

**“The only thing I could have done...was turn to God,  
cause only God could help me”.**

The lived experience of ‘schizophrenia’ for Afro-  
Caribbean Christians: An Interpretative  
Phenomenological Analysis.

by  
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## **Abstract**

There exists an abundance of literature demonstrating heightened rates of 'schizophrenia' diagnoses among those of Afro-Caribbean heritage. Such rates, however, are not matched within their native countries which begs the question concerning the factors contributing to this prevalence. As it stands, this research area is largely saturated with positivist and reductionist literature, with a focus on the biomedical perspective of serious mental illness. However, there is also an evidence base that highlights how many Afro-Caribbean's hold spiritual and/or cultural explanatory models regarding the phenomena of 'schizophrenia'. Despite this, there is a dearth of research exploring the intersections between religion, culture and 'schizophrenia'.

The present study aims to contribute to the literature by using a qualitative lens to explore the lived experience of 'schizophrenia' for individuals who identify as Afro-Caribbean by ethnicity and Christian by faith. Semi-structured interviews were conducted, and an interpretative phenomenological analysis approach was adopted to explore the data. The analysis highlighted the significance of the participants faith during their process of sense making and navigating through their experience of 'schizophrenia'. The analysis uncovered four group experiential themes (GETs) God as a healer of 'schizophrenia'; 'schizophrenia' fostering a closeness to the creator; 'schizophrenia' as a transformative experience; and 'the culture is spiritual'. Findings support the importance of considering one's faith and religious orientation when seeking to understand the experience of 'schizophrenia'. Implications for future research are highlighted in the discussion chapter, along with the limitations of the current study. Implications for clinical practice include the implementation of a set of guidelines that consider religio-cultural beliefs at an assessment and support level which seeks to explore and understand the diverse belief models of service users in order to offer care from a holistic perspective, which is inclusive of a diversity of belief models.

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## **GLOSSARY OF TERMS**

With reference to the literature cited within this thesis, the researcher has adopted the terminology used by the authors.

There is an acknowledgement regarding the grouping of African and Caribbean populations and the risk this may pose in masking the subtle nuances which exist within each individual culture (Agyemang, Bhopal & Bruijnzeels, 2005). Given this, it is important to note that for the purpose of this research, the terms Afro-Caribbean/African-Caribbean/Black/Black-Caribbean will be used interchangeably and in this context refers to individuals who are of African descent who are: 1) Black and born in the UK who have grandparents or parents who were born in the Caribbean and/or Africa, 2) Black and born in the Caribbean or in Africa.

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*Proverbs 3:5-6 "Trust in the LORD with all your heart; and lean not to your own understanding. In all your ways acknowledge Him, and He shall direct your paths."*

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## **Dedication**

In loving memory of Rushworth Campbell Sr. My number 1 supporter throughout my entire academic journey. We always spoke about me completing my doctorate and I am saddened you are not here physically to share this moment. Every single day I miss you and wish you were here. I love you always and forever daddy. God be with you 'till we meet again in heavenly glory.

## CHAPTER I: INTRODUCTION

### Chapter overview

This chapter will present the background which scaffolds this doctoral research, discussing concepts regarding culture, religion and 'schizophrenia' and how these areas intersect. A brief history considering the wider historical landscape will be offered as well as the researcher's personal context.

### Research Aims

The proposed study aims to contribute to the growing interest in cultural psychology. Therefore, I propose to explore the lived experience of being an Afro-Caribbean Christian with a diagnosis of 'schizophrenia', using an Interpretative Phenomenological Analysis (IPA) approach. This study will foster counselling psychology (CoP) humanistic values as well as mirror the relational stance on the subjectivity of the lived experience of the participants (Cooper, 2009).

### Culture and Religion

In its broadest sense, culture refers to a set of beliefs, norms, values or a common heritage (Moodley & Lee, 2021). All of us are born, raised, live and function within a culture, which subsequently develops and adapts our 'world view', our way of seeing, experiencing and making sense of the world (Bhugra et al., 2018). This culture, therefore, plays a significant role in how individuals frame and understand their identity and the totality of their lived experience. Culture encompasses '*language, religion, spirituality, family structures, life-cycle stages, ceremonial rituals and customs, as well as moral and legal systems*' (Bhugra et al., 2018, p. 3), while also offering a set of 'rules' regarding behaviours that fall within an 'acceptable' range of behaviours for that cultural group (Haviland, 1990).

From a social perspective, it could therefore be argued that what is considered 'normal' (that which falls within the socially 'acceptable' range) and 'abnormal' (that which falls outside the socially 'acceptable' range) are heavily determined and influenced by the culture of a group or society and can therefore be viewed largely as a social construct. This idea aligns with the theory of cultural relativism which states that behaviour can only be considered abnormal when measured against the prevailing cultural norms of that time (Rosado, 1994).

Alternatively, sociologists such as Michael Foucault propose that this ever-changing divide between normal and abnormal is a reflection of the relationship between power and knowledge, and when one defines something as abnormal this inherently *"establishes power relations, and allows those in power to discard, diagnose, or incarcerate threats to prevailing ideologies as transgressive crimes or illnesses"* (Metzl, 2010 p. 157). Consequently, actions that represent resistance in one context may be labelled as mental illness in another, for instance the rise of 'schizophrenia' diagnoses among African Americans and within China during the civil rights movement and the period following the Tiananmen Square protests respectively. It is important therefore to acknowledge the wider socio-political landscape of societies and cultures and how this dichotomy may be providing justification for controlling particular groups which deviate from the views of those in power.

In light of this, when an individual holds a set of beliefs, these inevitably influence how they relate to the world and serve as an experiential guide in how they respond to and understand their life experiences (Eccles & Wigfield, 2002). A Christian worldview is significant to many in that it provides a set of templates and principles which guide the followers of the faith's life (Jones & Butman, 2011; Tan, 2011).

Historically, the relationship between religion and psychology has been stained with controversy for greater than a century, leading to a division between pastoral and 'secular' mental health professionals (Kéri & Kelemen, 2020). Today, this culture is somewhat shifting, and we are witnessing the emergence of bridges closing the gap between religion and psychology, illustrated by the publication of the APA Handbook of Psychology, Religion, and Spirituality, (2013) as well as the handbook in the Religion, Spirituality and Psychiatric Section of the World Psychiatric Association (Verhagen et al., 2010).

Views in Westernised culture as it relates to race and psychology, however, are less optimistic. For a number of decades Afro-Caribbeans' have been diagnosed with 'schizophrenia' (inverted commas throughout indicate the terminology used within the dominant biomedical perspective as opposed to the phenomenological perspective wherein the research is located) at disproportionately higher rates than their white counterparts (Fearon & Morgan, 2006) with an increasing amount of literature continuing to support the increased rate of psychosis among Black and ethnic minorities (Coid et al., 2008; Kirkbride et al., 2012; Torteli et al., 2015), with no definite explanation to account for this prevalence.

### A brief history of Race and 'Schizophrenia'

Racially motivated discourses regarding mental health amongst healthcare professionals has existed for greater than a century, with some of the earliest documented accounts dating back to the colonial regime during the transatlantic slave trade (Faber et al., 2023; Metzl, 2009). The manufacturing of a superior-inferior dichotomy was the central pillar of the colonisation project (Césaire, 1972; Fernando, 1992) with the scientific expansion of the 'normal vs abnormal curve' being seen to construct a hierarchy based on power, privilege and subordination (Campbell, 2009; Chapman, 2014; Davis, 1995) which casted the white mind and body as superior to that of the other (Butler, 2016).

Literature has suggested that the presence of 'mental illnesses' were a rarity among the 'savage tribes of Africa' (Halliday 1828; Fernando, 1992) but common within the 'civilised nations of Western Europe' owing to the stress of 'civilisation' (Hickling, 2005). It has been argued that the initial psychopathological nosology related to Africans were based on racist colonialist perspectives (Hickling, 2005). The psychiatry of the time 'bolstered the slave trade by classifying the 'running away behaviour' of slaves as mental illness' (Gorman & LeFrançois, 2018, p. 110) a diagnosis coined as 'drapetomania' by physician Dr Samuel Cartwright in his article 'Diseases and Peculiarities of the Negro Race' (Fernando, 1992; Kanani, 2011). By pathologising natural survival responses by enslaved individuals Dr Cartwright weaponised medicine in the name of upholding white supremacy (Faber et al., 2023). It is within these contexts, and under these regimes that psychiatry as a discipline was developing (Fernando, 1992).



Such attitudes became more prominent within psychiatry where racialised populations were and are over-represented within the mental healthcare systems throughout Western societies (Cohen, 2014; Fernando, 1992; Fernando et al., 2012; Metzl, 2010; Voronka, 2013) with biases seen to date within healthcare's discriminatory practices and treatment of black service users (Faber et al., 2023). Authors such as Colin King discuss these concepts within the context of postcolonialism, he describes the parallels historically of '*white men in white sheets*' who '*chained, lynched and brutalised*' Africans to the present day '*white men in white coats*' who '*overly medicate, inject and lock up*' black men and women (King, 2007, p. 13).

The relationship, therefore, between the history of racism and the history of the biomedical model must be considered within today's framework regarding the mental healthcare system.

### Culture and The Medicalisation of Distress

It has been well established that different cultures view distress differently and that for decades the Westernised biomedical model has held the monopoly over explanations of human distress, despite this being widely criticised (Fernando, 2017). The biomedical model assumes mental health disorders such as 'schizophrenia' are a product of a 'biologically based brain disease' (Deacon, 2013). Due to this assumption, this perspective endorses the use of pharmacological treatment to address presumed underlying biological abnormalities.

It could be argued that when seeking to understand the lifeworld of an individual, this cannot and should not be reduced to variables which are constructed to identify the presence of a psychiatric diagnosis, but rather the focus should be placed on understanding the '*unrestricted personal accounts of particular experiences*' (James et al., 2014, p. 248). It is widely acknowledged that there exist cultures which view distress in a relational manner. Namely within Eastern cultures the mind, body and spirit are not viewed as distinct entities as typically seen within the West (Fernando, 2009), while for many belonging to the Afro-Caribbean culture, supernatural and religious causes are often cited as attributions for distress (James et al., 2014).

Despite the newfound appreciation of psychosocial approaches for understanding and conceptualising distress, the biomedical model inherently minimises the relevance of such contributions, proclaiming that psychological phenomena can be fully understood within a biological context (Lilienfeld, 2007). The biomedical model is still seen to dominate the majority of the research and practice as it pertains to 'schizophrenia' and is widely observed across Western societies as holding the monopoly of distress.

### Counselling Psychology and The Biomedical Model

The field of Counselling Psychology (CoP) emphasises a 'value base grounded in the primacy of the counselling or psychotherapeutic relationship'. Owing to the humanistic value base of the profession it inherently challenges the pathologising of distress by seeking to understand the subjectivity of one's lived experience as unique to every individual.

The British Psychological Society (BPS, 2017) best practice guidelines recognise the significance of not only understanding but appreciating the experiences typical to people from diverse ethnic and religious backgrounds and how this is conceptualised within their religio-cultural frameworks. The BPS encourages practitioners to have an awareness of the effects of historical racism and the presentation of such within the context of a bias Western model of psychopathology. A fundamental criticism of psychiatric diagnosis is that it is founded on judgements on the differences in social and cultural norms (Johnstone, 2008; Laing, 1960). The Health & Care Professions Council (HCPC) (2015) standards of proficiency echo this sentiment of the BPS, highlighting the importance of practitioners' awareness of the influence of culture, equality, and diversity on practice.

Alternative attributions to the origin of 'schizophrenia' and 'psychosis' vary from culture to culture (McCabe & Priebe, 2004), although it seems these are rarely considered in clinical practice. Research has demonstrated biological explanations for 'schizophrenia' have been associated with better adherence to treatment and relationships with mental health practitioners, however such views are less likely to be endorsed by ethnically minoritised

populations (Carter et al., 2016; McCabe & Priebe, 2004), thereby perpetuating the disproportionately high rates for these populations within mental health services. Black service users cite a range of views relating to their 'psychosis', predominately spiritual causes (Bard et al., 2021). As such, it is fundamental to treatment that practitioners can make adaptations in their clinical practice in order to meet the needs of ethnically diverse clients (Arredondo, 1999) and adopt a more systemic approach with regards to the relationship between culture, ethnicity and beliefs about 'psychosis' within clinical practice.

Counselling psychology practice would suggest this 'truth' should also be extended to research practice to produce ethically driven research that highlights the voices of the population the research is aiming to serve. Given that the central philosophy of counselling psychology is reliant upon the therapeutic relationship (Strawbridge & Woolfe, 2010), this highlights the importance of keeping the integrity of the discipline, as this relationship is one of the most significant factors in determining whether a client engages in therapy, and thus will directly impact outcomes (Sue & Sue, 2003). In order for CoP, as a profession, to make meaningful differences in the lives of the clients who engage in services, there must be a sensitivity to the importance of race and the unique experiences faced by clients from ethnically diverse backgrounds.

As Counselling Psychologists are both researchers and practitioners, the field is founded upon the conceptual frameworks of the 'scientist-practitioner' and the 'reflective-practitioner' models. Within this there is an emphasis placed on the unification and integration of these two approaches in practice (Blair, 2010; Gkouskos, 2016). As science is *'more an ethical attitude towards rigorous empirical inquiry, which involves observing, questioning and forming theories that can be tested in further inquiry'* (Strawbridge, 2016 p. 26) there exists a tension within the CoP paradigm when working within systems inspired by the medical model which contrast the humanistic framework the profession is striving to retain.

As a scientist-practitioner in order to produce research with integrity and rigour, I have to acknowledge the systems that I work within and how these systems may influence my research, my approach and my participants. Coming from a profession like Counselling Psychology where relationality is at the heart of the discipline, creates a tension when

working within remits where the significance of research in informing clinical practice and development of the field needs to be balanced by equally paying respect to the idiosyncratic presentations of each client and/or participants. This is particularly apparent within the current research when working with terms such as 'schizophrenia' where the general conceptualisation is still largely rooted and understood within the biomedical frame.

### Definitions and Terminology

'Schizophrenia', as defined by The Diagnostic and Statistical Manual of Mental Disorders (DSM 5; APA, 2013), is a 'complex condition' characterised by: disordered cognitions and perception which consists of one or more positive symptoms, referred to as 'delusions' and 'hallucinations' (Morris, 2017). 'Schizophrenia' is thought to run a chronic course, often having an adverse impact on an individual's wellbeing (McCrone et al., 2008), ability to live independently and maintain work and social relations (Janoutová et al., 2016).

Religion has been defined as an organised and institutional group or community which involves a set of beliefs and practices related to a divine, sacred entity or higher power (Cetty et al., 2022; Russinova & Cash, 2007). Members of a religious group or community often embrace shared values and core beliefs (Miller & Worthington, 2012).

Spirituality has been defined as feelings and experiences connected to a search for purpose and meaning in life (Henningsgaard & Arnau, 2008). Like Religion, spirituality also consists of a pursuit of the sacred and experience of the sacred, although, in this context the sacred is not necessarily considered God as seen within many religious contexts (Saroglou & Muñoz-García, 2008) but is more concerned with personal and existential meaning (Wink et al., 2005). There are many who identify as both religious and spiritual (Zinnbauer et al., 1997) with other expressing the contrary (Miller & Worthington, 2012).

While spirituality and religion differ in some ways they will be used interchangeably throughout the current paper.

### Personal context and the self in research

It is important to note how one's personal experiences predispose both their consideration and approach to a particular phenomenon. I identify strongly with the profession of counselling psychology's stance on subjectivity and the premium it places on an individual's lived experience as being central to the work in therapy.

As an Afro-Caribbean Christian myself, having worked across several mental health services from inpatient, forensic and secondary care I have witnessed time after time the views of black service users being dismissed and silenced by healthcare practitioners. I remember wondering about how disempowering and dismissive the experience of being silenced inadvertently, and at times advertently, may have felt for the service users, and how disheartening it must feel for your own conceptualisation of your experience not to be considered in your treatment plan.

My own experiences of prejudice and discrimination made me all the more sensitive to the injustices that I witnessed. I noticed that I would quickly become burnt out as a result of, at times, becoming over involved. The sense of powerlessness as I walked onto the ward as a junior member of staff, feeling unequipped to change the powerful structures and ideologies of healthcare services – ideologies which I felt oppressed people who looked like me. In speaking with service users, they would frequently tell me about their faith and spiritual experiences, and I noticed that at times many of their spiritual experiences correlated with mine. The tensions of feeling a sense of connection and togetherness while "working for" the wider oppressive system permeated my experience working across mental health services. All these experiences coupled together fuelled my passion and commitment to working in a way which empowered, respected and took seriously the diversity of views offered by those with lived experience.

I was motivated to adopt a hermeneutic phenomenological approach to explore the lived experience of 'schizophrenia' for Afro-Caribbean Christians. In consideration of my phenomenological epistemology, I was interested in gaining an in-depth understanding of the phenomena that is 'schizophrenia'. In adopting this approach, I hoped that their subjective experiences would be captured, and a voice would be given to a group who has for too long been marginalised and silenced within healthcare. It seemed vital to take

a perspective which differed from the standardised positivist approach, which is seen to dominate this research area, and move toward an approach which values the inclusivity of varying explanatory models. My research seeks to explore how this group made sense of their experience of 'schizophrenia' in the context of their faith and culture.

## **CHAPTER II: LITERATURE REVIEW**

### Chapter Overview

This section will present a critical literature review of the existing research within the areas of 'schizophrenia', race and religion, in so doing, I will aim to reveal the apparent gap and rationale for the research question, whilst highlighting the relevance of this research topic to counselling psychology.

### Researcher's Positioning

As I critique the literature, I am acutely aware of my position as a counselling psychologist and how this intersects with my identity as a person of faith. It is acknowledged that both aspects of my identities will influence my world view and as such will impact how I interact and engage with the literature I am critiquing and it is possible a researcher operating from an alternative perspective may have paid attention to different areas within the literature.

### Conceptualising 'Schizophrenia'

Research looking at concepts of 'schizophrenia' as not being a biological cause challenges the medical model's conceptualisation of distress (Bhugra & Bhui, 2018; Boyle, 1990), with research demonstrating individuals with 'schizophrenia' often attribute their experience to causes outside of the biological formulation, including but not limited to social (Rathod et al., 2010), cultural (Cartledge, 2017) and spiritual (Bard et al., 2021; Grover et al., 2014) explanations.

Though research has demonstrated such, these explanations are not commonly considered in practice (Drinnan & Lavender, 2006; O'Connor, 2010; Pierre, 2001) and there remains a lack of research focusing on the subjective experience of Afro-Caribbeans experience of 'schizophrenia'. Despite this, one cannot ignore the

intersectionality between race, mental health, and religion (Turner, 2021) and the role these factors play in the experience of a phenomena such as 'schizophrenia'.

Currently, there exists a host of quantitative research, primarily epidemiological surveys on 'schizophrenia' among Afro-Caribbeans. A central criticism of psychiatric diagnosis is that it is grounded on judgements on the diversities in social and cultural norms (Johnstone, 2008; Laing, 1960) and ignores the intersections that account for one's experience for diverse groups (Turner, 2021). Whilst these studies are useful in their own right, they remain grounded in the medical model, and provide no insight with regards to this over representation, but instead present a biased view of 'schizophrenia' (Fernando, 2017).

### Afro-Caribbeans and 'Schizophrenia'

A growing body of research has demonstrated an over representation of 'schizophrenia' among the Afro-Caribbean populations (Fearon, 2006; Pinto et al., 2008; Thomas, 2014) with a wealth of previous research noting higher rates of 'schizophrenia' in Afro-Caribbeans to the order of three to six times compared to their white counterparts (Dean et al., 1981; Rwegellera, 1977). Such findings have been matched in contemporary research (Cantor-Graee et al., 2005; Cantor-Graee & Pedersen, 2007; Coid, et al., 2008; Nazroo, 2020; NICE, 2014) and systematic reviews (Kirkbride, 2012; Tortelli et al., 2015) demonstrating the incidence showing consistency over time. Afro-Caribbeans are more likely to receive a diagnosis of 'schizophrenia' (Schwartz et al., 2019) be sectioned and hospitalised with a serious mental health concern at far higher rates than their white counterparts (Fearon et al., 2006; Morgan et al., 2005) have lengthier stays in inpatient hospitals (Mohan et al., 2006), higher rates of readmission (Morgan et al., 2017; Priebe et al., 2009) and poorer treatment outcomes (Bhugra & Bhui, 2001).

Kirkbride's (2012) systematic review notes that incidences of 'schizophrenia' in Afro-Caribbeans has been identified as the highest globally (Bourque et al., 2011; Kirkbride et al., 2012; Tortelli et al., 2015). While systematic reviews have the power to paint a picture of the profile under study, in line with the aims of the review the focus was exclusively on incidence of 'schizophrenia'. Whilst this increased our knowledge base regarding the widespread prevalence regarding the disproportionate rates, it would also be important to



explore the 'why' within a qualitative approach as such research does not further our understanding of this prevalence. Due to this there seems to be a need within this research area to go further than description and offer interpretation regarding these statistics.

It was interesting to note, such high rates are not reflected amongst this population within native countries (Harrison et al., 1988; Hickling, 2005; Hickling & Rodgers-Johnson, 1995; Mahy et al., 1999) and as such, for several decades the controversy regarding this prevalence remains an ongoing debate and currently remains unabated. Cooper et al., (2008) suggests this could be a reflection of culturally unfit assessment tools, which fail to take in to account alternate explanatory belief models. Others argue, the knowledge and/or training required to deliver culturally sensitive interventions is absent and/or poorly evidenced (Islam et al., 2015).

Pitt et al., (2009) attempted to address these issues in their qualitative, service user led study, exploring the impact of receiving a psychosis diagnosis. The data was analysed using IPA (Smith & Osborn, 2003). Results showed diagnosis to have both "*positive*" (*means of access to psychological support and medication*) and "*negative*" (*disempowerment from labelling*) elements. Whilst IPA was well suited to address the study aims, IPA requires the researcher to contextualise the lived experience reported in the data in relation to the social and cultural structures (Smith et al., 2009), however this does not seem to have been explored, despite the African-Caribbean participants reporting: '*the lack of understanding and awareness about cultural differences contributed to their sense of disempowerment*'. Attending to the intersectionality, would have strengthened this study and added an extra layer to the analysis. The study seems to have missed the opportunity to further our understanding of the cultural differences of what it means to receive a psychosis diagnosis. It is hoped the current research will address this area.

### Religion and 'Schizophrenia'

Exploring the rates of 'schizophrenia' in the absence of uncovering and understanding the cultural differences with respect to both societal and religious implications has its limitations, as such ignores a crucial element accounting for one's experience. Religiosity

has a profound influence on an individual's behaviour, experience, physical and psychological well-being, as well as their quality of life (Dutton & Madison, 2022) and worldview (Rowe & Allen, 2004). Therefore, religiosity has great implications for how individuals perform in groups and form their society. 'Schizophrenia' is one element that has been implicated in this respect, as it is often associated with religious delusions and hyper-religiosity (Brewerton, 1994; Dutton & Madison, 2022; Neeleman & Lewis 1994).

Dominant religions in the world are speedily changing, driven by a shift in societal norms and values. Worldwide, Christians account for 2.2 billion (32%) of the world's population (Pew Research Center, 2010), with approximately 90% of the population in the Caribbean identifying as Christian (Pew Research Center, 2010). There exists much speculation regarding the relationship between 'schizophrenia' and Religion (Grover et al., 2014). Cross cultural studies suggest a third of patients with 'schizophrenia' are highly involved in religious community (Huguelet et al., 2006), with religious practices among psychiatrically ill patients noted as most common in Europe (Kirov et al., 1998; Neeleman & Lewis, 1994) where the largest population of Christians are said to reside, accounting for 75% of the population (Pew Research Center, 2010).

An increase in the strength of religious beliefs were found in one quarter of individuals who experienced a psychiatric illness, (Kirov et al., 1998) with further studies demonstrating as high as 91% of patients reporting to engage in private religious or spiritual activities and 68% reporting participation in public religious services or related activities (Nolan et al., 2012). Moreover, research studies have shown religion plays an important role in coping with 'psychosis' (Heffernana et al., 2016; Pastwa-Wojciechowska et al., 2021; Szafranski, 2015). Such research highlights the importance of religious subscription in the lives of individuals with 'schizophrenia'.

The Health & Care Professions Council (HCPC, 2015) standard of proficiency highlight the significance of practitioners possessing an awareness of the influence of culture, equality and diversity on clinical practice with the BPS's report on 'Psychosis and Schizophrenia' (BPS, 2017, p. 55) noting '*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*'. If this is such, then it must be considered why more healthcare professionals do not seem to take this into account in their practice. There are

several factors that may account for the neglect of religious issues. Commonly noted are the following: an underrepresentation of religiously inclined professionals (Neeleman & King, 1993), lack of education for mental health professionals regarding religion, (Lukoff et al., 1995; Shafranske, 1996) and the tendency to pathologise the religious dimensions of life (Crossley, 1995; Dein & Cook, 2015; Larøi et al., 2014). This disregard of religious issues within psychiatry may also be related to the “rivalry” between medical and religious professionals, both of whom address the dilemma of human suffering, albeit from varying perspectives (Roberts, 1997; Sims, 1999). Such research highlights the significance of considering cultural context and meaning during assessment to avoid misinterpretation of culturally acceptable experiences (Dein & Cook 2015; Larøi et al., 2014).

McCaibe & Priebe, (2004) explored explanatory models of ‘schizophrenia’ across four ethnic groups and found that when biological and supernatural causes were compared, Black Caribbeans cited supernatural/spiritual causes more frequently than their white counterparts. More recently Carter et al., (2016) in a systematic review, found the way an individual understands their experience, has important consequences on subsequent health behaviour, with regards to treatment outcomes, attitudes toward their experience, and satisfaction within the therapeutic relationship. Research has demonstrated biological explanations for ‘schizophrenia’ are linked to better treatment adherence and relationship with mental health professionals. However, literature shows such belief models are less likely to be promoted by ethnically minoritised populations (Carter et al., 2016; McCaibe & Priebe, 2004). This raises the question of how these attitudes are perpetuating the discrimination and issues faced by Black service users, who frequently cite predominately spiritual causes to their ‘psychosis’ (Bard et al., 2021) and how this is received and approached by practitioners.

