Marcie: ...I think about suing everybody for putting me in this condition wherein I am labelled as being a paranoid schizophrenic and having mental illness as its described as 'paranoid schizophrenia' ... (Page 11).*

*Glendora: So they call it schizophrenic. That's what they call it. But even though they call it that I just say "I hear voices, bad voices in my head", but they call it schizophrenia. (Page 8).*

There is a sense that schizophrenia has been imposed on by Marcie and Glendora by others, specifically mental health professionals who have the authority to diagnose mental health conditions. The following quotes from Marcie and Glendora portray their anger and frustration over being diagnosed as paranoid schizophrenics. Marcie's intonation changed as she spoke passionately about wanting to sue those who contributed to her receiving the diagnosis. Marcie

feels she has been served an injustice and that “suing” would somehow help her reclaim what has been lost in her life. Glendora’s repetition of “they call it” reiterates the distance she places between herself and her diagnosis. “They call it schizophrenia” implies that this language has been forced on her and is not how she defines her experiences but someone who simply hears voices.

*NSNG9: [...] since I've had the diagnosis it's been a stigma for me. I've seen it more of as a label, more than anything else...Something that...er society, society thrust upon me as an individual and others as individuals. (Page 1).*

For NSNG9, schizophrenia has been an unhelpful stigmatising label that society has “thrust” upon him and others. NSNG9’s use of the words “thrust upon” sheds light on his powerlessness and limited choice in receiving the diagnosis. This phrase echoes Marcie’s comment about the diagnosis being “cast” upon her. In addition to mental health professionals, society has a dominant influence on how a person’s actions and behaviour are defined in the wider society.

NSNG9 further elaborated that the diagnosis of schizophrenia was like a “placeholder” for the society that he is in. He differentiates between how the diagnosis of schizophrenia is seen in British society in comparison to “ancient societies”. When NSNG9 stated that schizophrenia was like a “placeholder for the society that I'm in” (page 11), an image of a placeholder for a table immediately came to my mind. Image 1 depicts a similar image to the one I visualised. This was the only time whilst interviewing that I had an immediate visual response to what the participants were sharing.



Image 1: Name placeholder for table setting

A placeholder holds a name or message in place so it is visible to those in the vicinity. Likening his diagnosis to a placeholder draws attention to the notion that NSNG9's diagnosis is visible to others, leaving him open to being judged and stigmatised by others.

### **Summary**

This theme explores the many ways that participants define schizophrenia as well as how they perceive others to classify the condition. Some of the participants feared being rejected and/or stigmatised following disclosure. The fear of being rejected and/or stigmatised by others was so great that it influenced to whom the diagnosis was disclosed. There was a general sense from the participants that they have departed from what society would consider to be 'normal' behaviour. Some were comfortable with that fact that their behaviour was not considered as being 'normal' and considered that the problem was located within society as opposed to within them. Many spoke in detail about hearing voices. Hearing voices is the epitome of these participants' lived experiences of schizophrenia. The final sub-ordinate theme describes that schizophrenia was experienced as a label that has been "imposed" by others, such as mental health professionals and society.

### **Super-ordinate theme two: Living with schizophrenia is a dynamic sentence**

The second master theme, 'Living with schizophrenia is a dynamic sentence' captures the participants' journey following the diagnosis of schizophrenia. The notion that schizophrenia is a deliberate form of social control was common amongst the participants, particularly with the use of medicalised interventions such as ECT and section orders. The participants' accounts of the diagnosis conveyed tenets of being given a life sentence of imprisonment or living with a death sentence without going through the prison system.

### **Sub-ordinate theme one: Medicalised interventions of control**

*Mary: ...I was doing ridiculous things. So my family were frightened and I was put in a psychiatric hospital in xxxxxx...Then, erm I had ECT in the hospital three times I think then I was released when I was considered to be okay. (Page 1).*

*Mary: That was in the 80s. People didn't understand that it wasn't very right. ...I don't know if it was right or wrong. In the 80s, it was right but now I hear it's wrong, I don't know. (Page 2).*

The majority of participants had been sectioned either preceding or following their diagnosis. The length of hospital stays varies from one to approximately six months. However Roy was in a medium secure for fourteen years. Glendora recalled being hospitalised, although when asked, she stated that she had never been sectioned. Both Mary and Roy received Electroconvulsive Therapy (ECT) whilst under a section. ECT involves “passing sufficient electricity through the brain to cause a grand mal seizure and is usually performed 6-12 times over a three to four week period (Read, Bentall, Johnstone, Fosse & Bracken, 2013, p.90). Mary received ECT whilst she was living in Nigeria. Mary did not elaborate about her experiences of what it was like to be sectioned. The purpose of Mary being admitted to hospital was to contain her behaviour, receive treatment in the form of ECT and then “released” when it was considered that she was well enough to leave. Mary highlights the transience of treatment for mental health conditions over recent decades. She seems to take a moralistic stance as she ponders whether it was ethical to be a recipient of ECT.

Interviewer: ... some people don't like the word schizophrenia.

Roy: *I agree with it. It is a mental illness.*

Interviewer: You agree that you feel ill sometimes.

Roy: *Yeah of course. Sometimes my head shakes. (girlfriend) says “why is your head shaking like that?”*

Interviewer: Do you know when your head is shaking?

Roy: *No, but people tell me...I think I do know sometimes.*

Interviewer: So how was life for you when you came out of (hospital) when you came back? How was that for you?

Roy: *It was wonderful. I was so proud that I got out. They put an electric wire on my head you know, electric shock treatment.*

Interviewer: When you were in (hospital)?

Roy: *Yeah, of course.*

Interviewer: What do you feel that was meant to do?



Roy: *Blank, you right out. Steady your nerves.*

Interviewer: Is that what they told you?

Roy: *It's an old black people's saying*

Interviewer: Yes, 'steady the nerves' but I was just wondering if you felt that that's what they were doing.

Roy: *Yeah, of course.* (Page 16).

Roy has been living in various institutions since the age of 14. Roy seems to connect shaking his head as a sign of his "mental illness" and it is when others bring it to his attention that he is aware of it. Roy was the only participant that explicitly welcomed schizophrenia as a diagnosis. Following 14 years of admission, Roy was understandably pleased when he was discharged and I got the sense that this was a moment of achievement for him. The phrase "steady the nerves" generally refers to drinking alcohol to reduce one's anxiety and alcohol has the ability to "blank you right out". Again, this is an interesting choice of phrasing to that infers that I get the sense that Roy believes that ECT was used to calm him down his behaviour.

*Roy: He just took me to xxxxx hospital and all...about 60 policemen and five doctors in white suits. They said "Lie down boy" I said I'm not lying down. They said to the social worker "Is this the boy?" She said "yes". They said "He thinks his name is Leo, it's not it's Roy"...They said "lie down" I lied down on the floor right. They inject me with a needle, I couldn't really see, so you know what I done? I just pictured my mum's face in my eyes from the xxxxxxxx hospital all the way to xxxxxxxxx. I pictured her right, all the way and if I didn't picture her I would have died. They brought me in a van and brought me to (mental health hospital). It's far, far away. They brought me there in an ambulance. When I woke up there was about four or five of them sitting on me and I was in handcuffs. I said "get off me, get off me" they wouldn't get off me...(Page 15).*

Roy recalls an earlier incident of being sectioned when he was 17 years old. Roy presents an intense account of being sectioned and being detained by 60 policemen and five doctors. He became animated as he recalled this story and changed his voice and intonation to represent the different characters. It is difficult to ascertain whether Roy merged two incidents because at first, he states that his brother-in-law took him to the hospital and then recalls being taken to a mental health hospital. He depicts this as a near-death experience in which he thought he

was going to die. It was at the point of being unable to physically see that he visualised his mother which saved him from death. From moments of challenge and not conforming, the account ends with Roy being overpowered.

*Marcie: I was sectioned at that time because I was talking not in an um, everyday manner or tone or I was very concerned about religious aspects um, I was concerned about my race...this is what I was trying to express... (Page 8).*

*NSNG9: ..I was sectioned more or less twice a year...it will either be me having an argument with my neighbour or it will be because I have to er...at one point I had to continue with one of my set tasks standing in the street looking at the sky so I was sectioned about five times then and I got fed up with it and to my mind back then I couldn't understand why I kept getting sectioned all the time, all the time so I left, I left my flat. I handed in the keys to the council, I packed up my things at the time, saved money my thinking was to leave the country to...I was terrified at that time, I was younger than as well. I was terrified being sectioned absolutely terrified of being sectioned and I didn't understand why I was being sectioned...I ended up on the street for six years(Pages 5-6).*

Marcie and NSNG9 give examples of being sectioned as a result of speaking or acting in public in a way that is perceived to be inappropriate or unacceptable. NSNG9 stated that the last time he was sectioned was five years prior to the interview. The repetition of the word “terrified” reinforces the palpable dread of being sectioned. NSNG9 describes his fear and confusion as to why he was being sectioned. The incessant sections led NSNG9 to leave his home to escape and he ended up being homeless. Marcie and Paul’s accounts of talking about religion or talking about race in a public area or standing in the street looking at the sky appear to be innocuous behaviour, that from their point of view has been misunderstood. This is considered an example of medicalisation of ‘normal’ behaviour or actions which resulted in a medicalised intervention of control in the form of Marcie and Paul being sectioned. This is perceived as a punitive response to personal expression that does not conform to mainstream thinking or societal norms. Marcie and Paul’s examples concur with the literature review which highlights the danger of ‘normal’ responses to daily living being medicalised because it is deemed as

inappropriate in a particular context or culture (Johnstone, 2014; Boyle & Johnstone, 2014; Johnstone & Boyle, 2018).

### **Sub-ordinate theme two: Being “dismissed” by others**

*Sandra: ...my Mum said to go to the doctor and see if I can get any help...I did go to the doctor but they said that they couldn't find anything wrong with me...it's like they dismissed the situation of helping me [...]..nothing bothered him (boyfriend). So when I told him I'm having a problem it was like erm, he would have dismissed it because he didn't see it as a problem..Like me complaining and saying noise from above he didn't find it a problem. He was, he erm, didn't acknowledge that there was a problem (Pages 3- 4).*

*Mary: when I first moved in and I used to go out and start shouting at people because I thought, well oh goodness knows what I thought and I can't remember what I thought but I used to shout. So the neighbours whenever they see me they think to themselves oh no, it's the mad lady again, so they don't like me they are very hostile. (Page 5).*

In a similar fashion of visiting the doctor because of a physical condition, Sandra was encouraged to visit the doctor because she was hearing voices. Sandra's account ends with her stating that she felt that her boyfriend dismissed her experiences because he did not “see”, “find” or “acknowledge” them. There seemed to be a parallel process between Sandra talking about the doctor and her boyfriend with neither person taking her concerns seriously, which indicates that it was an isolating experience. Mary's behaviour of shouting at her neighbours has created a distance and therefore she believes that she is not liked. The action of shouting has intrinsically been attached by Mary to signify ‘madness’.

*NSNG9: I think, I think um...I think I scared off a few friends in fact [ Mmm] Yeah.*

Interviewer: How do you feel about that?

*NSNG9: Um, sad because when I look back it's almost like, um they're a part of my history. [...] So when I see my experiences of some of my friends not wanting to know so I kind of felt the same. Alright then, I don't want to know either, so yeah. (Pages 12- 13).*

*Kwame: They just said I was diagnosed as schizophrenic and F20. My mum...didn't personally want to know that much about it, but she knew that I was taking medication but she wasn't that bothered about it. But she was helping me put on my clothes before I was diagnosed. I'm not really close to my family and relatives. They don't see me as a normal human being, a normal British citizen. They're not bothered about it. (Pages 4-5).*

Sadness can be detected in the quotes from NSNG9 and Kwame. NSNG9's sadness Once NSNG9 was diagnosed with schizophrenia a gulf was wedged between him and his friends. He was alienated because of his behaviour perhaps through lack of understanding or awareness of what he was going through. He was rejected by his friends and in turn rejected them.

The disinterest in schizophrenia from his relatives had left Kwame feeling dehumanised. He refers to F20.0 which stands for 'paranoid schizophrenia' (WHO, n.d.2020), denoting the diagnosis to a figure compounds the thoughts of feeling less than human. His family's lack of interest may influence whether he shares the diagnosis with others. Being dismissed or alienated by significant others leaves those people with a psychiatric diagnosis vulnerable to further isolation.

### **Sub-ordinate theme three: Accepting a new identity**

*Sandra: I felt ashamed but there's nothing I could do about it because it was like I wanted to be at work. I wanted to be out with other people [Hmm]. I wanted to have a normal life. [Hmm] but through the diagnosis and what had happened my life came crumbling down (Page 14).*

*Glendora: It's affected my life because I should be working although I'm 58 but you know...I should have something for myself... (Page 11).*

Participants describe different ways of accepting a new identity following a schizophrenia diagnosis. All participants' identities, view of themselves and thoughts about how others perceived them changed markedly post-diagnosis. Sandra and Glendora exhibit strong feelings of shame, regret and possibly guilt about wanting to have a "normal life" and not achieving as much as they wanted to because of the diagnosis. Sandra's use of the word "crumbling" evokes

images of her internal and external world falling apart. Desiring to work and being unable to symbolises a loss of identity.

*Mary: ...I accept I'm not well. I accept I have experiences that other people don't experience. Other people don't hear voices in their head, other people don't hear voices that are coming from nowhere. (Page 11).*

Mary accepts that she is different from other people because she hears voices. This means that she stands out from others because she is “not well”. Mary’s acceptance of a new identity does not come without comparing herself to people who do not share her experiences.

*Peter: When I was introduced to the term schizophrenia I was a bit afraid but I wasn't as surprised and as ah...the doctor, the doctor seemed reluctant, if anything to make this announcement (Page 1).*

*Peter: probably one of the reasons why they didn't want to give the diagnosis, is because the patient...a diagnosis define...a diagnosis can also be like a sentence. It can...if a person is not prepared for it, it can be the beginning of the problem in a new way. So a person can be handcuffed in a sense that before the diagnosis is delivered there is a final...the handcuffs are there. But as the verdict is delivered what can happen if one is not careful, this could be the reason why they spent many years not giving their diagnosis. The persons have now start to put on the handcuffs themselves so...yes, yes, even though the person puts the handcuffs there [...] So the patient has to learn, the patient doesn't really have a choice. The patient can't escape unscathed, it's very...the human mind is one of the most amazing...certain schizophrenic people, sometimes they do things...they could be very unwell on a Monday and then on a Friday for no reason at all they would just function as if the illness had never existed. (Pages 25- 26).*

Peter often speaks in the third person. Peter was fearful but not surprised that he was diagnosed with schizophrenia. Despite being afraid, Peter resigns himself to the fact that he has this diagnosis. Peter also draws attention to the reluctance of the doctor who gave him the diagnosis. One can extrapolate that he believes his doctor did not want to give him the diagnosis. Peter offers empathy for the doctor or mental health professional because they know

that they are apportioning a psychiatric diagnosis which to some may encounter as a “sentence”. Peter uses terms such as “sentence” which evokes other phrases such as ‘death sentence’ or ‘prison sentence’ which symbolises the mental health professional signing off the ‘patient’s’ fate. Peter repeatedly says “handcuffs” and the word “verdict” which signifies the diagnosis as an entrapment in which his freedom has been taken or limited.

Peter uses language such as “patient”, “unwell” and “illness”. Part of adopting this new identity is accepting that he is “unwell” and a “patient”, which inherently means he is enlisted and dependent on a medicalised setting. The “handcuffs” can be a metaphor for the new identity that those living with schizophrenia carry. Not only are the “handcuffs” placed on the individual by the “reluctant” clinician, the individual can place the “handcuffs” on themselves assuming the role of a “patient”.

*NSNG9: ...I think psychosis itself has hindered my development in many aspects. But it's given me something else that I value.*

Interviewer: Mmm, yeah. Are you able to share what it is that you value?

*NSNG9: [Pause – 10 secs] [sighs]. ...and also my culture, where I come from (Pages 9).*

Since receiving his diagnosis, NSNG9 has been on a search to find out who he is. He recognises that on the one hand “psychosis” has “hindered” his progression in life. However on the other hand psychosis has opened up his “ability to think”, something he values greatly as he discovers new aspects of his identity and ancient culture.

#### **Sub-ordinate theme four: “I tell the psychiatry, there’s nothing with me”**

*Marcie: In my case, I can’t really say what it is because...um...I don’t think I’m ill. No, I don’t think I’m ill. I don’t think I’m ill. (Page 1).*

*Marcie: ...even now I wish I wasn’t diagnosed because it’s something that I have come to terms with I accept it because...I tell the psychiatry, there’s nothing wrong with me... (Page 14).*

Marcie equates illness to something being wrong and vehemently states that “there’s nothing wrong with me”. Her repetition of the statement “I don’t think I’m ill” stresses this point. Marcie continues to tell the psychiatrists that there is “nothing wrong with me”; this is perhaps her way to reject the diagnosis. If she has to continue telling psychiatrists that there is nothing wrong with her, one can assume that she believes she is not being listened to. There is underlying sadness here; Marcie seems to be in conflict with the diagnosis because she has had to accept an illness which she does not believe in.

*Glendora: I don’t like the diagnosis of schizophrenia...I prefer you call it ‘breakdown’. I mean, you just have a breakdown. But anytime you tell them that you’re hearing voices. They just put a label on it that says schizophrenic and I don’t understand that term of schizophrenia. (Page 15).*

Towards the end of the interview Glendora requested that I refer to schizophrenia as a ‘breakdown’ which I did for the remaining of the interview. Glendora’s rejection of her diagnosis comes in the form of disliking and dismissing the term schizophrenia. Similar to Peter’s reference to depression being socially acceptable, Glendora would rather use the term ‘breakdown’, perhaps finding it less stigmatising. The “label” of being a “schizophrenia” has been placed on her, however ‘schizophrenia’ does not provide the total meaning or understanding to her voice-hearing experiences. Similar to Marcie, the language she uses to define her experiences are in stark contrast to the way mental health professionals label their experiences. Some participants express a level of defiance to oppose the way professionals define their experiences. There is an inner resilience that seems to influence the degree to which participants accept their diagnosis. Marcie has voiced her rejection of schizophrenia as an “illness” to her psychiatrist. I wonder how this resistance is perceived by the psychiatrist and the wider mental health system in relation to rejecting the diagnosis yet still required to engage with the medicalised system. The stigma of having a diagnosis of schizophrenia for people who received the diagnosis more than 20 years ago is still profound today, despite the length of time that has passed.

## **Summary**

Receiving a diagnosis of schizophrenia is a meaningful and momentous aspect of participants' histories that will forever be etched in their minds. For some participants, one or two events led to the diagnosis while for others, it was a series of events. Many participants received the diagnosis whilst under section. Others cited a susceptibility to being sectioned simply because the schizophrenia diagnosis was attached to them. At the point of receiving their diagnosis, many participants were either alienated or dismissed by partners, neighbours, relatives and friends. Receiving the diagnosis was a turbulent and uncertain time for many. Acceptance of the diagnosis is an ongoing process. For some, this came in the form of resigning themselves to a new identity, a new way of being and a new way of being perceived by other people. However, others actively reject the diagnosis by attempting to tell mental health professionals that they do not have schizophrenia.

### **Super-ordinate theme three: “A spiritual dimension to this experience”**

Over half of the participant sample mentioned an element of spirituality in their interviews. The title for this super-ordinate theme are the words of NSNG9 and captures the importance of spirituality in understanding the lived experiences of schizophrenia. Spirituality in this context covers both an external form of spirituality, looking to God and religion to contribute to their subjective meaning and experience of schizophrenia. The other form of “spiritual dimension” explores embarking on a personal journey with spirituality that was triggered by the diagnosis of schizophrenia.

#### **Sub-ordinate theme one: “Only God knows...”**

*Mary: So as for what causes that only God knows. (Page 4).*

*Mary: I just accept it. I accept it from the hand of God because I believe whatever God gives one, one should open one's palms and accept it and I believe God loves me. (Page 10).*

*Mary: What I mean by God knows, only God knows, I can't explain it. I don't know why there's schizophrenia in this world. I don't know why people suffer from schizophrenia in this world. That's why I said only God knows, it's something beyond my*



*comprehension and it's I think it's beyond anybody's comprehension it's something that just happens to some people and only God can explain it. I don't know why. (Page 12).*

As Mary progressed through her interview, she elaborated on the theme of “only God knows” without direct prompting. The phrase “only God knows” reveals the speaker’s limited knowledge about a situation. It can also reveal the speaker’s frustration when there is no other possible explanation, “only God knows”. Mary’s second quote emphasises her acceptance of schizophrenia as she believes that it has been given to her by God. In the third quote, one can discern Mary’s frustration. She has been given something by God that causes her to suffer and is beyond anyone’s comprehension. This quote hints that Mary’s spirituality permits her to reluctantly accept the diagnosis.

### **Sub-ordinate theme two: “A shamanic experience”**

*NSNG9: So when I had, when this...when my psychosis presented itself it was the voices in my head would always allude to some kind of spiritual aspect, there was always a spiritual dimension to this experience. (Page 6).*

Interviewer: [...] do you define it as schizophrenia or do you say psychosis? How do you define the experience?

*NSNG9: I use psychosis as a shorthand [...] I treat it as a shamanic experience. [...] ..6 months, that very first full on psychotic episode there are things that I saw that were.. you have the auditory hallucinations but there was also the visual hallucinations and most of what I experienced... when the...when you talk about the shamanic experiences ..my very...personal psychotic episode with the...with the shamanic experience tallies up perfectly some of the things I saw are some of the things that I felt tally almost identical to, to the typical shamanic experience*

Interviewer: ... how would you define the shamanic experience?

*NSNG9: [Pauses – 5 secs] I was taken up and I saw things [Mmm]and I was brought back down again[...] But there's other information of a...other information within that experience...it will be hard for me to go into [that's okay].*

Interviewer: Don't feel you have to go into...go with what you feel comfortable sharing. It's about keeping yourself safe because I know we are talking about something that's actually very sensitive [yes it is].