The Equality Act (2010) protects individuals against unfair treatment and prevents discrimination on the grounds of a series of protected characteristics, religion being amongst them. Respecting diversities is a core ethical principal psychologists should be committed to promote in all aspects of their practice (BPS, 2017). Through this, adjustments and adaptations will be fostered to ensure treatment is appropriately delivered and fruitfully received. Given that the underpinning philosophy of CoP is reliant upon the therapeutic relationship (Strawbridge & Woolfe, 2010), it is fundamental as practitioners, that we are able to make adaptations to meet the needs of the diverse client

groups we work alongside (Arredondo, 1999) by adopting a more collaborative approach to working with intersectionality.

### Christianity and 'Schizophrenia'

Hearing the voice of God is a widely accepted phenomena in most religious sectors and is particularly endorsed as a crucial aspect of Christianity (Luhrmann & Morgain, 2012). Pathologising such 'symptoms' therefore, in those who identify as Christian can be problematic. Literature has demonstrated, that amongst Black Christians, there is a reported 'negativity about professional help' within the community and wider culture, (Rathod, 2010) with the fear that their religious beliefs may be misunderstood. These fears, however, are not unfounded, with research showing misdiagnosis on the grounds of non-pathological religious beliefs and behaviours are well documented (Bartholomew & O'Dea, 1998; Loewenthal, 1995). Religions such as Christianity, amongst others, are often perceived as complex and therapists have difficulties in distinguishing spiritual from 'psychotic' belief (Rathod et al., 2010).

Similarly, the negative symptoms of 'schizophrenia' such as withdrawal, lack of interest/motivation may be important areas for healthcare professionals (HCPs) to consider when examining how these are presented and perceived in the context of those with religious affiliation. For instance, behaviours such as becoming withdrawn may be interpreted from a medical perspective as affirming the negative symptoms of 'schizophrenia'. Such symptoms have been found to account for contributing to the long-term morbidity and poor functional outcome among individuals with a diagnosis of 'schizophrenia' (Galderisi et al., 2018), as well as being associated with "significant deficiencies in motivation, communication, affect and social functioning" (Correll & Schooler, 2020).

However, from a spiritual perspective, this behaviour could be framed in a different manner. For instance, there are instances within the Holy scriptures where there is mention of Jesus withdrawing himself from others in order to have closer fellowship with His heavenly father: "But Jesus often withdrew to lonely places and prayed" (Luke 5:16), "And rising very early in the morning, while it was still dark, he departed and went out to

a desolate place, and there he prayed” (Mark 1:35). In light of this, an individual becoming more withdrawn may not be indicative of a decline in mental health but rather may be communicative of what one believes to be spiritual enlightenment in which someone must remove themselves from others in order to gain a closer relationship with God. In order to accurately understand what an individual’s behaviour is a communication of, it is vital that HCPs consider and explore the wider context surrounding the individual to avoid potentially pathologising religious/culturally appropriate behaviours.

The Holy Bible is considered the most sacred text in Christianity and is frequently used as the blueprint for living a purposeful and fulfilling life that followers of Christ describe as pleasing in the eyes of God. The Bible presents several accounts of what could be considered contemporarily as ‘mental illness’, although is frequently referred to as ‘madness’ and ‘lunacy’. For example, “The LORD will afflict you with madness, blindness and confusion of mind” (Deuteronomy 28:28), “Lord, have pity on my son, for he is a lunatic and suffers severely; often he falls into fire, and often into water” (Matthew 17:15). There are instances within biblical text where God is seen to communicate with people “at many times and in various ways” (Hebrews 1:1). Some of these include God communicating with Moses through a burning bush: “There the angel of the Lord appeared to him in flames of fire from within a bush.... God called to him from within the bush” (Exodus 3: 1-4), and a thick cloud: “The LORD said to Moses, “I am going to come to you in a dense cloud, so that the people will hear me speaking with you and will always put their trust in you” (Exodus 19:9).

It could be argued that many of the ‘positive symptoms’ of ‘schizophrenia’, such as hearing voices and ‘delusions’, have significant overlap in the biblical descriptions of religious experiences (Bhargab et al., 2014). Therefore, by labelling such experiences as ‘delusions’ may not be regarded as such for those who ascribe to Christianity as such occurrences were noted in many biblical prophets and are perfectly in line with the theology of Christian belief systems.

Research exploring the role of Christianity in the recovery of ‘schizophrenia’ is limited. However, there is a degree of literature which has highlighted the role of religion in general terms being used as a coping strategy for mental ‘illnesses’ (Mohr, 2011; Smith et al., 2012; Webb et al., 2011; Yangarber-Hicks, 2004), the management of symptoms, (Ho et

al., 2016), stressful life situations (Pargament, 1997; Pargament et al., 2005) and 'reconstructing a sense of self' (Mohr & Huguelet, 2004). Moreover, research has noted that religion has been found to reduce distress, social alienation and anxiety related to 'psychotic' symptoms (Escamilla et al., 2014; Sweet, 2021) and has had a positive contribution during an individual's journey to 'recovery' (Fallot, 2009).

Classic case studies by Hansen (1995) report two cases of individuals who were considered 'mentally ill' by relatives and subsequently diagnosed with 'schizophrenia' by a psychiatrist, who had later been identified as going through a spiritual crisis. The paper states the participants later 'recovered completely' which concluded in 'better psychological balance, maturity and strength'. This notion is supported within the Christian faith where miraculous encounters of healing are widely noted within biblical text, these are frequently documented within the gospels throughout Christ's ministry. Examples include (Matthew 11:5) "The blind see and the lame walk; the lepers are cleansed and the deaf hear; the dead are raised up", (Luke 4:40) "He laid his hands on every one of them and healed them", (Mark 1:34) "He healed many who were sick with various diseases", (Luke 4:39) "Standing at her bedside, he rebuked the fever, and it left her" (Psalms 41:3) "The LORD sustains him on his sickbed; in his illness you restore him to full health".

For Christians part of their belief system involves the role of faith for healing to occur (Khan & Dixon, 2021) through practices such as prayer (Robinson, 2014). This fundamental belief underpins the faith, with the body-soul relationship opposing the body-mind conceptualisation inspiring modern medical and mental health practice (Khan & Dixon, 2021). This extends to our understanding of how Christians may interpret and navigate their experiences of mental health where there is often a strong reliance on God and their faith for strength, and healing (Khan & Dixon, 2021; Koenig, 2005, 2008, 2009). Further research regarding spiritual experiences highlights '*a sense of newly gained knowledge, diminishing of sense of doership, and complete surrender to the higher force in life for one's own needs*' (Bhargav et al., 2015, p. 1903). As such, an individual's reliance on spiritual resources have been found to impact help seeking behaviours from mental health services, viewing accessing help outside of reliance on God as a failure or weakness on their part (Edge, 2013).

In light of this, a clinicians' awareness of their client's religious orientation is paramount in assessing mental health. Literature recommends psychiatric evaluations should consider assessment of religious and spiritual beliefs (Penzner et al., 2010; Whitley, 2012) however such is not routinely practiced. Common explanations include but are not limited to, bias in clinical judgements due to the assessors' beliefs (Pierre, 2001), lack of insight into cultural beliefs which separate pathology and religion (Drinnan & Lavender, 2006) and plainly, religious beliefs considered delusions by some clinicians (O'Connor, 2010). Regardless of such, as healthcare professionals and researchers with integrity we should resist refraining from exploring themes so prevalent during those presenting with 'psychosis' (Ng, 2007) simply because they are conflicting with the well-established belief models. Whilst every clinician would possess their own individual beliefs and perspectives which may or may not align with the biomedical perspective, a call for transparency and reflectivity within practice is key in providing person centred quality care.

#### Intersectionality: Race, Religion and 'Schizophrenia'

The intersections of race and religion inform individuals identity (Turner, 2021), experience (Dutton & Madison, 2022) and belief models (Bard et al., 2021; Carter et al., 2016) yet appear to not be considered widely enough within psychological therapy and research (Ade-Serrano 2017; Post & Wade, 2009). Comparative studies exploring religious practices in patients with 'schizophrenia' to that of the general population have suggested that religious involvement is higher among the patient population (Mohr et al., 2012) whereas others have suggested that religious attendance is less in patients presenting with 'schizophrenia' (Cohen et al., 2010).

When considering the differences in outcomes it is important to examine the methods employed. Mohr & Huguelet (2004) noted that adherence to treatment may be impacted by religious delusions. For example, Doering et al., (1998) reported religious delusions and a strong religious faith were associated with poorer outcomes. When explored to find what measures of outcome were utilised, a host of quantitative tools were applied. Outcomes were measured using patient scores on the Brief Psychiatric Rating Scale

(BPRS), Global Assessment Scale and Clinical Global Impression Scale. While these tools measured outcomes according to the prescribed items listed, to draw conclusions regarding treatment outcomes from such measures, could be argued to be reductionist, as it ignores the richness of the clients account of their experience as it exists on a spectrum.

In addition, in this study, there was a 56% drop out rate, and patients included in the study were required to be medicated throughout. This sample, therefore, may not be reflective of a diverse pool of patients, as, arguably, only those who were in agreement with the medical model were included, as literature has highlighted help seeking among African-Caribbean individuals has been moderated by a '*fear of being medicated*' (Rathod, 2010). This inclusion criteria therefore, may have possibly resulted in the isolation of those with religious beliefs, who may attribute their 'symptomology' to supernatural causes as seen with many Afro-Caribbeans (Carter et al., 2016; Grover et al., 2014; Rathod et al., 2010) who often refuse medication (Mohr & Hugulet, 2004). Furthermore, given the typical treatment for 'schizophrenia' is predominantly pharmacological and based within the biomedical framework, these tensions could have significant consequences for treatment outcomes for those who do not endorse this view (Carter et al., 2016). As such models fail to be inclusive of beliefs around culture and religious belief models.

More fundamentally however, as a strong religious faith was associated with poorer outcomes it would be of great importance to know how the strength of religiosity was operationalised in this study, in order to draw such conclusions regarding such phenomena. The typical treatment for 'schizophrenia' is centred on the biopsychosocial model and involves the prescription of antipsychotic medication and psychological therapy (National Institute for Health and Care Excellence (NICE, 2014). While the model considers family history, it does not explicitly consider the cultural, or religious beliefs of the clients, despite religion and spirituality playing a significant role in the lives of individuals with 'schizophrenia' (Grover et al., 2014).



Earlier research such as Rwegella (1970) found religious phenomenology was more common in those from an Afro-Caribbean heritage in Britain, which is supported by Littlewood & Lipsedge (1981). The authors found, what they coined: 'religious flavour' was common in Caribbean populations as well as in migrants in general, irrespective of their religious membership. The authors go on to report that religious phenomenology is possibly related to the increase in diagnosis of 'schizophrenia' in Afro-Caribbeans but is however, not sufficient to account solely for the discrepancies. The methodology of this study consisted of reviewing the notes of patients admitted into a psychiatric hospital. All information regarding religious orientation and race were obtained solely from admission notes. Due to this, it ignores the multifaceted dimensions of religiosity and how this may have potentially changed over time, and also misses the richness of the clients account, which may give an indication to how connected they feel to their faith. It is also worth noting that there were significantly more Afro-Caribbean patients included in the study than other groups (37 Caribbean, 24 Irish, 9 West African and 13 European migrants) which may have further skewed the results.

Arguably, and most importantly, the term '*religious flavour*' which was used by these authors to draw to said conclusions, is defined as: '*a constant preoccupation with a religious or supernatural theme, religious delusions or hallucinations, a belief in a personal religious mission or interpretation of recent events in religious or magical terms*'. Such definitions could be considered derogatory and not inclusive of cultural differences and could be viewed as offensive. Namely, terms such as "magical" take away strength from the various explanations of 'psychosis' that exists outside of a Western model, and somewhat reduce them to merely "make belief". Moreover, given the central role of religion in forming one's identity what one would consider as a 'constant preoccupation' may differ from person to person. This further showcases the prejudice of Western psychology as the dominant paradigm and its inability to consider counter explanations as equally as 'true'.

Attributions for 'psychosis' have been categorised in a variety of ways: biological (genetics, neurological, chemical imbalance), psychosocial (stressors, trauma) and

spiritual (God's will, cultural beliefs and fate) (Carter et al., 2016). From a counselling psychology standpoint, it would be remiss to say any one of the above hold the monopoly over the other. What we do know however, is that, by and large, members of black communities within the UK attribute mental health concerns to spiritual causes such as Obeah or black magic, punishment for wrongdoings, social deviance, and structural racism (McCabe & Priebe, 2004; Rathod et al., 2010). Such attributions seem to fall widely outside the Western conceptualisation of psychosis. In light of this, it seems fundamental to consider the intersections of identity around race and religion and the psychological cost of "othering" faced by marginalised groups (Turner, 2021) and how this influences how a phenomenon is experienced, expressed and received by the other.

In another example, Siddle's (2002) study investigated the prevalence of religious delusions, and sampled individuals admitted to hospital with a diagnosis of 'schizophrenia'. The content of their delusions were observed, controlling for religious content and how such religious content predicted their general mental wellbeing. The results generated showed those with religious delusions had overall, a lower general functioning as measured by the Global Assessment of Functioning (GAF). Whilst the methodologies fit with the researchers aims, again, such could be considered reductionist as firstly, it ignores the lived experience and secondly, it employs pre-determined measures inspired by the medical model which has been long criticised for its ignorance toward diverse belief models (Fernando, 2017). By ignoring the subjective lived experience of the individual and failing to use culturally appropriate measures in line with the customs and beliefs of an individual's religious orientation, the research arguably could be viewed as lacking in validity. In other words, one cannot set out to measure what is considered in one culture a religious experience using tools created to denounce such beliefs.

Labelling such experiences as 'religious delusions', without considering the religious context during assessment (Penzner et al., 2010; Whitley, 2012) further highlights this point. For instance, in the context of the Christian belief system, for which the Bible is the blueprint, these experiences are widely noted: For example: Moses (Exodus 5:1), Ezekiel

(Ezekiel 38:10) both of whom report words spoken to them by God and Elijah, who heard God speaking to him in “a small still voice” (1 Kings 19: 11-12). In the context of the Christian faith therefore, this ‘symptomology’ is consistent in the Christian religious text, and as such are not regarded as ‘delusions’ in this context. It would be imperative for there to be an understanding of the shift in paradigms that occurred societally and culturally, as demonstrated, historically such experiences were understood from a religious framework whereas now they would be an indicator of a severe mental health ‘disorder’. The difference between religious experience within a clinical setting speaks to the fact that one cannot just consider one culture when assessing individual presentations.

Although not expressed explicitly by the authors, it can be seen that a positivist stance was adopted due to the language used around ‘schizophrenia’ and mental health being measured in accordance with a disease model, and the emphasis placed on observable phenomena through scientific quantitative methods (Bruce et al., 2008). Fostering a qualitative approach could have addressed the issues of validity and reductionism within this study, and as such may have allowed for greater exploration of individual belief models, regarding individuals view of their faith in relation to their experience (Dutton & Madison, 2022).

Caribbean culture has a rich history in Christianity (Chierici, 2004), and faith scripture and religious text are among the most influential forces when seeking professional help (Chierici, 2004), with the Clergy being used as the primary resource for mental health problems (Anthony et al., 2015; Hankerson et al., 2015; Stansbury et al., 2018). This knowledge is fundamental, considering the central role that attributions play in help seeking and subsequent health outcomes (Carter et al., 2016; Mohr & Huguelet, 2004). The church is often viewed as a safe space for exploring mental health concerns (Campbell & Winchester, 2020) and as such faith leaders are well placed to address the mental health needs of this population.

A qualitative study of pastoral care in black majority churches indicated from a thematic analysis, that clergy members tended to have a holistic view of mental health, stating mental health, physical health and spirituality are inextricably linked and not to be viewed in isolation (Stansbury et al., 2011). Furthermore, church-based interventions are often culturally adapted to highlight black culture and spirituality (Hankerson & Weissman,

2012). Therapy informed by this holistic perspective may be more in line with the values and beliefs of the black community. Given the authors adopted a constructivist lens, offers a refreshing take on research within this area, and highlights the significance of considering intersectionality, when tackling mental health (Turner, 2021).

In instances where mental health stigma exists within the clergy may impact upon the help seeking of the congregant. Literature has shown interpersonal difficulties arise when the clergy and the congregant's views regarding support provision, resolution, and the role of religious coping vs secular coping are at odds (Chatters, 2000). Such tensions can be a source of distress for the individual and can show up in prolonged periods of distress due to no access to psychological support. This is particularly concerning given the barriers to access those from the black community often face due to stigma and mistrust of HCPs (Hankerson et al., 2015; Hankerson & Weissman, 2012).

As not all clergy members are familiar and/or trained to work with congregants presenting with psychological distress (Anthony et al., 2015) the safe space for mental health dialogue created in churches (Campbell & Winchester, 2020) may serve well in tackling the barriers to service utilisation (Hankerson et al., 2018; Hankerson & Weissman, 2012). Churches are uniquely placed to respond to the mental health needs of the community and in these instances referrals to psychological support services are often made (Stansbury, 2011). Such literature highlights the need for greater collaboration between mental health professionals and members of the Clergy. Furthermore, through establishing links between 'secular' mental health services may support with reducing the stigma that exists on both sides and create greater awareness of both belief systems in order for a more tailored approach to be offered to service users.

It would be paramount however, for HCPs to consider the tensions that both they and the clergy hold in relation to mental health, acknowledging the different frameworks they are working within and how these conflicts may show up in the support that is offered to congregants and clients alike. In order to ensure that tensions do not adversely impact the populations they intend to serve would require cultivating an environment where transparent reflection and meaningful exploration is facilitated to allow both agencies to commit to working collaboratively and in a way which does not cause further distress.

Rowe & Allen (2004) argue that spirituality constitutes a central role of individual's worldview. In their research they found participants' initial reaction to 'illness' involved turning to their religious beliefs. Moreover, participants' ideas regarding health incorporated a spiritual element. Such findings are in line with the World Health Organisation's definition which views health as not simply the absence of disease, but rather the promotion of mental, spiritual and emotional wellbeing of an individual (World Health Organization, 2014).

The literature presented highlights that the link between race, religion and 'schizophrenia' is a complex one. Such a complex relationship, therefore, requires professionals from all disciplines to take a committed approach when seeking to understand the phenomenon of 'schizophrenia'. This committed approach would allow for greater collaborative working between HCPs and service users, where consideration is given to the role of an individual's race, culture and religious framework and how these areas may influence one's experience, expression and understanding of 'schizophrenia'.

### Relevance to Counselling Psychology and Rationale

Counselling psychology has had a considerable influence on working towards closing the bridge between mental health, religion, and race. With the field's inherent dedication to working collaboratively and compassionately, placing a premium on social justice allows for a committed approach to promoting the wellbeing of our diverse society whilst formulating a positive framework for psychological differences, paying respect to the protected characteristics around race and religion (BPS, DCoP).

On the basis of this literature review, given the heightened rates of 'schizophrenia' present in Afro-Caribbeans (Fearon & Morgan, 2006) and a number attributing such experiences to spiritual causes (Islam et al., 2015) the current study explores the lived experience of Afro-Caribbean Christians with a diagnosis of 'schizophrenia'. Approaching this research from a qualitative perspective using semi-structured interviews will allow for a rich account to be gathered without curtailing the participant's responses. Exploring this will provide useful insights into the role of faith from a population with critical rates of 'schizophrenia' and support in widening the provision of culturally inclusive healthcare.

Such an area is of great importance as it is possible that Afro-Caribbean Christians diagnosed with 'schizophrenia' who ascribe to cultural attributions that facilitate religious practices e.g., hearing the voice of God, or speaking in tongues (Cartledge, 2017) may experience conflicting feelings surrounding the genuineness of their religious experience, when such experiences are reduced to being a symptom of their diagnosis (Williams, 2018). In light of this, it is essential to advance culturally informed measures as well as culturally aware clinicians that are able to sensitively assess and support these presentations, without pathologising religious experience.

Although there has been movement concerning these issues in recent decades, for example, mental health being considered a continuum, as well as the changes made to the DSM-V criteria for 'schizophrenia' in its omission of subtypes. While such adaptations acknowledge that subtypes fall short in their reflection of the heterogeneity of 'schizophrenia' (Matilla et al., 2014) the notion of what is viewed as 'pathological' versus 'normal' remains to be problematic (Maj, 2012).

There exists a gap in the literature centring on the subjective lived experience of Afro-Caribbean Christians experience of 'schizophrenia'. To date, the research within this area has been largely governed by and adhered to positivist paradigms (Uba, 2012) thereby, negating the possibility of a subjective truth. Thus, the argument, for a qualitative approach, underpinned by a relational phenomenological epistemology, moving away from ill-fitting reductionist paradigms seems essential.

Given the focus on subjective lived experience, research from a counselling psychology perspective seems to be in a prime position to explore the issues highlighted within the literature review. Such findings will go a long way in creating an opening to the conversation surrounding diagnosis on the grounds of unconventional beliefs and practices that fall outside the Western 'norm'. These dialogues will further the support and improve the wellbeing of individuals from the Afro-Caribbean community who have for too long been marginalised within healthcare. It is hoped the research will contribute to a paradigm shift in thinking about cultural awareness within the allied HCPs. This is of great

importance particularly considering the enduring and chronic nature owed to a 'schizophrenia' diagnosis and everything that needs to be considered around this.

As demonstrated, the literature review has highlighted a gap in the literature regarding the exploration of the lived experience for this group, the current research therefore, endeavours to build upon the existing research within this area and explore the subjective experience of what is commonly known as 'schizophrenia' for Afro-Caribbean Christians. Therefore, the following research question has been devised:

#### Research question

How do Afro-Caribbean Christians make meaning of their lived experience of 'schizophrenia'?

## **CHAPTER III: METHODOLOGY**

### Chapter Overview

This chapter presents the methodological and epistemological position adopted in this research study. The rationale for the selected qualitative methodology of Interpretative Phenomenological Analysis (IPA) will be outlined. This will be followed by sections presenting the participants, data collection process, ethical considerations and data analysis.

### The Scientist-Practitioner Position

The underpinning of CoP is strongly rooted in humanistic philosophy and values, with humanism arguably forming the foundation of the counselling profession (Hansen et al., 2014). The ethos of humanistic psychology is its recognition of and focus on the function of the subjectivity of an individual's lived experience (Rogers, 1987). Founded on this premise, the underlying philosophy of CoP places a premium on the clients' subjective experience, a positioning that moves toward a less pathologising approach to understanding distress (BPS, 2017).

The scientist practitioner position is embedded within the discipline of Counselling Psychology (Strawbridge & Woolfe, 2010) and dictates that both scientific research and therapeutic practice should be integrated and given equal emphasis in the field (Blair, 2010; Vespia et al., 2006), translating into a way of working which in practice, is expressed by the employment and fostering of a scientific attitude (Jones & Mehr, 2007). Such a philosophy is at odds with the ethos underpinning CoP and thus often places the profession at a junction of competing paradigms, frameworks and ideologies that promote and endorse varying ideas as it relates to science, human experience and the nature of reality (Blair, 2010).



## **RESEARCH DESIGN**

### Research Paradigms in Counselling Psychology

The CoP profession is heavily rooted in humanistic psychology, which was developed during an age of great cultural and political change, where historical ideas relating to diagnostic and prescriptive approaches were being challenged and new-found expressions were being introduced (Hanley et al., 2016). Humanistic psychology is heavily influenced by phenomenological and existential paradigms, with its recognition of, and focus on, the role of subjectivity in individual experience (Douglas et al., 2016; Rogers, 1987). CoP significantly reflects humanistic values with humanism arguably being the ideological foundation on which the counselling profession stands (Hansen et al., 2014).

In its broadest sense, research endeavours to identify or understand a particular phenomenon and is underlined by philosophical paradigms. A paradigm, in this context, refers to a set of beliefs that represent a researcher's positioning as it relates to their world view and stance on reality (Denzin & Lincoln, 2005). These beliefs comprise of the researchers ontology, epistemology and methodology (Creswell, 1994). Ontology refers to beliefs concerning the nature of reality (Willis, 2007), while epistemology raises the question of how we discover knowledge and reality, (Kovacs et al., 2019) with methodology concerning itself with how we approach research and what appears to be known (Creswell, 1994). Willig, (2008; 2013) argued it is critical for a researcher to position themselves epistemologically prior to selecting a methodology as both are inextricably linked. These beliefs profoundly guide the researcher in their overall approach to the research as it relates to design, method and analysis (Denzin & Lincoln, 2005), and as such, a researcher's philosophical position is a significant consideration when conducting research.

There exists an ongoing philosophical debate within CoP with regards to the nature of reality. Ontology proposes a continuum ranging from relativism to realism referring to a belief in multiple realities to a single truth, respectively (Denzin & Lincoln, 2005). Historically, psychological sciences have been grounded in positivism – a paradigm which assumes *'valid knowledge can be generated only from objective empirical observation*

*experienced through the senses and carried out according to the scientific method* (Moon & Blackman, 2014, p. 1168). The positivist paradigm subscribes to a 'realist' ontology (Ponterotto, 2005), aligning with the biomedical model's conceptualisation of distress as 'symptoms' of an 'illness' that should be approached with a diagnosis in the same fashion as a physical health condition (Fletcher, 2012; Strawbridge & Woolfe, 2003).

The post-positivist framework, born out of critique of the positivist position, takes on a critical realist ontology, acknowledging there is an objective reality that can be captured, but such reality is measured imperfectly (Patomäki & Wight, 2000; Ponterotto, 2005). Both positionings propose cause and effect (Ponterotto, 2005), aiming to produce generalisable knowledge (Bhaskar, 1975) and as such lend themselves to a quantitative methodology. The prevalence of these positions have been seen to dominate the literature on 'schizophrenia' endorsing the idea of pathology and diagnosis (Fletcher, 2012; Schwartz et al., 2019). While research from this perspective has produced epidemiological studies that have significantly contributed to the literature within the area of 'schizophrenia', by remaining within the biomedical framework, it fails to challenge the diagnostic system and thus limits the possibility of increasing our understanding of the human experience (Fernando, 2017).

This view regarding the nature of knowledge however, fails to recognise the individuals' interpretation and how they make sense and attribute meaning to the world around them. This is a view that exists in tension with the inherent values of CoP as a profession with relationality at its heart, and a profession where the focus is on sense making, values, subjectivity, mutually constructed realities and less so on pathology (Milton et al., 2010). Therefore, despite the positivist position contribution to increasing our knowledge regarding the prevalence rates of 'schizophrenia' among Afro-Caribbeans, it falls short as it is unable to fully account for the subjective nature of an individual's experience as it exists on a spectrum (Moon & Blackman, 2014).

This tension has been addressed by other perspectives, challenging the historical views on the nature of reality and as such has informed the CoP discipline. One of these approaches has been the social constructionist perspective which rejects the idea of an objective "truth" and instead adopts the view of "truth" as constructed through our engagement and interpretation of the world and other social processes (Crotty, 1998).

Social constructionism (Gergen, 1985) assumes different individuals construct meaning of the same phenomena in different ways and that these constructions are informed by how we engage and understand the world as it relates to cultural, social, and historical perspectives. Therefore, meaning and truth arises through interaction with communities, leading to multiple, equally valid truths (Creswell 2009; Crotty 1998; Willig, 2013). Research approached from this position is interested with the cultural, political and societal landscape of a particular age/era, which informs/constructs psychological theory (Losantos et al., 2016).

The phenomena of 'schizophrenia' could be explored through a social constructionist lens however, the research question is focused on the individual lived experience, as opposed to the social processes which are central to a social constructionist lens and thus a phenomenological epistemology seemed a more rigorous fit. The phenomenological perspective is the study of a person's lived experiences (Smith, 2004). It is not interested in finding one truth but rather an account that is grounded in the words of individual subjective experience (Pringle et al., 2011). Similarly, to social constructionism, this position argues there are many worlds to be studied as everyone can experience phenomena in a different way (Willig, 2012). It is, in essence, a return to phenomena as it is uncovered, in contrast to beginning with scientific preconceptions that govern interpretation, as seen in positivism (Wertz, 2005).

It is worth noting that CoP as a discipline is pluralistic, meaning that it is not singular but rather it is interested in both empirical evidence and the co-creation of meaning and uncovering subjective truths (Orlans, 2009). CoPs therefore have an obligation to both empirical evidence and the co-construction of meaning. This approach positions the profession at a junction where knowledge is held tentatively within the post-modernistic understanding where multiple truths and perspectives are valued.

#### Rationale for selecting a phenomenological methodology:

Choosing a methodology first required me to reflect deeply on the research I wished to produce. I reflected on my view and perspective of reality and the phenomena of 'schizophrenia'. My aim is to explore the lived experience of 'schizophrenia' and how

those who identify as Afro-Caribbean Christians make meaning of this. Currently, quantitative methods are seen to dominate this research area and as such there exists a need for a more comprehensive subjective understanding of this phenomena.

There were two other qualitative methodological approaches informed by different epistemological and ontological underpinnings (Willig, 2008) which were considered for the current research: Thematic Analysis and Narrative Analysis.

Thematic analysis (TA) is a method for '*identifying, analysing and reporting patterns (themes) within data*' (Braun & Clark, 2006, p. 79) and differs from many qualitative methods as TA can be applied flexibly across epistemological positioning and therapeutic frameworks (Braun & Clark, 2006; Willig & Stainton-Rogers, 2017). TA attends to the "general" themes, seeking to identify common threads of meaning across data (Willig, 2013). I am proposing a different perspective, which looks at the in-depth experiential mode of a persons lived experience. As such, TA was discarded as a method and a phenomenological approach was adopted as this was congruent with the research question.

Narrative Analysis (NA) was also considered. In line with a phenomenological epistemology, NA is primarily concerned with individuals' lives and how they make sense of their experience (Murray, 2003; Riessman, 1993). More specifically, this type of analysis looks at how individuals sequentially construct events to make them meaningful for the listener (Murray, 2003; Riessman, 1993). Although Afro-Caribbean Christians lived experience of 'schizophrenia' could be explored through this lens, NA typically focuses on how one makes sense of a phenomena as it relates to their story and/or how they translate this into a narrative, rather than the experience of the phenomena itself (Griffin & May 2012). The research is seeking to uncover the lived experience of the phenomena of 'schizophrenia' and the sense making for the individual as opposed to the specific sequence or context. Moreover, there was a noted tension between a phenomenological stance and the social constructionist orientation NA adopts, which proposes stories are situated within a cultural and social context on both a macro and micro level (Braun & Clarke, 2013). Although this seemed relevant to consider due to its focus on cultural discourses, and the research seeks to explore lived experience as it relates to two arguable "social constructs" (race and religion), Ponterotto (2005) suggests, for CoP's it

is essential to consider their positioning in order to produce and conduct reflective and purposeful research.

In exploring my own epistemological stance, it was considered that the worldview held related to the nature of reality and was rooted in phenomenology, with a desire to explore the subjective meaning. As such, the NA approach was discarded and a phenomenological approach was adopted. The basis of the phenomenological approach selected will be explored later within this chapter.

### Researcher's Epistemological Stance

My epistemological positioning aligns with a phenomenological perspective. I believe in the significance of the meaning individuals make of their subjective human experience (Smith, 2004). Operating from this perspective I regard 'schizophrenia' as a phenomenon, an experience, like any other, and not a mere diagnosis. I believe the associated 'symptomology' of 'schizophrenia' (such as 'delusions' and 'hallucinations') cannot and more importantly should not be explained away using an arguably reductionist paradigm such as positivism, that the biomedical model frequently endorses. Phenomenology calls one to focus on the deep understanding of lived experience. I identify ontologically with relativism as I believe that there are multiple worlds and realities to be studied as every individual can experience 'reality' in a different way (Denzin & Lincoln, 2005; Willig, 2012).

This view extends to how 'schizophrenia' can be viewed, experienced and subsequently interpreted from individual to individual despite the same 'diagnostic features' being present. Adopting a phenomenological perspective, requires the researcher to suspend as much as possible ones theoretical, prejudicial biases and be sensitive to the lifeworld experienced by the individual (Husserl, 1859-1938). As the underpinning philosophy of the CoP discipline is grounded in humanistic values and phenomenology, both my epistemological and ontological perspective align with the CoP professions stance regarding the importance of subjectivity and adopting a relational approach in understanding the communities we serve (Wertz, 2005).

## Reflexivity

Reflexivity is central to any qualitative research in psychology (Lazard & McAvoy, 2017). This is particularly the case for IPA given the researchers interpretative role (Smith et al., 2009), and the centrality of the intersubjective relationship between research and participant which is both warranted and embraced (Willig, 2013).

I was acutely aware I shared the characteristics under study with my participants, being that I identify as both Afro-Caribbean and Christian. As such, it became all the more imperative that I made my own assumptions and preconceptions explicit, acknowledging any biases as to not impact the interpretation process. This was achieved by keeping a reflective journal during the research process (Kasket, 2012; Lazard & McAvoy, 2017), a practice encouraged by both Willig (2017) and Smith (2015). In doing so, I committed myself to being deeply reflective and reflexive by challenging my interpretations and ensuring the integrity of the participants voice is kept central (Willig, 2012).

I would consider my faith as the most central part of my identity. I take the teachings of Jesus Christ surrounding love and compassion as central to my approach and how I treat and view others. This I believe played a fundamental role in my chosen choice of career in Counselling Psychology and ultimately my research and the type of research I wished to produce. Therefore, I viewed my role as a researcher as an extension of my identity as a Christian and as such it was important to me that my approach embodied the values of my faith, as stated in Colossians 3:23 “Whatever you do, do it from the heart, as something done for the Lord”. In light of this, for me the stakes were higher than “just” a doctoral project. This perspective allowed me to be diligent during the recruitment process, it allowed me to be thorough when analysing/interpreting the transcripts and it allowed me to be thoughtful during the write up process.

As someone with my own spiritual experiences some of which many would perhaps describe as ‘pathological’ or ‘psychosis’ I was sensitive to stay attuned with my participants and to *hear* what they were reporting in order to stay with their subjective meaning. I believe my own experiences and working within systems that would disqualify my experiences as ‘symptoms’ of a ‘disorder’ allowed me to be more sensitive and compassionate which permitted me to accurately and truthfully stay with the experiences of my participants and the sense they made of the phenomena.

The closeness of my research topic to my own identity, alongside assuming the position of an “insider”, as well as my own personal, spiritual, and clinical experiences has motivated me to carry out this research. I was mindful my preconception of the beliefs held by Afro-Caribbean Christians could influence my interviewing skills. However, my clinical experience of conducting assessments, and training allowed me to be reflective and maintain an open mind allowing me to be explorative and maintain a phenomenological position.

During my clinical practice, it was both shocking and horrifying to see how black service users were treated by ‘professional’ helping services. I continuously witnessed the use of excessive force, restrictive practices and the use of punitive seclusion for minor incidents of perceived ‘deviance’ or ‘non-compliance’. The narrative of black service users somehow being ‘more dangerous’ than white service users to justify such tactics, and terms such as ‘treatment resistant’ and ‘unmotivated for change’ were used at rates which created great discomfort. From these experiences, I have developed strong views that this group is marginalised within healthcare. Anecdotally, many of the service users from Afro-Caribbean backgrounds would often cite a spiritual or cultural significance to their experiences of ‘psychosis’ and mental health, in which I witnessed this being dismissed by practitioners and not considered within treatment planning.

It is these concerns that have motivated me to research this area, to give a voice to this group whose views have too often been silenced. As a Counselling Psychologist in-training, I felt well placed to carry out this research given the professions’ stance on the significance of subjectivity (Cooper, 2009). It is fundamental as practitioners that we are able to make adaptations to meet the needs of the diverse client groups we service (Arredondo, 1999), by adopting a more collaborative approach to working with intersectionality. In order to be able to effectively do so, research must be conducted in a manner which reflects what we are trying to achieve in practice. Adopting a qualitative phenomenological perspective therefore was selected as the most fitting approach.

## Interpretative Phenomenological Analysis

The aim of the study is to explore Afro-Caribbean Christians' lived experience of the phenomena of 'schizophrenia', and therefore a qualitative approach that would provide rich and in-depth descriptions was chosen (Pietkiewicz & Smith, 2014).

I grappled with both streams of phenomenological research: Descriptive and Interpretative phenomenology. Descriptive phenomenology emphasises a return to the psychological subject matter through fostering an open attitude while evoking novel descriptions that illustrate the richness of psychological life as it is lived (Wertz, 2005). This approach proposes it is possible to minimise interpretation by suspending ones' preconceptions and focus on '*that which lies before one in phenomenological purity*' (Willig, 2008, p. 55). Such an approach is well suited for CoP's where our clinical and research practice maximally and mutually respects both the experience as well as the situational contexts of those we serve (Wertz, 2005). However, the research focuses on going further than description, by also gaining an in-depth understanding of the lived experience. From my reflexivity this was something I aligned with and thus fostered an Interpretative Phenomenological perspective, namely IPA.

Interpretative phenomenology rooted in the philosophy of phenomenology (Smith, 2009) views description and interpretation as inextricably linked. Therefore, it is not possible to fully suspend preconceptions when perceiving a phenomenon and therefore it must be accounted for within the method of inquiry (Heidegger, 1927/1962). IPA consist of different components and is founded on the philosophy of Phenomenology, Hermeneutics and Idiography (Shinebourne, 2011; Smith et al., 2009). Below is a description of each of these philosophical concepts.

Originally founded by Husserl, **Phenomenology** refers to the study of human experience (Smith & Nizza, 2022). Research with a phenomenological underpinning requires the researcher to possess a 'willingness and capacity to understand a perspective' of experience (Smith et al., 2022, p.9). Contrary to Heidegger, Husserl (1859-1938) suggested one must consciously set aside or 'bracket' their previous assumptions regarding a phenomenon in order to discover its true essence (Finlay, 2008). In IPA this



is considered as 'the meaning which something has for someone' (Smith et al., 2022, p.9). As such, this methodology allows for the detailed exploration of 'schizophrenia' and how Afro-Caribbean Christians made sense of this phenomena (Smith, et al., 2022).

**Hermeneutics**, the second theoretical underpinning of IPA refers to the theory of interpretation (Smith et al., 2009). Here, the researcher's role is recognised as central in the interpretation of experiences through what is known as the 'double hermeneutic cycle' (Smith & Eatough, 2007). This describes the process of 1) the participant forming an understanding of their experience of the phenomenon, and 2) the researcher making sense of the participants experience and making an interpretation (Smith & Osborn, 2008). Gadamer (1960/1998) understood this as the co-creation between researcher and participant whereby meaning transpires through a circle of reading, reflection and interpretation.

**Idiography** the third component, is concerned with the particular. IPA demonstrates this by its commitment to a detailed case by case analysis (Smith et al., 2022) seeking to understand how a particular phenomenon has been understood from an individual's perspective. IPA is a qualitative research methodology concerned with '*the detailed examination of human lived experience... it aims to conduct this examination in a way which as far as possible enables that experience to be expressed in its own terms, rather than according to predefined category systems*' (Smith et al., 2022, p. 26). In other words, it is concerned with how individuals experience and interpret the world, with a focus on the subjectivity of one's perception unincumbered by preconceptions and notions (Smith, 2004). As such, research aligned with this perspective seeks to understand a phenomenon by exploring the views of the individual's experience.

Another significant component of phenomenological research is paying attention to language as it is through language that the participants '*attempt to communicate their experiences to the researcher*' (Willig, 2013, p. 94). Smith et al., (2009) attest that both language and culture are fundamental frameworks for 'meaning making'. A key phenomenologist, Heidegger asserts '*Whenever something is interpreted as something,*

*the interpretation will be founded essentially upon fore-having, fore-sight and fore-conception'* (Heidegger, 1962, p. 191). Put simply, all humans are participants in a world of language and relationships, and it is our prior experiences that are embedded within interpretations. The sense-making of a particular phenomenon is extracted from the language the participants use, paying respect to the words, phrases and syntax used during interview.

Gadamer in support of Heidegger's perspective stated '*Language is the universal medium in which understanding occurs. Understanding occurs in interpreting*' (Gadamer, 1960/1998, p. 389). Gadamer focused on how language uncovers being (Langdridge, 2007), deducing that language is a significant factor in understanding experience. Although the central focus of IPA is on understanding experience, such meaning is entangled within language (Smith et al., 2009) and therefore must be considered.

To conclude, given the aim of the current research seeking to explore lived experience of 'schizophrenia' for Afro-Caribbean Christians, placing a central focus on the sense and meaning they attributed to their lived experience, in line with the ontological and epistemological basis, IPA was deemed an appropriate fit for the methodology.

## **METHOD: DATA COLLECTION**

### **Recruitment process**

Initially, the intention was to recruit participants through links established with groups under the Hearing Voices Network (HVN), mental health charities, black majority churches and social media. Ethical approval was granted from the University of East London's ethics committee, following the submission of an ethics application (Appendix A) and risk assessment form (Appendix B). Following approval for advertisement on agreed platforms as stated above, multiple groups under the HVN were emailed a research poster (Appendix J) inclusive of the research aims, background and information on how to participate. The HVN group leads agreed to advertise within their respective groups and post within their services, The National Paranoia Network also agreed to

advertise the research poster within their newsletter (Appendix E). Further emails were sent, and phone calls made to black majority churches and charities who support Christians and Black service users with mental health concerns such as The Black, African and Asian Therapy Network (BAATAN) (Appendix E) and Mind IRIE. Research was later posted on various social media pages, Eventbrite and within Facebook groups to widen the reach for potential participants.

When an individual reached out to participate, they were emailed the participant information sheet (Appendix F) and consent form (Appendix G). Upon the receipt of the signed consent form, an interview was scheduled and a debrief form was sent (Appendix I) following its completion.

### Sample

Aligning with the sampling orientation of IPA, purposive homogenous sampling was utilised during the data collection process (Smith et al., 2009). In the current study, homogeneity meant all participants had received a diagnosis of schizophrenia, self-identified as being Afro-Caribbean by ethnicity and Christian by faith.

It is worth noting that Christianity comprises of a variety of sects, all of which vary marginally in terms of doctrine and practice. While it could have been of relevance to consider focusing on a particular sect for the current research, the decision to consider 'Christians' in general was made and fulfils the homogeneity needed for an IPA study in the following ways: 1) According to the Holy Bible the church is considered the *people* of God who are referred to as the followers of Christ: "...as Christ loved the church and gave his life for it" (Ephesians 5:25). There are many instances throughout the scriptures where the church is referred to as a singular entity (Acts 20:28; Matthew 16:18), the word church being singular illustrates the oneness of the belief system, speaking to the monotheistic origin of the faith. In light of this and given that the fundamental beliefs which underpin the various sects are consistent, the decision was made not to create an exclusion criterion for a particular denomination as homogeneity would still be met if general definitions were utilised.

Moreover, the current study is focusing on lived experience in the context of the participants culture and faith. Therefore, it could be argued that creating an exclusion criterion could run the risk of excluding those who consider themselves Christian but do not affiliate with any particular denomination. As such this could potentially further discriminate the voices of those who are already unheard within research. Furthermore, given the research is adopting a phenomenological approach the use of open language such as 'Christian' would be in keeping with this epistemological positioning which moves away from the use of labels, as arguably using a term such as 'Baptist Christian' or 'Methodist Christian' may further contribute to a sense of being labelled. Avoiding such an inclusion/exclusion criterion allowed those from all denominations to participate in the study.

Recruitment was a challenging venture which extended throughout a course of nine months. In the initial four months of data collection, eight participants reached out to take part in the research. When screened, six of the eight were identified as meeting the inclusion criteria for the study, however due to a series of complications including, a change of heart, perceived lack of benefits for participation, a number of participants declined leaving the sample at two. Several efforts were made to continue to recruit, including submitting an ethics amendment form (Appendix C) to widen the data collection to include advertisement on reddit and Call For Participants. This venture returned a further two participants. Given the timeline for submission further efforts to recruit were no longer possible.

Smith et al., (2009/22) suggest for a Professional Doctorate, a typical sample size of between four and ten. Prior to data collection the target sample size of six was established and although four fell below the anticipated sample, this still falls within the "acceptable" range of IPA research (Smith et al., 2009) and can therefore be justified. Firstly, Smith et al., (2022, p. 46) state: *'the primary concern of IPA is with a detailed account of individual experience' and as such "IPA studies usually benefit from a concentrated focus on a small number of cases'*. Other authors such as Creswell & Poth (2019) note that

phenomenological research can include a sample size from one to upwards of 300, and Dukes (1984) suggested between three and ten. Both Van Manen (2014) and Smith et al., (2022) speak to the significance of the idiosyncratic approach to phenomenological research and reference the commitment to each case in their own right, thus arguing that sample size for hermeneutical phenomenology is inconsequential.

The idiographic roots of IPA also speak to the importance for research to remain sensitive to the subjectivity of the individuals experience. Moreover, phenomenology is concerned with the rich accounts relating to lived experience rather than factual significance (Van Manen, 1990) with other authors stating IPA research differs from quantitative methodology in that saturation is not the aim, but rather the focus is on obtaining rich personal accounts of an individual narrative which can arguably be gathered from a single case study (Hale et al., 2007). Furthermore, it could be argued that each individuals' experiences are unique and as such true saturation can never be achieved (Hale et al., 2007).

In line with this, the sample size of 4 was accepted following discussions with my Director of Studies (DoS) and the impact of this will be addressed in the Discussion chapter.

### Introduction to the Participants

All participants who took part in the research were given a pseudonym at transcription to maintain anonymity (BPS, 2018). Table 1 presents anonymised participant data. All participants who took part in the study met the inclusion criteria, in that they all had received a diagnosis of 'schizophrenia' and identified as Afro-Caribbean by ethnicity and Christian by faith.

*Table 1: Participant Demographics*

<b>Pseudonym</b>	<b>Age</b>	<b>Gender</b>	<b>Time since experience</b>
Noah	48	Male	26 years
John	49	Male	3.5 years
Peter *	--	Male	--

Matthew	39	Male	11 years
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*\*Peter was the first interview, and this data was not yet collected.*

Time since experience refers to the first instance that the participants experienced 'symptoms' that would have been considered 'schizophrenia'. The language of 'experience' rather than diagnoses was chosen to reflect the phenomenological basis the research adopts. The current research did not set a time scale as part of the inclusion/exclusion criteria as the voices of the sample population are typically unheard within research and it could be argued that setting a time scale would further silence the voices of potential participants. Furthermore, given the experiences of discrimination that black service users face within healthcare and societally as a whole, the current research was mindful not to contribute further to these exclusionary experiences.

The employment of semi-structured interviews were used in the current research as it is believed to be an efficient method of collecting data in IPA research (Braun & Clarke, 2013; Finlay, 2011; Smith et al., 2009; Smith et al., 2022). My interview schedule (Appendix H) comprised of non-directive, open questions and prompts to allow participants to account their personal experience without curtailment (Willig, 2017). Aligning with the phenomenological method, the interview schedule compromised of four main questions to allow participants to be expansive in their responses without restriction.

Examples of the questions included:

- *"In your own words, what is schizophrenia to you?"*
- *"Does your Christian faith shape how you interpreted your experience of schizophrenia? If so, how?"*

Interviews lasted between 45-65 minutes and were conducted and recorded via Microsoft Teams. At the start of the interview participants were thanked for agreeing to take part in the research and were asked if they had any questions regarding the research, consent form or any general queries. Participants were reminded they were free to withdraw from the research and were informed they could stop or take a break from the interview if they wished. They were informed regarding the number and nature of the questions and the potential time scale. Following the main interview questions participants were asked 'is

*there anything else you would like to add at all that we didn't cover?'. I was mindful throughout the interview, the potential for the research process to feel extractive, this question was used to address any potential experiences of power imbalances, and as a way of allowing the participant to openly share any details they deemed significant. Coupled with this, following the interview, participants were asked about their experience of the interview, to gain further insight into their experience and uncover unforeseen data for potential exploration. Participants were sent a debrief form (Appendix I) following the interview inclusive of relevant support services if needed.*

## **METHOD: DATA ANALYSIS**

Interviews were transcribed verbatim with participant details anonymised. Smith et al., (2009, 2022) guidelines for data analysis for IPA were followed to allow for the identification of shared themes across participants. Upon transcribing the interviews, each interview was re-read alongside the audio, this allowed for me to become fully immersed in not only the written data but also the audio-visual data that could only be captured through the participants tonality and expression. Recordings were then subsequently deleted.

### **Reading, Re-Reading & Initial Noting**

Firstly, each participant transcript was read and re-read diligently. IPA's commitment to idiography promotes a case-by-case detailed analysis before progressing to the next transcript (Smith et al., 2022). This approach allowed for full immersion in the data allowing for increased access to the participants world and experience (Smith et al., 2009). During this stage in order to remain close to the data and maintain the integrity of the participants voice and my epistemological stance, reflections were noted of both my initial thoughts and feelings to follow the practice of bracketing. Preliminary notes were also captured within the participant data regarding their descriptions, use of language and meanings within the narrative. This was achieved by analysing the transcripts line by line (Smith et al., 2009).

## **Developing Emergent Themes**

Data was clustered into emerging themes, moving from my initial notes of description toward capturing a deeper understanding of the participants account as a whole (Smith et al., 2009). Themes were formed close to the participants voice to ensure the interpretation was grounded in integrity (Smith et al., 2012).

## **Forming GETs**

This stage involved searching for patterns across the formerly identified themes and grouping connected themes in terms of similarities (Smith et al., 2022). This was achieved by abstraction, subsumption, polarisation, contextualisation, numeration, and function (Smith et al., 2012). Abstraction involved the process of clustering similar themes together; these themes were then clustered further to form GETs at the subsumption stage. Polarisation describes the procedure of identifying opposing themes which are in some way interlinked, with Numeration focusing on the frequency in which a theme is mentioned, with contextualisation and function considering the wider context and function of themes for the participant and the intertwined meaning. This was particularly relevant for the current research where the focus is on constructs surrounding culture and religion.

This process along with the previous stages was repeated for each participant transcript. Throughout I ensured to continue bracketing my ideas from the former transcripts in order to allow me to experience each participant individually in their own right (Smith et al., 2022).

## **Searching for Patterns**

Here, common themes and patterns were identified across the transcripts, collating the shared and unique features of the experience across the participants (Smith et al., 2022). These themes were grouped into a table of GETs and subthemes (Smith et al., 2009). This table is detailed in the following Analysis chapter.



## **ETHICAL CONSIDERATIONS**

### **Ethical approval and standards**

The research adhered to the British Psychological Society's 'Code of Human Research Ethics' (BPS, 2021) and ethical approval was granted by the University of East London's School of Psychology Research Ethics Committee prior to data collection (Appendix A). Where approval was needed to advertise, this was obtained by service providers via email (Appendix E).

### **Ethical Approach**

Working with a potentially vulnerable population, informed consent was considered throughout the entire research process, ensuring participants wholly understood the aims of the study as well as the nature of what participation involved. Participants were provided with the participant information sheet (Appendix F) inclusive of a full outline of the research objectives prior to their interview and had the opportunity to ask any questions during the interview. Participants were provided with a consent form (Appendix G) which they signed and returned via email confirming their participation.

In maintaining the BPS requirements to prioritise participants rights, interests and preserve dignity, no deception was used, and participants were aware of their right to withdraw from the study if they wished (BPS, 2014). Given that the research explored lived experience, this area can have the potential to evoke strong feelings and psychological distress. Following the interviews all participants were asked how they experienced the interview and were closely monitored throughout the interview for signs of distress. As a Counselling Psychologist in-training my clinical experience allowed me to be well placed to create a safe and sensitive environment. Participants were also sent a debrief form (Appendix I) inclusive of support services if needed.