*NSNG9: No, I'm not going to share...the actual, there's a lot of the detail that I won't share.[...] I'm not going to be specific about the auditory hallucinations. I'm not going to say what exactly I saw[...] and also with the visual hallucinations (Pages 8- 9)*

*NSNG9: In the olden days people would specifically seek out these experiences...The shaman, the medicine man so, so forth and the natural philosopher. They will seek out these experiences in the Americas, North America, South America, Africa, Australia and even the Far East. (Page 11).*

I noticed that NSNG9 referred to his experiences as “psychosis” and I continued to use ‘psychosis’ for the remaining of the interview. I observed that NSNG9 frequently pauses longer than 5 seconds and seems to be deep in thought during these moments or concentrating on the content he was communicating. Following the pause, it felt like NSNG9 was letting me into a secrets. The It was NSNG9 refers to his psychotic episodes as “shamanic” that have a spiritual element. Following the diagnosis, NSNG9 went on a journey of enlightenment to discover and understand his experiences through what could be considered to be an ‘alternative’ perspective. In naming those particular countries He resorts people sought out the experiences for which he is being stigmatised for. NSNG9 came to the interview with a piece of paper with points he wanted to cover about his “psychosis”. He referred to the paper to ensure he covered all his points. At the end of the interview, NSNG9 showed me the paper with the instruction. It was at this point that I realised that similar to the therapeutic relationship, NSNG9 was conveying trust in the participant-researcher relationship. In this segment, NSNG9 reinforces that his understanding of his psychosis is not of an illness but a shamanic experience that demonstrates spiritual depth. There were aspects of the shamanic experience that NSNG9 did not want to disclose. My focus was the participant's safety and I encouraged him to share what he felt comfortable sharing. NSNG9 made an informed choice that he will not share the full content of his shamanic experience(s).

### **Sub-ordinate theme three: Christianity and faith in God**

*Sandra: ...I kept saying Psalms 91 and I had a Christian friend and I told her about what I was going through [Hmm] and when I told her I wasn't well she came to the workplace with me and her name's called xxxxx and she saw the doctor with me and said erm if she, I'm not well enough to be at work at one point and if they could erm sort out my my my erm, my benefit or what I'm entitled to because she knew I wasn't well [Hmm] So erm, she was very supportive. (Page 9).*

Half of the sample specifically referred to Christianity and a belief in God that seemed to help them manage their difficult experiences. Sandra finds it helpful to read scriptures from the Bible when she is “hallucinating”. Psalm 91 specifically refers to God’s protection. It would seem that by repetitively saying the scripture she was evoking divine protection from the voices. During her interview, Sandra recalled a few occasions where her friends from church helped to advocate on her behalf, implying that she has a strong support network at the church.

*Glendora: ...sometimes I cry when I listen to this because he's been faithful otherwise I would have taken my life (Page 7).*

Glendora played a clip from a gospel song from her mobile phone entitled ‘He’s been faithful’, referring to God being faithful in difficult and challenging circumstances. Her belief in God has saved her life and given her comfort when death may have seen like the only other option.

*Mary: God has chosen me to go through this fire of torture to understand things to you know to get on a higher level not to stay on the staid...erm...How should I put it? Earthbound level that many people are on. I wanted to rise above that level and see things from afar and have foresight and see things as (sighs) that other people cannot see and being unable to...all I've been doing now is trying to explain schizophrenia. (Page 16).*

Mary elaborates on what could be considered a reluctant acceptance of schizophrenia. Mary believes God has chosen her to help her reach a spiritual and “higher level”, despite the “fire of torture”. The evocative phrase “Fire of torture” may also have connotations of hell where

she is being tortured by schizophrenia. For Mary to have metaphorical vision or to experience aspects of the spiritual realm she must “suffer” and be persecuted. Those who do not have the diagnosis are perceived as being “earthbound” perhaps implying that they are chosen to live by the status quo of society’s norms.

#### **Sub-ordinate theme four: Battle between good and evil**

*Glendora: Yeah, yeah God, I hear a calm voice in my heart telling me though...I still listen to the heart the good voice in my heart. Sometimes the voices are, can tell you to kill yourself, not hurt anybody. I don't know about anybody else but hurt yourself like take your...take an overdose, but I always listen to the calm voice in my heart...even though the voices in your head telling you “you’re no good”...“you’re evil, you’re wicked” ...it’s not very nice. (Page 1).*

When the participants describe their subjective experiences of schizophrenia, they perceive themselves as positioned between ‘good’ and ‘evil’ forces. In Glendora’s account, the “good voice” she associates with God is located in her heart and speaks to her calmly. In contrast, multiple negative voices in her head verbally abuse and torment her. Listening to the “good” and “calm” voice helps Glendora overcome and manage the barrage of persecutory voices.

*Mary: ...the thing with the unpleasant voices, is it's not just them I also in the night hear other voices that say, “Oh, I love this girl. Please leave her alone. Oh, God will help her please leave her alone. Don't rape her. Don't do this. Don't do that” and the horrible voices will say “I will I will and I'll do this” you know, it's like an argument between the good and the bad and I have to listen in, and I don't want to listen to this rubbish. (Page 4).*

*Mary: One of the voices is Jesus and one of the er voices is erm that I hear, angels talking to me. Saying “don't worry, you know that God is with you. God is fighting for you. He will protect you”. The same thing Jesus says so that cheers me up. (Page 5).*

Mary illustrates her frustration and annoyance over being forced to listen to the discussion between the good and bad voices. She describes both groups of voices as bargaining and vying

for her attention and arguing over her fate. Sandra is being continually harassed until divine beings communicate with her. Sandra finds comfort with the notion that “God”, a supreme being is defending and protecting her.

### **Summary**

More than half of the sample mentioned an element of spirituality in their interviews. This super-ordinate theme presents the strong emphasis participants placed on spirituality. Some participants received comfort believing there is a higher power who knows about their “sufferings”. In Sandra’s case the church formed a good support network in advocating on her behalf. Reading scriptures or playing gospel music was a coping mechanism for those who found the voices distressing. Some participants also felt that they had been “chosen” by God or a higher being to have experiences that allowed them to access a form of enlightenment. Others stated that they could hear Jesus or an angel speaking to them encouraging them to withstand the evil and “unpleasant voices”.

### **Super-ordinate theme four: Being Black with mental health issues**

The interview schedule did not include any direct questions about ethnicity and lived experiences of schizophrenia. However, half of the sample raised aspects of their Black identity in connection with schizophrenia and the mental health system. The final super-ordinate encapsulates the importance that being Black has on the participants’ identity, as well as the impact of internal racism and institutional racism. The third sub-ordinate theme (“I’ve always known my history, I’ve always loved my black skin” Cultural pride), appears to be a contrasting sub-ordinate theme in comparison to the first two sub-ordinate themes. Smith (2009, p.97) refers to contrasting sub-ordinate themes as polarization which is "the oppositional relationships between emergent themes by focusing upon difference instead of similarity". Polarization is one of the processes undertaken to look for patterns and connections between emergent themes in this study.

### **Sub-ordinate theme one: Racism and being othered**

Marcie: The system labelled me, they label a lot of Black people they put them, they put us in prison they erm...section... (Page 11).

Marcie: ...As a foreign person any land that you go to as a foreign person, you're not treated as good as the inhabitants and some other foreigners, especially if you're a Black person [...] the experiences of life it's not nice and when you think that people look at you and call you a Black bastard, you know, it would affect any race and the degrading treatment... (page 13).

Four participants mentioned race during their interviews, whether as a reflection of their lived experience as a Black person with schizophrenia or perceptions about the way society might perceive them as Black people with schizophrenia. While the first sub-ordinate theme covers racism and being 'othered', the second sub-ordinate theme explores internalised racism from one participant and the third sub-ordinate theme provides a polarised reflection, focusing on the cultural pride of identifying as a Black person.

This was one of the few times during her interview when Marcie became more emotive and her tone of voice changed. Her frustration and anger over being mistreated and experiencing injustice was tangible. Marcie argues that "the system" has labelled her and other Black people and they are consequently detained in both prison and mental health facilities. Marcie has personally been affected by institutional racism and notes that Black people have been labelled with schizophrenia have as a result of institutional racism. Marcie was born in the Caribbean and came to the UK in her teenage years and has been in the UK for almost four decades. Referring to herself as a "foreign person" and facing racism gives the impression that Marcie does not believe that she belongs. Marcie's lived experience of schizophrenia consists of unfair treatment because of her ethnicity and the diagnosis.

*Glendora: ...when I go out with my husband, a white man called me "black n\*\*\*\*r, "black n\*\*\*\*r" and all that, you know. (page 7).*

Glendora recalls a time in the 1970s when she was married to a White British man. They were walking down the street and another White male racially abused her. Glendora indicates that this was one of many racist incidents she suffered during her marriage before being diagnosed with schizophrenia. Glendora cites her husband's infidelity and the breakdown of her marriage as the factors that led to her diagnosis (page 4 ). One cannot help but wonder what effect external racism contributed to the breakdown of her marriage which in turn may have left her susceptible to the diagnosis. She expresses this story in the present tense with sadness and states that the impact of facing racial abuse nearly 40 years ago still has a profound effect on her.

**Sub-ordinate theme two: “Black people need something behind them to pull them in the right line”**

*Roy: I'd diagnose it myself if I was a doctor...I think black people need something behind them to pull them in the right line.*

Interviewer: Okay, tell me more about that. Why do Black people need something to put them in the right line?

*Roy: Because some of them are ignorant and they're violent to one another [...] and they keep fighting ...put them on schizophrenia, mental illness (Page 17).*

Roy is adamant that the purpose of schizophrenia is to give Black people the diagnosis as a means to control behaviour. As well as internalised racism, his level of disdain for other Black people maybe a projection of how he views himself. Being pulled in the “right line” was a recurring theme in Roy's interview. As a teenager he was sent to boarding school and Roy stated that this intervention was a reaction to his misbehaviour to get him back in the “right line”. The diagnosis is seen as a punishment to restore order.

**Sub-ordinate theme three: “I've always known my history, I've always loved my black skin” Cultural pride**

*NSNG9: For myself I have a collective identity and a meta-ethnicity...The collective ethnicity...I always have to use the shorthand that is the problem, my collective identity*

*is Nubian...That's just the shorthand though and then my meta-ethnicity is Manday Congo. (page 10).*

Following NSNG9's path of self-discovery and identity post-diagnosis, he no longer identifies himself as 'Black'. He states that he does not like the term "Black" as he feels that it is "pejorative" (page 10). He describes himself as being 'Nubian' and names his "meta-ethnicity" as 'Manday Congo'. He chose the name 'NSNG9' to reinforce his adapted connection to the Congolese culture. The process of rejecting the ethnicity classification can be considered a parallel process of rejecting another categorisation in the form of the diagnosis. Living with schizophrenia has expanded NSNG9's cultural awareness and expanding his identity in a manner that has been led and created by him.

*Marcie: ...and then you have to learn about slavery and what has happened to, that's why um...some people who don't know their history, they become haters of themselves because they do not know their history, you know with me I, I've always known my history, I've always loved my black skin (page 13).*

Marcie speaks about how her knowledge of history has influenced her love and understanding of who she is as a Black person. Loving her "black skin" symbolises cultural pride in her identity and promotes. The phrase "black skin" can be understood both literally and metaphorically. It is also synonymous with the 'Black is Beautiful' movement that started in the USA to counteract the effects of racial oppression both internally and externally. She emphasises that slavery is only one part of the history of African and Caribbean people and a lack of knowledge about historical events can influence Black people to become "haters of themselves" which can be translated as internal racism. In the backdrop of being integrated into a wider mental health system that has been described as being institutionally racist, Marcie's relationship with her self-perception as a Black person helps to manage the challenges of living with schizophrenia.



## **Summary**

Racial issues constitute a meaningful aspect of the participants' lived experiences of schizophrenia. This theme acknowledges the polarised positions of racism and cultural pride as a key aspect of the participants' identity. On one hand, experiencing racism and being 'othered' reveals oppression and a power imbalance. Roy's account demonstrates that internal racism is also present for Black people living with schizophrenia. Both Roy and Marcie highlight the belief that Black people are labelled with schizophrenia as a form of social control.

## **Discussion**

### **Introduction**

The analysis is centred on the participants' experiences and meaning-making of living with schizophrenia. Exploring the meaning-making processes embodies the phenomenological attributes of IPA. Understanding the meaning-making of the phenomenon involves acknowledging the role of the researcher in addition to the participants in the co-creation of knowledge. The interpretations were grounded within the participants' data and supported using data extracts to offer evidence of a transparent reading of the analytic journey. Reflexivity was used throughout the research project to locate my position as the researcher regarding the phenomenon and the experience of "making sense of participants trying to make sense of their world" (Smith & Osborn, 2015, p.26). Within the context of this research, the subjective world of receiving a diagnosis of schizophrenia for people of Black African and Black Caribbean heritage was explored. The remainder of this chapter contextualises the main findings in the literature, the contribution of this study to counselling psychology and the limitations of this study. This chapter concludes with a discussion of the participants and their diagnostic information, the four super-ordinate themes, the limitations, reflexivity, implications for counselling psychology and allied professions and suggestions for future research.

The inclusion criterion for the study included having a diagnosis of schizophrenia for a minimum of two years prior to the interview (NICE, 2014). He-Man (pilot interview) stated that he was diagnosed with schizophrenia approximately 36-37 years ago. Glendora and Roy were diagnosed over 30 years ago. He-Man was diagnosed with schizophrenia at the age of 21, the youngest of the participants. Marcie was 43 years old when she received her diagnosis of schizophrenia, and 51 years old when she received another diagnosis of paranoid schizophrenia. This context may provide information regarding Marcie wanting to sue "everybody" who gave her the diagnosis of paranoid schizophrenia. Marcie received her diagnosis at a later age than the other participants. Peter was the only other participant with two diagnoses: schizophrenia at the age of 31, and "psychosis-aggravated" at the age of 35. The demographic information, in addition to when the diagnosis was received, was collated at the beginning of the interviews. Neither Peter nor Marcie mentioned that they had two

diagnoses connected to schizophrenia during their interviews. Perhaps the length of time in receiving the diagnosis may affect the reliability of recall in understanding the lived experience of schizophrenia. However, the vivid accounts expressed as a result of phenomenological inquiry are testimony to the poignancy of the lived experiences of the diagnosis. Smith et al. (2009) do not stipulate a specific period in which someone can phenomenologically access their lived experience.

The average age of the participants was 53 years old. NSNG9 was the youngest participant at 40 years old and Marcie was the oldest participant at 63 years old. All of the participants were over the age of 40 which contributes to the homogeneity of the sample. Despite the sample coming from two services, the sample yielded participants with similar demographics. Marcie received the most recent diagnosis at 12 years before her interview. This was her second schizophrenia-related diagnosis. The participants' ages raise an interesting point for consideration. Marcie was 43 years old when she received a diagnosis of schizophrenia and 51 when she received a diagnosis of paranoid schizophrenia. The majority of participants were between the ages of 23 and 28 when they received the diagnosis. There is a significant length of time between the event of receiving the diagnosis of schizophrenia and making meaning of living with schizophrenia. This may infer that a certain amount of time is needed to process and articulate the subjective experiences of schizophrenia. It is possible that the participants were at an age where they were able to reflect on their experiences which may not have been feasible at the point of diagnosis.

The following section locates the four super-ordinate themes within the existing literature.

### **Schizophrenia is a form of social control**

The process of receiving a diagnosis of schizophrenia is complex and multifaceted. The nature of living with a diagnosis of schizophrenia can be a life-changing and profound encounter. This experience is not limited to the day the individual was informed of the diagnosis but has a longer-term effect as the recipient continues to battle with understanding schizophrenia and grapples to accept the effects of the diagnosis on areas such as personal relationships, social context and identity. Over the years, there has been much debate about schizophrenia as a valid scientific term. There have been many ways to conceptualise schizophrenia; however, in

line with IPA, the participants were afforded the opportunity to describe what their definitions and understandings of schizophrenia mean to them personally. The participants answered this question in diverse ways.

Generally, living with a diagnosis of schizophrenia was not perceived as a helpful or productive experience in managing emotional distress. For some participants, schizophrenia was synonymous with the fear of being rejected and stigmatised by friends, family members and the wider public. People with mental health issues are amongst the most stigmatised groups in society (Bloch and Singh, 1997), and those diagnosed with schizophrenia and psychosis are perceived to be at the polarised end of the spectrum (Morris, 2017). Once she received her diagnosis, Marcie's fear of receiving negative discrimination in the workplace prevented her from returning to work. Marcie's fears are congruent with Ucok et al. (2012) who conducted a study of 732 people diagnosed with schizophrenia from 27 countries. They found that 64% had stopped themselves from applying for work, training and education and 58% had stopped themselves from looking for a close relationship because of anticipated stigma. The researchers found that anticipated discrimination was strongly related to actual discrimination. Examining public attitudes to mental health diagnosis is important because they underlie discriminatory behaviour. Research with BME mental health users in the UK has demonstrated that stigma is a contributing factor in preventing people from accessing mental health services (Memon et al., 2016).

Stigma is essentially a social and psychological phenomenon (Mantovani, Pizzolatini & Edge, 2017). Corrigan and Watson (2002) conceptualise stigma in two dimensions: public stigma and self-stigma. Public stigma encompasses negative attitudes (prejudice), beliefs (stereotypes) and behaviour (discrimination) towards the stigmatised individual; and self-stigma is the internalisation of these experiences by the stigmatised person. Self-stigma is defined as a process of identity transformation wherein a person loses their previously held or desired identities (e.g. as a partner, friend, parent or employee) to adopt a stigmatised view of themselves (Yanos, Roe, Markus & Lysaker, 2008). Self-stigma is also called internalised stigma (van Brakel, Anderson, Mutatkar, Bakirtzief, Nicholls, Raju & Das-Pattanayak, 2006).

The sub-ordinate theme of “the fear of being rejected and stigmatised” is not intended to minimise the participants’ perceptions but to highlight the power that fear of rejection and stigma can have. It is, therefore, anticipated and unsurprising that the majority of people diagnosed with schizophrenia do not disclose it to others (Ucok et al., 2012). This was the case for both Kwame and Peter. Peter’s family believed he had been diagnosed with depression rather than schizophrenia. Peter thought that it was more socially acceptable for someone to have depression than to live with schizophrenia. This belief is in line with public perception. Wood, Birtel, Alsawy, Pyle and Morrison (2014) examined public stigma attitudes towards schizophrenia, depression and anxiety as diagnoses using the UK ONS opinions survey database (ONS, 2008). The researchers found that schizophrenia was significantly associated with the most negative stereotypes, least blamed for the diagnosis and viewed as least likely to recover compared with anxiety and depression.

Most participants considered themselves as differing from anyone else not diagnosed with schizophrenia. The participants’ use of “*they*” indicates an ‘us versus them’ scenario, which represents those who are inside (us), the phenomenon, and those who are outside (them). People living with schizophrenia are not generally accepted, but are instead rejected and seen as outsiders to the mainstream. Being “*in schizophrenia*” (Peter, page 32) is the antithesis of being outside. For Peter, there was a sense that he has resigned himself to the notion that he is both inside the phenomenon and outside the mainstream. The idea of being inside something offers an impression of protection. To be “*in schizophrenia*” also offers a sense of safety, with people who have a mutual understanding of what it is like to live with schizophrenia.

In differentiating herself from those who do not live with schizophrenia, Marcie used the term “*aberration*”. Whilst transcribing Marcie’s interview, I searched for the definition of “*aberration*”, which is described as a “departure from what is normal” (Oxford English Dictionary, n.d.). This definition is an apt way to capture the participants’ experiences and the second sub-ordinate theme was entitled: “Aberration” - Departure from what is ‘normal’. A departure from what is normal is in line with displaying behaviour that moves away from everyday societal norms. Many of the participants’ lived experiences of schizophrenia were extensively characterised by hearing voices, which is a phenomenon in its own right. Hearing

one or multiple voices in addition to one's own voice is an example of what might be perceived as a departure from the norm. NSNG9 was the only participant who explicitly normalised hearing voices, stating that, "*everybody experiences it sometime in their life*". A number of surveys have revealed that many people hear voices regularly, many would not identify themselves as having a 'mental illness' and do not come into contact with mental health services (Beavan et al., 2011).

Kwame stated that he had not heard any voices for sixteen years. Roy did not mention experiencing voice-hearing, although this does not suggest that he did not hear voices in the past. All the female participants spoke about hearing voices. The participants did not view hearing voices as being symptomatic of schizophrenia as a diagnosis compared with how it is seen within the medical model. Glendora was adamant there was a clear distinction between how she defines her voices and the way mental health professionals define her experiences. She reiterated that mental health professionals "label" her voice-hearing as schizophrenia and she does not believe it should be defined as being symptomatic of the diagnosis. The participants considered hearing voices to be a phenomenon that has been misunderstood and re-defined as schizophrenia by psychiatrists and psychologists. Diagnosed individuals who refute the professional accounts of their experiences may be labelled as lacking in insight because they have a mental "disorder" and, thus, it can be difficult for them to challenge or change medicalisation (Johnstone & Boyle, 2018).

During the interviews, there was a recurring theme of being labelled with the diagnosis of schizophrenia. Marcie expressed anger and frustration with the desperate wish to sue "*everybody*" that "*labelled*" her as a "*paranoid schizophrenic*". NSNG9 also viewed the diagnosis as a "*label*" that was "*thrust*" upon him. Using words such as "thrust upon" has connotations of the diagnosis being forcefully imposed, not only by mental health professionals, but also by the wider society. Connotations of the participants being branded were also evoked. Branding is the 'permanent marking of livestock or goods using a distinctive design made by hot or cold metal...for purposes of identification' (Encyclopaedia Britannica, n.d.). Slaves during the period of trans-Atlantic slavery were branded to demonstrate ownership and as a form of punishment (Fryer, 2018). Something in the permanency of a psychiatric diagnosis resonates with the concept of being branded.