The issue of misuse of power in research was a consideration that was also kept in mind. Proctor (2002) highlights the relationship between distress and powerlessness and emphasised the significance of being aware of one's own power as to not subject the client to further abuse of it. This notion can be extended to the research participant in the

same manner. The BPS's Standards for the accreditation of Doctoral programmes in counselling psychology echo this notion by stipulating the requirement of having an understanding regarding *'issues of power, discrimination and oppression, the psychological impact of these, and how to work with these issues psychologically'* (BPS, 2019, p. 16).

With respect to the current research the misuse of power was particularly relevant to consider given the experiences of black service users within the mental healthcare system. As highlighted in Chapter 2, research has demonstrated black service users are more likely to experience coercive pathways into healthcare (Lawrence et al., 2021; Mfoafo-M'Carthy, 2014), be sectioned (Degnan et al., 2023) and be subject to restrictive practices such as being heavily medicated, secluded and restrained (Payne-Gill & Beck, 2021). To avoid further misuse of power within the current research, the following steps were considered 1) I shared a picture of myself on the research poster (see Appendices J) to endorse a sense of transparency and reduce the power imbalance 2) participants were emailed information pertaining to the research ahead of the meeting so an informed decision could be made prior to engaging 3) open and non-directive questions comprised the interview schedule and participants were informed that they were free to divulge as much or as little information as they wish. Moreover, the selected methodology and epistemological position of the researcher account for the misuse of power by promoting empowerment of the participants due to its focus on the subjective lived experience being at the heart of the research. In addition, the phenomenological roots of the approach lend well to the social justice principles (Belyani & Marshall, 2020) on which CoP profession is built upon which acknowledges power imbalances and anti-oppressive practice (Cutts, 2013). This was important to consider particularly given the participant group, and the several impositions faced societally and within healthcare. The intentionality therefore was to ensure the research did not contribute to these impositions.

Additionally, it is also important to acknowledge the power dynamics which may exist between how the participants are likely to view God as 'powerful'/'all knowing' and the influence this may have had on their experience of 'schizophrenia'. Unlike the nature of the power dynamics mentioned above, for many Christians, God is seen as the ultimate power (Gifford, 2016) and a figure they can both rely on (Koenig, 2005) and turn to when experiencing difficulties (Ellison & Taylor, 1996). The contrast between the power

dynamics the participants may feel in relation to HCPs/mental health services and God may have coloured both their experience and interpretation of 'schizophrenia'. In order to be Psychologists with integrity one '*must develop an understanding of the importance of cultural and ethnic backgrounds and an awareness of difference....be able to work from a knowledge base of difficult cultural frameworks*' (BPS, p. 16). Such stipulations speak to the need for Psychologists to practice in a way which shares power rather than imposes.

### Validity and Rigour in IPA

The application of Yardley's (2017) principles were employed throughout all stages of the research process to ensure quality in qualitative research. These principles were four-fold: 1) Sensitivity to context, 2) Transparency and coherence, 3) Commitment and rigour and 4) Impact and importance.

**Sensitivity to context** was demonstrated throughout the entirety of the research process. As previously noted in Chapter 2, the literature in this area indicated black service users expressed a greater mistrust of services (Henderson et al., 2015) where contact has historically been of a coercive nature (Lawrence et al., 2021). Working within the healthcare system I was mindful of the potential to be seen as an extension of these services and was careful not to feed into these narratives. For example, when composing the interview schedule, I ensured to keep all questions non-directive and open in nature to ensure that participants were given the freedom to divulge as much or as little information as they wished without coercion. Moreover, the literature review demonstrates a wide-reaching understanding of the phenomena under study, which Smith et al., (2009) highlight as being crucial to the hermeneutic element of IPA, where an understanding of the 'whole' contributes to the interpretation process.

It is important in qualitative research to show sensitivity to data by '*not imposing pre-conceived categories*' but instead "*considering carefully the meanings generated by the participants*' (Yardley, 2017, p. 295). This notion supports the roots of a phenomenological epistemology and how research is approached with an open and receptive attitude, allowing the researcher to be inspired by the subjectivity of the participants and keep their

voice central throughout the interviews and analysis. Sensitivity to context was also demonstrated during recruitment. Namely, when advertising the research on social media, careful attention was paid to omit social media groups that were created by service users for service users. Whilst this may have limited the participant pool, it felt important to be sensitive to the context and respect the aims of these support groups and advertising research here would have felt imposing.

**Transparency and Coherence** was ensured by maintaining a reflective and open stance throughout. It seemed imperative to maintain transparency as I shared the characteristics under study. Therefore, I was mindful to maintain my reflective journaling following interviews and throughout the research process to bracket my assumptions to ensure this did not influence the data as per IPA protocol and my epistemological positioning. Transparency was practiced throughout the research process as evidenced by writing about my epistemological stance, my position on 'schizophrenia' as well as detailing the steps involved in the participant recruitment, interview and analysis process (Smith et al., 2012).

Dedication to a phenomenological epistemology allowed me to sensitively and consistently approach every interview with the same level of curiosity and **commitment**, being attentive to each participant at interview and during the analysis (Smith et al., 2009). **Rigour** was evidenced by following the stages proposed by Smith for IPA research which allowed for the research to be thorough through the careful and meticulous examination of each transcript line by line for in-depth interpretations.

### ***Impact and importance***

Yardley (2017) states research should generate knowledge which is '*useful – whether in terms of practical utility.or changing how we think about the world*' (p. 296). This research is a call to move away from ill-fitting paradigms and explore the intersections between race, religion, and mental health. This approach is in alignment with CoP values, as it places a premium on subjective lived experience (BPS, 2017) and adopts a less pathologising approach to mental health, which contributes to the existing literature in a unique way, by allowing the voice of the service users to be heard, starkly contrasting the heavily diagnostic positivist research base.

The ongoing health inequalities experienced by black service users within the mental health care system is an important area of study, and as a Counselling Psychologist in-training I believe I was well placed to conduct this research due to CoP's promotion of social justice. Moreover, the research is important in that it is timely in the wake of the Black Lives Matter movement and increasing global discourses around equality for diverse groups of all kinds. It is hoped that this research will further our understanding of how to work sensitively with culturally and religiously diverse groups, widen the provision for culturally inclusive healthcare and promote an attitudinal change in practitioners and services, where the insights gained can be successfully integrated into therapeutic approaches to holistically support the diverse needs of the clients we work alongside.

#### Summary:

This chapter outlined the philosophical and theoretical orientation of the chosen methodology, data collection procedure, analysis as well as key ethical considerations. The following chapter will present a detailed exploration of the identified themes resulting from the analysis.

## CHAPTER IV: ANALYSIS

### Chapter overview:

This chapter will present an overview and exploration of the Group Experimental Themes (GETs) and subthemes discovered from the four semi-structured interviews regarding the participants lived experience of 'schizophrenia'. The IPA strategy outlined in the previous chapter was applied to the participants interviews and returned four GETs and eight sub-themes (See Table 2). Direct quotations from participant interviews are presented in italic grey font to differentiate them from the researchers' interpretations and the main text. Related bible passages have been noted within the analysis to highlight the participants lived experience and to consider the wider context and function of the themes as per IPA protocol. Although the themes that have been identified are a result of following a rigorous process of analysis rather than arbitrary selection, I recognise that interpretations are subjective and as such the interpretations presented are likely only one potential perspective of the discovered themes and are not claiming to cover all facets of the participant's subjective lived experience of 'schizophrenia'. It is worth noting the researcher's role in the process of data collection and subsequent interpretation, due to this, strict adherence to Yardley's recommendations on transparency were applied for rigor (Yardley, 2017).

The interpretations represent the double hermeneutic cycle inherent to IPA, where the researcher is attempting to make sense of the participant making sense of their personal experience (Smith et al., 2022). Arriving at the themes first required me to look at the descriptive and linguistic themes within the data before clustering the emergent themes identified and searching for patterns across the participants. Themes were identified based on the connection to the research question: How do Afro-Caribbean Christians make meaning of their lived experience of 'schizophrenia'?

Table 2: Summary of GETs and Subthemes.

GETs	Subthemes
I. I cried unto the LORD, and he heard me: <i>“GOD as a Healer of schizophrenia”</i> .	I. The healing power of faith in God.  II. The centrality of spiritual practices.
II. ‘Just A Closer Walk with Thee’: <i>“Schizophrenia’ fostering closeness to the Creator”</i> .	III. Distance comes before closeness.  IV. Fulfilling God’s will.
III. ‘The only thing I could have done...was turn to God, ‘cause only God could help me’: <i>“Schizophrenia as a transformative experience”</i> .	V. Changing as a person.  VI. Powerlessness in adjusting through loss.
IV. Culture and Religion go together’: <i>“The Cultural and Spiritual Crossroad”</i> .	VII. ‘The culture IS spiritual’.  VIII. ‘Culture and othering’.

Key re. excerpts in the transcript

[...] represents omitted text.

... represents a pause.

**GET I: I cried unto the LORD, and he heard me: “*GOD as a Healer of schizophrenia*”.**

When discussing their lived experiences of ‘schizophrenia’ all the participants recalled accounts regarding the role of God in healing them from ‘schizophrenia’. The subthemes capture the role of employing spiritual practices that were believed to ‘please God’ which in turn would lead to them receiving a blessing of healing.

***Subtheme I: The healing power of faith in God***

Within their accounts of ‘schizophrenia’, all four of the participants detailed the role their faith in God had in bringing about healing. This is illuminated by Noah’s account of his first episode of psychosis:

*“[...] My first episode...my first couple of year... I mean I came... I believed I believed enough I believed enough in God through my first episode where I know and I believed that God will cure me.” (Noah, lines 179-181)*

Noah expressed the strength of his belief in God during his first episode and spoke to it being the strength of his belief that would bring healing from God. There seems to be a strong sense regarding the role of the self in receiving healing from God as Noah notes that he had ‘*believed enough*’ that God would heal him, suggesting the strength of the belief may be a “condition” to receiving Gods healing. Noah’s repetition of the word ‘*believed*’ adds veracity to this. This sentiment is echoed by Peter who shared how he put his faith and trust in God during his experience:

*“I would say my faith played a whole whole kind of role”. (Peter line 110)*

*“Yeah, I I just know that all normally due to my faith. I believe in God so much. so it was more of like me just saying prayers to the only supreme being I believe in with all manner of faith and trust I was hoping to it would work.” (Peter lines 359-361)*

*“[...] he's the only one that can take me out, regardless of every other, umm, intervention...he's the only one that can really help me, regardless of all the other*



*interventions. it could come as assistant. But yeah, healing first of all comes from God”*  
(Peter, lines 378-380)

Peter’s narrative here speaks to how he trusted wholly in the power of God for healing and held his beliefs above other interventions which he describes would only be an ‘assistant’. Similarly to Noah, Peter’s extract alludes to the strength of his belief being central to him receiving his healing where he describes he had ‘*all manner of faith and trust*’. Peter’s repetition of ‘*he’s the only one*’ adds further veracity to this. It would appear that the theme of holding a strong faith and hope for healing is core in how the participants have made sense of their experience. This would be in alignment with biblical scriptures where having faith and hope is encouraged while waiting for an outcome: “Now faith is confidence in what we hope for and assurance about what we do not see” (Hebrews 11:1). It is probable that the participants knowledge of the scriptures and the role of faith which is seen as central to the Christian belief system played a role in how they made sense of their experience and how this shaped their subsequent behaviour.

Noah also shares this sentiment regarding God being above other interventions: “[...] *God will heal me not tablets*” (Noah line 62). From this, it would seem that Noah made sense of his experience as needing to wholly put his trust and reliance in God for his healing. This is common within Christian doctrine where God promises to heal: “I am going to bring to it healing and a remedy, and I will heal them; and I will reveal to them an abundance of peace and truth” (Jeremiah 33:6). Such notions are widely accepted across the various existing Christian denominations and may have likely been adopted by the participants given their conceptualisations.

John’s narrative also spoke of how he would consult God during his experience:

*[...] consulting would bring bring some wisdom, some insight and also would umm bring some healing from the trauma”* (John lines 142-143)

It appears that John see’s God as a consultant that he had to seek in order to gain wisdom, insight and his healing. This powerful portrayal conveys the extent of his belief, trust and dependency within his relationship with God. There appears to be reliance on the communication between John and God and the inherent faith that comes along with

this as almost a pre-requisite for healing. Matthew spoke in a similar regard, where in his extract he speaks to the significance of faith in receiving healing citing the scriptures as the source of his beliefs:

*“God is a healer ... you know he says in his word that ‘by his stripes we are healed’, so I knew that he would heal me. At first my faith was shakey so um it was shakey so he didn’t heal me but when I believed and trusted in him as a healer I knew he would heal me and he did.” (Matthew lines 139-142)*

Matthew speaks of the confidence he had in his knowledge that God would heal him during his experience and how his belief was strengthened and supported by the holy scriptures – ‘By his stripes we are healed’ (Isaiah 53:5). The language used by John ‘*I knew*’ and the repetition of such, like Noah speaks to the level of conviction he had in his belief in God for healing during his experience. Each of these extracts communicate the participants level of faith in the healing power of God. It seems that the magnitude of the conviction held by the participants was a source of great strength during their journey and contributed to how they made sense and navigated through their subjective experiences.

This theme is inextricably linked to the second subtheme: ‘*The centrality of spiritual practices*’, as the role and engagement with spiritual practices are seen as central to receiving healing from God by the participants.

### ***Subtheme II: The Centrality of Spiritual Practices***

In line with subtheme I, all of the participants spoke to the role of engaging in spiritual practices as part and parcel of their experience of ‘schizophrenia’. They seem to allude to the use of spiritual practices as central to how they made sense of their experiences, with all the participants seemingly conveying a reliance on God, and it was through their engagement with these spiritual practices they submit his sovereignty both in how they both navigated though their experiences and the overall outcome of their experience.

*“[...] I got the sense that you don’t need the medication...um that part of healing part of the power of healing is that we believe in God enough so I was fasting all the time and*

*when the church fasted I fasted with them .... And joined the prayer meetings and all of that stuff.”(Noah lines 74-77)*

*“[...] even if I don’t now, even if I don’t take my medication I can’t do it because they got me, they monitor the injection I’m on the depot all the time. But I still obviously pray to God that one day maybe I’ll not need the medication and God did answer my prayer about about a month ago, when they psychiatrist came to me, because I used to take it every 2 weeks and now they changed it to every 2 weeks to every month. and then now out of the blue saying he’s gonna start giving me once every three months and there’s going to review it from there” (Noah lines 107-113)*

It seems that Noah perceived both fasting and praying as essential spiritual practices needed to overcome ‘schizophrenia’. He goes on to testify his subsequent improvements conceptualised by his decrease in medication as evidence of God answering his prayers. Matthew shares a similar view where he states how he made sense of his experience from a religious perspective and not the bio-medical view:

*“[...] Because to me it’s a religious experience because I’m a religious person” (Matthew line 39)*

*“[...] you can’t really cure it only by the physical, which is the drugs...” (Matthew lines 331-332)*

There seems to be an agreement among the participants within how they understood ‘schizophrenia’ as not being ‘resolved’ via the use of psychiatric medicine, but rather by engaging in spiritual practices and putting their faith in God. There is an evident conflict between the effectiveness of medication versus the effectiveness of prayer when navigating thorough the phenomena of ‘schizophrenia’, with prayer being held in higher regard by the participants. This can be identified in Christianity where prayer and fasting are considered to be the ‘ideal’ concoction for healing: “This kind can only come out by nothing but prayer and fasting” (Mark 9:29). It is likely that the participants internalised this view and perspective and subsequently used this as a lens to prevail through their experiences. This testimony seems to be shared by Peter who stated:

*“So it was more like I would just say some silent prayers in my mind and be like ‘God just takeover cause I don’t know anything about this. Yeah, I can’t go through this alone’ and I think he heard a heart cry of mine. And yeah, I think that was it You know, it’s kind of praying really helped a lot of during that time.” (Peter lines 378-380)”*

It seems that Peter feels, through his prayers, God answered him. His dictation similarly to Noah, suggests he surrendered completely to God and viewed God as the only source of his help. Throughout their experiences there is a strong reliance on God evidenced by Peter stating, *‘I can’t go through this alone’* and Noah attesting his answered prayer. John also reflects on the role of prayer during his experience:

*“[...] I was working in a ... I was working at a detention centre. So that was, you know, that was pretty pretty much of a draining occupation during the pandemic. Yeah. And there was lots of conflicts. Lots of conflicts. Physical conflicts. Emotional going on. Yeah And the potential was to to be highly stressed in that environment, there was a high potential of being on edge all the time If you didn’t do like meditation and self-care, you know prayer and all those stuff” (John lines 26-29)*

*“[...] It was mostly doing it by myself and virtually with um congregations. um its its my my own sacred practices at home - prayer and um you know, services with um congregations in the States and around the world. So that was very, very helpful. (John lines 132-134)*

*“[...] All these things were very positive.” (John lines 96-97) .... “whether it’s reading the holy books or Prayer, meditation, contemplation.” (John lines 101-102)*

*“[...] religion was...is very helpful...It helped me to get into prayer and then to meditation and to you know visualisation and reflection on the struggles of the Christ and the way in which Christ was able to resurrect himself. All these things were very positive.” (John lines 94-97)*

John’s repetition of the word *‘very’* communicates the great strength he holds in his perception regarding the role of prayer and *‘sacred practices’* in mediating the difficult effects of his experience. Just as Peter and Noah speak to the significance of communing with God through prayer and the result of answered prayers, In addition, John appears

to, alongside this, find strength in reflecting on the struggles and subsequent resurrection of Christ, which seems to have shaped how John made sense of his experience in that he seems to have understood his experience and present suffering as only for a period, allowing him to understand his experience and frame it in a '*positive*' manner. This would be in line with biblical scriptures – “but rejoice to the extent that you partake of Christ’s sufferings, that when His glory is revealed, you may also be glad with exceeding joy” (1 Peter 4:13).

Matthew also reflects on fasting and praying, citing biblical scriptures as his evidence for its effectiveness:

*“I engaged in the fasting like I say I fasted I think that was the main the main practice that was the main thing that I did.” (Matthew lines 178-179).*

*“I would go to church, pray of course ‘praying without ceasing’ you know as well as that... And also just try and be a good person, you know... Those are the main things Just trying to be charitable and um... fast, yeah...” (Matthew lines 195-197)*

Matthew seems to have viewed fasting as well as being a good and charitable person a core practice and principle to maintain during his experience. He seems to regard prayer, almost as a “given” stating '*pray of course*' before citing scriptures - 1 Thessalonians 5:17 "*pray without ceasing*" suggesting he feels this is a practice that should be continually applied. Across all the participants there appears to be a theme of having to consult, surrender and put their petitions to God through prayer and sacrifice in fasting in order to make sense of their experience through the lens of their faith and receiving subsequent healing.

## **GET I Summary**

It would appear the apparent golden thread connecting the sub-themes is the internalised sense the participants adopted regarding the character of God as a healer and their role in engaging in spiritual practices as a token or indication of their commitment and faith in order to access healing from God. The connection between these areas seem to go hand

in hand for the participants, where the employment of spiritual practices like prayer and fasting is evidence of their belief, hope and faith in God. The outcome of the participants faith and belief during their 'episodes' is explored further in GET II which illuminates the participants account regarding their relationship with God prior and during their experiences.

## **GET II: 'Just A Closer Walk with Thee': “*Schizophrenia*’ fostering closeness to the Creator”.**

This second GET seems to have followed on from the first GET as all the participants viewed their experience of 'schizophrenia' as fostering a closer relationship with God. Two subthemes were identified that focus on the relationship between feeling distant from God prior to the experience and how this fostered a closeness that manifested in fulfilling God's will and purpose for their lives.

### ***Subtheme III: Distance comes before Closeness.***

This subtheme describes how the participants went through a journey prior to their experience, where they felt distant from God, describing a relationship that was detached and engaging in a lifestyle that did not reflect God's will for their lives. They describe how through their 'episode(s)' of 'schizophrenia' they fostered a closeness to God. This theme is illustrated in the following extracts taken from Matthew's interview:

*“Researcher: ... how was your faith and relationship with God before your experience?”*

*Matthew: Well as I said I grew up a church person but um I wouldn't say I slipped totally away I would just you know just little silly things hang around with the wrong people um I know that it's not pleasing... it wasn't really pleasing to God you know we used to um... I'd say maybe we'll do um... you know just foolish little things you know... hang around places get into fights I'll be amongst people who would um... I'll be searching for people to you know... even though I would say that it wasn't um it wasn't extreme you know not like I badly hurt anyone or something but I was around people and around a culture that was kind of wrong that I knew to be wrong so I knew that that path... I shouldn't really be*

*on that path um but I always I always um had God in my life... I know because I knew it was wrong you know as the bible says; "blessed is he who walketh not in the counsel of the ungodly nor standeth in the way of sinners nor sitteth in the seat of the scornful, but his delight is in the law of the Lord and on his law does he meditate day and night..." like that strengthens me and I used to kind of... that's when I kind of would kind of switch more to meditating on God's word and to stop walking in the counsel of the ungodly." (Matthew lines 109-122)*

[...]

*"Researcher: Yeah I see I see and what was your faith and relationship with God like during your experience would you say?*

*Matthew: "I think I seemed to be rather close to God in that I feel I felt kind of close to the spiritual world, you know, so I kind of felt close to God so I would say that um my relationship was uh was what would be a... what would be a close one... God is a healer he says in his word so I know he would ... I know he would heal me and um yeah yeah I felt closer to God yeah" (Matthew lines 135-139)*

Matthew describes his relationship with God prior to his experience as distant, he seems to attribute this to him living a lifestyle which was not pleasing to God, which led to the estrangement of their relationship. Matthew's use of biblical scripture: 'blessed is he who walketh not in the counsel of the ungodly...' (Psalms 1:1) appears to play a role in how he made sense of his experience of 'schizophrenia' as in some way a result of his non-compliance to the word of God.

This is echoed in Noah's account where he understood his experience as a result of disobedience to God:

*"[...] But you know what happened to me...disobedience. I was disobedient...I went back to smoking marijuana. And then after that. I couldn't get that same back... but I believe that God did cure me in my first episode." (Noah 181-183)*

Matthew's reiteration of 'close' to describe his relationship with God during his experience seems to have been understood to be the direct outcome of his submission to God. This sentiment is shared by Peter who expresses:

*"[...] Afterwards, I actually had a whole lot of like, should I say like a trial and temptations. So, it was more like I passed through my feeling and my faith got actually got stronger. Yeah. And I I actually had this personal relationship during this phase. With God like it was like a phase. I just needed to be alone and so it actually made my faith in God actually stronger because yeah, I I did I okay. Yeah, cause many people thought that I wasn't actually going to come out and it was very deep like I said. Ohh yeah, so I could see the mercies of God. I would say it is the mercies of God" (Peter lines 126-132)*

Peter like Matthew describes that through his experience his relationship and his faith in God strengthened. Peter's use of the phrase 'trial and temptations' suggest there were difficulties during his experience which he seems to have understood as part and parcel of the 'enrolment' expected before closeness is achieved. This would be a common belief and practice for those of the Christian faith - taken from the book of 1 Peter 5:10 "After you have suffered a little while, the God of all grace, who has called you to his eternal glory in Christ, will himself restore, confirm, strengthen, and establish you". It would seem that Peter's faith and understanding of biblical text was central in the way he made sense of his experiences of 'schizophrenia' as he likens this to 'trial and temptations'.

John also spoke of a change in his relationship with God:

*"Researcher: And how was your faith or I guess relationship with God prior to the last two years and that experience?"*

*John: oh, it was more distant it was more distant more distant it was more recreational and it became more serious more day to day more integrated in my in my in my living routine. We were doing doing, doing more sacred things every day.*

*Researcher: Right. So, it sounds like they like your relationship with your faith and God had changed from before. The experience to during and experience is that right?*



*John: Oh, it was much better. Much better*

*Researcher: Much better. Mhmm.*

*John: It was much better. Much, much relief. relief of tension.*

*Researcher: Mmm. Relief of tension. Do you wanna say a bit more about that?*

*John: Yeah just the tension from the paranoia. Just um knowing that the creator is there to assist regardless of the Big Brother” (John lines 108-127)*

John’s significant use of repetition throughout this extract is worth noting. Firstly, his repetition of the word ‘*distant*’ highlights the level of separateness he felt from God prior to his experience, his subsequent repetition of ‘*much better*’ starkly contrasts this and highlights the closeness of their relationship during and post his experience. John seems to attribute part of this developed relationship to his devotion to ‘*sacred practices*’ that he engaged with in a more ‘*serious*’ way. This view is also reflected in Noah’s passage:

*“[...] because once I knew that once I knew I had mental health problems schizophrenia disorder I also read the bible and one verse in the bible was talking about how Joshua had to deal with mental health problem at one stage of his life so that sort of made me continue as well. So, if if Joshua had it then anyone could have that problem...but umm what I notice is every time I go off the medication, I go into prayer and fasting. And it does I do see a connection where I am spiritually close to God” (Noah lines 101-104)*

This extract suggests that Noah closely correlates his experience of ‘*schizophrenia*’/ ‘*mental health problems*’ as driving him further into his faith. Similarly to the other participants, he speaks of engaging in spiritual practices during his experience and noticed a spiritual connection and closer relationship with God as a result. It would seem for the participants that the role of submitting to God was central in how they made sense of their experience with their submission and obedience creating the pathway to foster a closer relationship with God.

The role of submitting appears to be related to the second subtheme: *'Fulfilling God's Will'*, as the participants seem to view their experience of fostering a close relationship with God, and their relationship with God subsequently permitting them to carry out His will.

#### ***Subtheme IV: Fulfilling God's Will***

This subtheme captures the essence of the participants experience of 'schizophrenia' as it relates to their belief that they, in part, were fulfilling God's will. The notion that 'schizophrenia' was a factor in guiding the participants to carry out God's will was seen to be present across the participants narratives.