Labelling and increased social exclusion have been noted as some of the limitations of receiving a mental health diagnosis (Hayne, 2003; Pitt et al., 2009). Labelling can create a power imbalance that is exercised over an individual or groups of people. The one who assumes the authority to categorise someone's behaviour automatically seizes control, rendering the one in receipt of the label powerless. During the interviews, two of the participants no longer wanted to refer to schizophrenia as their diagnosis but used terms such as "*psychosis*" and "*breakdown*". I interpreted this wish as a way for the participants to take some form of control, from an imposed label to a chosen term that defines their experiences.

### **Living with schizophrenia is a dynamic sentence**

For the participants, the effects of receiving the diagnosis extended beyond the day they were informed that they were "*schizophrenic*". The psychiatric diagnosis was followed swiftly by medicalised interventions such as prescribed medication, being admitted to hospital under a section order and using ECT. Medicalisation and psychiatric diagnosis are grounded firmly within the medical model. When medication and other forms of medical treatment become the default route to addressing human distress, it leaves little room for alternative interventions. There is no doubt that the use of medication may bring relief; however, there is no evidence that they are the sole treatment for particular mental "illnesses" such as schizophrenia (Johnstone and Boyle, 2018). There is an assumption that everyone benefits from anti-psychotic medication, which in some cases is no better than a placebo for most recipients and may have such severe adverse effects that the majority discontinue them within a few months (Hutton et al., 2014).

Whitaker (2010) argues that anti-psychotic medication taken long-term may harm the brain. An example of a severe side-effect is Tardive Dyskinesia, which is the rhythmic, involuntary movements of tongue, face and jaw (NICE, n.d.). Tardive Dyskinesia can develop during long-term therapy, but can also develop during short-term treatment with low doses (NICE, n.d.). Sadly, the effects of Tardive Dyskinesia can be irreversible, even after medication is stopped (NICE, n.d.). Anti-psychotic medication may still have a function in psychiatry, but its use should be reviewed. In *The Anatomy of an Epidemic* (Whitaker, 2010), Robert Whitaker cites Open Dialogue's approach to anti-psychotic medication. Open Dialogue provides a person-centred model of mental healthcare originated by a Finnish group in western Lapland in the

1980s. Through using anti-psychotic medication in a cautious and selective manner, data from non-randomised trials with first-episode “patients” demonstrated that 85% of “patients” were either working or back in school, and that only 20% were taking anti-psychotic medication at the end of the five-year period. The study indicates that people living with schizophrenia can have a better quality of life in countries where the prescription of anti-psychotic medication is actively being monitored.

In addition to medication, being detained or sectioned in a psychiatric establishment is a common occurrence for someone living with schizophrenia. Some participants have been sectioned multiple times. Roy, Marcie and NSNG9 described examples of being sectioned that brought terror, fear and disempowerment as their liberty was restricted. Under the Mental Health Act (1983), an individual can be sectioned without their agreement. The Act is structured in many sections, and an individual can be detained under its legislation. In 2017, the Government commissioned an independent review of the Act, and 154 recommendations were made to improve people’s experiences under the Act and to reduce the need to detain people (Wesseley, 2018). The mandate for the review was to consider the reasons for rising rates of detention, the disproportionate number of BAME individuals sectioned and the outdated processes currently in the mental health system.

Halvorsrud et al. (2018) carried out a systematic review and meta-analysis study in England, with the results revealing that Black Caribbean patients are three and a half times more likely and Black African patients are three times more likely than White patients to experience compulsory admission under the Mental Health Act (1983). The researchers found also that Black Caribbean patients are two and a half times more likely and Black African patients three and a half times more likely than White patients to have contact with the police before admission (Halvorsrud et al., 2018). Such police contact consisted of involvement in the person’s pathway to care-related or special measures, such as a police escort to psychiatric services with or without patients being detained. However, Nazroo, Bhui and Rhodea (2020) refute that the significantly higher numbers of Black Caribbean and Black African people being admitted to hospitals and receiving treatment for psychosis-related conditions reflects institutional racism.



Medicalised interventions include ECT. Roy and Mary disclosed that they received ECT whilst under section. Mary received ECT whilst she was in Nigeria, and raised an ethical question about the use of ECT as a treatment. The use of ECT was founded on the notion that schizophrenia could be treated by generating epileptic seizures due to a belief in the 1920s and 1930s that schizophrenia and epilepsy were biologically connected (Read et al., 2013). ECT continues to be a debated and controversial form of intervention and has been criticised for inducing psychological effects such as “feelings of humiliation, increased compliance, failure, worthlessness, betrayal, lack of confidence and degradation and a sense of having been abused and assaulted” (Johnstone, 1999, p.76). Physiological adverse effects of ECT, such as permanent memory loss (Squire & Slater, 1983; Rose, Fleischmann, Wkyes, Lesse & Bindman, 2003) and permanent brain damage (Frank, 1978; Breggin, 2008;), have been recorded.

The UK NICE guidelines on ECT (NICE, 2009, p. 14) recognise that some people report “feelings of terror, shame and distress and found it positively harmful and abusive invasion of personal autonomy, especially when it was administered without their consent”. The ethical issue of obtaining informed consent has been a matter of concern. Amendments to the Mental Health Act (1983) provide people with the right to refuse ECT in some circumstances, unless their psychiatrist thinks they need it urgently (Mental Health Act, 2007). When the amendment was introduced in November 2008, there was a 23% decrease in the number of non-consenting patients (Care Quality Commission, 2010). However, ECT is still considered an effective treatment and is readily available on the NHS and in private establishments.

Although, researchers have reported a steady decline in the number of ECT individual administrations in England (Read, 2004; Singhai, 2011). Nevertheless, recent statistics indicate that the trend may be moving in the opposite direction. NHS Digital, the national information and technology partner for the health and care system, has been accused of withholding data that may confirm that there has been a year-on-year increase of ECT administration in England (Davis & Duncan, 2017; ICO, 2018; Mental Health Today, n.d.). The use of ECT continues to be a contentious point of discussion for the NHS, other stakeholders and, particularly, the recipient.

### **“A spiritual dimension to this experience”**

The majority of participants spoke about the importance that spirituality has for them in their lived experience of schizophrenia. There were three key dimensions surrounding spirituality that emerged from the data: only a higher power or entity can understand the purpose of schizophrenia; following a religion such as Christianity; and searching for spiritual meaning in the experiences. Spirituality is a personal and subjective experience. Ade-Serrano (2017, p.70) defines “spirituality as a connective tool with which one ascertains one’s positioning to the other”. Barker and Buchanan-Barker (2008, p.63) frame spirituality as being about “journey and exploration”, an experience that is the “antithesis of rationality” within the mental health context. In the West, there appears to be a shift from people associating themselves with an identified religion to a form of spirituality (Milton, 2010). The BPS’s report on ‘Psychosis and Schizophrenia’ (BPS, 2017 p. 55) states that, “many people who believe that there is a spiritual element to their experiences find support from others with similar beliefs invaluable, for example within faith communities”. The meaning I extrapolated from Mary’s interview is that her experiences of hearing voices were different to her experiences of following Christianity. Mary was integrated within a church with other people who shared the same belief system as she did. In times of distress, Mary’s pastor and a particular church sister offered support when they could see changes in her behaviour. Mary found their input particularly supportive when they attended appointments with her doctor or psychiatrist. This also highlighted the importance and need of a supportive network around people living with schizophrenia.

In NSNG9’s experience, he attempted to engage with traditional religions or faith communities. He concluded that this was not the path to develop his spirituality. NSNG9 described his “*psychotic episodes*” as “*shamanic*”. “Shamanic” is defined as “relating to the beliefs and practices associated with a shaman” (OED, n.d.). A “shaman” is ‘a person regarded as having access to, and influence in, the world of good and evil spirits, especially among some peoples of northern Asia and North America. Typically such people enter a trance state during a ritual, and practise divination and healing’ (OED, n.d.). NSNG9 named non-Western countries where people deliberately seek shamanic experiences, experiences that he has been stigmatised for. His shamanic experiences consisted of “*auditory hallucinations*” and “*visual hallucinations*”. NSNG9 was willing to name his experiences as shamanic; however, he did not want to expound on the details of the auditory and visual encounters. In some communities, hearing voices is considered a spiritual gift (Romme & Escher, 1993). NSNG9’s spiritual

experiences expose the limitations of using psychiatric diagnosis with non-Western cultures (Owusu-Bempah & Howitt, 2000). A significant criticism of psychiatric diagnosis is that it is based on judgements on the differences in social and cultural norms. (Laing, 1960; Szasz, 1964; Johnstone, 2008). The denial of NSNG9's spiritual experiences may be an example of what Fernando (2010) and Mills (2013) coined as psychiatric imperialism or colonisation which is the imposition of naming people's experiences in alienating terms that deny personal meanings and experience.

The use of metaphors was prevalent in this super-ordinate theme as the participants used striking and intense imagery to describe elements of their spirituality. Mary described schizophrenia as the "*fire of torture*", which has connotations of hell and suffering, offering the reader an impression of what living with schizophrenia is like for Mary.

### **Being Black with mental health issues**

The first and second sub-ordinate themes are centred around external and internal racism. The final sub-ordinate theme diverges (Smith et al., 2009) from the other two sub-ordinate themes. The final theme involved two of the participants conveying cultural pride about being Black despite the systemic inequalities of the mental health care system. Marcie stated that "*the system labelled*" her and continues to "*label*" other Black people, not only in the mental health system but also the prison system. Marcie's belief concurs with existing literature regarding institutional racism within the mental health system (Nazroo et al., 2020; Fernando, 2008; Bhui, 2002). Research has found that discrimination affects the type and quality of mental healthcare received. For example, Black patients are more likely to experience complex pathways of care within mental health services, with a greater likelihood of police involvement and compulsory detention compared with other ethnicities (Bhui et al., 2003).

The first sub-ordinate theme 'Racism and being othered' encapsulates the racism and othering experienced by the participants. Othering can be defined as "a process that identifies those that are thought to be different from oneself or the mainstream, and it can reinforce and reproduce positions of domination and subordination" (Johnson et. al, 2004, p. 253). Turner et al. (2016) explore a psychotherapeutic standpoint of othering, through looking at the unconscious connection between the other and the majority. Turner et al. (2016) claim that in some point

in time, everyone experiences being the other. The concept of othering has been linked to psychology ingroup and outgroup effect (Billig & Tajfel, 1973; Geher, 2019). In relation to the participants, they all recalled accounts of being othered and continually having to engage with a process of othering which is reinforced within their lived experiences of schizophrenia. Mental health professionals can also engage in a process of othering, whereby they construct a distance between themselves and the person living with a psychiatric diagnosis to diminish potential discomfort (Goodwin, 2017). If the process of othering is not identified or addressed in mental health professionals in forums such as clinical supervision, this may exacerbate people living with schizophrenia to be stigmatised further.

Roy's diverged sub-ordinate theme of "*Black people need something behind them to pull them in the right line*" is the opposite of the continuum of the final sub-ordinate theme of "'*I've always known my history, I've always loved my black skin*" – Cultural pride'. Smith et al. (2009, p. 97) refer to this process within IPA as "polarization", which is the examination of transcripts for the difference and "oppositional relationships" between emergent themes. The polarization of the sub-ordinate themes highlight the complexity and interconnectedness of issues about race and schizophrenia. Both NSNG9 and Marcie described a path of self-discovery to find the culture and identity they choose to align themselves with. NSNG9's self-discovery ensued following his diagnosis. Receiving the diagnosis represented a form of enlightenment for NSNG9 when he searched for a non-medicalised explanation for his voice-hearing experiences.

Race was not explicitly introduced in the current study which was reflected in the interview schedule. This allowed participants to share experiences or issues about race according to their own volition without making the assumption that they had to speak about race. I was aware that experiences of race may not have been the most important issue for the participants to discuss. True to the nature of semi-structured interviews, the interview did not always follow the sequence of the interview schedule and it was more appropriate to follow the flow of the participants' experience. Corbin & Morse (2003) advocate this stance for the qualitative researcher and acknowledge that although the researcher gives the interview its initial direction with questions, the emergent nature of the interview can and within the IPA framework should shift control to that of the participant. An interview is a "research method that gives a

privileged access to our basic experience of the lived world” (Kvale, 1996, p.54). Interviews with the participants were an engaging part of the research process where new insights into the participants’ lived world made interviewing a very enriching experience. Despite not including questions on race or culture in the interview schedule half of the sample spoke about racism and racial issues associated with schizophrenia. Other researchers may specifically want the participant to attend to experiences of being Black and living with schizophrenia and choose to include a question in the interview schedule.

Nazroo et al. (2020) argue that, to achieve an adequate understanding of ethnic inequalities in healthcare, the ways in which identities are racialised and the consequent effects on the lives of BAME communities need to be understood. Empirical research suggests that Black patients with psychosis are less likely than White patients to receive psychologically based interventions (Das-Munshi et al., 2018). Furthermore, Black patients are over-represented in assertive outreach services that have the authority to enforce supervised treatment orders on individuals who do not engage with treatment in community settings (Patel et al., 2011). The “coercive nature of these services undermines personal agency and autonomy for patients living in the community” (Nazroo et al., 2020, p.10).

### **The role of language and metaphors in IPA research**

Using language has a significant role in phenomenological research, as the participants explore through interpreting their language (Smith and Osborn 2008). Meaning-making about a phenomenon is extrapolated from the words, phrases and metaphors used. Language is the “means by which participants attempt to communicate their experiences to the researcher” (Willig, 2013, p.94). Heidegger describes language within phenomenology as “the house of Being” where our “interpretation of experience are always shaped, limited and enabled by language” (Smith et al., 2009, p.194). Language is not the primary focus of IPA research; however, meaning is enmeshed within language (Smith et al., 2009).

Individuals utilise metaphors to structure their thoughts, so they can better explain and understand their experiences (Lakoff and Johnson, 1980). Furthermore, metaphors can

highlight aspects of phenomena that had not been noticed (Lakoff and Johnson, 1980) or identified previously. Metaphors can arouse emotion, which enables the reader to engage and connect with the experiences (Patton, 1990). A “great deal of meaning can be conveyed in a single phrase with a powerful metaphor” (Patton, 2002, p.505). Metaphors are important aspects of phenomenological analysis, which yields “meaningful responses” to the lived experience (Smith et al., 2009, p.159).

An example of a powerful metaphor in this research is when Peter described having a diagnosis as like wearing a pair of “handcuffs”. Peter used this metaphor to describe how he experienced schizophrenia as taking on a new persona; a persona that inhibits his liberty and is a form of imprisonment. Using this metaphor was an effective way of demonstrating the emotional and psychological effects of living with a psychiatric diagnosis.

## **Limitations**

### **Limitations of IPA**

IPA was chosen as an appropriate methodology to answer the research question due to its focus on the phenomenological approach for understanding the lived experience of participants (Smith, 2017). The research question sought to explore the lived experience of receiving a diagnosis of schizophrenia for people of Black African and Black Caribbean heritage. There are many strengths in using IPA as a methodology. As a novice researcher, I found IPA to be an innovative research methodology that enabled me to examine the lived experience of schizophrenia in close detail. Introducing IPA into the field of psychology has made phenomenological methodology comprehensible and accessible to those who do not have a philosophical background (Willig, 2013). However, IPA has been criticised for a lack of generalisability. In line with the principles of IPA, the data for this study were obtained from a small sample that is not representative. However, this aspect is not relevant, to an extent, because of the intended idiographic nature and interpretation of the data. Furthermore, generalisability of findings has never been the objective of IPA.

### **Limitations of the current study**

There are limitations to the current study. I conducted in-depth interviews and spent considerable time undertaking thorough data analysis to obtain a rich level of detail from the

data. This approach yielded a substantial number of data, but it was not possible to include all the data in the write-up due to the word-count parameters of this research project. When deciding what to present, I focused on the following: the fundamentals foregrounded by the participants in their interviews; the aspects of the lived experience that they spoke of most emphatically; the elements identified by them as most important; and the features they kept returning to throughout the interview. However, it is conceivable that concentrating on particular aspects of the data stressed particular segments of the participants' experiences. Data are interpreted in a subjective manner and, thus, other researchers may interpret the same data differently and regard other parts of the participants' experiences as more or less central (Smith et al., 2009). Therefore, my interpretation of the data is my subjective examination and influenced by my world view.

Another limitation is that none of the participants were aged under 40 years old. The onset of schizophrenia is typically between 15 and 30 years of age (Drake et al., 2019). All the participants were in their early to mid-20s when they were diagnosed with schizophrenia. In addition, it was 12 years since any of the participants received a diagnosis of schizophrenia (the second time that Marcie received a diagnosis related to schizophrenia). The NICE guidelines state that someone diagnosed with schizophrenia should be outside the initial crisis period for two to five years from the point of diagnosis (NICE, 2014). All the participants were outside of this crisis period by a considerable length of time. The age range of participants will be considered in suggestions for future research.

### **Reflexivity**

Researcher reflexivity is the “capacity of the researcher to acknowledge how their own experiences and contexts... inform the process and outcomes of inquiry” (Etherington, 2004, p.32). Reflexivity involves the researcher attempting to engage in self-awareness. Researchers are encouraged to consider how their values and experiences might influence the research and how the research might influence them.

This was my first time using IPA, and I consider myself to be a novice researcher. Smith et al.'s (2009) book on *Interpretative Phenomenological Analysis* was my core text as I learnt the theoretical concepts and steps for analysis. Both IPA's emphasis on lived experience and the

focal point on subjectivity connected with my clinical work as a trainee counselling psychologist.

During the research, I learnt that the interview process is a dynamic means to engage with people with lived experience. Interviewing is not just a data collection method but a live and powerful tool to enter the subjective experiences of the participants. Following the pilot interview, I had the following reflections: I felt excited and nervous at the same time. I felt the weight and reality of interviewing people with lived experience of schizophrenia. After completing a research proposal and seeking ethical approval, the reality of engaging with lived experiences of the diagnosis and the layers of meaning attributed to this diagnosis became a reality. I had spoken to many people with psychiatric diagnoses in various clinical settings; however, this was my first time as a researcher. The pilot interview allowed me to practise foregrounding the participant's voice and the content they wanted to explore. At times, I was tempted to ask further questions about an interesting point but recognised this may have taken us away from the foregrounded content and research question. At that moment, I had to bracket my own thoughts or questions and stay close to the participant's foregrounded content.

Extending the research to the second service initially created anxiety as I wondered whether I could recruit participants. Similar to the first service, the second service was supportive in helping me to engage with potential participants and remind the participants of their interview appointments. This process increased the likelihood of participants committing to the interviews. At times, I wondered whether the participants felt coerced to engage in the research. To address this concern, I verbally went through the Consent Form (Appendix 7) and Participant Information Sheet (Appendix 6) with the participants and reiterated that they had a right to withdraw without prejudice or any effect on their service provision at the respective services.

It is essential to review the role of the researcher in IPA research, particularly the notion of being an insider/outsider researcher. The insider researcher shares traits with the group being studied, such as experience, gender and ethnicity (Griffith, 1998). In comparison, the outsider researcher shares no commonality with the participant group. Some writers dismiss this



concern this as a one-dimensional view and instead suggest a continuum in which the researcher can occupy both positions (Acker, 2000; Dwyer & Buckle, 2009). I could be considered an insider researcher because I share the same ethnicity as some of the participants, particular those of Caribbean descent. However, one cannot assume that we completely understand each other based on ethnicity alone. The participants may have perceived me as an “outsider” due to my profession being a trainee counselling psychologist, and I do not have a psychiatric diagnosis. The insider perspective relates to the hermeneutic turn in IPA. IPA operates through the combination of a hermeneutic of empathy and a hermeneutic of questioning.

The IPA researcher can adopt an insider’s perspective to determine what the phenomenon is like from participant’s viewpoint whilst simultaneously standing alongside the participant to unpack and ask questions about their experiences. An example of this approach is when NSNG9 described his diagnosis as a “*placeholder*” (NSNG9, page 11). This was a profound moment, as an image of a table placeholder came to mind. I shared this with NSNG9 (see Image 1). The appearance of the image helped to bring further understanding about the meaning-making of the diagnosis for NSNG9.

The implication of the findings for counselling psychology and other allied fields are now discussed.

### **Implications for counselling psychology and other allied fields**

There is dearth in research exploring psychiatric diagnosis and the lived experience of schizophrenia for people who are of Black African and/or Black Caribbean heritage. It is intended that the current study will significantly contribute to filling the gap of both knowledge and clinical experience for counselling psychologists and allied health professionals. The research is timely as the Black Lives Matter movement stand against, structural racism and racial injustices across the globe. The disproportionate numbers of COVID-19 deaths amongst ‘BAME’ communities (Public Health England, 2020) has also put racial inequalities to the forefront. It is also time for the inequalities in the mental health system to also be addressed.

Institutional racism and internalised racism were crucial aspects of participant' lived experience of schizophrenia. Moodley (2005) emphasises that it is inevitable that racial issues or racism will enter the therapy room when working with someone who identifies as being Black, Asian or from other 'minority ethnic' group. However if left unexplored, can alienate the client and create anxiety in therapists. Bains (2010) stresses that it is imperative for therapists to acknowledge racism experienced by clients as a trauma. The author highlights that there is a tendency for therapists to trivialise the impact of racism because of the "fearful and defended nature of racism" (Bains, 2010, p.41). This can have a detrimental effect on a client's mental health. An unwillingness to explore racism may leave the client with the belief that racism is an unspoken topic in a clinical space. Bains (2010) suggests that the therapist should actively be anti-racist in their clinical practice, however stipulates that racism can only be explored sufficient trust and safety has been established in the therapeutic relationship.