*"Researcher: Mmhmm. And What were you hoping that was gonna do.. the umm the evangelism?"*

*Noah: Yeah, yeah it was basically to draw people to God and just to tell people about about God really and about faith and that there is a God out there that does care for us where wherever we are , whatever we... He still cares for us...yeah just to tell people about the gospel but I know sometimes you can do it by by joining a church becoming a member and do it in an organised way and that stuff but sometimes... at that time the spirit hit me to go and speak and that's what I did" (Noah lines 409-417)*

In this extract, as mentioned in previous themes, part of Noah's experience included street evangelism. It seems that Noah believed that this was part of his fulfilment of God's will which involved spreading the gospel. Noah also alludes to feeling compelled/led by the holy spirit to spread the gospel: *"that time the spirit hit me to go and speak and that's what I did"* thus following what he feels was God's calling. It would seem that Noah made sense of his experience in relation to fulfilling the will of God, to some extent as out of his control, this is highlighted in his use of language, particularly the use of the word *'hit'* gives the impression in some way of the spontaneous nature of his calling to spread the gospel.

He goes on to state:

*“Yeah ‘cause I used to do that quite a lot I used to go, I used to comeback from church sometimes and give leaflets and shout at the top of my voice about God and Jesus and all that stuff, yeah.” (Noah lines 405-407)*

*“[...] God said no you’re actually using your voice for me, and telling people about me and who I AM” (Noah lines 486-487).*

*“I enjoyed doing that and used to feel at peace and I also felt a connection with God as I was doing that...doing God’s work, but I had high blood pressure and I thought to myself I’ll leave it for now, and go to God and pray about it and maybe one day I’ll go back again and and and do that again with the church or or friends.” (Noah lines 397-401)*

Here, Noah explicitly states that he was *‘doing God’s work’* in spreading the gospel, this is strengthened with a quote from earlier in Noah’s interview where he stated God told him *“go and preach the word to the people in that country”* (Noah line 25). This practice is consistent with biblical text where throughout Christ’s ministry this was promoted as an essential practice among His followers: “And he said to them, “Go into all the world and proclaim the gospel to the whole creation” (Mark 16:15). It may be that for Noah part of how he understood his experience aligned with what he believed was an essential part of the practice of Christianity. Through this understanding, Noah believes that it is part of his duty to *‘preach the word’* in order to fulfil God’s will.

Similarly to Noah, Matthew’s passage alludes to how he understood his duties as a Christian and how this shaped his understanding of his ‘episode’:

*“[...] “because I knew it was wrong you know as the bible says; “blessed is he who walketh not in the counsel of the ungodly nor standeth in the way of sinners nor sitteth in the seat of the scornful, but his delight is in the law of the Lord and on his law does he meditate day and night...” like that strengthens me and I used to kind of... that’s when I kind of would kind of switch more to meditating on God’s word and to stop walking in the counsel of the ungodly.” (Matthew lines 117-122)*

*“I believe that that will bring you closer to God really because it’s almost like you’re cleaning yourself out... the body’s like a temple I see it... and in order to be closer to God*

*sometime we must um kind of just clean ourselves out so God can work in us you know... not satisfy the flesh but satisfy the spirit... it pleases God you know" (Matthew lines 183-185)*

The language Matthew uses '*clean ourselves out*' carries connotations suggestive of a self that is in essence 'full' but absent of God - or an empty temple as he alludes to. This would be consistent with scriptures where one's body is considered a temple where Christ lives: "your bodies are temples" (1 Corinthians 6:19); (Galatians 2:20) "Christ lives in me". In a similar vein to Noah, in Matthew's extract he appears to believe it is God's will that he lives a life that '*pleases God*' which involves making room for God to '*work in*' him and this will in turn be a fulfilment of God's will.

It would seem that this is similar to Noah's understanding of his experience where Matthew seems to imply the control is in the hands of God who does the '*work*' in him and as such satisfying his Holy spirit and not the flesh, which is understood as the selfish nature of man. This is strengthened by his use of '*clean ourselves out*' suggesting the selfish nature of man needs to be denied in order for God to dwell within him and for God's will to be fulfilled. This idea would be in line with the biblical text: "Then said Jesus unto his disciples, if any man would come after me, let him deny himself, and take up his cross, and follow me" (Matthew 16:24). This suggests a need for wholly following the will of God which can be evidenced through the denial of oneself.

John also speaks to making sense of his experience from what he refers to as a 'Christ consciousness' perspective:

*"Researcher: [...] Yeah. nice. And when you were going through this experience, did you have a uh cultural or religious interpretation of what was going on when going to be felt Big Brother was watching and the and and the paranoia, was there a particular reason you had?"*

*John: Yeah yeah, it was the Christ consciousness, I mean that I think was was operating. you know just trying to. Go through life as um With a Christ consciousness and living according to you know what Christ would have done in these circumstances..it's very important." (John lines 183-191)*

[...]

*Researcher: Mmhm right, and you say what Christ would have done was something that you took on board for your experience. And was there anything in in, in particular, from Christ teaching that you....*

*John: ...Yeah love love forgiveness. You know, charity hearing despite being being um put in a situation by others which you think was not right. For the ability to love despite violations” (John lines 199-205)*

Similarly to Noah and Matthew, John seems to have navigated and understood his experience in a manner which he feels reflected the principles and teachings endorsed by Christ. John, in a similar manner to Peter in the previous subtheme, believes his actions during his experience must align with the scriptures, in this case, in order to please and fulfil God’s will. His use of language suggests that there is an expectation for him to ‘forgive’ and ‘love despite’ of ‘violations’ and as such, through these actions, he is fulfilling God’s will. This is in alignment with scriptures where Christ states: “Love your enemies, do good to those who hate you, bless those who curse you, pray for those who mistreat you” (Luke 6: 27-28). It would seem that in some way, John understood his experience as needing to convey the teachings of Christ’s ministry in order to fulfil his duties and God’s will, Peter also speaks to his experience being part of ‘God’s plan’:

*“I I think it was also God’s plan. So I felt the the whole outcome even right now, it’s actually God’s plan” (Peter lines 372-373)*

While dissimilar in some ways to the other participants, in that Peter’s extract suggests his role in fulfilling God’s will was more ‘passive’ in a sense, this extract still communicates how Peter interpreted his experience from a stance that framed God’s will as the guiding force behind his experience.

## GET theme II Summary

The two subthemes that populate this GET represent the sense of comfort the participants cultivated in their relationship with God, throughout their experience and the connection and peace found in making sense of their experience as a fulfilment of God's will. It is likely the strength of their connection with God allowed for the participants to conceptualise their experiences as part of God's plan for their lives. This notion of a change in relationship with God prior and during their experience in this theme is developed further in the focus of GET III where the idea of change in relation to self as a result of a change in relationship with God is explored.

**GET III: 'The only thing I could have done...was turn to God, 'cause only God could help me': "*Schizophrenia as a transformative experience*".**

The third GET: '*Schizophrenia as a transformative experience*' illustrates the participants journey through adjustment and change. The concept of 'schizophrenia' as both a response and a catapult for change was present throughout all the participants' accounts. The participants' accounts convey their experience as in some way changing them as a person and as a vehicle for driving them through the adjustment of trauma and loss.

### ***Subtheme V: Changing as a Person.***

All the participants spoke to 'schizophrenia' as playing a role in changing them as a person in some way.

*"it's kind of like um when you've been through something with someone you kind of go closer to them...it changes you you know it changes you. You become closer to them."*  
(Matthew lines 159-160)

Matthew's extract illustrates the experience of 'schizophrenia' as transformative in his self-identity. His repetition of '*it changes you*' speaks volumes to the evolution Matthew

underwent as a result of his experience. This notion of 'evolution' is present throughout his interview where he likens his view of 'schizophrenia' to an evolutionary process:

*"I mean, are you familiar with the concept of evolution? Who's to say that these people who are experiencing certain things, if they're still in control of themselves, are not on a higher level than them." (Matthew lines 375-377)*

[...]

*"Matthew: [...] I am a Christian, I don't believe in evolution in the science way... But it's funny how the scientists who believe in evolution physically and even mentally they somehow believe it has stopped... But if it hasn't stopped then wouldn't the so called hospitals and places like this and these types of experiences... some of these could be something where people are moving on to a different level.*

*Researcher: That's interesting. So... I know you've mentioned that you don't believe in evolution as you're a Christian... But that kind of notion of things evolving seems quite central here. In terms of...."*

*Matthew: Yes but it's not really evolution in that way... I see it more as what Christ says when He says you're 'born again'... if it is another thing that is done in a certain way it's what Christ says when you're 'born again'. You become a new creature. A new creature in God." (Matthew lines 397-410)*

Evolution and the process of the self as changing seem to be pertinent in Matthew's extract here. He seems to have made sense of his experience in evolutionary terms adopted with a Christian lens, citing scriptures to describe his change as being '*born again*' and becoming a '*new creature in God*' (2 Corinthians 5:17). It would seem for Matthew that a change must take place, more specifically a change in oneself, before reaching a '*higher level*' where closeness to God can occur. This would tie in with scriptures where Christ states: "Truly, truly, I say to you, unless one is born again, he cannot see the kingdom of God" (John 3:3). This experience of change is echoed by Noah:

*“[...] yeah it all at that point must have taken its toll on me. But I wouldn’t change nothing from what I went through...I wouldn’t change it for the world it had it had to shape me up to be the person I am today if I didn’t go through all that I probably wouldn’t be the person I was today [Noah lines 439-442)*

*“So yeah so I had to have that experience of God to find out who I was really was and how God was was really in my life for me to go through all of that . Otherwise umm.. I might say “oh Noah hasn’t got schizophrenia Noah is fine” but would I really be spiritually aware? or would I know things about God? or or am I close to God in that sense, even though I got schizophrenia I don’t think I would be the same I wouldn’t be the same person.” (Noah lines 446-451)*

Noah, like Matthew appears to have understood his experience as transformative in that it not only brought him closer to God but also shaped him into the person he is today and feels he would not be the same person had he not experienced ‘schizophrenia’. Both Noah and Matthew speak to going through their experience *with* God suggesting God plays a central role in changing them as a person through their experience. This would suggest, as similar to the previous theme, that the participants seem to view their change as a result of God’s will and a result of their own efforts. This is highlighted in Noah’s extract where he states he ‘*had to have that experience of God to find out*’ who he ‘*really was*’.

Both Peter and John on the other hand, appear to speak of their experience in relation to isolation. Reflecting on the process of being alone as transformative in changing the self:

*“[...] like compared to... cause my whole relationship and way of talking to people, would change I was so much isolated to myself so I would change a whole lot of things about me.” (Peter lines 307-309)*

*“Yeah, I was actually, hoping it will just change the whole situation like I used to hear of testimonies. Yeah so I was actually really believing anyone at that moment whereby I’ll*



*just change, you know, to a different reality, like to my normal self to be who I used to be. But I just hoped I think it was also God's plan. So I felt the the whole outcome even right now, it's actually God's plan."* (Peter lines 369-373)

*"But like I said, it was also... based on Big Brother it was also something which took lots of work...that's a deep reflection... unwarranted isolation at times. Um, but um at the end of the day it was very helpful to get me here."* (John lines 195-197)

Peter seems to speak to a battle where he desired to connect and return to his '*normal self*' before seeming to allude to accepting and finding peace with his new self, describing this as '*God's plan*'. John also speaks to a process of '*deep reflection*' that appeared to be a challenging and oscillating process which changed him, illustrated by his statement of: '*it was very helpful to get me here*'.

#### **Subtheme VI: Powerlessness in adjusting through loss.**

During the interviews all of the participants seem to have made meaning of their experiences as related to a precipitating factor involving 'loss' and/or an accumulation of 'stressors'. The sense of powerlessness that came with this and having to manage the adjustments together seemingly resulted in the birth of their 'episodes'.

*"OK, so actually I had a lost one. I lost someone but actually it wasn't really the cause of the last one cause already I was going through some anxiety problems and so I just felt the whole... it was just a whole collision of different events and yeah, and I also had school problems."* (Peter lines 62-65)

*"[...] because what happened...and then I thought to myself you know what what exactly happened to me was...when I was studying at university my degree and all of a sudden there was like three things that hit me on the sudden like that...which was the bereavement of my mum. Like I said she already ... um I had not passed my first year because of like ... I told you when I was indulging in my marijuana and alcohol and partying late night ... I think all of that ... I didn't pass my exams and it all hit me at the same time. So, when I decided to go on holiday, I feel that pressure and that and I was working as*

*well. I couldn't sleep because there's too much partying and wild nights and it all drained me down...being in a different country it all just drained me down.” (Noah lines 427-435)*

Both Peter and Noah in these extracts highlight the role of loss/bereavement and a subsequent accumulation of stressors as central in the formation and understanding of their experiences. Their accounts seem to give the impression of a contributing sense of powerlessness. Particularly in Noah's use of the word '*sudden*' and Peter's use of '*collision*' which carry connotations regarding the unexpected and unanticipated nature of their episodes which they appear to have experienced as happening *to them* speaking to a sense of feeling defenceless. This is highlighted further in Noah's interview when he describes turning to God:

*“[...] the only thing I could have done that time was turn to God cause only God could help me” (Noah lines 625-626).*

This extract speaks to the sense of powerlessness felt by Noah and his complete and total reliance on God as the source of his help when navigating through trauma and loss. His use of language, particularly the use of the word '*only*' highlights this sense of dependency Noah feels on God. For Matthew and John, similarly to Peter and Noah, both suffered loss in some capacity and attributed this to contributing to their experience.

*“[...] I was going through you know you know a relationship breakdown. So, it just didn't work out.” (John lines 51-52) “[...] it's more that and like more that and the pandemic that that enhanced things” (John lines 57-58)*

*“[...] I guess regarding whether it's government, you know whether it's encroachment into your daily daily living. Telling you what to do. So mostly that. Big Brother syndrome” (John lines 86-88)*

*“[...] something happened to me um I did um I had a death in the family it affected me and I started to really um kind of question and ask myself questions about what is this thing called life and start to go deeper into spiritual things and then um well I guess I must have been um quite... must have gotten into it a lot I was going to try to be... and then you know I had um a kind of um fast I fasted because I know it's most of the people that*

*supposed to be holy people described in history where they they fasted so I attempted to fast a long fast and um next thing I know I'm waking up with white coats all around me..."(Matthew lines 51-58)*

For John the sense of powerlessness was also present, this is illustrated in how he describes his experience throughout the pandemic and the '*encroachment*' into his life. His use of language '*Big brother*' syndrome a term suggestive of a people under constant surveillance and lack of privacy, paints a vivid picture in understanding John's experience and the sense of powerlessness he may have felt within this system. This could also be understood in the context of the pandemic as a time of great uncertainty where the sense of powerlessness permeated culture and society as a whole.

This notion is somewhat mirrored in Matthew's account where he seems to have attempted to make sense of loss and reconcile his way through the adjustment by embarking on a spiritual journey through fasting before finding himself surrounded by '*white coats*'. This powerful metaphor illustrates and speaks to a sense of feeling at the mercy of others.

### **GET III Summary**

These two subthemes connect in that they represent the process of transformation in self-change and adjustment. Through the process of self-change, the participant's conceptualise their experiences from a framework shaped by their faith; in that they believed God changed them through their experience which in turn allowed them to navigate the challenges of adjustment regarding loss and trauma. The fourth and final GET draws together the tensions experienced between the spiritual and the cultural understandings of 'schizophrenia' and how this tension presented itself for the participants.

#### **GET IV: ‘Culture and Religion go together’: “*The Cultural and Spiritual Crossroad*”.**

The final GET concludes the analysis and includes two subthemes that centre on the intersectionality between two dimensions: the culture and the spiritual. The preceding three themes have described the level of faith displayed by the participants and the strength of their faith in fostering a closer relationship with God and how this had led to self-transformation. The focus of this final theme is centred on the way in which participants have integrated their understanding of their experience through their cultural and faith lenses, alongside the sense of feeling othered.

##### ***Subtheme VII: The Culture IS Spiritual***

This subtheme captures the view that three of the participants held, in that culture is in a way inherently spiritual in its conceptualisation of ‘schizophrenia’ / ‘mental health’. Peter expresses the view of his culture viewing ‘schizophrenia’ as relating to a spiritual phenomenon.

*“[...] my ancestry beliefs in Christianity and all that, so it was more like more of umm more of like um.. as as much as it was more mental. It was more of like seen as something kind of spiritual there from my family.” (Peter lines 27-29)*

*“[...] Coming from the African roots, you know it's more of like um anything anything that patterns to the mental state is more looked upon, like spiritual, than kind of Mental in this state.” (Peter lines 91-93)*

*“I know that culture exist and I really respect yeah, I respected it whole lot, but I just know that some things are not just always culture, somethings are just generic like you just have to imbibe to the general view of those things” (Peter lines 415-418)*

It would seem that Peter experiences a conflict where on one hand he desires to be ‘open minded’ (Peter line 49;87;400;412) holding the belief of ‘schizophrenia’ as ‘genetical’ (Peter line 260;262) and on the other hand experiences problems in the family relating to his diagnosis: ‘issues in my family concerning that’ (Peter line 97). In this regard, there

appears to be a tension noted by Peter when making sense of his subjective experience due to the opposing paradigms of his own internal frame and that of his culture and family. There seems to be a paradox in Peter's communication regarding his conceptualisation of 'schizophrenia' by framing it as '*genetical*' while also desiring to remain open minded. It would appear that Peter formulated his view of being open minded as being open to ideas and understandings outside of the commonly held spiritual conceptualisations within his culture. The understanding of 'schizophrenia' being viewed as a spiritual phenomenon is also pertinent within Matthew's extract:

*"Well, in our culture, in the Africans in the Caribbean I think it's a place that has most churches per square mile in my country of Jamaica... So um... we're very much um spiritual based and Bible based in that way... So no doubt it had an impact in that I was raised a Christian... And it's a particular type of Christianity with the Pentecostal... Which is um to do with to do with the spirit... The spirit, when the spirit dropped on the apostles at the day of Pentecost... So yeah, that kind of spiritual aspect um would have had an effect on me"* (Matthew lines 227-233)

*"I would say a spiritual experience... So it's similar to what I believe"* (Matthew lines 307)

*"[...] I would agree with the Africans because to me, I think that that's what it is... I... Not only how I've been raised, but through my experience of it I wouldn't say that it's only a chemical thing I would say that what must come first is the spiritual thing"* (Matthew lines 321-323)

Matthew differs from Peter in that while they both believe their culture views 'schizophrenia' as spiritual; this view seems to align with Matthew's understanding of his subjective experience. Matthew interestingly references his sect of Christianity, Pentecostalism, which places an emphasis on the effect of the spirit, more specifically the Holy spirit in directing an individual's behaviour. He cites the book of Acts 2:4 referencing the day of Pentecost: "All of them were filled with the Holy spirit and began to speak in other tongues as the spirit enabled them". Matthew's use of this scripture colours our understanding of how Matthew views the role of spirituality and God being the central force in facilitating his lived experience. This provides great insight into how he has

married aspects of both his faith and culture to understand his experience highlighting how these areas are interconnected.

John also agrees with both Matthew and Peter, where he states culture and religion go together:

*“[...] culture and religion. They go together. They’re very useful consulting with lots of Africans from the same faith was very helpful around the world. Yeah, the cultural paradigm, cultural paradigm is very important.” (John lines 153-155)*

John seems to have made sense of his experience through the integration of culture and religion:

*“[...] I find it very helpful for the practices, whether it’s, um you know, anything to do with you know, counsel from the elders or you know the ability to stay integrated in the community” (John lines 162-164)*

*“[...] counsel with the elders. We talk about their experiences, similar situations. And therefore, create an experiential guide for you.” (John lines 169-170)*

It seems that John found strength in connecting with his community which seemingly allowed him to make sense of his experience through the experiential guide provided by the elders within the culture. This highlights the connection between culture and religion and highlights similarly to Matthew how John married these two concepts. Noah however, takes a different angle when communicating his view of culture:

*“[...] I was visiting one of my aunties and we went to Africa and she said “don’t talk to yourself Noah it’s the first sign of madness”, so culture...culture wise people would say that yeah.” (Noah lines 463-465)*

*“[...] then I tried my best not to...when I’m on the street or when I’m outside on the bus, I try not to say nothing at all. And even when I was street evangelising [...] only once it came to my mind...I said “am I speaking to myself?” I said to myself “am I speaking to myself? Like my aunty said is this the first sign of craziness?” (Noah lines 476-482) “[...]”*

*then God said no you're actually using your voice for me, and telling people about me and who I AM" (Noah lines 486-487)*

*"[...] I don't see it like that no, it mean I mean even through...people want to use their vocal cords...I mean I see I see some people talking on the street talking to themselves they're not abusive or nothing just letting something off their mind... I see it as someone letting something off their mind that's bothering you, and sometimes talking about it to yourself helps to remove it yeah." (Noah lines 500-504)*

Noah speaks to the cultural narrative around the common 'symptomology' of 'schizophrenia' as it relates to speaking to oneself. It would seem that Noah internalised this ideology where during his experience he communicates that he suppressed this element, yet the ideology presented itself during his street evangelism. Similarly to Peter, it appears that Noah was subject to an internal battle, between how he made sense of his experience and his culture's understanding of his experience. This theme links to the previous theme '*the healing power of faith in God*', where Noah describes his belief and trust in the character of God, as central in allowing him to navigate through the tensions he experienced from his own worldview and that of the culture he lives in.

### ***Subtheme VIII: Culture and Othering.***

In his account Noah talks about the feeling of being othered due to his experience of 'mental problems':

*"[...] if I go back to Africa and they're gonna say...they're gonna start having this saying "ohh like so he's got he's got mental problems and he's a crazy man he is a mad man..." (Noah lines 525-527)*

*"[...] And even if they love me they love me but we're not on your side regarding your mental health problem because that's where they've that's where it's been taught. That's where they've been brought up." (Noah lines 542-544)*

It would appear that Noah experienced both his culture and Western culture as exclusionary. With regard to his culture, Noah may have in some ways understood his experience as 'different' and as creating a separation between him and others.

*"[...] the psychiatrist what they said to me in my report was "when when Noah is about to get ill he starts praying too much he starts avoiding people and he goes into his own shell. He doesn't communicate with nobody" (Noah lines 296-299)*

Additionally, Noah extends this idea of feeling othered to health care practitioners, where the sense and meaning he made of his experience from a religious context was in essence dismissed and framed as a precursor to being 'ill'. This could be understood as the 'culture' of the west and the way in which mental health is conceptualised which frequently discounts religio-cultural explanatory models.

Matthew seems to share a similar perspective:

*"[...] on the whole, I would say that some of them would be unsympathetic mostly to certain things... they might immediately see it as a negative thing" (Matthew lines 263-264).*

Matthew holds a similar view regarding his culture holding the narrative of 'schizophrenia' in an 'unsympathetic' and 'negative way', whereas he prefers to *"[...] just see it as an experience, that something that happened to me and I'd like to view it in a... a positive manner."* (Matthew lines 256-257). It would appear that despite the segregations inherent to both culture's conceptualisation of 'schizophrenia', Matthew chose to make sense of his experience in a 'positive' manner. For Matthew the role of having an integrated understanding of his own experience was central in allowing him to avoid internalising this notion of othering but instead come to terms with his experience in light of contrary beliefs. This seems to have safeguarded him against the harmful effects of feeling othered.

In a similar fashion, as explored in the previous theme, Peter alluded to the tension experienced between his culture/family views and his own conceptualisation of his experience.



*“[...] my family had every right to just feel the way they felt in their opinion. But it was more like, OK, I just allowed it be I didn't really care how they were reacting, it was more me against...more me against all the things, it was more me against me and against all the things, yeah.” (Peter lines 184-187)*

Here, it would seem that Peter had the sense of feeling othered in his experience. For example, the language he uses around *“me against all the things”* suggests he viewed himself as separate to that of the ‘other, painting a vivid picture of an ‘us versus them’ analogy. The repetition of this sentiment further highlights the degree of alienation Peter may have felt. It appears that throughout the course of Peter’s ‘episode’ he eventually arrived at some sort of ‘resolve’ between the tensions he experienced where he describes he *‘allowed it be’*. From this it would seem that Peter resigned to his own belief regardless of the view of his culture and others.

Finally, for John this sense of othering was described as self to self. Throughout his narrative he speaks of *“big brother”* and it’s *“[...] encroachment into your daily daily living. Telling you what to do” (John line 87)* and his response of *“[...] getting more into seclusion and not um not wanting to be around or being suspicious being suspicious of uh others” (John lines 5-6).*

It would seem that for John, this denotes a tension where the othering of himself impacted upon the way he integrated with others and the understanding of his experience. This final subtheme communicates the complex battle between self and other. The tensions experienced by the participants in previous themes relating to transformation and change can be seen to re-emerge here. This could be understood as part and parcel of the oscillating process inherent to change in and of itself.

#### **GET IV Summary**

The final cluster of subthemes represent the complexities experienced for participants when living in a culture or belonging to a culture which has competing views regarding the origin and conceptualisation of ‘schizophrenia’. This theme highlights the apparent tension the participants came up against and how they made sense of what they encountered in light of these conflicts and experience of subsequent othering.

## **CHAPTER V: DISCUSSION**

### Chapter Overview

This chapter presents a summary of the research findings pertaining to the specific themes and considerations of how this relates to the existing literature within this area as identified in chapter 2. This chapter will also consider further research not previously cited in the literature review, reflecting the inductive nature inherent to IPA. The discussion will critically evaluate the research with regards to the methodology and other limitations and will close with the implications for the field of counselling psychology and recommendations for future research.

### Summary of the Research

The present study sought to explore the lived experience of 'schizophrenia' for individuals who identify as Afro-Caribbean Christians. An interview schedule was devised, and semi-structured interviews were employed to gather information to answer the following research question: How do Afro-Caribbean Christians make meaning of their lived experience of 'schizophrenia'?