Psychiatric diagnosis holds a central position within mental health services for understanding human distress and experiences and has become a fully integrated and often unquestioned part of mental health practice. Diagnostic thinking is engrained not only in the mental health system, but also in "administrative systems for services and in society as a whole, for example, in record-keeping, service planning, outcome measures, reimbursement and welfare systems, and the legal system" (Johnston & Boyle, 2018, p.31). At times, this approach may be in direct juxtaposition to counselling psychology's humanistic values.

The current research study has revealed issues such as racism, spirituality, the meaning attributed to psychiatric diagnoses and how these factors may affect one's psychological wellbeing. To reduce the risk of pathologising individuals, psychologists are encouraged to 'seek to supplement or replace diagnoses, wherever appropriate, with evidence-based individual psychological formulations, models and theories as a way of informing their recommendations and interventions' (BPS, 2012, p. 2). There are alternative approaches for addressing human distress other than diagnosis, such as a formulation, which can be used in conjunction with a diagnosis. A formulation is a hypothesis drawn from psychological theory between client and psychologist to explore the client's difficulties in the "context of their

relationships, social circumstances, life events, and the sense that they have made of them” (Johnstone & Boyle, 2018, p.303). Formulations “give a central role to the exploration of meaning” (Johnstone, 2008, p.17) and place the individual’s experiences at the centre of their care.

Johnstone and Boyle (2018) elaborated on the concept of formulation and created *the power threat meaning framework* (PTMF), which places meaning at the centre of the individual’s experiences, expressions and understandings of their distress. The authors present the PTMF as a complete alternative to diagnosis. The PTMF is based on the premise that “humans are social beings” who have “core needs” that include experiencing “a sense of justice and fairness within their wider community...to feel valued and effective within family and social roles” and “to have a sense of hope, belief, meaning and purpose in their lives” (Johnstone & Boyle, 2018, pp.189-190). This approach seems more in line with the humanistic values of counselling psychology. However, the model is more detailed than I can present in this paper.

Counselling psychologists and other allied clinicians can implement a shift in diagnostic thinking by applying the PTMF in their clinical practice. The model replaces “What is wrong with you?” with four key questions: “What has happened to you?” (How is Power operating in your life?); “How did it affect you?” (What kind of Threats does this pose?); “What sense did you make of it?” (What is the Meaning of these situations and experiences to you?); and “What did you have to do to survive?” (What kinds of Threat Response are you using?) (Johnstone & Boyle, 2018, p.190). The PTMF is not the only example of an alternative to diagnosis, the Open Dialogue approach concentrates on an innovative systemic approach that supports people experiencing a mental health crisis and their families or networks. This approach is not an alternative to the psychiatric system but is the predominant psychiatric provision in Finland. Open Dialogue started in the 1980s in Finland and was established in the UK in 2012. Both these examples demonstrate that there are ways to challenge diagnostic thinking conceptually and in the functional form of a mental health system.

The majority of the participants in the current research believed there was a spiritual dimension to their experiences. This aspect may form a dilemma for clinicians who do not acknowledge the significance of religion or spirituality in the therapy room. An awareness of the therapist’s

own judgements, stereotypes and beliefs about religion or spirituality is, therefore, essential. A review of studies on religion and spirituality found that therapists were more likely to pathologise religious or spiritual beliefs they had little knowledge of (Post and Wade, 2009). Ade-Serrano (2017, p. 76) states that clinicians are at “risk (of) intellectualising what spirituality epitomises for clients”. Implementing religion and spirituality-related themes within the context of supervision and the core tenets of counselling psychology and other allied professions’ training programmes may facilitate this process. The BPS’s Division of Counselling Psychology (DCoP) established the Spirituality Interest group in 2013. The group aims to embrace ‘difference and diversity within spiritual beliefs, experiences and practices and promotes open exploration of a range of issues relevant to counselling psychology philosophy and practice’ (BPS [DCoP], n.d.). Ade-Serrano, (2017, p. 76) suggests that a “working definition model” of spirituality is utilised when exploring this theme with clients.

The working definition model of spirituality creates a definition of spirituality that is appropriate for the client’s subjective purpose and understanding of their experiences. Each client will have their own unique working definition. A way to include spirituality into clinical practice is to actively include this necessary component to the assessment and formulation. Being curious about a client’s faith or belief systems can set the groundwork for open communication about spirituality and spiritual experiences. Clinicians can incorporate a working definition of spirituality and a formulation working collaboratively with the client. For practitioners, this therapeutic process does not differ from the core aspects of clinical work; that is, supporting clients to explore the meaning of experiences and the intricate aspects of self.

Living with a psychiatric diagnosis such as schizophrenia can be stigmatising for the recipient. It is intended that there will be increased awareness about the lived experiences of schizophrenia for people of Black African and/or Black Caribbean heritage. Mental health inequalities amongst Black African and Black Caribbean communities have plagued the mental health system in the United Kingdom for over six decades (Fernando, 2008, 2010, 2017; Nazroo, 2020). Lee et al., (2018, p.32) state that social justice concentrates on issues of “oppression, privilege, and social inequities”. For counselling psychologists and allied health

professionals this implies that social justice should be evident in professional conduct and clinical practices that opposes all forms of discrimination and oppression. Lee et al., (2018, p.33) suggest that there are three concepts that are essential for therapists to engage in social justice: empowerment, advocacy and the therapist “as an agent of social change”. It is the first two concepts which provide the foundation for the role of the therapist as a social change agent. Encompassing a social justice agenda in counselling psychology involves working towards a fair society and challenging systems of oppression (Speight and Vera, 2008). The BPS’s DCoP Social Justice Network (BPS [DCoP], n.d.) states that their ‘mission is to promote a social justice perspective in counselling psychology practice, training, research and scholarship’.

Counselling psychologists hold tremendous power and influence in various medical and healthcare settings (Morrall, 2008; Parker, 1999), often working with individuals who frequently experience inequalities in society. However, it seems that we are engaging less with dialogues about the social power held by psychologists (Spong, 2012). Part of the resistance to engaging with social justice is the perception that such justice bears no relevance to counselling psychology. This resistance is despite counselling psychology being grounded in humanistic values (Cooper, 2009; Strawbridge & Woolfe, 2010). Social justice action does not have to be a static event. The principles of social justice can be interwoven through challenging diagnostic thinking in multidisciplinary teams using formulations in clinical practice.

### **Suggestions for further research**

Future research could consider exploring the role that language has amongst people diagnosed with schizophrenia. This idea is based on the importance some of the participants laid on how their experiences were defined. For example, participants emphasised the necessity to change the use of ‘schizophrenia’ during the interviews and instead refer to their experiences as “psychosis” or a “breakdown”. Foucauldian Discourse Analysis would be a fitting methodology due to the focus on “language and its role in the constitution of social and psychological life (Willig, 2013, p. 130). Foucauldian Discourse Analysis is based on the work of Michael Foucault and explores the relationship between language, subjective meaning and the implications for psychological research (Willig, 2013). An interesting finding in the current research, is that the majority of participants highlighted that there was a spiritual dimension to their experiences of schizophrenia. Future research could specifically focus on the role that spirituality has on the

person diagnosed with schizophrenia or psychosis using IPA. Another variation to this research topic is to explore counselling psychologists' subjective experiences of engaging with spirituality in the therapeutic process using IPA. Future research studies that have a participant sample of people living with schizophrenia or psychosis can specifically target adults between eighteen to forty years old. This will also indirectly give an opportunity to explore the lived experience of schizophrenia of people who have had the diagnosis for less time than the participants in the current study. Finally, another option for further research is the exploration of 'diagnostic thinking' for counselling psychologists working in multidisciplinary settings that actively work within the medical model. An IPA study can closely examine the subjective experiences of counselling psychologists and the personal meaning they attribute to diagnostic thinking.

### **Conclusion**

The findings of this study support those found in the wider literature exploring the lived experiences of people receiving a diagnosis of schizophrenia for people of Black African and/or Black Caribbean descent. For many of the participants, receiving a psychiatric diagnosis marked a period of distress and crisis, which resulted in them having a medicalised intervention and entering the mental health system. Examining the phenomenon of receiving a psychiatric diagnosis highlighted that the effect of living with a diagnosis is felt continuously beyond the day the participants were diagnosed. The majority of participants are still processing the personal meaning of the diagnosis, still battling with the stigma of being a "schizophrenic". Schizophrenia was predominantly considered by participants to be an imposed label by psychiatry and other people in society. For some of the participants, hearing voices epitomised the meaning attributed to the diagnosis of schizophrenia, and schizophrenia was rejected as a diagnosis by them. At times, a clear distinction was made between the way the participants defined their experiences and the way that the mental health professionals observed their experiences. Spirituality was a prevalent theme amongst the participants because they witnessed a "spiritual dimension" in their experiences. Experiences of being Black within the mental health system encompassed experiencing institutional and internalised racism. A polarised stance to the themes of racism was a sense of cultural pride. The implications of the findings for counselling psychologists and allied professionals include

challenging diagnostic thinking within multidisciplinary teams, encompassing spirituality within the therapeutic process and acknowledging social justice within clinical settings.

**This page is intentionally left blank**



## **References**

- Acker, S. (2000). In/out/side: Positioning the researcher in feminist qualitative research. *Resources for Feminist Research*, 28(1–2), 189–210.
- Ade-Serrano, Y. (2017). The essence of spirituality and its applicability to practice – an alternative perspective. In Y. Ade-Serrano, O. Nkansa-Dwamena, & M. McIntosh (Eds.), *Race, culture and diversity: A collection of articles*. The British Psychological [BPS], Division of Counselling Psychology.
- <https://www.bps.org.uk/sites/bps.org.uk/files/Member%20Networks/Divisions/DCoP/DCoP%20-%20Race%20and%20culture%20booklet%20web.pdf>
- Ade-Serrano, Y., Nkansa-Dwamena, O., & McIntosh, M. (2017). *Race, culture and diversity: A collection of articles*. The British Psychological Society.
- <https://www.bps.org.uk/sites/bps.org.uk/files/Member%20Networks/Divisions/DCoP/DCoP%20-%20Race%20and%20culture%20booklet%20web.pdf>
- Afridi, A., & Warmington, J. (2009). *The Pied Piper: The BME third sector and UK race relations policy*. BRAP.
- Agyemang, C., Bhopal, R., & Bruijnzeels, M. (2005). Negro, Black, Black African, African Caribbean, African American or what? Labelling African origin populations in the health arena in the 21st century. *Journal of Epidemiology and Community Health*, 59(12), 1014–1018.
- Allsop, K., Read, J., Corcoran, R., & Kinderman, P. (2019). Heterogeneity in psychiatric diagnostic classification. *Psychiatry Research*, 279, 15–22.
- Alvesson, M. (2011). *Interpreting interviews*. SAGE.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5(5th ed.)*. American Psychiatric Association.

American Psychological Association. (n.d.). In *APA Dictionary of Psychology*.

<https://dictionary.apa.org/ecological-validity>

Atwood, G., & Stolorow, R. (1984). *Structures of subjectivity: Explorations in psychoanalytic phenomenology*. The Analytic Press.

Bains, S. (2010). Racism as a trauma reflective anti-racist practice in action. In C. Lago & B. Smith (Eds.), *Anti-discriminatory practice in counselling & psychotherapy*. SAGE Publications.

Barbato, A. (1997). *Schizophrenia and public health*. World Health Organization.

Barker, P., & Buchanan-Barker, P. (2008). Spirituality. In R. Tummey & T. Turner (Eds.), *Critical issues in mental health* (pp. 58–71). Palgrave Macmillan.

Beavan, V., Read, J., & Cartwright, C. (2011). The prevalence of voice-hearers in the general population: A literature review. *Journal of Mental Health*, 20(3), 281–292.

Bebbington, P. (2009). Childhood sexual abuse and psychosis. *Epidemiology and Psychiatric Sciences*, 18, 284–293.

Benning, T. B., O’Leary, M., Avevor, E. A., & Avevor, E. D. (2006). Biology and stigma. *British Journal of Psychiatry*, 188, 89.

Bentall, R. P. (2003). *Madness explained: Psychosis and human nature*. Penguin Books Ltd.

Bentall, R. P., & Beck, A. T. (2004). *Madness explained: Psychosis and human nature*. Penguin.

Beresford, P. (2005). Social approaches to madness and distress. In J. Tew (Ed.), *Social perspectives in mental health: Developing social models to understand and work with mental distress* (pp. 32–52). Jessica Kingsley Publishers.

Bhaskar, R., & Hartwig, M. (2010). *The formation of critical realism*. Routledge.

Bhugra, D., Hilwig, M., Hossein, B., Marceau, H., Neehall, J., Leff, J., Mallett, R., & Der, G. (1996). First contact incidence rates of schizophrenia in Trinidad and one-year follow up. *British Journal of Psychiatry*, 169, 587–592.

- Bhui, K. (2002). *Racism & mental health: Prejudice and suffering*. Jessica Kingsley Publishers.
- Bhui, K., Stansfeld, S., Hull, S., Priebe, S., Mole, F., & Feder, G. (2003). Ethnic variations in pathways to and use of specialist mental health services in the UK: Systematic review. *The British Journal of Psychiatry: The Journal of Mental Science*, 182(2), 105–116.
- Billig, M., & Tajfel, H. (1973). Social categorization and similarity in intergroup behaviour. *European Journal of Social Psychology*, 3, 27–52.
- Blackman, L. (2001). *Hearing voices: Embodiment and experience*. Free Association Books.
- Blair, L. (2010). A critical review of the scientist practitioner model for counselling psychology. *Counselling Psychology Review*, 25(4), 19–29.
- Bloch, S., & Singh, B. (1997). *Understanding troubled minds: A guide to mental illness and its treatment*. Melbourne University Press.
- Bor, R., & du Plessis, P. (1997). Counselling psychology research in health care settings. *Counselling Psychology Review*, 12, 19–22.
- Bourque, F., van der Ven, E., & Malla, A. (2011). A meta-analysis of the risk for psychotic disorders among first- and second-generation immigrants. *Psychological Medicine*, 41(5), 897–910.
- Bowell, T., & Kemp, G. (2010). *Critical thinking: A concise guide* (3rd ed.). Routledge.
- Bowlby, J. (1969). *Attachment. Attachment and loss: Vol. 1. Loss*. Basic Books.
- Bowling, A. (2009). *Research methods in health: Investigating health and health services* (3rd ed.). Open University Press.
- Boyle. (1990). *Schizophrenia: A scientific delusion?* Taylor & Frances/Routledge.
- Boyle, M., & Johnstone, L. (2014). Alternatives to psychiatric diagnosis. *The Lancet Psychiatry*, 1(6), 409–411.
- Bradby, H. (2010). Institutional racism in mental health services: The consequences of compromised conceptualisation. *Sociological Research Online*, 15(3).

- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. SAGE Publications Ltd.
- Breggin, P. (2008). *Brain-disabling treatments in psychiatry*. Springer.
- British Psychological Society. (2014b). *Code of human research ethics*. British Psychological Society.
- British Psychological Society. (2014a). *Understanding psychosis and schizophrenia: Why people sometimes hear voices, believe things that others find strange, or appear out of touch with reality, and what can help*. British Psychological Society.
- British Psychological Society. (2013). *Division of counselling psychology strategy: Towards a culture and diversity strategy within and across ethnic minorities*. British Psychological Society.
- British Psychological Society. (2017). *Understanding psychosis and schizophrenia (Revised)*. British Psychological Society [BPS], Division of Clinical Psychology.
- British Psychological Society. (2019). *Standards for the accreditation of doctoral programmes in counselling psychology*. British Psychological Society [BPS].  
<https://www.bps.org.uk/sites/www.bps.org.uk/files/Accreditation/Counselling%20Accreditation%20Handbook%202019.pdf>
- British Psychological Society [BPS]. (2011). *British Psychological Society response* (pp. 1–26). British Psychological Society. <https://dxrevisionwatch.files.wordpress.com/2012/02/dsm-5-2011-bps-response.pdf>
- British Psychological Society (BPS). (2018). *Code of ethics and conduct*. British Psychological Society [BPS]. <https://www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy%20-%20Files/BPS%20Code%20of%20Ethics%20and%20Conduct%20%28Updated%20July%202018%29.pdf>

British Psychological Society [BPS]. (2018). *Code of ethics and conduct*.

<https://www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy%20-%20Files/BPS%20Code%20of%20Ethics%20and%20Conduct%20%28Updated%20July%202018%29.pdf>

British Psychological Society [BPS], Division of Counselling Psychology [DCoP]. (n.d.).

*Spirituality Special Interest Group*.

<https://www.bps.org.uk/system/files/Member%20Networks/Divisions/DCoP/Members/DCoP%20Spirituality%20interest%20group.pdf>

British Psychological Society [BPS], Professional Practice Board. (2012). *Diagnosis—Policy and*

*guidance*. BPS. [https://www.bps.org.uk/sites/bps.org.uk/files/Policy/Policy%20-](https://www.bps.org.uk/sites/bps.org.uk/files/Policy/Policy%20-%20Files/Diagnosis%20-%20Policy%20and%20Guidance%20%28Mental%20and%20Behavioural%20Classification%20Systems%20-%202013%29.pdf)

[%20Files/Diagnosis%20-](https://www.bps.org.uk/sites/bps.org.uk/files/Policy/Policy%20-%20Files/Diagnosis%20-%20Policy%20and%20Guidance%20%28Mental%20and%20Behavioural%20Classification%20Systems%20-%202013%29.pdf)

[%20Policy%20and%20Guidance%20%28Mental%20and%20Behavioural%20Classification](https://www.bps.org.uk/sites/bps.org.uk/files/Policy/Policy%20-%20Files/Diagnosis%20-%20Policy%20and%20Guidance%20%28Mental%20and%20Behavioural%20Classification%20Systems%20-%202013%29.pdf)

[%20Systems%20-%202013%29.pdf](https://www.bps.org.uk/sites/bps.org.uk/files/Policy/Policy%20-%20Files/Diagnosis%20-%20Policy%20and%20Guidance%20%28Mental%20and%20Behavioural%20Classification%20Systems%20-%202013%29.pdf)

Brooks, J. (2015, August). Learning from the ‘lifeworld’. *The Psychologist*, 28(8), 642–646.

Bruce, N., Pope, D., & Stanistreet, D. (2008). *Quantitative methods for health research*. John

Wiley & Sons Ltd.

Bury, D., & Strauss, S. M. (2006). *The modern scientist-practitioner: A guide to practice*

*psychology* (D. Lane & S. Corrie, Eds.). Routledge.

Butts, H. (1979). Frantz Fanon’s contribution to psychiatry: The psychology of racism and

colonialism. *Journal of the National Medical Association*, 71(10).

Cabinet Office. (2018). *Race Disparity Audit: Summary findings from the ethnicity facts and*

*figures website*. Cabinet Office.

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/686071/Revised\\_RDA\\_report\\_March\\_2018.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/686071/Revised_RDA_report_March_2018.pdf)

- Cadge, C., Connor, C., & Greenfield, S. (2019). University students' understanding and perceptions of schizophrenia in the UK: A qualitative study. *BMJ Open*, 9(4), 1–10.  
<https://bmjopen.bmj.com/content/9/4/e025813.info>
- Care Quality Commission. (2010). *Monitoring the use of the Mental Health Act in 2009/10*.  
[https://www.cqc.org.uk/.../CQC\\_Monitoring\\_the\\_use\\_of\\_the\\_Mental\\_Health\\_Act\\_in\\_2009\\_10\\_Main\\_report\\_Tagged.pdf](https://www.cqc.org.uk/.../CQC_Monitoring_the_use_of_the_Mental_Health_Act_in_2009_10_Main_report_Tagged.pdf)
- Carr, S., Unwin, N., & Pless-Mullioli, T. (1997). *An introduction to public health and epidemiology* (2nd ed.). Open University Press.
- Cechnicki, A., Angermeyer, M. C., & Bielańska, A. (2011). Anticipated and experienced stigma among people with schizophrenia: Its nature and correlates. *Social Psychiatry and Psychiatric Epidemiology*, 46(7), 643–650.
- Chakraborty, A., Patrick, L., & Lambri, M. (2013). Racism and mental illness in the UK. In R. Woolfolk & L. Allen (Eds.), *Mental disorders: Theoretical and empirical perspectives*.  
<https://www.intechopen.com/books/mental-disorders-theoretical-and-empirical-perspectives/racism-and-mental-illness-in-the-uk>
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Sage.
- Clough, P., & Nutbrown, C. (Eds.). (2008). *A student's guide to methodology: Justifying enquiry*. SAGE Publications Ltd.
- Coid, J., Hickey, N., Kahtan, N., Zhang, T., & Yang, M. (n.d.). Patients discharged from medium secure forensic psychiatry services: Reconvictions and risk factors. *British Journal of Psychiatry*, 190, 223–229.

- Cooper, M. (2009). Welcoming the other: Actualising the humanistic ethic at the core of counselling psychology practice. *Counselling Psychology Review*, 24(3–4), 119–129.
- Cooper, M., & McLeod, J. (2007). A pluralistic framework for counselling and psychotherapy: Implications for research. *Counselling and Psychotherapy Research*, 7(3), 135–143.
- Corbin, J., & Morse, J. (2003). The unstructured interactive interview: Issues of reciprocity and risks when dealing with sensitive topics. *Qualitative Inquiry*, 9(3), 335–354.
- Corrie, S., & Callahan, M. (2000). A review of the scientist-practitioner model. *British Journal of Medical Psychology*, 73(3), 413–427.
- Corrigan, P. W., & Watson, A. C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice*, 9, 35–53.
- Cosgrove, L., & Krinsky, S. (2012). A comparison of DSM-IV and DSM-5 panel members' financial associations with industry: A pernicious problem persists. *PLOS Medicine*, 9(3).
- Cowan, D. (2009). *Research issues in health and social care*. M&K Update Ltd.
- Critical Psychiatry Network. (2011). *The case against schizophrenia: Critical psychiatry network*. <http://www.criticalpsychiatry.co.uk/index.php/articles/35-documents/46-the-case-against-schizophrenia>
- Das-Munshi, J., Bhugra, D., & Crawford, M. J. (2018). Ethnic minority inequalities in access to treatments for schizophrenia and schizoaffective disorders: Findings from a nationally representative cross-sectional study. *BioMed Central Medicine*, 16(1), 55.
- Data Protection Act. (2018). <http://www.legislation.gov.uk/ukpga/2018/12/contents/enacted>
- Davids, M. F. (2011). *Internal racism*. Palgrave Macmillan.
- Davies, H. (2013). *Counselling psychologists' experience of working with clients who have been given a psychiatric diagnosis. A grounded theory analysis* [University of the West of England]. <https://ethos.bl.uk/OrderDetails.do?uin=uk.bl.ethos.601192>
- Davies, J. (2014). *Cracked: Why psychiatry is doing more harm than good*. Icon Books Ltd.

- Davis, N., & Duncan, P. (2017, April 17). Electroconvulsive therapy on the rise again in England. *The Guardian*. <https://www.theguardian.com/society/2017/apr/17/electroconvulsive-therapy-on-rise-england-ect-nhs>
- Denscombe, M. (2012). *The Good research guide: For small-scale social research projects* (4th ed.). Open University Press.
- Department of Health. (2009). *Delivering race equality in mental health care: A five year review*. National Institute for Mental Health in England.
- Department of Health [DoH]. (2005a). *Delivering race equality in mental health care: An action plan for reform inside and outside services and The Government's response to the independent inquiry into the death of David Bennett*. National Institute for Mental Health in England.
- Department of Health [DoH]. (2005b). *Mental capacity act*. HMSO.
- Department of Health [DoH]. (2011). *No health without mental health: A cross-government mental health outcomes strategy for people of all ages*. Department of Health.
- Dickerson, F., Sommerville, J., Origoni, A. E., Ringel, N. B., & Parente, R. (2002). Experiences of stigma among patients with schizophrenia. *Schizophrenia Bulletin*, 28(1), 143–155.
- Dillon, J., Johnstone, L., & Longden, E. (2014). Trauma, dissociation, attachment and neuroscience: A new paradigm for understanding severe mental distress. In E. Speed, J. Moncrieff, & M. Rapley (Eds.), *De-medicalizing misery II: Society, politics and the mental health industry* (2nd ed., p. 228). Palgrave Macmillan.
- Dwyer, S. C., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *The Space Between: On Being an Insider-Outsider in Qualitative Research*, 8(1), 54–63.
- Dyson, H. (2016). *An investigation of the experience for people given the diagnosis of Borderline Personality Disorder* [University of Surrey]. <http://epubs.surrey.ac.uk/812305/>



- Eatough, V., & Smith, J. A. (2006). I feel like a scrambled egg in my head: An idiographic case study of meaning making and anger using interpretative phenomenological analysis. *Psychology and Psychotherapy: Theory, Research and Practice*, 79, 115–135.
- Eckensberger, L. H. (2014). Integrating the emic (indigenous) with the etic (universal): A Case of squaring the circle or for adopting a Culture Inclusive Action Theory perspective. *Journal for the Theory of Social Behaviour*, 45(1).  
<http://nous.niu.edu.tw/web/images/ckfinder/files/20141106103924.pdf>
- Ellis, C., & Flaherty, M. (Eds.). (1992). *Investigating subjectivity: Research on lived experience*. SAGE Publications Ltd.
- Encyclopaedia Britannica. (n.d.). *Branding*. <https://www.britannica.com/topic/branding-identification>
- Equality and Human Rights Commission. (2016). *Healing a divided Britain: The need for a comprehensive race equality strategy*.  
[https://www.equalityhumanrights.com/sites/default/files/healing\\_a\\_divided\\_britain\\_-\\_the\\_need\\_for\\_a\\_comprehensive\\_race\\_equality\\_strategy\\_final.pdf](https://www.equalityhumanrights.com/sites/default/files/healing_a_divided_britain_-_the_need_for_a_comprehensive_race_equality_strategy_final.pdf)
- Eriksen, K., & Kress, V. E. (2006). The DSM and the professional counselling identity: Bridging the gap. *Journal of Mental Health Counseling*, 28(3), 202–217.
- Etherington, K. (2004). *Becoming a reflexive researcher: Using our selves in research*. Jessica Kingsley Publishers.
- Fade, S. (2004). Using interpretative phenomenological analysis for public health nutrition and dietetic research: A practical guide. *Proceedings of the Nutrition Society*, 63(4), 647–653.  
<https://doi.org/10.1079/PNS2004398>
- Fanon, F. (2008). *Black skin, white masks* (Z. Sardar, Ed.). Pluto Press.  
<https://ebookcentral.proquest.com/lib/ucl/detail.action?docID=3386656>.

- Farrelly, S., Clement, S., Gabbidon, J., Jeffery, D., Dockery, L., Lassman, F., Brohan, E., Henderson, R. C., Williams, P., Howard, L. M., & Thornicroft, G. (2014). Anticipated and experienced discrimination amongst people with schizophrenia, bipolar disorder and major depressive disorder: A cross sectional study. *BMC Psychiatry*, 14(157).
- Fearon, P., Kirkbride, J., Morgan, C., Dazzan, P., Morgan, K., Lloyd, T., Hutchinson, G., Tarrant, J., Fung, W. L. A., Holloway, J., Mallett, R., Harrison, G., Leff, J., Jones, P., & Murray, R. (2006). Incidence of schizophrenia and other psychoses in ethnic minority groups: Results from the MRC AESOP Study. *Psychological Medicine*, 36(11), 541–1550.
- Ferguson, I. (2017). *Politics of the mind: Marxism and mental distress*. Bookmarks and Publication.
- Fernando, S. (2002). *Mental health, race and culture* (2nd ed.). Palgrave Macmillan.
- Fernando, S. (2008). Institutional racism and cultural diversity. In R. Tummey & T. Turner (Eds.), *Critical issues in mental health* (pp. 41–57). Palgrave Macmillan.
- Fernando, S. (2010). *Mental health, race and culture* (3rd ed.). Palgrave Macmillan.
- Fernando, S. (2017). *Institutional racism in psychiatry and clinical psychology: Race matters in mental health*. Palgrave Macmillan.
- Finlay, L. (2011). Interpretative Phenomenological Analysis. In *Phenomenology for therapists: Researching the lived world* (pp. 139–147). John Wiley & Sons.
- Finlay, L., & Gough, B. (Eds.). (2003). *Reflexivity: A practical guide for researchers in health and social sciences*. Blackwell Science.
- Fitzpatrick, R., Kumar, S., Nkansa-Dwamena, O., & Thorne, L. (2014). *Ethnic inequalities in mental health: Promoting lasting positive change*. <https://lankellychase.org.uk/wp-content/uploads/2015/07/Ethnic-Inequality-in-Mental-Health-Confluence-Full-Report-March2014.pdf>

- Fletcher, R. (2012). Introduction: Dealing with diagnosis. In M Milton (Ed.), *Diagnosis and Beyond* (pp. 1–12). PCCS Books.
- Frank, L. (1978). *The history of shock treatment*. Frank.
- Freeth, R. (2007a). *Humanising psychiatry and mental health care: The challenge of the person-centred approach*. Radcliffe.
- Freshwater, D. (2006). *Mental health and illness*. Whurr Publishers Ltd.
- Fryer, P. (1984). *Staying power: The history of Black people in Britain*. Pluto Press.
- Fulford, K. W. M., & Howse, K. (1993). Ethics of research with psychiatric patients: Principles, problems and the primary responsibilities of researchers. *Journal of Medical Ethics*, 19, 85–91.
- Fusch, P., & Ness, L. (2015). Are we there yet? Data saturation in qualitative research. *Qualitative Report*, 20(9), 1408–1416.
- Gallais, T. L. (2008). Wherever I go there I am: Reflections on reflexivity and the research stance. *Reflective Practice: International and Multidisciplinary Perspectives*, 9, 145–155.
- Geekie, J., Randal, P., Lampshire, D., & Read, J. (Eds.). (2012). *Experiencing psychosis: Personal and professional perspectives*. Routledge.
- Geekie, J., & Read, J. (2009). *Making sense of madness: Contesting the meaning of schizophrenia*. Routledge.
- Geher, G. (2019). The psychology of ‘othering’: Outgroup psychology and the roots of social conflict. <https://www.psychologytoday.com/gb/blog/darwins-subterranean-world/201904/the-psychology-othering>
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Aldine.
- Goodwin, A. J. (2017). “Us vs Them” inpatients or fellow inmates? An autoethnographic exploration. [Unpublished Doctoral thesis]. City, University of London.

- Greenberg, G. (2013). *The book of woe: The DSM and the unmaking of psychiatry*. Blue Rider.
- Grey, T., Sewell, H., Shapiro, G., & Ashraf, F. (2013). Mental health inequalities facing UK minority ethnic populations: Causal factors and solutions. *Journal of Psychological Issues in Organizational Culture*, 3(S1), 146–157.
- Griffith, A. I. (1998). Insider / outsider: Epistemological privilege and mothering work. *Human Studies*, 21, 361–376.
- Guerin, B. (2017). *How to rethink mental illness: The human contexts behind the labels*. Routledge.
- Halvorsrud, K., Nazroo, J., Otis, M., Hajdukova, E. B., & Bhui, K. (2019). Ethnic inequalities in the incidence of diagnosis of severe mental illness in England: A systematic review and new meta-analyses for non-affective and affective psychoses. *Social Psychiatry and Psychiatric Epidemiology*, 54(11), 1311–1323.
- Hare-Mustin, R. T., & Marecek, J. (1997). Abnormal and clinical psychology: The politics of madness. In D. Fox & I. Prilleltensky (Eds.), *Critical Psychology: An introduction* (pp. 104–120). Sage.
- Harper, D. (2012). Choosing a qualitative research method. In *Qualitative research methods in mental health and psychotherapy*. Wiley-Blackwell.
- Harper, D., & Thompson. (2012). *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners*. John Wiley & Sons Ltd.
- Harris, J., & White, V. (2013). *Oxford dictionary of social work and social care*. Oxford University Press.
- Harrison, J., & Gill, A. (2010). The experience of people with mental health problems, the impact upon people with schizophrenia: A way forward. *Journal of Psychiatric Mental Health Nursing*, 17, 242–250.

- Hayne, Y., M. (2003). Experiencing psychiatric diagnosis: Client perspectives on being named mentally ill. *Journal of Psychiatric Mental Health Nursing*, 10, 722–729.
- Hearing Voices Network [HVN]. (n.d.). *Hearing voices network—Find a group*. Retrieved 25 July 2019, from <https://www.hearing-voices.org/hearing-voices-groups/find-a-group/>
- Hefferon, K., & Gil-Rodriguez, E. (2011, October). Interpretative phenomenological analysis. *The Psychologist*, 24(No. 10).
- Hickling, F. W., & Rodgers-Johnson, P. (1995). The incidence of first contact schizophrenia in Jamaica. *The British Journal of Psychiatry*, 167(2), 193–196.
- Hiles, D., & Cermak, I. (2008). Narrative psychology. In Carla Willig & W. S. Rogers (Eds.), *The Sage Handbook of Qualitative Research*. Sage.
- Honos-Webb, L., & Leitner, L. M. (2001). How using the DSM causes damage: A client's report. *Journal of Humanistic Psychology*, 41(4), 36–56.
- Hood, S., Mayall, B., & Oliver, S. (Eds.). (1999). *Critical issues in social research: Power and prejudice*. Open University Press.
- Howe, L., Tickle, A., & Brown, I. (2014). 'Schizophrenia is a dirty word': Service users' experiences of receiving a diagnosis of schizophrenia. *Psychiatric Bulletin*, 38, 154–158.
- Hudis, P. (2015). *Frantz Fanon: Philosopher of the barricades*. Pluto Press.  
<https://ebookcentral.proquest.com/lib/uel/detail.action?docID=3440451>.
- Huggett, C., Birtel, M. D., Awenat, Y. F., Fleming, P., Wilkes, S., Williams, S., & Haddock, G. (2018). A qualitative study: Experiences of stigma by people with mental health problems. *Psychology and Psychotherapy: Theory, Research and Practice*, 91(3), 380–397.
- Husserl, E. (1970). *Logical investigation*. Humanities Press.
- Hutton, P., Weinmann, S., Bola, J., & Read, J. (2014). *Antipsychotic drugs* (pp. 105–124).

- Information Commissioner's Office [ICO]. (2018). *Freedom of Information Act 2000 (FOIA)—Environmental Information Regulations 2004 (EIR)*. <https://ico.org.uk/media/action-ve-taken/decision-notice/2018/2259978/fs50723337.pdf>
- Information Commissioner's Office [ICO]. (2019). *Guide to data protection*. ICO. <https://ico.org.uk/media/for-organisations/guide-to-data-protection-1-1.pdf>
- Institute of Race Relations. (2014). *Race & Class*.
- Ion, R. M., & Beer, M. D. (2003). *Valuing the past: The importance of an understanding of the history of psychiatry for healthcare professionals, service users and carers*. 12(4), 237–242.
- ISL. (2012). *ISL releases preliminary findings*. <http://www.schizophrenia inquiry.org/news/isl-releases-preliminary-findings.html>
- Jackson, P., & Penrose, P. (1993). Introduction. In P. Jackson & P. Penrose (Eds.), *Constructions of race, place and nation* (pp. 1–23). UCL Press.
- Jenkins, J., & Carpenter-Song, E. (2009). Awareness of stigma among persons with schizophrenia. *The Journal of Nervous and Mental Disease*, 197(7), 520–529.
- Jeong, H., & Othman, J. (2016). Using interpretative phenomenological analysis from a realist perspective. *The Qualitative Report*, 21(3), 558–570.
- Johanson, A., Gustafson, L., Risberg, J., Rosen, I., Sjöbeck, M., & Silfverskiöld, P. (2005). *Long-term follow-up in depressed patients treated with electroconvulsive therapy*. 21(4).
- Johnson, J. L., Botorff, J. L., Browne, A. J., Grewal, S., Hilton, B. A., & Clarke, H. (2004). Othering and being othered in the context of health care services. *Health Communication*, 16(2), 255–271.
- Johnson, R. N., & Holloway-Friesen, H. (2011). *The psychology of racism: How internalized racism, academic self-concept, and campus racial climate impact the academic experiences and achievement of African American undergraduate*. BiblioBazaar.

- Johnstone, L. (2006b). Controversies and debates in formulation. In *Formulation in Psychology and Psychotherapy: Making sense of people's problems*. Routledge.
- Johnstone, L. (1999). Adverse psychological effects of ECT. *Journal of Mental Health*, 8, 69–85.
- Johnstone, L. (2000). *Users and abusers of psychiatry* (2nd ed.). Routledge.
- Johnstone, L. (2008). Psychiatric diagnosis. In R. Tummey & T. Turner (Eds.), *Critical issues in mental health* (pp. 5–22). Palgrave Macmillan.
- Johnstone, L. (2014). *A straight talking introduction to psychiatric diagnosis*. PCCS Books.
- Johnstone, L., Boyle, M., Cromby, J., Dillon, J., Harper, D., Kinderman, P., Longden, E., Pilgrim, D., & Read, J. (2018). *The Power Threat Meaning Framework: Towards the identification of patterns in emotional distress, unusual experiences and troubled or troubling behaviour, as an alternative to functional psychiatric diagnosis*. British Psychological Society [BPS], Division of Clinical Psychology. [https://www.bps.org.uk/sites/bps.org.uk/files/Policy%20-%20Files/PTM%20Framework%20%28January%202018%29\\_0.pdf](https://www.bps.org.uk/sites/bps.org.uk/files/Policy%20-%20Files/PTM%20Framework%20%28January%202018%29_0.pdf)
- Johnstone, L., & Dallos, R. (2006). Introduction to formulation. In L. Johnstone & R. Dallos (Eds.), *Formulation in Psychology and Psychotherapy: Making sense of people's problems*. Routledge.
- Jones, J. L., & Mehr, S. L. (2007). Foundations and assumptions of the scientist-practitioner model. *American Behavioral Scientist*, 50(6), 766–771.
- Kalathil, J., & Faulkner, A. (2015). Racialisation and knowledge production: A critique of the report Understanding Psychosis and Schizophrenia. *Mental Health Today*, 22–23.
- Kareem, J., & Littlewood, R. (2000). *Intercultural therapy* (2nd ed.). Blackwell Science.
- Kasket, E. (2012). The counselling psychologist researcher. *Counselling Psychology Review*, 27(2).
- Kasket, E. (2013). The counselling psychologist researcher. In G. Davey (Ed.), *Applied Psychology*. BPS Blackwell.

- Kirkbride, J. B., Errazuriz, A., Croudace, T. J., Morgan, C., Jackson, J., Boydell, J., Murray, R. M., & Jones, P. B. (2012). Incidence of schizophrenia and other psychoses in England, 1950–2009: A systematic review and meta-analyses. *PLoS One*, 7(3).
- Knox, S., & Burkard, A. (2009). Qualitative research interviews. *Psychotherapy Research*, 19(4–5), 566–575.
- Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. SAGE Publications Ltd.
- Laing, R. D. (1960). *The divided self: An existential study in sanity and madness*. Tavistock Publications.
- Laing, R. D. (1964). *The politics of experience*. Penguin.
- Lakoff, G., & Johnson, M. (1980). *Metaphors we live by*. University of Chicago Press.
- Lammy, D. (2017). *The Lammy review. An independent review into the treatment of, and outcomes for, black, asian and minority ethnic individuals in the criminal justice system*. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/643001/lammy-review-final-report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/643001/lammy-review-final-report.pdf)
- Lane, D., & Corrie, S. (2006). *The modern-scientist practitioner: A guide to practice in psychology*. Routledge.
- Langdridge, D. (2007). *Phenomenological psychology: Theory, research and method*. Pearson Education Limited.
- Langdridge, D., & Hagger-Johnson, G. (2009). *Introduction to research methods and data analysis in psychology* (2nd ed.). Pearson Education.
- Larkin, M., & Thompson, A. R. (2012). Interpretative phenomenological analysis in mental health and psychotherapy research. In *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (pp. 101–116). John Wiley & Sons Ltd.



- Larsson, P. (2011). *Counselling psychologists' talk about the diagnosis of 'Schizophrenia'* [University of Roehampton].  
<https://pure.roehampton.ac.uk/portal/en/studentTheses/counselling-psychologists-talk-about-the-diagnosis-of-schizophren>
- Larsson, P., Brooks, O., & Loewenthal, D. (2012). Counselling psychology and diagnostic categories: A critical literature review. *Counselling Psychology Review*, 27(3).
- Lasalvia, A., Penta, E., Sartorius, N., & Henderson, S. (2015). Should the label 'schizophrenia' be abandoned? *Schizophrenia Research*, 162, 276–284.
- Lee, C., Baldwin, R., Mamara, M. S., & Quesenbury, L. (2018). Counselors as agents of social justice. In C. Lee (Ed.), *Counseling for social justice* (3rd ed.). American Counseling Association.
- Lightburn, A. (2005). *Handbook of community-based clinical practice*. Oxford University Press.
- Lloyd, J., Lloyd, H., Fitzpatrick, R., & Peters, M. (2017). Treatment outcomes in schizophrenia: Qualitative study of the views of family carers. *BioMed Central Psychiatry*, 17(1), 266.
- Lyons, E. (2007). Analysing qualitative data: Comparative reflections. In E. Lyons & A. Coyle (Eds.), *Analysing qualitative data in psychology* (London, England, pp. 158–173). SAGE Publications Ltd.
- Macpherson, W. (1999). *The Stephen Lawrence inquiry. Report of an inquiry*. The Stationary Office.  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/277111/4262.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/277111/4262.pdf)
- Mahy, G. E., Mallett, R., Leff, J., & Bhugra, D. (July 1999). First-contact incidence rate of schizophrenia on Barbados. *British Journal of Psychiatry*, 175, 28–33.
- Mallett, R., Leff, J., Bhugra, D., Pang, D., & Zhao, J. (2002). Social environment, ethnicity, and schizophrenia. *Social Psychiatry and Psychiatric Epidemiology*, 37(7), 329–335.