The analysis of the participant accounts highlights the significance of one's faith in the lived experience of 'schizophrenia' in the context of being an Afro-Caribbean Christian. Across the themes, front and centre seemed to be the participants identity as Christians that took the fore when it came to how they interpreted and understood their experience. Throughout all of the participants' accounts it would seem the participants told a story of how they initially felt distant from God, and through their experience embarked on a journey of healing through re-establishing their relationship with God, and this being experienced as transformative in and of itself. Three of the four GETs: 'God as a healer' 'closeness to God' and 'transformative experience' highlight this journey respectively.

## Discussion of the themes in relation to existing literature

### **GET I: God as a healer.**

Within this GET, the participants made sense of their experience through their understanding of God as a healer and how their conceptualisation of God as a healer would extend to Him healing them of their 'schizophrenia'. This GET was separated into two subthemes: 'the healing power of faith in God' and 'the centrality of spiritual practices'. 'The healing power of faith in God' referenced participants' experience of God being a healer of 'schizophrenia' when they diligently sought Him and their reliance on their faith as a primary source of support during their experience. Research focusing on the role of faith in God as a source of healing for 'schizophrenia' is limited, however there is some research where inferences can be made and used as a lens to understand the current research findings, the first of which is Rowe & Allen (2004) who found spirituality constitutes a fundamental role in an individual's worldview. The authors highlighted that participant's initial reaction to 'illness' involved turning to their religious beliefs. These findings correlate with more recent research by, Adeosun et al., (2013) who found in their study of 138 inpatients diagnosed with 'schizophrenia' 69% consulted religious or traditional healers as a first contact.

Other research demonstrates 70% of patients reported consulting spiritual healers prior to accessing mental health services (Agara & Makanjuola, 2006). These findings can be extended to the current research to support in the understanding of how the participants sought God as the primary source of their help. Throughout all their accounts the participants noted their belief in God was greater than their belief in psychological intervention for healing. Particularly of note were Noah's and Peter's accounts where they stated: "[...] *God will heal me not tablets*" (Noah line 62) and "*healing first of all comes from God*" (Peter, line 380).

These findings are supported in a study by Mohr et al., (2006). In their study they sought to assess the role of religion in coping with 'psychotic illness' and found 71% of participants reported religion instilled hope and 54% reported religion as lessening their 'psychotic' and general symptoms. Callaghan's (2015) quantitative study found significant

results from an ANOVA analysis regarding participants belief in religious healing as a treatment option for psychosis, with 50.3% and 65.3% of individuals stating they would *'turn to God for direction and help'* and *'are aware of God attending to them in times of need'* respectively. These findings highlight the position religion plays in the lives of those with 'schizophrenia'/ 'psychosis' and their reliance on God as a source of support and intervention. As highlighted in Chapter 2, part of the Christian belief system involves the role of faith for healing to occur (Khan & Dixon, 2021), through practices such as prayer (Robinson, 2014), and it is this belief which underpins many Christian sects and extends to understand how Christians may interpret and navigate their experience through their reliance on God, and their faith for strength and healing (Koenig, 2005, 2008, 2009).

Despite the limited literature exploring the interplay between seeking God for healing and 'schizophrenia', the example literature cited highlights the importance of one's religious beliefs in gaining healing and in the interpretation of experiences. Findings from the current research contributes to the knowledge base, with the outlined research highlighting the significance of religion in the lives of those diagnosed with 'schizophrenia'. The analysis showed that the participants made sense of their experience and deliverance from 'schizophrenia' as a result of their application and faith in practices such as prayer and fasting, which were believed to be a pathway to accessing God's healing.

The second subtheme 'centrality of spiritual practices' centred on the participants use of such practices and their testimonies of the outcomes in their experience. This theme was present throughout all of the accounts and has been cited within literature in the vein of spiritual and/or religious coping.

Earlier research by Kirov et al., (1998) assessed how often 'psychotic illness' can inform a change in the strength of religious faith and how frequently the use of religious coping was utilised among patients with 'psychosis'. The authors found patients reported an increase in the strength of their religious beliefs since the onset of their 'psychosis', with 61.2% reporting to use religion to cope with their 'illness'. Further empirical support of this was found in a study by Pargament (1997, 2013) where the author notes that bible reading, and prayers are supportive in coping with psychological distress including grief and loss. These findings could also be extended to understand how the participants faith

supported them in their adjustment through loss as highlighted in GET six: 'powerlessness in adjusting through loss'.

Further support for this subtheme comes from Nolan et al., (2012). In their research they investigated the religious coping and quality of life among 'schizophrenic' outpatients. The authors found 68% of outpatients engaged in religious activities such as prayer groups, 91% engaged in private religious or spiritual practices such as prayer, meditating and spiritual reading, and 79% prayed at least once a day.

Literature has highlighted the powerful influence of one's beliefs in health and illness and how one's beliefs can both facilitate or block wellbeing, with faith, prayer and spiritual practices being shown to strengthen one's health and subsequent healing by prompting emotions that influence physiological systems (Hill & Pargament, 2003; Koenig et al., 2001). The findings highlighted a correlation with the current study's outcomes, where spiritual practices such as prayer were seen as central to the participants meaning making of their lived experience of 'schizophrenia'. For the participants in the current study, this was at the core of how they made sense of their lived experience but also how they navigated through it.

Such findings have been duplicated when in the context of physical wellbeing where prayer has been seen as a positive coping mechanism for 84% of patients with advanced cancer (Vallurupalli et al., 2008), with religion and spirituality being associated with improved health outcomes for substance abuse (Koenig, 2012), cardiovascular disease (Chida et al., 2009), and possible influences regarding lower mortality (Powell et al., 2003). While outside of the scope of this present study, these findings highlight the role of religion and/or spiritual practices in the lives of many with both mental and physical health conditions, and is important to note, given the comorbidity that exists across these domains and the increased mortality rate for those diagnosed with 'schizophrenia' (Charlson et al., 2018).

In consideration of qualitative research, Cinnirella & Loewenthal's (1999) study across 5 cultural-religious groups (Hindu, Muslim, Black Christians, White Christians, and Jews) found for 'schizophrenia', prayer was found to be the most salient of religious interventions and was widely regarded as helpful across all religious groups. Among the Black

Christians there was a reported '*negativity about professional help*', fearing religious beliefs and behaviours may be misunderstood. Such fears, however, are not unfounded, as misdiagnosis on the grounds of non-pathological religious behaviour and beliefs are not only possible (Bartholomew & O'Dea, 1998) but well documented (Loewenthal, 1995). Such beliefs were alluded to within the current study by both Matthew and Noah who speak of their religious beliefs and practices being viewed as a precursor for them being unwell: "*I attempted to fast a long fast and um next thing I know I'm waking up with white coats all around me*" (Matthew lines 57-58), "*when Noah is about to get ill he starts praying too much, (Noah lines 297-298)*". It is worth considering the role of Western ideologies that fall outside the conceptualisations typically held by ethnic groups and how this shows up in frameworks/diagnosis. For instance, the spiritual or culturally 'alternative' conceptualisations of 'schizophrenia' may be dismissed by Western HCPs leading to high diagnosis rates which would impact on the mental wellbeing of the individual.

All things considered, the subtheme of 'centrality of spiritual practices' can be understood in terms of the role that religious coping plays in mediating the adverse impact of mental and physical conditions. In the case of the participants in the present study, such practices were fundamental in supporting the navigation through the uncertainty of their experience. The testimonies offered by the participants speak to the faith they had in their religious beliefs as the primary intervention for a cure and preventative measure. Positive correlations have been identified between religious worship and outcomes for black service users with 'schizophrenia', where they were less likely to be hospitalised if they prayed once daily as opposed to more often (Chu et al., 1985). This can be extrapolated from Noah's interview where the psychiatrist believed Noah's 'relapses' were a result of him '*praying too much*' (Noah line 298). This is explored further in discussion relating to the final subtheme 'culture and othering'.

Widely accepted across many Christian denominations is the idea of the healing power of the Holy spirit to bring about restoration in one's mental, physical, psychological and social areas (Fee, 1996), tying into the belief that God is the ultimate power to restoration and making one whole (Gifford, 2016). This belief was shared by all the participants within the current study, in which they viewed their faith in God and the implementation of spiritual practices as greater than any psychological or pharmacological interventions. Pieper, (2004) found psychiatric inpatients were more likely to '*work with God in solving*

*problems (collaborative religious coping) rather than solely relying on God for solutions’.* This notion of working *with* God could be extended to how the participants understood how they would be healed. Throughout their accounts within this theme there was a strong sense of their role in receiving their healing, which in part involved the implementation of these practices to in some way ‘activate’ God’s healing or rather the activation of these practices would *‘please God’ (Matthew line 186)* and through this, healing would be achieved, highlighting God as a *‘source of strength, sustenance, and healing’* (Levin, 2007, p. 98).

The results from the current study with regards to this GET, supports existing literature which highlights the role religious commitment plays in improving how one copes with ‘mental’ illness’ and its role in facilitating recovery (Matthews et al., 1998). As Walsh, (2009) highlights *‘spiritual resources are not simply another problem-solving tool or set of therapeutic techniques. Instead, they are embedded in a larger worldview and facilitate the spiritual journey of an individual.... They are resources for living and struggling with life’s challenges. They can enable our clients and ourselves to tap reservoirs of hope, meaning, connection, and inspiration’* (p. 56).

### ***GET II: ‘Schizophrenia’ fostering closeness to the Creator.***

All participants highlighted an experience of feeling closer to God during their experience of ‘schizophrenia’ and spoke to the closeness of their relationship which was maintained both after and presently. ‘Distance comes before closeness’ was one of the subthemes identified, in that all participants universally described an estrangement in their relationship with God prior to the onset of ‘schizophrenia’.

Again, research directly exploring the interplay between closeness to God as a product of ‘schizophrenia’ is limited, however such findings can be viewed as consistent with literature where research has explored attachment to God when experiencing psychological distress. Empirical studies highlight that individuals view God as an attachment figure with believers turning to God when *‘facing chronic strains or major life*

events' (Ellison & Taylor, 1996; Pargament, 1997). Pargament et al., (1998, 2000) found in their study that individuals often seek spiritual support and comfort from God through cultivating a '*dynamic partnership with the divine*' and it is through this collaboration they are able to address personal difficulties. Such findings correlate with the sentiments offered by the participants in the current study, within this subtheme, where their accounts highlighted the development of their relationship with God as being a result of 'schizophrenia'.

Heffernana et al., (2016) found in their qualitative research individuals who had experienced 'psychosis' reported a '*sense of genuine connection to God*' and described a reciprocal relationship with God as being the central factor in their recovery process. In addition, participants in this study reported scripture offered a set of guidelines which supported in developing a closer relationship with God. These findings are consistent with the current research, in which participants spoke of the influence of practices highlighted in the initial GET in fostering their close relationship with God throughout their experience.

Further studies have shown an attachment to God moderates the intersections between stressful events and psychological distress (Ellison et al., 2012) and has been positively associated with improved mental health (Bradshaw et al., 2010; Granqvist, 2014). This can be seen in the participant's narrative where they have spoken to a sense of peace they derived through their relationship with God during their experience. Particularly of note was John's testimony where he described that consulting with God would bring about '*healing from the trauma*' (John line 143) which was a '*relief of tension*' (John line 122) and Noah's account where he reported feeling '*at peace and I also felt a connection with God*' (Noah lines 397-398).

This is echoed in a cross-sectional study conducted by Nolan et al., (2012), as stated in the previous section they sought to explore the relationship between religious coping and quality of life among outpatients with a diagnosis of 'schizophrenia'. The authors found a positive correlation between religious coping reinforcing beliefs in a '*benevolent higher power*' with participants citing '*a stronger connection with God*'. The idea of the experience of 'schizophrenia' cultivating a deeper connection with God/one's faith was heavily mentioned throughout the participants accounts within the present study.



On the other hand, however, Nolan et al., (2012) highlighted the role of what they described as '*negative religious coping*' where participants reported feeling '*punished by God for lack of devotion*'. Research regarding views of 'schizophrenia' being a punishment from God has been cited within the literature (Callaghan, 2015; Compton et al., 2008). To some extent these beliefs were also present within the current study where a lack of devotion could be conceptualised as '*disobedience*' (Noah line 181). Matthew also described '*walking in the counsel of the ungodly*' (Matthew lines 122) and living a life which was not '*pleasing to God*' (Matthew lines 111) as a precipitating factor for his experience of 'schizophrenia'.

The subtheme of 'Fulfilling God's will' speaks to the view the participants held with regards to 'schizophrenia' being part of God's divine plan for their lives. Literature has identified similar ideas regarding how individuals have "*benevolent religious reframing*" which is described as "*attribution of negative events to the will of God*" (Mohr & Hugulet, 2004). Within this paper, participants cite beliefs regarding God putting them through a test: '*God puts you to the test, He sends you something for your search for spirituality to win against illness*' (p. 373). This seems to be a similar opinion shared by the participants within the current research. The literature exploring this notion of God's will is very limited, therefore this subtheme contributes to the knowledge base regarding how individuals interpret their experience considering the wider religious-cultural context to which they belong.

### **GET III: 'Schizophrenia' as a transformative experience.**

The focus of this GET is on the participants journey of transformation through their experience. The subthemes capture the sense of 'changing as a person' and the sense of powerlessness the participants experienced in their adjustment through the inherent loss of change. This theme of 'changing as a person' in the context of 'schizophrenia' has been explored within recent systematic reviews (Conneely et al., 2021) and literature has highlighted many experiencing 'psychotic symptoms' as well as those diagnosed with a 'psychotic disorder', cite the profound influence this has upon their lives and their sense of identity (Deegan, 1993; Holt & Tickle, 2014; McCarthy et al., 2013; McGrath, 1984;). This literature notes the experience of change in one's identity qualifies 'schizophrenia'

as a disorder of self-experience, (Bleuler, 1911; Sass, 2003) while others argue that identity is a fundamental channel to recovery involving '*rebuilding or redefining a positive sense of identity*' (Conneely et al., 2021, p. 309) this notion is supported in literature elsewhere (Hamm et al., 2018; Leamy et al., 2011; Shanks et al., 2013; Slade, 2009).

The latter seems to resonate in the case of the participants in the current study, where the notion of redefining a positive sense of self was described by all the participants; Matthew in his nod to 'evolution' and process of being '*born again*' and '*a new creature in God*' (Matthew lines 408-410), Noah's where he stated "*I had to have that experience of God to find out who I was really*" (Noah line 446), John where he described his experience as being '*very helpful to get me here*' (John line 197) and Peter where he accounts his experience as part of '*God's plan*' (Peter lines 372;373). Qualitative case analysis demonstrated the experience of 'spiritually advanced' individuals and individuals with 'psychosis' both display changes in their sense of self (Bhargav et al., 2015). In the authors view, they understood psychotic experiences as originating from a '*derangement of the personality*' characterised by a '*lack of sense of self*' and '*questioning existence*', with spiritual transformation involving a '*gradual thinning out of the selfish ego*' where '*individual consciousness merges into universal consciousness*'. Similar themes have been noted in literature elsewhere (Jackson & Fulford 1997; Stanghellini & Fusar-Poli 2012).

This seems to be contrary to the accounts offered by the participants in this study, in which their experience seemed to fit the authors description of 'spiritual transformation', where the participants described embarking on a journey where they were in total surrender to God and trusting in His plan and purpose for their lives. This suggests the participants had a framework they were working within when seeking to understand their experience, and it is this framework that provided the preservation of sense of self. This process of denial or disassembling of one's old self and making room for a new self, was described by Matthew explicitly in his interview where he referred to being '*born again*' (Matthew lines 408-409). This notion was also highlighted by the other participants within their accounts referring to the new self that was born as a result of their experience.

The way in which the participants within the study seemed to have framed their experience is supported in literature citing religion plays a role in reconstructing a sense

of self (Mohr & Huguelet, 2004) and within a systematic review and narrative synthesis exploring identity changes in 'psychosis' by Conneely et al., (2020), where highlighted themes surrounding '*personal growth*' and the role of 'psychosis' in leading to '*meaningful transformation in an individual's sense of self*' were noted. Other themes included understanding identity change as a '*consequence of loss*', this ties in with the sixth subtheme of 'powerlessness in adjusting through loss'. Within this subtheme participants described a sense of powerlessness and loss as precipitating factors in their experience. Research has highlighted the notion of stress as a precipitating factor for 'psychosis' (Corcoran et al., 2003) with an '*excess of adverse life events*' prior to onset cited also (McIntosh & Story, 2020; Morrison et al., 2003). Further evidence comes from Vallath & Ravikanthb et al., (2020) who explored the role of psychological trauma in psychosis. Psychological trauma was operationalised as '*an experience an individual has to any negative life event that is perceived as beyond one's resources to cope*' (p. 2)

The results from their IPA found loss to be a central contributor to the onset and maintenance of 'psychotic disorder', with '*additive stressors*' being found to reduce participants coping resources leading to a worsening of symptoms. This supports the current research findings where it was an accumulation of stressors that the participants cited as factors in the lead up to their episodes. The participant's experience could be understood in the context of this as they were all vocal about their experiences of a build-up of stressors leading to the onset of their episode of 'psychosis'. In particular, the sense of feeling powerless and almost the depiction of the experience being *done to* them to some extent. The analysis uncovered the participants use of language to shed light on this, particularly of note were the uses of '*sudden*' and '*collision*' in both Noah and Peter's extracts respectively, lending to this heightened sense of powerlessness within their narratives.

There is an increasing awareness surrounding the relationship between trauma and 'psychosis' (Van Nierop et al., 2014; Varese et al., 2012). Research has demonstrated a high incidence of post-traumatic stress disorder (PTSD) in individuals who have a primary diagnosis of 'psychosis' (Frame & Morrison, 2001; Lundy, 1992; McGorry et al., 1991; Shaw & Bookless, 1997; Williams-Keeler et al., 1994) with further research suggesting those with a diagnosis of PTSD may go on to develop 'psychotic' experiences (Butler et

al., 1996). Kilcommons & Morrison, (2005) examined the prevalence of trauma exposure and PTSD among individuals with 'psychotic' diagnoses and found 94% of the participants reported experiencing at least one traumatic event throughout their lifetime, and over half (53%) met the DSM-IV criteria for current PTSD. When considering these findings alongside the current research in relation to this theme, all of the participants reported to have experienced what could be considered as a traumatic event prior to their experience of 'schizophrenia'. Although, the experiences of the participants within this study vary in terms of the specific 'triggers', such as John citing a relationship breakdown, and Matthew, Noah and Peter all mentioned bereavement, the role of distress or psychological trauma and the interplay with severe mental 'illnesses' has been documented within literature (Mueser et al., 2002) with the current research adding to the evidence based regarding 'psychosis' being trauma induced (Kilcommons & Morrison, 2005). The interplay between these areas is a complex one that would benefit from further exploration.

#### ***GET IV: 'Culture and Religion go together': "The Cultural and Spiritual Crossroad".***

The final GET centres on the culture and spiritual crossroad and the participants experience of being othered. It highlights the way in which the participants have understood their experience as an amalgamation of their Afro-Caribbean culture and spiritual beliefs which are viewed as inextricably linked. This is illuminated in the subtheme: 'The culture IS spiritual'.

Explanatory models of mental health are largely influenced by culture (Huguelet et al., 2011) and form our way of viewing and organising reality (Weiss & Somma, 2010) and therefore also how we understand and make sense of our lived experience within this. This is particularly true for the participants within the current study, who described ideas which convey that Afro-Caribbean culture cannot be separated from spirituality, and thus their interpretation of their experience considers this approach in the same token.

Afro-Caribbeans attributing a cultural or spiritual significance to their 'schizophrenia' or 'psychosis' has been cited within literature (Carter et al., 2016; McCabe & Priebe, 2004),

with the BPS (2017) report on 'Psychosis and Schizophrenia' echoing this sentiment: *'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'* (p. 55). Research has demonstrated for ethnic groups, religion is inextricably linked to their cultural traditions and their identity (Worland & Vaddhanaphuti, 2013). This is seen within an African framework where spirituality and religiosity comprise an essential dimension of their cultural heritage (Wane & Sutherland, 2010). Other studies in rural Jamaica attribute positive 'psychotic' symptoms to Obeah or one's soul falling out of alignment with God, which is thought to result in the devil occupying one's body (Arthur et al., 2010) resulting in the manifestation of mental 'illness'. Such literature highlights the narratives the participants described in relation to complexities regarding the amalgamation of the culture and the spiritual and coincides with their testimonies highlighted within this theme where culture and religion were inseparable.

This also ties in with the last subtheme 'culture and othering'. Within this subtheme the participants described their experience of being othered, some within their communities and others by the healthcare system. Research has indicated for individuals with a diagnosis of 'schizophrenia' behaviours in line with religious coping have been seen to be misdiagnosed as psychopathology (Menezes & Moreira-Almeida, 2010; Mohr et al., 2010). This understanding correlates with Noah's reference to his experience regarding the psychiatrist who stated: *"when Noah is about to get ill he starts praying too much"* (Noah lines 297-298). This highlights the view that permeates western philosophy illustrating what Fernando (2010) and Mills (2013) defined as psychiatric imperialism, which denotes the defining of one's experience in terms which disallow personal meaning. The sense of 'othering' described by the participants could be considered in this regard, where the participants described their interpretation of their experience was unwelcomed by both their native community and the Western community.

From a social psychological perspective, the concept of self/identity and what we know about ourselves is largely derived from others (Stets & Burke, 2003). Identity can be seen as continuously changing throughout one's life course and can be defined differently across many domains including culture, nationality and heritage (Abdulmagied, 2020). When considering social identity theory, and the role that group membership has on an individual's self-esteem both positively and negatively (Abdulmagied, 2020) we can

further enhance our understanding of this theme, particularly in relation to the participants sense of feeling othered.

Literature has shown that where there is disagreement within a social group this can lead to a lack of belonging which can result in discrimination and out-casting (Trepte, 2006). This is in line with the current theme where participants spoke to their experience of feeling othered by members of their cultural group as a result of their experience of 'schizophrenia'.

Moreover, it is worth noting, that within many Caribbean cultures, the prominence of religiosity means that 'schizophrenia' or symptoms akin to this diagnosis are at times believed to be a result of demon possession, black magic or witchcraft (Arthur et al., 2010; Ellis, 2012; Incayawar et al., 2009; Olmos & Paravisini-Gebert, 2011; Weiss, 1997). Such beliefs then go on to promote fear and avoidance of those who are 'mentally ill' resulting in a stigmatisation (Campbell-Livingston, 2016). Such attitudes play a significant role in how 'mental illness' is viewed (Ellis, 2012) and consequently, those diagnosed with a 'mental health disorder' would be stigmatised and socially rejected (Olmos & Paravisini-Gebert, 2011). This could be extended to understand how othering may have been experienced by the participants within this study. Particularly of note is Noah's narrative where he stated the community was *"Not on your side regarding your mental health problem because that's where they've that's where it's been taught. That's where they've been brought up"* (Noah lines 542-544). This testament was also shared by Matthew who confirmed his culture would *"immediately see it ('schizophrenia') as a negative thing"* (Matthew line 264) and Peter's exclusion resulting in him having to navigate his experience independently: *"me against all the things"* (Peter line 187). This highlights the deeply entrenched views regarding the origin of 'schizophrenia' within Afro-Caribbean culture and how it manifests in the beliefs of the community and its subsequent treatment of those who have a schizophrenia diagnosis and those who are considered 'mentally ill'.

## LIMITATIONS

The selected methodology, IPA, was chosen to explore the lived experience of 'schizophrenia' for those identifying as Afro-Caribbean Christians. This section will consider the inherent limitations of IPA and the limitations of the current research.

### Limitations of IPA

As a novice qualitative researcher, my experience of implementing IPA was enriching in that I was able to fully immerse myself in the worldview of my participants to examine the experience of 'schizophrenia'. I found the practice of IPA co-operated well with my CoP trainee identity and experience in previous clinical practice.

IPA however, has been critiqued for its focus on language (Willig, 2008). Its reliance on the content of language can potentially restrict the researcher's ability to capture the various levels and nuances that make up an individual's lived experience. For instance, the non-verbal cues are unable to be captured at a transcript or analysis level. An additional step which considers the different levels of communication and how a description of a phenomena is being conveyed (other than through words) within this could add a greater level of depth and understanding regarding the experience described.

Van Manen (1997) in a similar vein criticised IPA for lacking phenomenological depth, cautioning against its adherence to prescriptive analytical steps. It could be argued that the rigidity of the analytical steps are too rigid a structure to fully illuminate the participants experience of 'schizophrenia'. This critique of IPA as phenomenologically tenuous is shared by Zahavi, (2020).

It is possible my visibly apparent shared characteristics with the participants and my role as part of the healthcare profession created a tension which may have affected the current research interviews. The adverse experiences of black services users within the healthcare system is widely cited in literature (Halvorsrud et al., 2018; Lawrence et al., 2021; Mfoafo-M'Carthy, 2014; Morgan et al., 2004; Payne-Gill et al., 2021) thus it is

possible if I was being viewed as an extension of these systems, this may have had an impact on the language the participants used to convey their experience, the content they disclosed and therefore the subsequent interpretations which were made.

#### Limitations of the current research:

Returning to Yardley's (2017) guiding principles for quality in qualitative research the study could be critiqued in a few ways. Whilst the research adopted a phenomenological positioning, and every attempt was made to bracket including the use of a reflective journal. It is important to understand the limits of interpreting one's experience and the experience of the researcher within this dynamic. As participant experiences are interpreted in a subjective manner, my worldview would have played a role within this process as another researcher may have interpreted the same data in a different way (Smith et al., 2009).

In addition, whilst IPA does not consider generalisability as part of its aim, but rather respects the idiosyncratic nature of the individual experience, the current study population only included men's experiences. While this produced meaningful research, it further highlights the considerably higher rates of 'schizophrenia' within Afro-Caribbean men in particular (Ngaage & Agius, 2016). Further research would benefit from exploring the experience of 'schizophrenia' for Afro-Caribbean Christian women in order to widen the perspective.