- Mantovani, N., Pizzolati, M., & Edge, D. (2017). Exploring the relationship between stigma and help-seeking for mental illness in African-descended faith communities in the UK. *Health Expectations*, 20(3), 373–384.
- Mantovani, N., Pizzolati, P., & Gillard, S. (2017). Engaging communities to improve mental health in African and African Caribbean groups: A qualitative study evaluating the role of community well-being champions. *Health & Social Care in the Community*, 25(1), 167–176.
- Martinez, A. G., & Hinshaw, S. P. (2016). Mental health stigma: Theory, developmental issues, and research priorities. In D. Cicchetti (Ed.), *Developmental psychopathology: Risk, resilience, and intervention* (pp. 997–1039). John Wiley & Sons Inc.
- Mbuthia, J. W., Kumar, M., Falkenström, F., Kuria, M. W., & Othieno, C. J. (2018). Attributions and private theories of mental illness among young adults seeking psychiatric treatment in Nairobi: An interpretive phenomenological analysis. *Child and Adolescent Psychiatry and Mental Health*, 12(1), 28.
- McAdams, D. P. (1993). *The stories we live by: Personal myths and the making of the self*. Guilford Press.
- McKenzie, K., & Bhui, K. S. (2007). Institutional racism in mental health care. *British Medical Journal*, 334(7595), 649–650.
- McLeod, J. (2003b). *Doing counselling research* (2nd ed.). Sage.
- McManus, S., Bebbington, P., Jenkins, J., & Brugha, T. (Eds.). (2014). *Mental health and wellbeing in England: Adult Psychiatric Morbidity Survey*. NHS Digital.
- Memon, A., Taylor, K., Mohbati, L., Sundin, J., Cooper, M., Scanlon, T., & de Visser, M. (2016). Perceived barriers to accessing mental health services among black and minority ethnic (BME) communities: A qualitative study in Southeast England. *British Medical Journal Open*, 6.
- Mental Health Act*, (1983). <http://www.legislation.gov.uk/ukpga/1983/20/contents>

- Mental Health Act*, (2007). <http://www.legislation.gov.uk/ukpga/2007/12/contents>
- Mental Health Today. (n.d.). *Exclusive—NHS Digital: ‘Monitoring rising shock therapy is no longer a priority’*. <https://www.mentalhealthtoday.co.uk/news/in-our-right-mind/exclusive-nhs-digital-monitoring-rising-shock-therapy-is-no-longer-a-priority>
- Mills, C. (2013). *Decolonizing global mental health: The psychiatrization of the majority world*. Routledge. <https://0-ebookcentral-proquest-com.catalogue.libraries.london.ac.uk/lib/ulondon/reader.action?docID=1673606>
- Milton, M. (2012). *Diagnosis and beyond: Counselling psychology contributions to understanding human distress*. PCCS Books.
- Milton, M. (2010). *Therapy and Beyond*. Wiley.
- Minchin, S. (2016). *Meaning-making in the voice-hearing experience: The narratives of African-Caribbean men who have heard voices* [University of Hertfordshire]. <https://pdfs.semanticscholar.org/acc2/cc513e54f2bce1baee7c6436607417e93f58.pdf>
- MIND, (National Association for Mental Health). (n.d.). *Understanding psychosis*. [https://www.mind.org.uk/media/4862926/understanding-psychosis\\_2016.pdf](https://www.mind.org.uk/media/4862926/understanding-psychosis_2016.pdf)
- Moodley, R. (2005). Outside race, inside gender: A good enough “holding environment” in counselling and psychotherapy. *Counselling Psychology Quarterly*, 18(4), 319–328.
- Morall, P. (2008). *The trouble with therapy. Sociology and Psychotherapy*. Open University Press.
- Morgan, C., Dazzan, P., Morgan, K., Jones, P., Harrison, G., Leff, J., Murray, R., & Fearon, P. (2006). First episode psychosis and ethnicity: Initial findings from the AESOP study. *World Psychiatry*, 5(1), 40–46.
- Morris, G. (2017). *The lived experience in mental health*. CRC Press Taylor & Francis Group.

- Murray, M. (2003). Narrative psychology and narrative analysis. In P. M. Camic, J. Rhodes, & L. Yardley (Eds.), *Qualitative research in psychology: Expanding perspectives in methodology and design* (pp. 95–112). American Psychological Association.
- National Centre for Social Research, & Department of Health Sciences, University of Leicester. (2009). *Adult psychiatric morbidity in England, 2007*. National Centre for Social Research.
- National Collaborating Centre for Mental Health. (2014). *Psychosis and schizophrenia in adults: Treatment and management*. National Institute for Health and Care Excellence.
- National Institute for Health and Care Excellence. (2014). *Psychosis and schizophrenia in adults: The NICE guideline on treatment and management* (National Clinical Guideline Number 178).
- National Institute for Health and Care Excellence [NICE]. (n.d.). *Tardive Dyskinesia*.  
<https://bnf.nice.org.uk/treatment-summary/psychoses-and-related-disorders.html>
- National Institute for Health and Care Excellence [NICE]. (2009). *Guidance on the use of electroconvulsive therapy* (p. 14). NICE.  
<https://www.nice.org.uk/guidance/ta59/resources/guidance-on-the-use-of-electroconvulsive-therapy-pdf-2294645984197>
- National Institute for Health Research. (2013). *Good practice guidance for involving people with experience of mental health problems in research*. National Institute for Health Research.
- Nazroo, J. (2015). Ethnic inequalities in severe mental disorders: Where is the harm? *Social Psychiatry and Psychiatric Epidemiology*, 50, 1065–1067.
- Nazroo, J. Y., Bhui, K. S., & Rhodes, J. (2020). Where next for understanding race/ethnic inequalities in severe mental illness? Structural, interpersonal and institutional racism. *Sociology of Health & Illness*, 42(2), 262–276.
- Newnes, C. (2014). The Diagnostic and Statistical Manual: A history of critiques of psychiatric classification systems. In E. Speed, J. Moncrieff, & M. Rapley (Eds.), *De-medicalizing*

*misery ii: Society, politics and the mental health industry* (2nd ed., pp. 190–209). Palgrave Macmillan.

NHS Digital. (2018). *Mental Health Act Statistics, Annual Figures 2017-18*. NHS Digital.  
<https://files.digital.nhs.uk/34/B224B3/ment-heal-act-stat-eng-2017-18-summ-rep.pdf>

NHS Digital. (2019). *Prescriptions dispensed in the community—Statistics for England, 2008-2018*. <https://digital.nhs.uk/data-and-information/publications/statistical/prescriptions-dispensed-in-the-community>

Nicholas, E. (2012). *Service users' experiences of receiving information about a first episode of psychosis: An interpretative phenomenological analysis* [Doctorate in Clinical Psychology]. University of Leicester.

Office for National Statistics [ONS]. (2008). *ONS Opinions Survey*.  
<https://beta.ukdataservice.ac.uk/datacatalogue/doi/?id=6797#!#1>

Office for National Statistics [ONS]. (2018). *England and Wales 2011 Census*. Office for National Statistics. <https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/national-and-regional-populations/population-of-england-and-wales/latest>

Olsen, C. (2010). Ethics: The fundamental dimension of counselling psychology. In Martin Milton (Ed.), *Therapy and beyond: Counselling psychology contributions to therapeutic and social issues*. John Wiley & Sons, Ltd.

Olusoga, D. (2016). *Black and British: A forgotten history*. Macmillan.

Osborn, M., & Smith, J. A. (1998). The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis. *British Journal of Health Psychology*, 3, 65–83.

Owusu-Bempah, K., & Howitt, D. (2000). *Psychology beyond western perspectives*. BPS Books.

Oxford English Dictionary [OED]. (n.d.). *Aberration*.  
<https://en.oxforddictionaries.com/definition/aberration>

- Oxford English Dictionary [OED]. (n.d.). *Shaman* [Personal communication].
- Oxford English Dictionary [OED]. (n.d.). *Shamanic*. <https://www.lexico.com/definition/shamanic>
- Palmer-Barnes, F., & Murdin, L. (2001). *Values and ethics in the practice of psychotherapy and counselling*. Oxford University Press.
- Parker, I. (1999). Critical psychology: Critical links. *Radical Psychology*, 1(1), 3–18.
- Patel, V., & Prince, M. (2010). Global mental health: A new global health field comes of age. *The Journal of the American Medical Association*, 303(19), 1976–1977.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Sage.
- Patton, M. Q. (2002). *Qualitative evaluation and research methods*. SAGE Publications Inc.
- Pelle, J. (2013). *African and African Caribbean carers' experience of caring for a family member with an enduring mental health problem in contemporary Britain*. University of Southampton.
- Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. *Czasopismo Psychologiczne – Psychological Journal*, 20(1), 7–14.
- Pinto, R., Ashworth, M., & Jones, R. (2008). Schizophrenia in black Caribbeans living in the UK: An exploration of underlying causes of the high incidence rate. *British Journal of General Practice*, 58(551), 429–434.
- Pitt, L., Kilbride, M., Welford, M., Nothard, S., & Morrison, A. P. (2009). Impact of a diagnosis of psychosis: User-led qualitative study. *Psychiatric Bulletin*, 33, 419–423.
- Ponterotto, J. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of Counseling Psychology*, 52(2), 126–136.
- Post, B. C., & Wade, N. G. (2009). Religion and spirituality in psychotherapy: A practice-friendly review of research. *Journal of Clinical Psychology*, 65, 131–146.

- Powell, A., Francis-Devine, B., & Foley, N. (2020). *Unemployment by ethnic background: Briefing paper 6385*. House of Commons. <https://commonslibrary.parliament.uk/research-briefings/sn06385/>
- Pringle, J., Drummond, J., McLafferty, E., & Hendry, C. (2011). Interpretative phenomenological analysis: A discussion and critique. *Nurse Researcher*, 18(3), 20–24.
- Public Health England. (2020). *Disparities in the risk and outcomes of COVID-19*. Public Health England. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/908434/Disparities\\_in\\_the\\_risk\\_and\\_outcomes\\_of\\_COVID\\_August\\_2020\\_update.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/908434/Disparities_in_the_risk_and_outcomes_of_COVID_August_2020_update.pdf)
- Pyke, K. (2010). What is internalized racial oppression and why don't we study it? Acknowledging racism's hidden injuries. *Sociological Perspectives*, 53(4), 551–572.
- Rafalin, D. (2010). Counselling psychology and research: Revisiting the relationship in the light of our 'mission'. In *Therapy and beyond: Counselling psychology contributions to therapeutic and social issues* (pp. 41–55). Wiley.
- Read, J. (2004). ECT. In J. Read, L. Mosher, & R. P. Bentall (Eds.), *Models of madness: Psychological, social and biological approaches to schizophrenia*. Psychology Press.
- Read, J. (2013). Childhood adversity and psychosis. In J. Read & J. Dillon (Eds.), *Models of madness* (2nd ed., pp. 249–275). Routledge.
- Read, J., Bentall, R. P., Johnstone, L., Fosse, R., & Bracken, P. (2013). Electroconvulsive therapy. In J. Read & J. Dillon (Eds.), *Models of madness: Psychological, social and biological approaches to psychosis* (2nd ed.). Routledge.
- Read, J., & Dillon, J. (2013a). Creating evidence-based, effective and humane mental health services: Overcoming barriers to a paradigm shift. In J. Read & J. Dillon (Eds.), *Models of madness: Psychological, social and psychological approaches to psychosis* (2nd ed., pp. 392–407). Routledge.

- Read, J., & Dillon, J. (Eds.). (2013b). *Models of madness* (2nd ed.). Routledge.
- Read, J., & Mayne, R. (2017). Understanding the long-term effects of childhood adversities: Beyond diagnosis and abuse. *Journal of Child and Adolescent Trauma*, 10(3), 289–297.
- Read, J., van Os, J., Morrison, A. P., & Ross, C. A. (2005). Childhood trauma, psychosis and schizophrenia: A literature review with theoretical and clinical implications. *Acta Psychiatrica Scandinavica*, 112, 330–350.
- Rees, R., Stokes, G., Stansfield, C., Oliver, E., Kneale, D., & Thomas, J. (2016). *Prevalence of mental health disorders in adult minority ethnic populations in England: A systematic review*. EPPI-Centre, Social Science Research Unit, UCL Institute of Education.
- Reid, K., Flowers, P., & Larkin, M. (2005, January). Explored lived experience. *The Psychologist*, 18(No. 1).
- Revier, C., Renninghaus, U., Dutta, R., Fearon, P., Murray, R., Doody, G., Croudace, T., Dazzan, P., Heslin, M., Onyejiaka, A., Kravaratti, E., Lapping, J., Lomas, B., Kirkbride, J., Donohue, K., Morgan, C., & Jones, P. (2015). Ten-year outcomes of first episode psychoses in the MRC AESOP-10 study. *The Journal of Nervous and Mental Disease*, 203(5), 379–386.
- Reynolds, T. (2004). *Caribbean families social capital and young people's diasporic identities*. London South Bank University, Families & Social Capital ESRC Research Group.
- Ridley, D. (2012). *The literature review: A step-by-step guide for students* (2nd ed.). SAGE Publications Ltd.
- Riessman, C. K. (1993). *Qualitative research methods, Vol. 30: Narrative analysis*. SAGE Publications Inc.
- Rogers, C. (1961). *On becoming a person*. Houghton-Mifflin.
- Rose, D., Fleischmann, P., Wykes, T., Leese, M., & Bindman, J. (2003). Patients' perspectives on ECT. *British Medical Journal*, 326, 1363–1366.



- Saxena, S., Thornicroft, G., Knapp, M., & Whiteford, H. (2007). Resources for mental health: Scarcity, inequity and inefficiency. *Lancet*, 370(9590), 878–889.
- Segal, D. L., Corcoran, J., & Coughlin, A. (2002). Diagnosis, differential diagnosis, and the SCID. In M. Hersen & L. K. Porzelius (Eds.), *Diagnosis, conceptualization, and treatment planning for adults: A step-by-step guide*. Elbaum.
- Seligman, M. (2011). *Flourish: A visionary new understanding of happiness and well-being*. Free Press.
- Shah, A., Banner, N., Newbiggin, K., Heginbotham, C., & Fulford, B. (2009). The early experience of consultant psychiatrists in the application of the Mental Capacity Act: Issues for black and minority individuals. *Ethnicity and Inequalities in Health and Social Care*, 2(2), 4–10.
- Sharpley, M., Hutchinson, G., Murray, R. M., & McKenzie, K. (2001). Understanding the excess of psychosis among the African-Caribbean population in England: A review of current hypotheses. *The British Journal of Psychiatry*, 178(S40), s60–s68.  
<https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/understanding-the-excess-of-psychosis-among-the-africancaribbean-population-in-england/37A85E99A5907554E3B18CC01448CC9C>
- Shaw, R. (2010). Embedding reflexivity within experiential qualitative psychology. *Qualitative Research in Psychology*, 7(3), 233–243.
- Silver, J. (2013). Narrative Psychology. In Carla Willig (Ed.), *Introducing Qualitative Research in Psychology* (3rd ed., pp. 142–145). Open University Press.
- Silverman, D. (1993). *Interpreting qualitative data: Methods for analysing talk, text and interaction*. Sage.
- Singhai, A. (2011). ECT and its place in the management of depression. *Progress in Neurology and Psychiatry*, 15, 19–26.

- Skehan, D., Larkin, W., & Read, J. (2012). Childhood adversity and psychosis: A literature review with clinical and societal implications. *Psychoanalysis, Culture & Society*, 17(4), 373–391.
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1, 39–54.
- Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health*, 11, 261–271.
- Smith, J. A. (2007). Hermeneutics, human sciences and health: Linking theory and practice. *International Journal of Qualitative Studies on Health and Well-Being*, 2(1), 3–11.
- Smith, J. A. (2015a). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to methods* (pp. 53–80). Sage.
- Smith, J. A. (2015b). *Qualitative psychology: A practical guide to research methods*. SAGE Publications Ltd.
- Smith, J. A. (2017). Interpretative phenomenological analysis: Getting at lived experience. *The Journal of Positive Psychology*, 12(3), 303–304.
- Smith, J.A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain*, 9(1), 41–42.
- Smith, J.A., & Eatough, V. (2007). Interpretative phenomenological analysis. In *Analysing Qualitative Data in Psychology* (pp. 35–50). SAGE Publications.
- Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research* (SAGE Publications LTD).
- Smith, J.A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods*. Sage.

- Smith, J.A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J Smith (Ed.), *Qualitative psychology: A practical guide to methods*. Sage.
- Speed, E., Moncrieff, J., & Rapley, M. (Eds.). (2014). *De-medicalizing misery II: Society, politics and the mental health industry*. Palgrave Macmillan.
- Speight, S. L., & Vera, E. M. (2008). Social justice and counseling psychology: A challenge to the profession. In S. D. Brown & R. W. Lent (Eds.), *Handbook of counseling psychology* (pp. 54–67). John Wiley & Sons Inc.
- Spencer, L., & Ritchie, J. (2012). In pursuit of quality. In D. Harper & A. R. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (pp. 227–242). Wiley-Blackwell.
- Spong, S. (2012). Validity, vision and vocalisation: Social responsibility arguments and power-sensitised. *Counselling. Psychotherapy and Politics International*, 10(1), 69–75.
- Squire, L., & Slater, P. (1983). ECT and complaints of memory dysfunction. *British Journal of Psychiatry*, 142, 1–8.
- Strauss, A., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. SAGE Publications Ltd.
- Strawbridge, S., & Woolfe, R. (2003). Counselling psychology in context. In R. Woolfe, W. Dryden, & S. Strawbridge (Eds.), *Handbook of counselling psychology* (2nd ed., pp. 3–22). SAGE Publications Ltd.
- Strawbridge, S., & Woolfe, R. (2010). Counselling psychology: Origins, developments and challenges. In R. Woolfe, W. Dryden, & S. Strawbridge (Eds.), *Handbook of counselling psychology* (3rd ed., pp. 3–22). SAGE.
- Strong, T. (2017). *Medicalizing counselling: Issues and tensions*. Palgrave Macmillan.
- Szasz, T. (1964). Schizophrenia: The sacred symbol of psychiatry. *British Journal of Psychiatry*, 129, 308–316.

- Szasz, T. (2010). *The myth of mental illness: Foundations of a theory of personal conduct*. Harper Perennial.
- The Association for Humanistic Psychology in Britain. (2013). *The Association for Humanistic Psychology in Britain*. <https://ahpb.org/>
- Thomas, L. K. (2013). Empires of mind: Colonial history and its implications for counselling and psychotherapy. *Psychodynamic Practice*, 19(2), 117–128.  
<https://www.tandfonline.com/doi/abs/10.1080/14753634.2013.778484>
- Thomas, P., Bracken, P., Cutler, P., Hayward, R., May, R., & Yasmeen, S. (2005). Challenging the globalisation of biomedical psychiatry. *Journal of Public Mental Health*, 4(3), 23–32.
- Thomas, P. (2014). *Psychiatry in context: Experience, meaning and communities*. PCCS Books.
- Thompson, A. R., & Chambers, E. (2012). Ethical issues in qualitative mental health research. In D. Harper & A. R. Thompson (Eds.), *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners*. Wiley-Blackwell.
- Thompson, W., & Hickey, J. (2005). *Society in focus*. Pearson.
- Thornicroft, G. (2008). Stigma and discrimination limit access to mental health care. *Epidemiology and Psychiatric Sciences*, 17(1), 14–19.
- Thornicroft, G., & Tansella, M. (2003). *What are the arguments for community-based mental health care?* World Health Organization.  
[http://www.euro.who.int/\\_data/assets/pdf\\_file/0019/74710/E82976.pdf](http://www.euro.who.int/_data/assets/pdf_file/0019/74710/E82976.pdf)
- Tortelli, A., Errazuriz, A., Croudace, T., Morgan, C., Murray, R. M., Jones, P. B., Szoke, A., & Kirkbride, J. B. (2015). Schizophrenia and other psychotic disorders in Caribbean-born migrants and their descendants in England: Systematic review and meta-analysis of incidence rates, 1950–2013. *Social Psychiatry and Psychiatric Epidemiology*.  
<https://discovery.ucl.ac.uk/id/eprint/10024708/1/Tortelli%20et%20al.%20-%202015%20->

[%20Schizophrenia%20and%20other%20psychotic%20disorders%20in%20Caribbean-born%20migrants%20and%20their%20descendants%20in%20England%20systema.pdf](#)

Trenchard, S., & Read, J. (2012). Abandoning 'schizophrenia'. *Open Mind*, 14.

<http://www.schizophreniainquiry.org/schizophreniainquiry.org/sites/default/files/documents/Abandoning%20schizophrenia.pdf>

Tribe, R. (2014). Culture, politics and global mental health. *Disability and the Global South*, 1(2), 251–265.

Tribe, R., Freeman, A., Livingstone, S., Stott, J. C. H., & Pilling, S. (2019). Open dialogue in the UK: Qualitative study. *Cambridge University Press*, 5(4).

<https://www.cambridge.org/core/journals/bjpsych-open/article/open-dialogue-in-the-uk-qualitative-study/9400A61DC7AF33A4AFC24CB3D1FB4EA2>

Tuffour, I. (2017). A critical overview of interpretative phenomenological analysis: A contemporary qualitative research approach. *Journal of Healthcare Communications*, 2(No.4:52), 1–5.

Tuffour, I., Simpson, A., & Reynolds, L. (2019). Mental illness and recovery: An interpretative phenomenological analysis of the experiences of Black African service users in England. *Journal of Research in Nursing*, 24(1–2), 104–118.

Tully, S., Wells, A., & Morrison, A. P. (2017). 'You've got your own demons that you've got to fight every day': A qualitative exploration of how people respond to the experience of psychosis. *Psychology and Psychotherapy: Theory, Research and Practice*, 90(4), 550–566.  
<https://doi.org/10.1111/papt.12124>

Tummey, R., & Turner, T. (2008). *Critical issues in mental health*. Palgrave Macmillan.

Turner, D., Callaghan, J., & Gordon-Finlayson, A. (2016). Being the other: A creative exploration of the identity of the other. *British Journal of Play Therapy*, 12, 22–34.

- Twigg, E. (2015). Quantitative methods. In A. Vossler & N. Moller (Eds.), *The Counselling and psychotherapy research handbook* (pp. 131–151). SAGE Publications Ltd.
- Ücök, A., Brohan, E., Rose, D., Sartorius, N., Leese, M., Yoon, C. K., Plooy, A., Ertekin, B. A., Milev, R., & Thornicroft, G. (2012). Anticipated discrimination among people with schizophrenia. *Acta Psychiatrica Scandinavica*, 125, 77–83.
- University of East London. (2014). *Code of good practice in research*. University of East London.
- van Brakel, W. H., Anderson, A. M., Mutatkar, R. K., Bakirtzief, Z., Nicholls, P. G., Raju, M. S., & Das-Pattanayak, R. K. (2006). The Participation Scale: Measuring a key concept in public health. *Disability and Rehabilitation*, 28(4), 193–203.
- van der Kolk, B. (2014). *The body keeps the score: Mind, body and brain in the transformation of trauma*. Penguin.
- van Deurzen, E., & Arnold-Baker, C. (2005). *Existential perspectives on human issues*. Palgrave Macmillan.
- Vassiliou, A. (2016). *The Intersubjective arena of the psychotherapy for psychosis: A phenomenological account of therapists' experiences* [Doctorate in Counselling Psychology and Existential Psychotherapy]. Middlesex University.
- Vellenga, B. A., & Christenson, J. (1994). Persistent and severely mentally ill clients' perceptions of their mental illness. *Issues in Mental Health Nursing*, 15(4), 359–371.
- Vossler, A., & Moller, N. (Eds.). (2015). *The Counselling and psychotherapy research handbook*. SAGE Publications Ltd.
- Wagstaff, C., Jeong, H., Nolan, M., Wilson, T., & Tweedlie, J. (2014). The accordion and the deep bowl of spaghetti: Eight researchers' experiences of using IPA as a methodology. *E Qualitative Report*, 9(24), 1–15.
- Walker, W. (2011). Hermeneutic inquiry: Insights into the process of interviewing. *Nurse Researcher*, 18(2), 19–27.

- Watson, H., Harrop, D., Walton, E., Young, A., & Soltani, H. (2019). A systematic review of ethnic minority women's experiences of perinatal mental health conditions and services in Europe. *PLoS ONE*, 14(1).  
<https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0210587>
- Watters, E. (2011). *Crazy like us: The globalization of the mind*. Robinson.
- Waugh, W., Lethem, C., Sherring, S., & Henderson, C. (2017). Exploring experiences of and attitudes towards mental illness and disclosure amongst health care professionals: A qualitative study. *Journal of Mental Health*, 26(5), 457–463.
- Wesseley, S. (2018). *Modernising the Mental Health Act—Increasing choice, reducing compulsion: Final report of the Independent Review of the Mental Health Act 1983*.  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/778897/Modernising\\_the\\_Mental\\_Health\\_Act\\_-\\_increasing\\_choice\\_reducing\\_compulsion.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/778897/Modernising_the_Mental_Health_Act_-_increasing_choice_reducing_compulsion.pdf)
- Weston, H. (2016). *How do counselling psychologists make sense of their clients' psychiatric diagnoses: An interpretative phenomenological analysis* [London Metropolitan University].  
<http://repository.londonmet.ac.uk/1150/1/WestonHolly%20-%20DProf%20-%20Full%20Thesis.pdf>
- Whitaker, R. (2010). *The anatomy of an epidemic*. Broadway.
- White, R. (2013). The globalisation of mental illness. *The Psychologist*, 26(3), 182–185.
- Williams, L. M. (2016). Precision psychiatry: A neural circuit taxonomy for depression and anxiety. *The Lancet Psychiatry*, 3(5), 472–480.
- Williams, P. (2012). *Rethinking madness: Towards a paradigm shift in our understanding and treatment of psychosis*. Sky's Edge.
- Willig, C. (2007). Reflections on the use of a phenomenological method in qualitative research. *Qualitative Research in Psychology*, 4, 209–225.

- Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Open University Press.
- Willig, C. (2008). *Introducing qualitative research in psychology: Adventures in theory and method* (2nd ed.). Open University Press.
- Willig, C. (2012). *Qualitative interpretation and analysis in psychology*. Open University Press.
- Willig, C. (2013). *Introducing qualitative research in psychology* (3rd ed.). Open University Press.
- Winklbaur, B., Ebner, N., Sachs, G., Thau, K., & Fischer, G. (2006). Substance abuse in patients with schizophrenia. *Dialogues in Clinical Neuroscience*, 8(1), 37–43.
- Wood, L., Birtel, M., Alsawy, S., Pyle, M., & Morrison, A.P. (2014). Public perceptions of stigma towards people with schizophrenia, depression, and anxiety. *Psychiatry Research*, 220(1–2), 604–608.
- Wood, L., Byrne, R., Burke, E., Enache, G., & Morrison, A. P. (2017). The impact of stigma on emotional distress and recovery from psychosis\_ The mediatory role of internalised shame and self-esteem | Elsevier Enhanced Reader. *Psychiatry Research*, 255, 94–100.  
<https://doi.org/10.1016/j.psychres.2017.05.016>
- Woolfe, R., Dryden, W., & Strawbridge, S. (2003). *Handbook of counselling psychology* (2nd ed.). Sage.
- World Health Organization [WHO]. (2008). *Mental health Gap Action Programme (mhGAP): Scaling up care for mental, neurological and substance abuse disorders*. World Health Organization.
- World Health Organization [WHO]. (n.d.). *Schizophrenia, schizotypal and delusional disorders*.  
<https://apps.who.int/classifications/apps/icd/icd10online2005/fr-icd.htm?gf20.htm+>



- World Health Organization [WHO]. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. World Health Organization.  
<https://apps.who.int/iris/handle/10665/37958>
- World Health Organization [WHO]. (2005). *Mental health atlas 2005*. World Health Organization [WHO].
- World Health Organization [WHO]. (2010). *mhGAP intervention guide for mental, neurological and substance use disorders in non-specialized health settings: Mental health Gap Action Programme (mhGAP)*. World Health Organization [WHO].
- World Health Organization [WHO]. (2020). *The ICD-11 International Statistical Classification of Diseases and Related Health Problems* (11th ed.). World Health Organization.
- Wrathall, M. (2005). *How to read Heidegger*. Granta Publications.
- Yanos, P. T. (2018). *Written-off: Mental health stigma and the loss of human potential*. Cambridge University Press.
- Yanos, P. T., Roe, D., Markus, K., & Lysaker, P. H. (2008). Pathways between internalised stigma and outcomes related to recovery in schizophrenia spectrum disorders. *Psychiatric Services*, 59, 1437–1442.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15(2), 215–228.
- Yardley, L. (2017a). Demonstrating the validity of qualitative research. *The Journal of Positive Psychology*, 12(3), 295–296.
- Yardley, L. (2007). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Research Methods* (pp. 235–251). SAGE Publications.

## **APPENDICES**

## **Appendix 1 – Ethics review decision letter**

## NOTICE OF ETHICS REVIEW DECISION

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

**REVIEWER:** David Harper

**SUPERVISOR:** Claire Marshall

**STUDENT:** Abigail Gordon

**Course:** Professional Doctorate in Counselling Psychology

**Title of proposed study:** What is the lived experience of receiving a diagnosis of schizophrenia for people of Black African and/or Black Caribbean heritage?

### DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.
2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.
3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

### DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY

*(Please indicate the decision according to one of the 3 options above)*

**Minor amendments required (for reviewer):**

1. It was good to include the letter of permission from the Service manager. Are they in a position to give such consent? I checked online and it wasn't clear whether the service has a contract with the local authority or NHS. If so, then further permission might be necessary. If it is a standalone NGO which doesn't receive such funding then the manager's permission might be enough. I saw that the form said HRA approval was not needed – was some advice sought about this (eg from HRA or UEL)?

2. The transcripts should also be in password-protected files.

3. Physical versions of the contact details should be stored separately from the transcripts (Section 19, p.13)

4. A number of changes are required to the information sheet:

a) The sheet is written at too high a level for most people. I did a Flesch readability check and it suggested it was comprehensible only to college graduates. Use shorter and simpler words and sentences and use more active (rather than passive phrasing). Explain uncommon words like 'anonymised' or 'transcript'. It might help to structure it FAQ style – e.g. 'what is the study about?', 'what am I being asked to do?', 'what will happen to my data?' etc.

b) There is a blank space for a mobile number at the top – a personal mobile number should not be used.

c) There are a number of standard aspects missing from the sheet: briefly explaining what the study is about (the title is too complicated for this purpose); why the person has been approached; specifically what they will be asked to do (the current phrasing is a bit opaque); any risks or benefits of the study; what will happen to their data (eg storage) and how long it will be retained for; whether there might be reasons to breach confidentiality (eg if any risk is disclosed); and a clearer statement about right to withdraw. It is confusing to say they can withdraw and then say you retain the right to use data. It would be clearer to say they can withdraw up to X date after which analysis will begin and you then reserve the right to use (anonymised) data.

Three issues that are not amendments on ethical grounds (and so could be ignored) but which might be worth noting:

a) The interview schedule is a bit ambiguous in how the term 'diagnosis' is used and participants may also be confused. Are you wishing to focus on the effects of receiving a diagnosis (eg given what we know about the stigmatising effects of receiving a psychiatric label) or are you interested in the problems/symptoms/experiences etc that the person is finding challenging? If both, then it might be worth using different terms.

b) The schedule begins by asking about 'psychosis'. Might it be better to ask if they know what their diagnosis is and to share it with you? Psychosis isn't a specific diagnosis (they may be diagnosed with 'schizophrenia, schizo-affective disorder, bipolar etc).

c) Incidentally, the version submitted still had comments boxes in and a question that was possibly from the DoS was left in the text in Section 19.

**Major amendments required** (for reviewer):

**Confirmation of making the above minor amendments** (for students):

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name (Typed name to act as signature): *A. Gordon*

Student number: u1622712

Date: 30.9.2018

*(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)*

**ASSESSMENT OF RISK TO RESEACHER** (for reviewer)

Has an adequate risk assessment been offered in the application form?

YES / NO

**Please request resubmission with an adequate risk assessment**

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐

HIGH

**Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.**

☒

MEDIUM (Please approve but with appropriate recommendations)

☐

LOW

**Reviewer comments in relation to researcher risk (if any).**

*The applicant appears to have taken appropriate precautions with respect to interviewing service users whilst staff are available*

**Reviewer** (*Typed name to act as signature*):

David Harper

**Date:** 26 July 2018

*This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee*

**RESEARCHER PLEASE NOTE:**

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

## **Appendix 2 – Request for title change to an ethics application**



# University of East London Psychology



## **REQUEST FOR TITLE CHANGE TO AN ETHICS APPLICATION**

### **FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS**

**Please complete this form if you are requesting approval for proposed title change to an ethics application that has been approved by the School of Psychology.**

By applying for a change of title request you confirm that in doing so the process by which you have collected your data/conducted your research has not changed or deviated from your original ethics approval. If either of these have changed then you are required to complete an Ethics Amendments Form.

### **HOW TO COMPLETE & SUBMIT THE REQUEST**

1. Complete the request form electronically and accurately.
2. Type your name in the 'student's signature' section (page 2).
3. Using your UEL email address, email the completed request form along with associated documents to: [Psychology.Ethics@uel.ac.uk](mailto:Psychology.Ethics@uel.ac.uk)
4. Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.

### **REQUIRED DOCUMENTS**

1. A copy of the approval of your initial ethics application.

Name of applicant:	Abigail Gordon
Programme of study:	Professional Doctorate in Counselling Psychology
Name of supervisor:	Dr. Claire Marshall

Briefly outline the nature of your proposed title change in the boxes below

Proposed amendment	Rationale
<b>Old Title:</b> <u>What is the lived experience of receiving a diagnosis of schizophrenia for people of Black African and/or Black Caribbean heritage?</u>	I would like the title of the research project to reflect both the voice of the participants and the research question.
<b>New Title:</b>  "At the time I didn't know what was going on, so they diagnosed me with schizophrenia". The lived experience of being diagnosed with schizophrenia for people of Black African and/or Black Caribbean heritage: An Interpretative Phenomenological Analysis.	

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	√	
Does your change of title impact the process of how you collected your data/conducted your research?		√

Student's signature (please type your name): Abigail Gordon

Date: 06/04/2020

**TO BE COMPLETED BY REVIEWER**

<b>Title changes approved</b>	APPROVED	
<b>Comments</b>		

Reviewer: Glen Rooney

Date: 15/04/2020

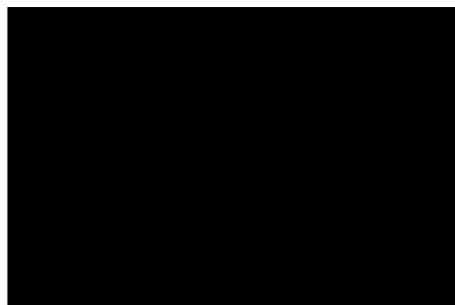
## **Appendix 3a — Approval letter from service 1**



Abigail Gordon



8<sup>th</sup> May 2018



Re: Doctorate in Counselling Psychology (DPsych) at the University of East London

Dear Abigail,

Thank you for forwarding the working title of your doctoral study: What is the meaning-making of receiving a diagnosis of psychosis for African Caribbean people? An Interpretative Phenomenological Analysis Study.

Regarding your request to recruit 6-8 service users at [REDACTED] Centre as participants in your research between June and May 2018. I am happy to say that we can give permission for this to take place. I look forward to receiving more information regarding your research subject and the requisite consent forms and publicity for our members.

I have a consultation meeting with our members on 24<sup>th</sup> May and this would be a good opportunity to recruit participants if you would have information ready for this date.

Yours



Area Manager  
Hestia, RBKC Integrated Mental Health Service

Email: [malcolm.phillips@hestia.org](mailto:malcolm.phillips@hestia.org)  
Mobile:




## **Appendix 3b — Approval letter from service 2**



Monday 4<sup>th</sup> February 2019

**Re: Abigail Gordon's Doctoral Research Project**

**The Research Title: What is the lived experience of receiving a diagnosis of schizophrenia for people of Black African and/or Black Caribbean heritage?**

I am writing to confirm that I give permission for Abigail to carry out research with  on the above topic.

Yours sincerely,



**Director**





## **Appendix 4 - Example of research poster**



**Have you received a diagnosis of  
schizophrenia?**

**Would you like to share your experiences  
of living with Schizophrenia?**

**If so, I would like to hear from you!**



I am conducting a research study into exploring the **individual lived experience** of people from an **African and/or Caribbean heritage** with a diagnosis of schizophrenia and the **meaning** that you may connect to this diagnosis.

I am looking for women and men who received the diagnosis at least two years ago.

Interviews will be conducted at the **XXX Centre** and will last approximately **60-90 minutes**. The interviews are semi-structured and will feel like an informal chat.

**Participation will be anonymous and confidential, and you are free to withdraw at any time.**

For further information, please contact me:

**Abigail Gordon, Counselling Psychologist in-  
Training University of East London  
Email: [u1622712@uel.ac.uk](mailto:u1622712@uel.ac.uk) or speak to XXX(XXX  
Centre)**

## **Appendix 5 - Interview schedule**



## **INTERVIEW SCHEDULE**

1. In your own words, what is schizophrenia?
  2. What was life like before receiving the diagnosis of schizophrenia?  
-Prompt: What factors contributed to you receiving the schizophrenia?
  3. Describe what happened when you received the diagnosis of schizophrenia?
  4. How do you feel about having the diagnosis of schizophrenia?
  5. How has the diagnosis affected your everyday life?  
-Prompt: Work, interests, relationships
  6. If you had to describe what the diagnosis of schizophrenia means to you, what would you say?  
-Prompt: What words come to mind? Images? Do you have a nickname for it?
  7. Has having the diagnosis made a difference to how you see yourself?  
-Prompt: If so how do you see yourself now, compared to prior to you receiving the diagnosis? Have there been any changes? If so, how?
  8. Describe how other people view your diagnosis?  
-Prompt: Family members? Friends? Others?
- 
- 
9. Is there anything that you would like to add that you feel that we have not covered?

Feedback about the interview experience:  
How have you experienced the interview?

### **Further prompts:**

**What do you mean by...?**

**Can you tell me a bit more about that?**

**How do you feel after...?**

**Can you explain...?**

## **Appendix 6 – Example of participant information sheet**



## **PARTICIPANT INFORMATION SHEET**

**Project Title: What is the lived experience of receiving a diagnosis of schizophrenia for people of Black African and/or Black Caribbean heritage?**

### **Introduction**

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the research that is being done and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask for any further information that you would like to help you make your decision.

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

The aim of this research is to explore the individual lived experience of people from an African and/or Caribbean heritage with a diagnosis of schizophrenia and the meaning that you may connect to this diagnosis.

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

It is your choice whether or not you decide to take part in this research study. If you decide to take part, you will be given this information sheet to keep and asked to sign a consent form.

Agreeing to participate in the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason or a decision not to take part at all. A decision to withdraw at any time, will not affect any aspect of treatment or care.

Before you take part you may wish to seek advice from someone independent e.g. family member, a friend, someone who has similar experiences to you or a trusted worker.

### **Are there any age or other restrictions that may prevent me from participating?**

You are eligible to take part in the research if you meet the inclusion criteria.

Inclusion criteria for participants:

- Identifies as being of Black African and/or Black Caribbean descent (Born or parents were born in Africa or the Caribbean).
- Participants were required to be over 18 years of age.
- Received a diagnosis of schizophrenia a minimum of two years ago.

- English speaking.
- Mental capacity to make an informed decision to consent and participate in the research.

Exclusion criteria for participants:-

- Non-English speaking individuals.
- Mental disturbance that may affect ability to consent and participate in the study.
- Under the age of 18 years old.
- Currently experiencing moderate to severe psychological distress (e.g. related to psychosis)
- Currently using substances or alcohol.

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

Once you have consented to take part in the study, the first thing to happen will be to arrange an interview, in person with me, the researcher. It is anticipated that the interview will last for approximately 60-75 minutes.

At the end of the interview, we can discuss your experience of the interview and you can feedback on the interview process.

### **Where will the interview happen?**

The interview will take place at the xxxxxxxx Centre.

### **What are the possible disadvantages of taking part?**

The potential disadvantages to all participants have been considered and are to be maintained at a minimum. However, it is possible that you may find the interview process distressing, for example, talking about some difficult experiences that you may have had.

Your safety and wellbeing will be paramount during the interview. If you begin to feel distressed or upset during the interview, you may take a break and/or stop the interview. At the end of the interview, contact details of relevant local support groups and helplines will be provided to you.

### **What are the possible benefits of taking part?**

It is an opportunity to have your experience heard. This may be helpful not only for researchers and professionals of academic and scientific communities but also for people in the wider society.

### **How will my information be kept confidential?**

All data information will be kept strictly confidential and will be anonymised. This means that no names or identifying elements will be kept with any of the study information. A coded number will be given to each participant and stored on a password protected document on a secure computer.

Some direct quotes from the interview transcripts may be used in the thesis and possible journal articles however, quotes will not contain identifying features or names.

Once the study is complete, all data information is securely stored and archived in a lockable cabinet for 5 years. Other data is deleted and destroyed securely.

### **What will happen to the data collected within this study?**

After all the data is collected, it will be analysed and the study findings will be written in a thesis as part of my doctorate. There will be no identifying features or names written in the thesis. There may be some direct quotes taken from the interview, however anonymity and confidentiality will be maintained.

If you change your mind at any time during the study you can withdraw at any time, without giving a reason. If you decide to withdraw from the study at a later time, your data will be destroyed and this will not affect any services you receive or may require in the future e.g. with [REDACTED]. You can withdraw your data from the study before 1<sup>st</sup> January 2019, after which analysis will begin and I then reserve the right to use the anonymised data.

### **Will I be reimbursed for my time and effort for taking part?**

Participation in the study is not paid and travel cannot be reimbursed.

### **Who has reviewed this study?**

The ethics review for the study has been approved by the University of East London (School of Psychology Research Ethics Committee).



### **What happens after the study?**

After the study, there is no further requirement of you. After the study all the data will be discarded accordingly. If you are interested, you will be able to request a copy of the final published thesis.

Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form prior to your participation. Please keep this information form for reference.

**The researcher:** Abigail Gordon

Contact Details: [u1622712@uel.ac.uk](mailto:u1622712@uel.ac.uk)

Mobile number: (Please note that this is not my personal number but is solely to be used for arranging and confirming the interview).

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor

Dr. Claire Marshall, Arthur Edwards Building, School of Psychology, University of East London, Water Lane, London E15 4LZ. Email: [c.marshall@uel.ac.uk](mailto:c.marshall@uel.ac.uk).

Or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4493. Email: [m.finn@uel.ac.uk](mailto:m.finn@uel.ac.uk))

Thank you in anticipation.

Yours sincerely,

Abigail.

## **Appendix 7 - Consent form**



### **CONSENT FORM**

#### **What is the lived experience of receiving a diagnosis of schizophrenia for people of Black African and/or Black Caribbean heritage?**

**Please TICK the boxes to show that you understand the statements.**

I have read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

☐

I understand that my involvement in this study and particular data from this research, will remain strictly confidential; unless you disclose that you or another person is at risk of harm. Only the researcher involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

☐

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after analysis of the data has begun.

☐

Participant's Name (BLOCK CAPITALS)

.....  
Participant's Signature

.....  
Researcher's Name (BLOCK CAPITALS)

.....  
Researcher's Signature

Date: .....

## **Appendix 8 - Example of debriefing sheet**



### **DEBRIEFING INFORMATION SHEET**

Title of research: **What is the lived experience of receiving a diagnosis of schizophrenia for people of Black African and/or Black Caribbean heritage?**

Thank you for your participation in my study on the experiences when receiving a diagnosis of schizophrenia.

If you have any concerns or questions following your participation in this study please do not hesitate to get in touch with either myself, or my supervisor. Our contact details are as follows:

#### **Abigail Gordon**

University of East London, School of Psychology, Stratford Campus, Water Lane  
London E15 4LZ Email: [u1622712@uel.ac.uk](mailto:u1622712@uel.ac.uk)

#### **Dr. Claire Marshall (Research Supervisor)**

University of East London, School of Psychology, Rm 1.20 Arthur Edwards Building,  
Stratford Campus, Water Lane, London E15 4LZ Email: [c.marshall@uel.ac.uk](mailto:c.marshall@uel.ac.uk)

If you feel you need additional support as a result of taking part in this interview or as a result of the topics discussed we recommend that you consider contacting the following:

- Your keyworker or staff member at the XXX on tel XXXX
- In an emergency, if your GP surgery is closed, go to a hospital's accident and emergency (A&E) desk or call Samaritans on 08457 90 90 90.
- Out of hours urgent advice line (Kensington & Chelsea mental health service users) on 0800 0234 650. This number is in operation 5pm to 9am, Monday to Friday and on Saturdays, Sundays and bank holidays.