The study may also be critiqued in reference to the number of interviewees. There exists a dilemma within qualitative research regarding when data saturation has been achieved (Bowen, 2008; Kerr et al., 2010). The aim of interpretative phenomenology is its focus on the idiosyncratic subjective accounts thus, saturation is not considered one of its objectives (Hale et al., 2007). Therefore, the sample size is in keeping with the chosen methodology despite the sampling limitations. Moreover, the themes uncovered from the analysis may speak to the difficulties experienced when recruiting. The participants reliance on their faith as an intervention and their experiences of feeling unheard by HCPs may have played a role in their reluctance to engage. Moreover, reluctance to engage with the present study may also speak to the ongoing hostility between black service users



and the mental healthcare system. Thus, If the study was viewed as representing the healthcare profession this may also have impacted recruitment.

The current research could also be critiqued for its focus on Christians as a general homogenous group. It could be argued that members belonging to the various sects of Christianity may experience the phenomena of 'schizophrenia' in different ways. For instance, in Matthew's interview, he spoke to his orientation being rooted within a Pentecostal belief system and how this played a role in how he viewed and interpreted his experience. An area for future research could focus on the specific denominations and how the experience of 'schizophrenia' may or may not vary in light of the different perspectives that are adopted across the sects.

As outlined in the methodology chapter, the current research did not specify for exclusion on the basis of time of since experience (or 'diagnosis') given the focus was surrounding the lived experience as subjectively felt by the participants. However, it is worth mentioning that it has been documented within the literature the impact that time has on memory and the interpretation of a phenomenon (Inda et al., 2011; McGaugh, 2000). The passage of time may have impacted the recollections offered by the participants within the present study and therefore subsequently influenced the findings. Moreover, given the range between the participants initial experiences (3.5 years to 26 years) it could be argued that the socio-political landscape concerning race, religion and mental health from 1997 to 2020 has evolved widely, both in its conceptualisation of mental health as well as its views on religion and race. These changes in social contexts could have had an impact on how the participants experienced the phenomenon of 'schizophrenia' which may have impacted the research findings.

With reference to the current paper, mental health service delivery in the 1990s compared to the later part of the 2000s would differ widely in its treatment provision, e.g., the closure of old asylums/care being moved into the community (Salisbury et al., 2016), the endorsement of increasing access to talk therapies (Mechanic, 2007) as well as the World Health Organisation's promotion of improving treatment and care, and safeguarding human rights of service users (Funk et al., 2010). Existing within these contexts may have had an impact on the participants experience of 'schizophrenia', therefore, it would be

worth considering the differences that exist between the participants in this regard and how this may have potentially had an influence.

In a similar vein, demographic variables were also not considered as part of the data collection process. As discussed, homogeneity is an important factor within IPA research, and it is possible that the lack of consideration for demographic variables may have brought the homogeneity of the research into question. As a novice qualitative researcher this is an area that was overlooked. Upon reflection consideration of demographic variables may have allowed for a deeper and more focused exploration of the phenomenon, nevertheless it is important to acknowledge the diversities of opinion and experience that may exist even within a shared experience.

#### Implications for counselling psychology and allied professionals

As demonstrated there exists a wealth of research highlighting the excessive rates of 'schizophrenia' diagnosis among those of Afro-Caribbean heritage, with many belonging to this group attributing a spiritual or cultural significance to their experience. The current research aimed to fill the gap in literature and contribute to widening the knowledge base supporting cultural provision in clinical practice for counselling psychologists and other allied professionals.

In order to be ethically sound practitioners, one must aim to meet the diversity of need reflected in the various presentations that present across ethnic groups within clinical practice. The analysis from the current study highlighted the complexity and nuances to Afro-Caribbean Christians interpretation of their experience of 'schizophrenia'. The first GET 'God as a healer' suggests the reliance that Afro-Caribbean Christians have on their faith beliefs as a primary intervention. As such, clinicians should seek to incorporate spirituality assessment and an exploration of explanatory beliefs regarding 'schizophrenia' and other mental health 'disorders' as a minimum standard. Exploring the possible tensions that exist for Afro-Caribbeans within healthcare systems is an area ripe for exploration and would potentially improve the clinical outcomes for this group who have continuously been shown to have poorer treatment outcomes.

Supportive treatment pathways could be achieved by devising a set of guidelines that consider religious and cultural beliefs at an assessment and treatment level and how these views are manifesting for the client and the role this plays within the therapy room. It is the responsibility of all clinicians to be committed to offering a service which is adapted to the clients subjective and individual needs. CoP commitment to social justice and subjectivity lend well to facilitating the change needed within mental health provision. Through dissemination and further research these essential issues could be addressed, as stated by Allen & Khan (2014), having an understanding of *'Christian healing practices and/or the epistemological framework can be a powerful psychological tool for holistic health and wellbeing'*.

Seeing that the findings of the current research indicated the experience of 'schizophrenia' being a transformative one that ties into the process of adjustment, it is imperative that clinicians take an approach which considers the process and impact of change. Current clinical practice considers the role of loss and grief and the impact on the self, it would be key for CoP and allied professionals to consider 'change' and adjustment in reference to receiving a diagnosis of 'schizophrenia' and what this means for the individual and the consequences of othering from the community and othering of the self. If concerns such as this present within the therapy room, it would be vital for intervention to be delivered in a sensitive manner as to not contribute further to the clients feeling of being othered. Psycho-education leaflets or resources could be co-produced with service users/experts by experience and disseminated to normalise facets of the lived experience and contribute to reducing the stigma.

To this end, where practitioners are adequately trained regarding cultural practices would serve beneficial in increasing the quality of meaningful healthcare provided for this population. Through this, a greater understanding will be obtained which has promising implications for mental health services, allowing for a greater collaborative working between mental health services and pastoral care professionals in order to create organisations that meet the cultural, spiritual and individual needs of service users. Thus, allowing for the development of innovative and collaborative care models which value holistic person-centred care.

### Considerations for further research

Based on the findings of the current study, further research could benefit by considering how Afro-Caribbean Christians with a diagnosis of 'schizophrenia' view and engage with mental health services. The current study revealed a lack of 'faith' in western based psychological interventions as meaningful resources for coping with 'schizophrenia'. Further research exploring these beliefs may shed light on the way in which modern psychology can collaborate with pastoral care to make for an inclusive mental healthcare system that is accessible and beneficial for all and reduces the global burden of disease akin to 'schizophrenia'.

### Conclusions

The results of the current study provide new and meaningful insights into the lifeworld's of Afro-Caribbean Christians experience of 'schizophrenia'. For the participants, 'schizophrenia' marked a period of significant surrender to God as the source of their healing and source of their insight in how to navigate their experience. In exploring the lived experience of 'schizophrenia' for Afro-Caribbean Christians the research highlighted the fundamental role one's faith and religious orientation has on both the interpretation of an experience and the subsequent help seeking behaviours. The implications of the current research for CoP and other allied professionals should consider the collaboration of religious and cultural perspectives within clinical settings to commit to working in an empowering way, which embodies the core values of social justice and subjectivity.

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## APPENDICES

### Appendices A – Ethic review decision letter

#### School of Psychology Ethics Committee

#### NOTICE OF ETHICS REVIEW DECISION LETTER

**For research involving human participants**

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

**Reviewer:** Please complete sections in **blue** | **Student:** Please complete/read sections in **orange**

#### Details

<b>Reviewer:</b>	Please type your full name <b>Hannah Sela</b>
<b>Supervisor:</b>	Please type supervisor's full name <b>Claire Lewry</b>
<b>Student:</b>	Please type student's full name <b>Maelaudene Campbell</b>
<b>Course:</b>	Please type course name <b>Prof Doc Counselling in Psychology</b>
<b>Title of proposed study:</b>	<b>How do Afro-Caribbean Christians make meaning of their lived experience of "Schizophrenia"?: An Interpretative Phenomenological Analysis.</b>

#### Checklist

(Optional)

	YES	NO	N/A
Concerns regarding study aims (e.g., ethically/morally questionable, unsuitable topic area for level of study, etc.)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Detailed account of participants, including inclusion and exclusion criteria	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerns regarding participants/target sample	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Detailed account of recruitment strategy	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerns regarding recruitment strategy	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
All relevant study materials attached (e.g., freely available questionnaires, interview schedules, tests, etc.)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Study materials (e.g., questionnaires, tests, etc.) are appropriate for target sample	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clear and detailed outline of data collection	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Data collection appropriate for target sample	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If deception being used, rationale provided, and appropriate steps followed to communicate study aims at a later point	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
If data collection is not anonymous, appropriate steps taken at later stages to ensure participant anonymity (e.g., data analysis, dissemination, etc.) – anonymisation, pseudonymisation	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerns regarding data storage (e.g., location, type of data, etc.)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concerns regarding data sharing (e.g., who will have access and how)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Concerns regarding data retention (e.g., unspecified length of time, unclear why data will be retained/who will have access/where stored)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If required, General Risk Assessment form attached	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any physical/psychological risks to the researcher have been sufficiently considered and appropriate attempts will be made to minimise	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If required, Country-Specific Risk Assessment form attached	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
If required, a DBS or equivalent certificate number/information provided	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If required, permissions from recruiting organisations attached (e.g., school, charity organisation, etc.)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
All relevant information included in the participant information sheet (PIS)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information in the PIS is study specific	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Language used in the PIS is appropriate for the target audience	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All issues specific to the study are covered in the consent form	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Language used in the consent form is appropriate for the target audience	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All necessary information included in the participant debrief sheet	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Language used in the debrief sheet is appropriate for the target audience	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Study advertisement included	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Content of study advertisement is appropriate (e.g., researcher's personal contact details are not shared, appropriate language/visual material used, etc.)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Decision options

<b>APPROVED</b>	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.
<b>APPROVED - BUT MINOR AMENDMENTS ARE REQUIRED <u>BEFORE</u> THE RESEARCH COMMENCES</b>	In this circumstance, the student must confirm with their supervisor that all minor amendments have been made <b><u>before</u></b> the research commences. Students are to do this by filling in the confirmation box at the end of this form once all amendments have been attended to and



	<p>emailing a copy of this decision notice to the supervisor. The supervisor will then forward the student's confirmation to the School for its records.</p> <p><b>Minor amendments guidance:</b> typically involve clarifying/amending information presented to participants (e.g., in the PIS, instructions), further detailing of how data will be securely handled/stored, and/or ensuring consistency in information presented across materials.</p>
<p><b>NOT APPROVED - MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED</b></p>	<p>In this circumstance, a revised ethics application <b><u>must</u></b> be submitted and approved <b><u>before</u></b> 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.</p> <p><b>Major amendments guidance:</b> typically insufficient information has been provided, insufficient consideration given to several key aspects, there are serious concerns regarding any aspect of the project, and/or serious concerns in the candidate's ability to ethically, safely and sensitively execute the study.</p>

## Decision on the above-named proposed research study

Please indicate the decision:	APPROVED - MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES
-------------------------------	--

## Minor amendments

Please clearly detail the amendments the student is required to make

1. Raw data must be stored separately to the anonymised data so that they cannot be associated.
2. Clarification is needed to indicate that all data will be stored only on UEL OneDrive and not on any personal accounts.
3. Clarification is needed regarding how long anonymised transcripts will be kept for.
4. Clarification is needed regarding what the researcher means by data being kept for 'future research use'.
5. Evidence that the Hearing Voice Network will likely support recruitment attempts must be included as an appendix.
6. Question 3 of the Interview Schedule (Appendix D) needs to be rephrased.

*Please see the comments in the application form for more details*

## Major amendments

Please clearly detail the amendments the student is required to make



--

<b>Assessment of risk to researcher</b>		
<b>Has an adequate risk assessment been offered in the application form?</b>	<b>YES</b> <input checked="" type="checkbox"/>	<b>NO</b> <input type="checkbox"/>
	If no, please request resubmission with an <u><b>adequate risk assessment.</b></u>	
<b>If the proposed research could expose the <u>researcher</u> to any kind of emotional, physical or health and safety hazard, please rate the degree of risk:</b>		
<b>HIGH</b>	Please <b>do not approve a high-risk</b> application. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not be approved on this basis. If unsure, please refer to the Chair of Ethics.	<input type="checkbox"/>
<b>MEDIUM</b>	Approve but include appropriate recommendations in the below box.	<input type="checkbox"/>
<b>LOW</b>	Approve and if necessary, include any recommendations in the below box.	<input checked="" type="checkbox"/>
<b>Reviewer recommendations in relation to risk (if any):</b>	Please insert any recommendations	

<b>Reviewer's signature</b>	
<b>Reviewer:</b> (Typed name to act as signature)	<b>Dr Hannah Sela</b>

<b>Date:</b>	<b>01/08/2023</b>
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***This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology 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 Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UEL's Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard.

### **Confirmation of minor amendments**

(Student to complete)

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

<b>Student name:</b> (Typed name to act as signature)	<b>Maelaudene Campbell</b>
<b>Student number:</b>	<b>2184887</b>
<b>Date:</b>	<b>04/08/2023</b>

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

## Appendix B – Risk assessment



Pioneering Futures Since 1898

### UEL Risk Assessment Form

Name of Assessor:	Maelaudene Campbell	Date of Assessment:	30/06/2023
Activity title:	Doctoral Research Project	Location of activity:	Microsoft Teams or face to face and voice recorded
Signed off by Manager: (Print Name)	Dr Claire Lewry	Date and time: (if applicable)	

Please describe the activity/event in as much detail as possible (include nature of activity, estimated number of participants, etc.). If the activity to be assessed is part of a fieldtrip or event please add an overview of this below:

Doctoral research project exploring Afro-Caribbean Christians lived experience of Schizophrenia. Research will involve participants taking part in a 60–90-minute interview surrounding their lived experience of diagnosis and exploring how they made meaning of their experience as it relates to their culture and faith. The estimated number of participants is between 6-8 and data will be collected remotely via Microsoft team video call or face to face and voice recorded

#### Overview of FIELD TRIP or EVENT:

Recorded interviews for doctoral research as part of the Professional Doctorate in Counselling Psychology.

#### Guide to risk ratings:

a) Likelihood of Risk	b) Hazard Severity	c) Risk Rating (a x b = c)
1 = Low (Unlikely)	1 = <u>Slight</u> (Minor / less than 3 days off work)	1-2 = <u>Minor</u> (No further action required)
2 = Moderate (Quite likely)	2 = Serious (Over 3 days off work)	3-4 = Medium (May require further control measures)
3 = High (Very likely or certain)	3 = Major (Over 7 days off work, specified injury or death)	6/9 = High (Further control measures essential)

### Hazards attached to the activity

Hazards identified	Who is at risk?	Existing Controls	Likelihood	Severity	Residual Risk Rating (Likelihood x Severity)	Additional control measures <u>required</u> (if any)	Final risk rating
Potential distress inspired by retelling potentially difficult experiences during research interviews.	Participants	Be vigilant of signs of distress during interview, ensuring to provide participants the opportunity to take a break from the interview and/or stop the interview. Providing participants with contact details for psychological support services.	2	1	1	Any issues will be discussed with DoS in supervision. Participants will also be provided with emergency numbers for the Samaritans and crisis services in the area	1

Potential distress inspired by listening to difficult experiences reported and observing potential distress in participants.	Researcher	Be mindful of own feelings, taking any concerns to supervision and personal therapy.	1	1	1	Inform colleague/friend/ DoS pre and post interview to ensure researcher safety.	1
Interviews/recruitment online then potential bandwidth interference.	Researcher/ Participant	Agree when starting interview that I will call participant back online if cut off.	1	1	1	Check bandwidth status, ensure computer is charged.	1

**Review Date**  
30/06/23

## Appendix C – Ethic amendments application

### School of Psychology Ethics Committee

#### **REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION**

For BSc, MSc/MA and taught Professional Doctorate students

**Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology**

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor or contact Dr Trishna Patel (Chair of the School Research Ethics Committee).

#### How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	When submitting this request form, ensure that all necessary documents are attached (see below).
4	Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: <a href="mailto:t.patel@uel.ac.uk">t.patel@uel.ac.uk</a>
5	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.
6	Recruitment and data collection are <b><u>not</u></b> to commence until your proposed amendment has been approved.

#### Required documents

A copy of your previously approved ethics application with proposed amendment(s) added with track changes.	<b>YES</b> <input checked="" type="checkbox"/>
Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc.	<b>YES</b> <input checked="" type="checkbox"/>
A copy of the approval of your initial ethics application.	<b>YES</b> <input checked="" type="checkbox"/>

#### Details

Name of applicant:	Maelaudene Campbell
--------------------	---------------------

<b>Programme of study:</b>	<b>Professional Doctorate in Counselling Psychology</b>
<b>Title of research:</b>	<b>Afro-Caribbean Christians experience of Schizophrenia</b>
<b>Name of supervisor:</b>	<b>Dr Claire Lewry</b>

## Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

<b>Proposed amendment</b>	<b>Rationale</b>
Advertise research on 'call for participants site', 'Eventbrite' and 'Reddit'	To extend data collection method to increase reach for participants.
Proposed amendment	
Proposed amendment	Rationale for proposed amendment
Proposed amendment	Rationale for proposed amendment

## Confirmation

<b>Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?</b>	<b>YES</b> <input checked="" type="checkbox"/>	<b>NO</b> <input type="checkbox"/>
--	---	---------------------------------------

## Student's signature

<b>Student:</b> (Typed name to act as signature)	<b>Maelaudene Campbell</b>
<b>Date:</b>	<b>09/02/2024</b>

## Reviewer's decision

<b>Amendment(s) approved:</b>	<b>YES</b> <input checked="" type="checkbox"/>	<b>NO</b> <input type="checkbox"/>
<b>Comments:</b>	Please enter any further comments here	
<b>Reviewer:</b> (Typed name to act as signature)	<b>Trishna Patel</b>	

<b>Date:</b>	<b>21/02/2024</b>
--------------	-------------------

## Appendices D – Change title request

### School of Psychology Ethics Committee

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

For BSc, MSc/MA and taught Professional Doctorate students

**Please complete this form if you are requesting approval for a 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 Application Amendment Form'.

#### **How to complete and submit the request**

1	Complete the request form electronically.
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 Dr Jérémy Lemoine (School Research Ethics Committee Member): <a href="mailto:j.lemoine@uel.ac.uk">j.lemoine@uel.ac.uk</a>
4	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.

#### **Required documents**

A copy of the approval of your initial ethics application.	<b>YES</b> <input checked="" type="checkbox"/>
--	---

#### **Details**

<b>Name of applicant:</b>	<b>Maelaudene Campbell</b>
<b>Programme of study:</b>	<b>Professional Doctorate in Counselling Psychology</b>
<b>Title of research:</b>	<b>How do Afro-Caribbean Christians make meaning of their lived experience of "Schizophrenia"?: An Interpretative Phenomenological Analysis.</b>
<b>Name of supervisor:</b>	<b>Dr Claire Lewry.</b>



## Proposed title change

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

<b>Old title:</b>	How do Afro-Caribbean Christians make meaning of their lived experience of “Schizophrenia”? An Interpretative Phenomenological Analysis.
<b>New title:</b>	“The only thing I could have done...was turn to God, cause only God could help me”. The lived experience of ‘schizophrenia’ for Afro-Caribbean Christians: An Interpretative Phenomenological Analysis.
<b>Rationale:</b>	I am requesting a title change to reflect the voice of the participants.

## Confirmation

<b>Is your supervisor aware of your proposed change of title and in agreement with it?</b>	<b>YES</b> <input checked="" type="checkbox"/>	<b>NO</b> <input type="checkbox"/>
<b>Does your change of title impact the process of how you collected your data/conducted your research?</b>	<b>YES</b> <input type="checkbox"/>	<b>NO</b> <input checked="" type="checkbox"/>

## Student’s signature

<b>Student:</b> (Typed name to act as signature)	<b>Maelaudene Campbell</b>
<b>Date:</b>	<b>12/07/2024</b>

## Reviewer’s decision

<b>Title change approved:</b>	<b>YES</b> <input checked="" type="checkbox"/>	<b>NO</b> <input type="checkbox"/>
<b>Comments:</b>	<b>The new title reflects better the research study and will not impact the process of how the data are collected or how the research is conducted.</b>	
<b>Reviewer:</b> (Typed name to act as signature)	<b>Dr Jérémy Lemoine</b>	
<b>Date:</b>	<b>15/07/2024</b>	

## Appendices E – A few confirmation emails from organisations agreeing to advertise research.

**From:** BAATN Administrator <administrator@baatn.org.uk>

**Date:** Tuesday, 17 October 2023 at 06:10

**To:** Maelaudene CAMPBELL <u2184887@uel.ac.uk>

**Cc:** social@baatn.org.uk <social@baatn.org.uk>

**Subject:** Re: Doctoral Research Enquiry -

Hi Maelaudene

Thank you for your newsletter submission. This is to confirm your event advert has now been included in the newsletter due out on Monday 30th October

If you aren't subscribed to the BAATN mailing list and require to see the advert in the newsletter, I'd recommend signing up to our mailing list as we are unable to send confirmation once the newsletter has gone out.

I've placed the link below for your reference if needed.

[https://my.sendinblue.com/users/subscribe/js\\_id/3kku7/id/1](https://my.sendinblue.com/users/subscribe/js_id/3kku7/id/1)

Warm Wishes

Sam Pierre

**Administrator**

**BAATN - The Black, African and Asian Therapy Network**

**Please note that I work part-time. I will aim to respond to your query within 48 hours.**

**Email:** [administrator@baatn.org.uk](mailto:administrator@baatn.org.uk)

**Web:** [www.baatn.org.uk](http://www.baatn.org.uk)

**Connect with us**

**From:** Voice Collective <hello@voicecollective.co.uk>

**Date:** Thursday, 26 October 2023 at 15:34

**To:** Maelaudene CAMPBELL <u2184887@uel.ac.uk>

**Subject:** Re: Doctoral Research Enquiry

Hi Maelaudene,

Thanks very much for your email, and sorry for the delay in replying. We're a very small, part-time team at Voice Collective, so it can take us a while to get back to people. Someone will always respond when possible, though.

We'd be very happy to advertise this to our network through our newsletter. I hope to send out the next issue of the newsletter before November, and will include your research poster.

With best wishes,

Shanika

**From:** Catherine Perez Phillips [REDACTED]  
**Date:** Thursday, 19 October 2023 at 17:26  
**To:** Maelaudene CAMPBELL <u2184887@uel.ac.uk>  
**Subject:** FW: Doctoral Research Enquiry

Hi Maelaudene,

I've posted this on our Facebook page.

Kind regards

Catherine

Catherine Perez Phillips  
Deputy Director  
020 3960 7454  
020 3911 8845 Direct line

Healthwatch Hackney  
1st Floor, Block A  
St Leonard's Hospital  
Nuttall Street  
London N1 5LZ



**From:** peter bullimore [REDACTED]  
**Date:** Monday, 16 October 2023 at 09:16  
**To:** Maelaudene CAMPBELL <u2184887@uel.ac.uk>  
**Subject:** Re: Doctoral Research Enquiry

Hi Maelaudene  
I can advertise it in the National Paranoia Network Newsletter which goes global could you let me have a breakdown of the wording that you would like me to put in  
Best Wishes  
Peter

On Saturday, 14 October 2023 at 16:32:24 BST, Maelaudene CAMPBELL <u2184887@uel.ac.uk> wrote:

Dear Lyn & Peter

Good afternoon. I hope this email finds you really well.

My name is Maelaudene, I am a trainee Counselling Psychologist , and I am doing a research study to understand the cultural and religious understandings of schizophrenia. I am looking for Black/Afro Caribbean Christians who would like to take part in my doctoral research study.

I am enquiring about the possibility of my research being advertised in the Sheffield Hearing Voices Group/Newsletter, I do hope it is okay that I have reached out to you all via email, my apologies if I overstepped a boundary. It is hoped the research will make a positive difference in the lives of those living with a mental health condition, and to use to insights from the research to support services and practitioners in accommodating the diverse cultural and religious needs of its service users.

## **Appendices F – Participant information sheet**



### **PARTICIPANT INFORMATION SHEET**

**Title of research (How do Afro-Caribbean Christians make meaning of their lived experience of “Schizophrenia”?)**

**Contact person: Maelaudene Campbell (Researcher)**

**Email: [u2184887@uel.ac.uk](mailto:u2184887@uel.ac.uk)**

You are being invited to participate in a research study. Before you decide whether to take part or not, please carefully read through the following information which outlines what your participation would involve. Feel free to talk with others about the study (e.g., friends, family, etc.) before making your decision. If anything is unclear or you have any questions, please do not hesitate to contact me on the above email.

#### **Who am I?**

My name is Maelaudene. I am a postgraduate student in the School of Psychology at the University of East London (UEL) and am studying for a Doctorate in Counselling Psychology. As part of my studies, I am conducting the research that you are being invited to participate in.

#### **What is the purpose of the research?**

I am conducting research on what it is like to experience what is known as “Schizophrenia” as an Afro-Caribbean Christian. My aim is to understand the unique experience of Schizophrenia for Afro-Caribbean Christians, and to what extent their faith and culture played a role in the interpretation of their experience. It is hoped that this research will allow your voice and experience to be heard, to help promote change within mental health services and help create culturally inclusive healthcare systems that respect diverse cultural and religious beliefs in practice.

#### **Why have I been invited to take part?**

To address the study aims, I am inviting Afro-Caribbean Christians with a diagnosis of Schizophrenia to take part in my research. If you identify as: Afro- Caribbean, Christian, and have a diagnosis of Schizophrenia and are aged 18 years or above you are eligible

to take part in the study. As this study is about unique lived experience, you do not need to agree with the diagnosis, or identify as having “Schizophrenia” and I warmly welcome those who disagree/believe they have been misdiagnosed to also participate.

It is entirely up to you whether you take part or not, participation is voluntary.

### **What will I be asked to do if I agree to take part?**

If you agree to take part, you will be asked to take part in an informal conversation about your experiences of ‘Schizophrenia’ and how you feel your faith as a Christian as well as your Culture as a Black Caribbean may have shaped your experience/interpretation of your experience. The conversation will last approximately 60-90 minutes and will take place via Microsoft teams video call (or face to face if possible). The conversation will be audio recorded and stored securely in a password protected confidential account.