**Thank you for your participation!**

## **Appendix 9 – Entry from my research journal**

25<sup>th</sup> April 2019

### **Entry following research supervision**

I presented my initial notes and themes that were extracted from the first transcript. I raised my concerns about being mindful not to interpret the data through the lens of a therapist or misinterpret the voice of the participants.

I was encouraged to be confident and find my own voice as the researcher whilst interpreting the data and entering the hermeneutic circle. I was reminded of striking the balance of "suspending" or bracketing my own thoughts and beliefs as I progress through analysing each interview.

Claire (research supervisor) also highlighted that whilst I am interpreting the data I should consider the following :-

- the participant's relationship with others
  - the participant's relationship with self
  - the participant's relationship with the world
  - the participant's relationship with objects
  - the participant's relationship with me as the researcher
- and in reverse e.g. what or how do others interact with the participant?

I realise that I have increased anxiety since completing the analysis from the first participant's data. Anxiety about conducting IPA research for the first time. Anxiety about representing the voices of all of the participants in a correct manner that reflects their lived experiences. The notion of making sense of the participants' meaning making of the diagnosis is a weighty cross to bear. Whenever I feel like I am losing my way on this research journey, I particularly find it helpful to keep the research question and ultimately the participants at the centre of the entire research process.

## **Appendix 10 Example transcript of interview with Kwame**



**Kwame:** No I've put that aside now.

**Interviewer:** Okay. Okay. Can you tell me what happened in 2002, so when you actually received the diagnosis?

**Kwame:** They just said I was diagnosed as schizophrenic and F20. My mum ...didn't personally wanted to know that much about it, but she knew that I was taking medication but she wasn't that bothered about it. But she was helping me put on my clothes before I was diagnosed. I was actually sectioned...I was put to the hospital for one month. Then I was sectioned after one month I was put into xxxxxxxxxxxx hospital.

**Interviewer:** Was that before 2002?

**Kwame:** That was 2002 when I was put in hospital.

**Interviewer:** Right. Is that when you received the diagnosis?

**Kwame:** That's when I received after the diagnosis.

**Interviewer:** So you you've been hospital...sorry.

**Kwame:** After the diagnosis they put me in a hospital for one month.

**Interviewer:** Right. Okay.

**Kwame:** Yeah because they had to do the initial assessment first.

**Interviewer:** And so who did that initial assessment?

**Kwame:** It was xxxxx xxxxxxx in xxxxxxxx.

**Interviewer:** Yeah. You said your mum didn't...

**Kwame:** She wasn't too bothered by it, no, no.

**Interviewer:** Did she know that you had the diagnosis?

**Kwame:** She knew but she wasn't bothered.

**Interviewer:** How do you think she viewed schizophrenia?

**Kwame:** She noticed that I couldn't put on my clothes and she would just check on me when I'm going to bed and one day she noticed that I couldn't put on my clothes properly. I said to my mum I wasn't feeling well, I couldn't eat properly and all that.

**Interviewer:** Yeah.

**Kwame:** So I said to myself, let me go for a check-up.

**Interviewer:** Yeah. How did other people view your diagnosis like your dad and any family members or friends?

**Kwame:** I'm not really close to my family and relatives. They don't see me as a normal human being, a normal British citizen. They're not bothered about it. It's just really, it's myself really. Pull myself together and aiming high, the future and resolve myself and be what I want to be. I mean there's plenty of goals out there.

**Interviewer:** Yeah. What do you mean by they don't see you like a human being?

**Kwame:** They don't really want to know me like...they'd rather have me dead and all that.

**Interviewer:** Oh right.

**Kwame:** Yeah. I've never really got on with my mum.

**Interviewer:** Okay.

**Kwame:** My father was okay. It wasn't that bad. It was okay. But I really don't know why my family...they disowned me.

## **Appendix 11. Extract from first case analysis – Marcie**

- \* Themes recorded on the left hand side
- Exploratory comments recorded on the right side
- Linguistic comments also noted.

Exploratory  
Comments

Schizophrenia

is an illness

Involvement with profession

Hearing voices is a psychic experience

Psychic experience

Repetition

departure from what is normal

Who says?

The professionals not allowed to talk about psychic experiences

Experiences have been labelled

Difference in how experiences are described by professionals and (M)

Talking is connected to illness.

Themes:

I am not ill

Experience of hearing voices

Not allowed to have psychic experiences

Experiences have been categorised into Label. a diagnosis

Diagnosis equates to being ill I am not ill

Rejects schizophrenia

29

1 I: Okay, it's on now. Hi Marcie.  
2 P: Hello.  
3 I: Hi, in your own words, what is schizophrenia?  
4 P: (Giggles) In my case, I can't really say what it is  
5 because .. um.. I don't think I'm ill.  
6 I: Mmm, hmm.  
7 P: And I tell the psychiatrist, I tell the psychologist I but  
8 um, if it's for hearing voices and it's for sometimes I'm seeing  
9 things that they say is not really there and hearing things that's  
10 not really there but I am determined, um.. (raised voices can be  
11 heard in the garden downstairs) I see some things and I'm  
12 determined that I hear things. Sometimes I say hearing voices  
13 is sometimes a psychic ear. This is what I was telling the  
14 psychologist and um ..I say a lot of people hear voices and um, a  
15 lot of people who hear voices are psychic. Anyway, cos I've had  
16 experiences where in what I hear is the reality and truth and  
17 um.. (raised voices can still be heard in the garden downstairs)  
18 when it comes to seeing things I was explaining that they're  
19 different dimension, that not everybody could see through but I  
20 can see things that is actually there. It must be there because  
21 I'm seeing it and sometimes I can describe what I see. So  
22 whether it's um.. seen in a different space, different dimension,  
23 or if whether it's an aberration I don't know what it is.  
24 I: Mmm.  
25 P: But um, it doesn't happen too often, but I do  
26 occasionally experience.  
27 I: So you mention that at times you see things and hear  
28 things would you say that other people can see and hear them?  
29 (woman's voice can be heard talking loudly in the garden)  
30 P: Well we're not supposed to talk about hearing voices,  
31 but we always do.  
32 I: Mmm and you've mentioned this a number of times to  
33 both the psychiatrists and the (woman's voice can be heard  
34 talking loudly in the garden) um..[psychologists] the  
35 psychologists. Do you believe that they have an understanding  
36 of what you're experiencing?  
37 P: Well they seem to do. So under, what I've said to you,  
38 probably goes under and sometimes I, not so much now but I  
39 used to think others are talking about me and I (woman's voice  
40 can be heard talking loudly in the garden) don't know what I  
41 explained to them. If it goes under the label of paranoid  
42 schizophrenic.  
43 I: Right, but you started to also say you don't believe that  
44 you are ill.  
45 P: No, I don't think I'm ill. I don't think I'm ill because I  
46 have been a very, very quiet person until I was erm.. in my 50s, I  
47 started talking when I say talking I..if, if I'm under a sort of um..  
48 attack that is egotistical or aimed at me, I do address it there  
49 and then. So ...

repetition.

Linguistic comments: (M) uses repetition to emphasise her point. Noise outside affecting flow of interview

Assumption is that quietness is associated with wellness. Addresses egotistical attacks. Schizophrenia = illness

## **Appendix 12 - Marcie's initial list of themes**

**Marcie - Initial List of Themes (chronological order as they appear in transcript)**

I am not ill  
Spiritual/psychic experience - Departure from what is normal  
Spiritual/psychic experience – Not permitted  
Schizophrenia is a label  
Diagnosis equates to being ill  
Schizophrenia is an illness  
Witnessed traumatic experience  
Spiritual/psychic experience – Senses activated  
Life spiralled out of control  
Life before the diagnosis  
Left behind – life has been stunted  
Traumatic loss  
Loss - deaths  
Loss of friendships  
Loss of self  
Wanting to return to former self  
Power imbalance of mental health professionals  
Does not trust what mental health professionals say  
Separation from mother  
Anger followed by regret  
Experiences categorised to fit in with ‘label’  
Failing to meet other people’s expectations  
Speaking out against societal norms  
Silenced  
Being Black in the work environment  
Not feeling accepted in the work environment  
Diagnosis is imposed by others  
Hating the work environment  
Black people are forced out of their jobs  
Shame  
Taken advantage of – vulnerability  
My illness  
Schizophrenia is depression  
What is schizophrenia?  
Imposed label  
Lack of control – label given by others  
Lack of control – professionals delving into background  
Lack of control – God knows...has a plan  
Anger towards system for labelling her  
Anger towards system for labelling Black people  
Loneliness  
Loss – unfulfilled dreams  
Life has been affected negatively  
Perceived negatively by others  
Reality of living with a mental illness  
Experiences of being racism  
Proud of being Black  
Schizophrenia – negative connotations

Power imbalance  
Nothing wrong with me  
Taking medication prevents illness  
Medication will make you better  
Role of medication  
Side effects of medication  
“Take your medication”  
Psychological support – not offered in hospital  
Psychological support – Talking therapy is good  
Cultural differences in mental health services

### **Clustering of Themes**

#### **Spiritual/psychic experience**

Departure from what is normal  
Not permitted  
Senses activated

#### **Lack of control**

Label given by others  
Professionals delving into background  
God knows...has a plan  
Power imbalance of mental health professionals  
Does not trust what mental health professionals say

#### **Use of medication**

Taking medication prevents illness  
Medication will make you better  
Role of medication  
Side effects of medication  
“Take your medication”

#### **Psychological support**

Not offered in hospital  
Talking therapy is good

#### **Issues of race**

Experiences of racism  
Proud of being Black  
Cultural differences in mental health services  
Being Black in the work environment  
Not feeling accepted in the work environment  
Black people are forced out of their jobs  
Hating the work environment  
Power imbalance

#### **Experiencing loss**

Unfulfilled dreams

Left behind – life has been stunted  
Traumatic loss  
Multiple deaths  
Loss of friendships  
Loss of self  
Separation from mother

### **Feelings**

Anger towards system for labelling her  
Anger towards system for labelling Black people  
Shame  
Loneliness  
Happy (past & present tense)  
Anger (at self) followed by regret

### **Self...**

Nothing wrong with me  
Perceived negatively by others  
I am not ill  
Taking advantage of – vulnerability  
Wanting to return to former self  
Speaking out against societal norms  
Failing to meet other people's expectations

### **What is schizophrenia?**

Negative connotations  
My illness  
Schizophrenia is depression  
Imposed label  
I am not ill  
Reality of living with a mental illness  
Silenced (by diagnosis)  
Diagnosis is imposed by others  
Schizophrenia is a label  
Diagnosis equates to being ill  
Schizophrenia is an illness  
Experiences categorised to fit in with 'label'  
Power imbalance

### **Life before and after the diagnosis**

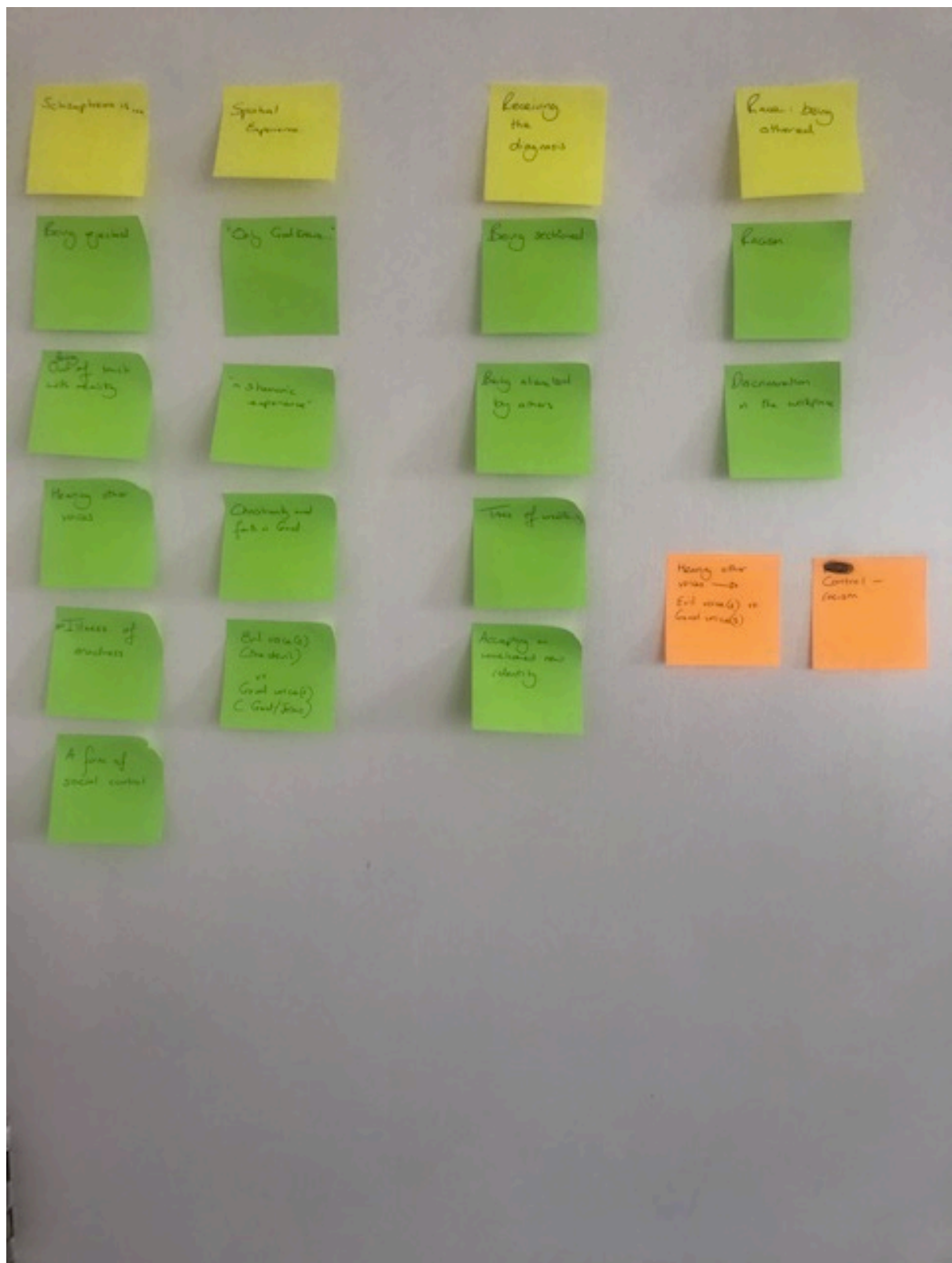
Life before the diagnosis  
Life spiralled out of control  
Life has been affected negatively

### **Misc.**

Witnessed traumatic experience



## **Appendix 13 -Picture of initial clustering of super-ordinate and sub-ordinate themes**



## **Appendix 14 - Master table of super-ordinate themes and frequency**

**Master table of super-ordinate themes and frequency**

	<b>Schizophrenia is a form of social control</b>	<b>Living with schizophrenia is a dynamic sentence</b>	<b>“A spiritual dimension to this experience”</b>	<b>Being Black with mental health issues</b>
Marcie	Yes	Yes	Yes	Yes
Kwame	Yes	Yes	No	No
NSNG9	Yes	Yes	Yes	Yes
Roy	Yes	Yes	No	Yes
Glendora	Yes	Yes	Yes	Yes
Sandra	Yes	Yes	Yes	No
Mary	Yes	Yes	Yes	No
Peter	Yes	Yes	No	No
<b>Present in half of sample</b>	Yes	Yes	Yes	Yes

## **Appendix 15 - Efforts to promote quality and validity in the research process**

## **Efforts to promote quality and validity in the research process**

It is important to assess and monitor the quality of qualitative research. Smith et al. (2009) focus on Yardley's (2007) criteria for assessing quality and validity in IPA research. Yardley (2000) has produced four principles for evaluating the quality of qualitative research, which are: *sensitivity to context, commitment and rigour, transparency and coherence* and *impact and importance*. Yardley (2000) proposes that these principles are not meant to be applied strictly but rather used flexibly in order to apply to a range of qualitative methodologies. These principles will now be discussed in relation to the current research.

### **Sensitivity to Context**

Yardley (2000) posits that a good qualitative study will demonstrate sensitivity to the context of the research. Choosing IPA as a suitable methodology promotes, within the researcher, an appreciation of the context of receiving a mental health diagnosis. From the start of the research process, my intention was to approach the topic and the participants with sensitivity and care. My previous experience of working with people in the community who had a mental health issue or a dual-diagnosis informed my approach as a researcher. For example, I was aware that a degree of flexibility might often be needed when involving such individuals. Kwame did not attend his first scheduled interview and for the second scheduled interview, he was twenty minutes late despite confirming that the time was suitable. I recognised that it was important to be flexible to accommodate the needs of the potential participants.

To give another example of sensitivity to context, in one instance one of the service managers introduced a male potential participant to me. He relayed that he had informed this man of the research topic and that he met the inclusion criteria. This potential participant then agreed to take part in the research. We went into the room where the interview was about to take place. I went through the participant information sheet and the individual expressed surprise that the research was about schizophrenia and he stated that he was not diagnosed with schizophrenia. On feeding this back to the manager, she checked the individual's file and confirmed that he was indeed diagnosed with schizophrenia. I considered the context of the situation and this allowed me to recognise several possible reasons that this man had not wanted to engage in the research. Firstly, he might have felt coerced to take part because the manager approached him. Perhaps he felt unable to decline the offer because of the power dynamic between service user and manager. Secondly, the reality of giving a first-person account of schizophrenia was challenging at that point in time.

## **Commitment to rigour**

Yardley (2000) describes *rigour* as the total sum of the data collection and analysis. In addition, Spencer and Ritchie (2012, p.231) define rigour as being “synonymous with methodological validity” and suggest that, in the context of qualitative research, the safe conduct of the research refers to the suitability of research decisions and the reliability of the data. Yardley (2000) posits that, in line with *commitment*, the researcher must immerse themselves in the data and engage with the topic. In IPA research there is an expectation that commitment will be shown in the degree of attentiveness to the participant during data collection and the care with which the analysis of each case is carried out” (Smith et al., 2009, p.181).

As a trainee counselling psychologist, I used basic counselling skills and showed empathy during the interview process. The role of a researcher and that of a psychological therapist are distinct in their nature and purpose. However, my experience as a therapist contributed to the phenomenological approach of the interviews and also supported the participants by allowing me to follow their pace.

I also immersed myself in the relevant literature for this research topic. I joined the London IPA group to broaden my knowledge of IPA and facilitate my analysis of the data. Rigour is evident in the current study by seeking a homogenous sample that met the inclusion criteria. Rigour is also evident in the analytic work as each transcript has clearly been examined line-by-line following the idiographic focus of IPA. During the analysis stage, I presented my first case analysis and emergent themes to my research supervisor. This ensured that I remained accountable to another academic and stayed congruent with my research question.

The need to commit to rigour is required throughout the research process, from the point of submitting the research proposal to writing up the research project. It can be argued that a commitment to rigour does not end at the write-up stage but will continue with the pursuit to disseminate the research.

## **Transparency and coherence**

Coherence refers to the philosophical thread that runs from the research question throughout the methodology to the point of analysis (Yardley, 2000). I would also add that the thread of coherence must continue post-analysis to the time of writing the project.

Yardley (2000) emphasises that qualitative researchers need to demonstrate transparency throughout the research process. Transparency in the current study is exhibited through the analytic procedure. The idiographic analysis of each participant’s interview led to clear themes and interpretations derived from the data. At all points in the analysis, the reader can track how the data was analysed and how the results

were obtained (Yardley, 2000). Appendices 10 to 14 provide an audit trail of the analysis. Furthermore, the participant information provided conveyed the exact nature of the research and outlined the expectations of the researcher and those of the participant. Maintaining a reflective journal and noting my thoughts following each interview, following research supervision and recording my reflections throughout the research process also demonstrates transparency as it provides an acknowledgement of my experiences and the motives underpinning the research.

### **Impact and importance**

The fourth principle focuses on the contribution of the research findings to clinical practice and theoretical knowledge. Yardley (2000) stresses that the true test of quality is whether research tells the reader something useful, interesting or important. Smith et al. (2009) argue that all IPA researchers must aspire to conduct research in this manner. This study contributes to an increased understanding of the participants' subjective experiences of being diagnosed with schizophrenia. The study also offers findings which could be considered for future clinical practice of counselling psychologists (and other allied professions). The impact and importance of this current research will be discussed further in the discussion chapter.

### **Validity**

Validity can be defined as "the extent to which ..research describes, measures or explains what it aims to describe, measure or explain" (Willig, 2013, p.24). There is a difference in how qualitative and quantitative research approach validity. Qualitative research gives room for validity issues to be addressed during the research process (Willig, 2013). One way to evaluate validity in qualitative research is to obtain feedback on the findings from the participants involved. This is known as participant validation. Participant validation is an invaluable way of engaging participants in the research and ensuring that their views are not misrepresented. However, including participant validation in IPA may raise a number of issues and generate unnecessary tensions. If a research topic was difficult to talk about in the first place, it may not be ethically fitting to ask participants to revisit the subject matter. In this sense, the appropriateness of further participant involvement post-interview or analysis is arguably dependent on the research topic. It could also be further argued that a researcher using IPA does not need to incorporate participant validation because their perspective is explicitly an essential component of the double hermeneutic and may differ from the participant's viewpoint. Consequently, it was decided that participant validation would not be used in this research.

Another method of validating the research is through reflexivity. The writing of the research journal is suggested to portray validity (e.g. in producing an audit trail) and also record and reflect the researcher's



role in the research. A third consideration in exploring the validity of qualitative research is ecological validity. This is ‘the degree to which results obtained from research or experimentation are representative of conditions in the wider world’ (American Psychological Association, n.d.). Willig (2013, p.24) suggests that qualitative research which takes place in real-life settings such as workplaces has “higher ecological validity” than research that is carried out in an artificial setting. An example of an artificial setting might be a laboratory where findings were then transferred onto a real-life situation. This research took place at mental health services in the community, arguably providing the kind of ecological validity that Willig (2013) describes.