### **Can I change my mind?**

Yes, you can change your mind at any time and withdraw without explanation up to 3 weeks after the interview without disadvantage or consequence. If you would like to withdraw from the study, you can do so by sending an email to the research at the email: [u2184887@uel.ac.uk](mailto:u2184887@uel.ac.uk). If you withdraw, your data will not be used as part of the research.

Separately, you can also withdraw from the interview at any point and/or request to withdraw your data from being used even after you have taken part in the study, provided that this request is made within 3 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible).

### **Are there any disadvantages to taking part?**

Given the potentially sensitive nature of the research discussion around your lived experience, it is possible that you may find the conversation distressing, for example, when talking about difficult experiences you may have had. Your wellbeing and safety is the priority, and if you feel you are beginning to experience distress or upset, you may take a break and/or stop the conversation. In the event of any distress or upset please see below services you can contact for further support: Please see debrief sheet for further support and services.

**Heart & Mind** – a low-cost counselling service committed to providing psychological support online and across greater London in a confidential and safe environment.

Website: <https://www.heartandmind.london/low-cost-counselling>

Appointment Booking page: <https://bookwhen.com/heartandmind#focus=ev-srhe20230101000000>

Opening hours: Monday – Friday 08:00 – 17:00

**Associations of Christians in Counselling and Linked Professions:** Christian UK-Wide counselling organisations Facilitating quality counselling, psychotherapy, pastoral care.

Email: [office@acc-uk.org](mailto:office@acc-uk.org)

Website for further information: <https://www.acc-uk.org/find-a-counsellor/search-for-a-counsellor.html>

\*In an emergency, if out of GP hours, please **present to your local Accident and Emergency (A&E)** support desk or **call 999\***

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

This research is an opportunity to have your voice and experience heard. We hope the insights from this study will be used by both researchers and healthcare professionals to help in the development of culturally aware practitioners, able to tailor treatment to meet the diverse cultural and religious needs of service users accessing mental health services.

### **How will the information I provide be kept secure and confidential?**

Participants will not be identified by any of the data collected during the study or in any write up of the research. The consent forms including your name will be stored in a password protected file only accessible by myself and subsequently deleted upon completion. All information collected during the conversations will be anonymised through the use of pseudonyms to protect your identity. The data will be accessible by the supervisor and examiner upon request, but information identifying you will not be included. No personal information will be retained for further contact/research. All audio recordings gathered from the research will be stored on the University of East London's secure password protected One drive account and will only be accessible to the researcher. The recordings will be transcribed and anonymised to protect your identity and audio recordings will then be deleted. Anonymised transcripts will be sent to the supervisor and examiner upon request via the University of East London's secure email or via the Secure shared one drive. Anonymised transcripts may be retained by the researcher for further research but will not contain any of your identifiable information. All information will be kept confidential and anonymous, however if risk to self or others has been identified, confidentiality may be breached to protect the wellbeing of yourself and others, however you will be made aware of this prior.

For the purposes of data protection, the University of East London is the Data Controller for the personal information processed as part of this research project. The University processes this information under the 'public task' condition contained in the General Data Protection Regulation (GDPR). Where the University processes particularly sensitive data (known as 'special category data' in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the University processes personal

data please see [www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection](http://www.uel.ac.uk/about/about-uel/governance/information-assurance/data-protection)

### **What will happen to the results of the research?**

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL's online Repository. Findings will also be disseminated to a range of audiences (e.g., academics, clinicians, public, etc.) through journal articles, conference presentations, talks, magazine articles, blogs. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally. All identifying information will either be removed/replaced.

### **Who has reviewed the research?**

My research has been approved by the School of Psychology Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

### **Who can I contact if I have any questions/concerns?**

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Name: Maelaudene Campbell.

Email: [u2184887@uel.ac.uk](mailto:u2184887@uel.ac.uk)

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor Dr Claire Lewry, School of Psychology, University of East London, Water Lane, London E15 4LZ,

Email: [c.lewry@uel.ac.uk](mailto:c.lewry@uel.ac.uk)

**or**

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.

(Email: [t.patel@uel.ac.uk](mailto:t.patel@uel.ac.uk))

**Thank you for taking the time to read this information sheet.**

## Appendices G – Consent form



### CONSENT TO PARTICIPATE IN A RESEARCH STUDY

**Title of research (How do Afro-Caribbean Christians make meaning of their lived experience of “Schizophrenia”?)**

**Contact person: Maelaudene Campbell**

**Email: u2184887@uel.ac.uk**

	<b>Please initial</b>
I confirm that I have read the participant information sheet dated __/2024 for the above study and that I have been given a copy to keep.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation in the study is voluntary and that I may withdraw at any time, without explanation or disadvantage.	
I understand that if I withdraw during the study, my data will not be used.	
I understand that I have 3 weeks from the date of the interview to withdraw my data from the study.	
I understand that the interview will be recorded using Microsoft teams or Dictaphone if face to face.	
I understand that my personal information and data, including audio recordings from the research will be securely stored and remain confidential. Only the research team will have access to this information, to which I give my permission.	
It has been explained to me what will happen to the data once the research has been completed.	
I understand that short, anonymised quotes from my interview may be used in material such as conference presentations, reports, articles in academic journals resulting from the study and that these will not personally identify me.	
I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to.	
I agree to take part in the above study.	



Participant's Name (BLOCK CAPITALS)

.....  
.....

Participant's Signature

.....  
.....

Researcher's Name (BLOCK CAPITALS)

.....  
.....

Researcher's Signature

.....  
.....

Date

.....  
.....

## Appendices H – interview schedule



### **INTERVIEW SCHEDULE**

**1. In your own words, what is Schizophrenia to you?**

*-Prompts: How would you describe Schizophrenia to somebody? What words? Images? Come to mind?*

**2. How does that description of Schizophrenia tie in with your experience?**

*-Prompt: What was your experience of schizophrenia like for you? What was happening before? during?*

**3. Does your Christian faith shape how you interpreted your experience of schizophrenia? if so, how?**

*-Prompts: How was your faith/relationship with God before your experience? During your experience? After? Has anything about your faith changed since you first experienced Schizophrenia? If so, how? Did you engage in any spiritual practices during/before your experience? If so, why? And what did you think it would do?*

**4. How do you feel your culture as an Afro-Caribbean influenced your perspective/experience of Schizophrenia?**

*-Prompt: how do you feel as an Afro-Caribbean with a diagnosis of Schizophrenia? How do you think Afro-Caribbean culture views schizophrenia on a whole? Do you agree/disagree? If so, why?*

**5. Is there anything else that you would like to add at all that we didn't cover?**

*- Feedback re. interview experience:*

*-How did you experience the interview?*

*-Prompts: How do you feel after? When you say... what do you mean? Can you say more about...?*

## **Appendices I – Debrief form.**



### **PARTICIPANT DEBRIEF SHEET**

#### **Title of research (How do Afro-Caribbean Christians make meaning of their lived experience of “Schizophrenia”?)**

Thank you for participating in my research study on Afro-Caribbean Christians lived experience of Schizophrenia. This document offers information that may be relevant in light of you having now taken part.

#### **How will my data be managed?**

The University of East London is the Data Controller for the personal information processed as part of this research project. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. More detailed information is available in the Participant Information Sheet, which you received when you agreed to take part in the research.

#### **What will happen to the results of the research?**

The research will be written up as a thesis and submitted for assessment. The thesis will be publicly available on UEL’s online Repository. Findings will also be disseminated to a range of audiences (e.g., academics, clinicians, public, etc.) through journal articles, conference presentations, talks, magazine articles, blogs. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally. All identifying information will either be removed/replaced.

#### **What if I been adversely affected by taking part?**

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise distress or harm of any kind. Nevertheless, it is possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways, you may find the following resources/services helpful in relation to obtaining information and support:

**Heart & Mind** – a low-cost counselling service committed to providing psychological support online and across greater London in a confidential and safe environment.

Website: <https://www.heartandmind.london/low-cost-counselling>

Appointment Booking page: <https://bookwhen.com/heartandmind#focus=ev-srhe20230101000000>

Opening hours: Monday – Friday 08:00 – 17:00

**Associations of Christians in Counselling and Linked Professions:** Christian UK-Wide counselling organisations Facilitating quality counselling, psychotherapy, pastoral care.

Email: [office@acc-uk.org](mailto:office@acc-uk.org)

Website for further information: <https://www.acc-uk.org/find-a-counsellor/search-for-a-counsellor.html>

**The Awareness Centre:** Offer affordable low-cost counselling and psychotherapy, on a short- and long-term basis.

Tel. 020 8673 4545

Appointment Booking Email: [appointments@theawarenesscentre.com](mailto:appointments@theawarenesscentre.com)

Website for further information: <https://theawarenesscentre.com/therapy-services/low-cost-counselling/>

**The Guild of Psychotherapists:** Offer weekly psychotherapy for up to two years, either face-to-face at Nelson Square (47 Nelson Square, Blackfriars Road, London SE1 0QA) or remotely by phone or video link.

Tel: 020 7401 3370

Email: [clinic@guildofpsychotherapists.org.uk](mailto:clinic@guildofpsychotherapists.org.uk)

Website for further information: <https://guildofpsychotherapists.org.uk/psychotherapy/reduced-fee-clinic/#.ZHZreHbMJPY>

\*In an emergency, if out of GP hours, please **present to your local Accident and Emergency (A&E)** support desk or **call 999\***

### **Who can I contact if I have any questions/concerns?**

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Name: Maelaudene Campbell

Email: [u2184887@uel.ac.uk](mailto:u2184887@uel.ac.uk)

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor Dr Claire Lewry, School of Psychology, University of East London, Water Lane, London E15 4LZ,  
Email: [C.Lewry@uel.ac.uk](mailto:C.Lewry@uel.ac.uk)

**or**

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.  
(Email: [t.patel@uel.ac.uk](mailto:t.patel@uel.ac.uk))

**Thank you for taking part in my study**

# AFRO-CARIBBEAN CHRISTIANS' EXPERIENCE OF SCHIZOPHRENIA PARTICIPANTS NEEDED

## What is the research?

This study aims to explore Afro Caribbean Christians lived experience of schizophrenia.

## Why am I interested in speaking with you?

Research shows that Afro-Caribbeans are up to six times more likely to receive a diagnosis of Schizophrenia than their white counterparts, and for several decades the controversy regarding these statistics remains an ongoing debate.

Research has shown that "symptoms" associated with "schizophrenia" (i.e., seeing or hearing things others may not) are common experiences within the population, and that many Afro-Caribbeans often report a spiritual or cultural significance to their experiences. Despite this, these views are rarely considered by mental health services and practitioners.

It is hoped this research will give you the opportunity to have your voice and experiences heard, to inspire change within mental health services and promote a culturally inclusive healthcare system that respects the diversity of cultural and religious beliefs.

## What would your participation involve?

You will be invited for a 60minute informal conversation about your experience of "Schizophrenia" and how you feel your faith and culture has influenced your interpretation of your experience.

This study is about lived experience as uniquely experienced by you, therefore, I warmly welcome those who disagree with their diagnosis, believe they have been misdiagnosed and/or have alternative beliefs that go against the western view of schizophrenia.

## Will this be confidential?

The study is completely confidential and anonymous. This means your name or any information that could identify you will not feature in this study.

## Entry Requirements:

Are you 18+?

Are you a Christian?

Are you Afro-Caribbean?

Have you received a  
diagnosis of Schizophrenia?

Would you like your voice and  
experiences heard?

## Contact details

If you are interested and would  
like to participate (or to ask further  
questions) you are very welcome  
to contact me via email:

Maelaudene Campbell (Researcher)  
Email: [u2184887@uel.ac.uk](mailto:u2184887@uel.ac.uk)





# AFRO-CARIBBEAN CHRISTIANS' EXPERIENCE OF SCHIZOPHRENIA PARTICIPANTS NEEDED

## What is the research?

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## Why am I interested in speaking with you?

Research shows that Afro-Caribbeans are up to six times more likely to receive a diagnosis of Schizophrenia than their white counterparts, and for several decades the controversy regarding these statistics remains an ongoing debate.

Research has shown that "symptoms" associated with "schizophrenia" (i.e., seeing or hearing things others may not) are common experiences within the population, and that many Afro-Caribbeans often report a spiritual or cultural significance to their experiences. Despite this, these views are rarely considered by mental health services and practitioners.

It is hoped this research will give you the opportunity to have your voice and experiences heard, to inspire change within mental health services and promote a culturally inclusive healthcare system that respects the diversity of cultural and religious beliefs.

## What would your participation involve?

You will be invited for a 60-90minute informal conversation about your experience of "Schizophrenia" and how you feel your faith and culture has influenced your interpretation of your experience.

This study is about lived experience as uniquely experienced by you, therefore, I warmly welcome those who disagree with their diagnosis, believe they have been misdiagnosed and/or have alternative beliefs that go against the western view of schizophrenia.

## Will this be confidential?

The study is completely confidential and anonymous. This means your name or any information that could identify you will not feature in this study.



## Who am I?

My name is Maelaudene, I am a Trainee Counselling Psychologist, and as part of my Professional Doctorate in Counselling Psychology, I would like to speak with Afro-Caribbean Christians about their experience of Schizophrenia.

**Are you 18+?**

**Are you a Christian?**

**Are you Afro-Caribbean?**

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

**Would you like your voice and experiences heard?**

## Contact details

If you are interested and would like to participate (or to ask further questions) you are very welcome to contact me via email:

Maelaudene Campbell (Researcher)  
Email: [u2184887@uel.ac.uk](mailto:u2184887@uel.ac.uk)





## Appendices K – Audit Trail

88 Researcher: Hm ... and does your Christian faith... you've spoken about um unclear spirits  
 89 in the Bible and Paul's experience um... does your Christian faith shape how you  
 90 interpreted your experience of schizophrenia, and if so how?  
 91  
 92 Matthew: Yes I would say my faith has um shaped my interpretation and that I believe that  
 93 what the scriptures say to be true and I think that my experience proves it to be true,  
 94 because I didn't really notice anything outside of um... anything that happened to me that  
 95 couldn't be explained by the bible anyway so um whether or not it shaped my experience or  
 96 not I can't really tell to me it just seems to be the truth it's like if you are a psychologist  
 97 and you have your textbook is your experience of me shaped by what you've read or do you  
 98 consider that to be true...  
 99  
 100 Researcher: Hm...  
 101  
 102 Matthew: It's kind of hard to um... say.  
 103  
 104 Researcher: Hm... hm... that's interesting ... yeah... and... and how was your relationship or  
 105 your faith with God before your experience? You said that you weren't living a very good life  
 106 prior to that I'm curious about... how.. yeah how was your faith and relationship with God  
 107 before your experience?  
 108  
 109 Matthew: Well as I said I grew up a church person but um I wouldn't say I slipped totally  
 110 away I would just you know just little silly things hang around with the wrong people um I  
 111 know that it's not pleasing... it wasn't really pleasing to God you know we used to um... I'd  
 112 say maybe we'll do um... you know just foolish little things you know... hang around places  
 113 get into fights I'll be amongst people who would um... I'll be searching for people to you  
 114 know... even though I would say that it wasn't um it wasn't extreme you know not like I  
 115 badly hurt anyone or something but I was around people and around a culture that was  
 116 kind of wrong that I knew to be wrong so I knew that that path... I shouldn't really be on that

*Handwritten notes:*

- experiences does script the to be 'true'* (pointing to line 92)
- scripture guides / used as a guide to understand / make sense of experience* (pointing to line 92)
- faith based interpretation* (pointing to line 92)
- Bible as explanation of experience* (pointing to line 93)
- Repetition of the 'truth' suggests 'absolute' / there is no doubt in truth* (pointing to line 98)
- formative exp in church / committed to church?* (pointing to line 109)
- suggesting a slip / fall away from the faith? / when?* (pointing to line 110)
- lifestyle was not pleasing God before* (pointing to line 112)
- lifestyle was 'wrong' according to his faith / religion* (pointing to line 116)
- David's behavior* (written vertically on the left margin, pointing to lines 113-116)
- unstable environment* (written on the right margin, pointing to line 116)



117 path um but always always um had God in my life... I know because I knew it was wrong

118 you know as the bible says: "blessed is he who walketh not in the counsel of the ungodly

119 nor standeth in the way of sinners nor sitteth in the seat of the scornful, but his delight is in

120 the law of the Lord and on his law does he meditate day and night..." like that strengthens

121 me and I used to kind of... that's when I kind of would kind of switch more to meditating on

122 God's word and to stop walking in the counsel of the ungodly.

123 Researcher: Hm-mhm... yeah that's really... yeah... that's really interesting and what was

124 your relationship like during um when you decided to stop walking in the counsel of the

125 ungodly ...um yeah what was your relationship like during your experience? You mentioned

126 that you were fasting a lot and you had drawn inspiration from some of these figures in the

127 Bible, what was your relationship like during? Do you want to say a bit about that?

128 Matthew: During my...

129 Researcher: Yeah what was your faith and relationship with God like during your

130 experience would you say?

131 Matthew: I think I seemed to be rather close to God in that I feel I felt kind of close to the

132 spiritual world, you know, so I kind of felt close to God so I would say that um my

133 relationship was um was what would be a... what would be a close one... God is a healer he

134 says in his word so I know he would... I know he would heal me and um yeah yeah I felt

135 closer to God yeah. God is a healer... you know he says in his word that 'by his stripes we

136 are healed', so I knew that he would heal me. At first my faith was shaky so um it was

137 shaky so he didn't heal me but when I believed and trusted in him as a healer I knew he

138 would heal me and he did.

139 Researcher: Hm, and how about after?

140

141

142

143

144

145

Repetition

Time 7th Repetition

Heath  
said is  
God's word.

a change? in attitude?  
+ behavior?  
does what God wants?

suggesting he was busy + therefore not blessed  
+ experienced schizophrenia?

Use of  
scripture  
what author  
experience  
Contextual  
experience  
in religion  
Matthew  
in the scriptures

Repetition of  
'close' 'close'  
highlight 'heal'  
of relationship  
with God.

faith in  
God as a  
healer

belief is the  
scriptures as  
evidence  
you're used to  
back up belief.

'is'  
conviction  
in self

suggests a  
sense of  
certainty

Answer  
prayer?  
and one of his  
beliefs?

Repetition of  
'and as a healer'  
- character of God  
as a healer?

suggests  
condition to receiving  
healing?  
faith = healing  
no faith = no  
healing?

when he believed  
then he was healed.  
belief = healing from  
god

Repetition of  
'heal' / 'healer'



146 Matthew: After now well... it's like what happened to me I see as um a confirmation of um  
 147 these things that are in the Bible you know um of the existence of God and things like this  
 148 so (think it's good) and I'm I'm here I don't think I have any lasting... I don't... I don't see it as  
 149 a negative really I try and think of it in a positive way...  
 150 Researcher: And has anything about your faith changed since your experience of  
 151 schizophrenia and if so how?  
 152 Matthew: Faith change um... it just get stronger you know... I just think it's gotten  
 153 stronger... or um more... evolved you know... just stronger  
 154 Researcher: Hm.  
 155 Matthew: it's kind of like um when you've been through something with someone you kind  
 156 of get closer to them... it changes you you know it changes you. You become closer to them.  
 157 Kind of like that I would describe it...  
 158 Researcher: Yeah... so you think in this experience you've been through something with  
 159 God and now you've fostered a closer relationship with him?  
 160 Matthew: 'A Closer Walk With Thee'....  
 161 Researcher: Right...  
 162 Matthew: As the song goes...  
 163 Researcher: Hm-m ... okay ... nice... yes just a closer walk with thee! and I guess you've  
 164 touched on this a little bit um... but did you engage in any spiritual practices... um during or  
 165 before your experience and if so why and what did you think that would do? So I know you

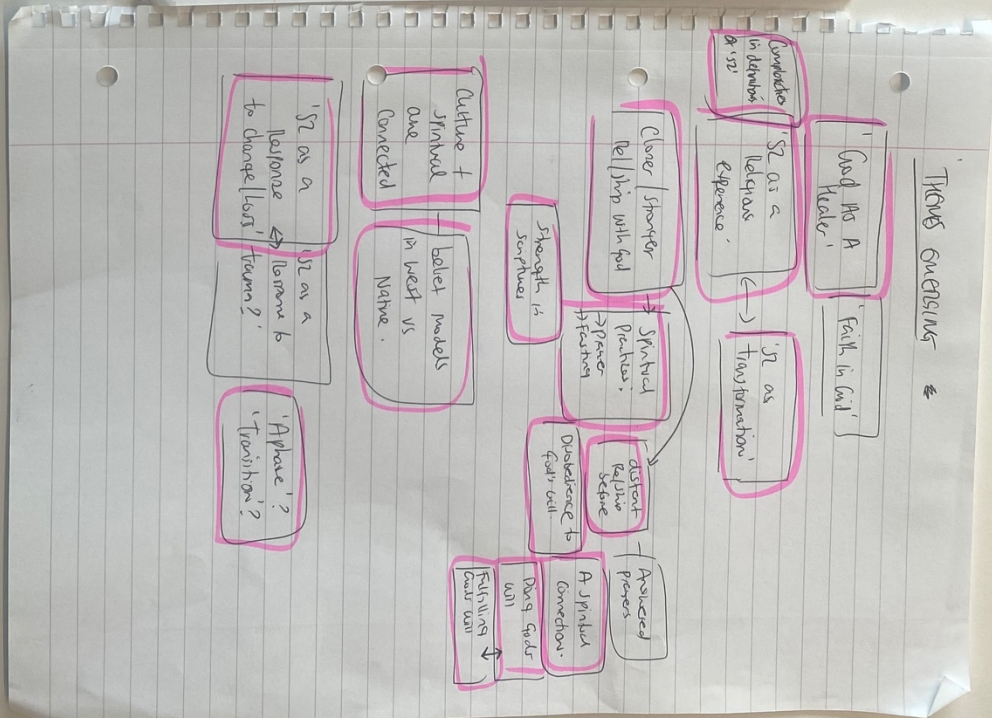
*Handwritten notes:*  
 - 'Confirmation' of his understanding of his faith? the Bible?  
 - experience is documented in the Bible?  
 - strengthened his belief in God?  
 - scriptures as guide to understand experience.  
 - experience confirms existence of God?  
 - Faith/belief framed as positive?  
 - when experience is a positive was faith/religious/secured allowed experience to be framed in a positive way.  
 - Penetration of stronger highlights depth of relationship  
 - suggestive of faith continuing to get stronger.  
 - suggestive of a 'change' in relationship -> evolved: improvement? development? a progression?  
 - 'With someone' he suggested he went through the experience with God.  
 - A change in self? 'evolved' -> a different person after the experience?  
 - God present throughout the entire experience?  
 - Penetration of 'closer' again highlights strength of relationship with God. during exp.

*Left margin notes:*  
 - 'Confirmation' of his understanding of his faith? the Bible?  
 - Faith framed in exp? as against previous experience?











## Themes - Penultimate (?)

(( Super & Sub  
themes ))

"GOD AS  
A HEALER"

"Closer to God"  
"Stronger Faith in God"

\* FAITH HEALS  
\* PRAYER  
\* FASTING  
\* READING  
SCRIPTURES  
\* CHARACTER OF  
GOD AS A HEALER.

\* STRONGER FAITH /  
TRUST IN GOD  
\* ESTRANGED RELATIONSHIP  
BEFORE 'D'  
\* DISOBEDIENCE vs  
OBEDIENCE.

'D' as  
"APHASE"

"The Culture & spiritual  
are connected"

\* 'A PHASE /  
ADJUSTMENT  
\* RESPONSE TO CULT  
\* ARGUMENT /  
RELATIONSHIP BREAKDOWN  
\* TRANSITION PERIOD /  
PHASE.

\* Culture + spiritual  
one 'one'  
\* West vs Native  
\* Strength drawn  
from the Community  
vs  
\* Othered by the  
Community

## Thener — Finalizing (1) ⑧

### 'GOD AS A HEALER'

- > Healing & God /  
Healing power of God (Faith).
- > Prayer & Fasting  
receiving healing.

### 'CLOSER RE/SKIP W/ GOD'

- > Distance before  
closeness
- > Fulfilling 'God's will,  
work & Purpose.

### 'SI' AS A TRANSFORMATIVE PHASE

- > A different Person /  
Change in self
- > Change through loss,  
trauma & bereavement /  
'Adjustment'

### 'CULTURE + SPIRITUAL'

- > Culture is spiritual.
- > Culture view vs  
West view dilemma (?)
- > Othering — self/  
Culture.



## Final Themes (Subject + sub) \*

### "GOD AS A HEALER"

- The healing power of faith in God
- The centrality of spiritual practices

### "SZ AS A TRANSFORMATIVE EXP"

- changing an a person
- powerlessness in adjustment through com.

### "CLOSER REL/SHIP w/ GOD"

- Distance comes before closeness
- Fulfilling God's will.

### "CULTURE & SPIRITUAL GROWING"

- The culture is spiritual
- Culture & othering.

Appendices L - Table 3: GETs and Subthemes and frequency.

GETs	Subthemes	Noah	Matthew	Peter	John
I cried unto the LORD, and he heard me: <i>"GOD as a Healer of schizophrenia"</i>	The healing power of faith in God.	✓	✓	✓	✓
	The centrality of spiritual practices.	✓	✓	✓	✓
'Just A Closer Walk with Thee': <i>"Schizophrenia' fostering closeness to the Creator"</i> .	Distance comes before closeness.	✓	✓	✓	✓
	Fulfilling God's will.	✓	✓	✓	✓
'The only thing I could have done...was turn to God, 'cause only God could help me': <i>"Schizophrenia as a transformative experience"</i> .	Changing as a person.	✓	✓	✓	✓
	Powerlessness in adjusting through loss.	✓	✓	✓	✓
Culture and Religion go together': <i>"The Cultural and Spiritual Crossroad"</i> .	'The culture IS spiritual'.		✓	✓	✓
	'Culture and othering'.	✓	✓	✓	✓