The Lived Experience of UK Forensic Carers of African-Caribbean Heritage Caring for Someone with Psychosis: An Interpretative Phenomenological Analysis

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Abstract

For more than six decades, African-Caribbean communities have faced mental health inequalities in the UK. This study focuses on carers of individuals detained in an NHS forensic mental health hospital (FMHH), most specifically on the experience of carers from racialised communities such as African-Caribbean heritage. This is because carers from African-Caribbean heritage are more likely to care for service users who are overrepresented in FMHH and have increased incidence of psychosis across all major psychotic disorders. To date, few studies have focused on forensic carers. The majority of research into caregivers' experiences supporting a service user with psychosis in forensic settings has focused on caregivers who were white European parents, mostly mothers, and therefore the evidence base is built on a particular political, economic and social and cultural context.

Therefore, the present qualitative study aimed to explore the lived experience of forensic carers of African-Caribbean heritage who support an individual with psychosis in an FMHH. Seven participants were purposively recruited and participated in semi-structured interviews. An interpretative phenomenological analysis found four superordinate themes: 1) The role is "too much for humanity": Emotional, physical and relational challenges, 2) Cultural and Community – Norms and Values, 3) It is a Terrible Battle Relating to Services and Professionals and 4) Ways to Survive the Emotional Demands of the Role.

The findings highlighted participants' caregiving roles impacted various aspects of their lives. Also, participants' caregiving behaviour and attitude within FMHH were influenced by culture and the social-political context of living in the UK. Furthermore, participants' relationship with forensic services and professionals was problematic, overshadowed by fear and mistrust given their experience of institutional racism. Additionally, a lack of information and power imbalance between carers, professionals and services acted as barriers to adequate care within FMHH. Caregivers used several strategies to survive the emotional demand of the role.

It is crucial that the needs and values of this group of carers are recognised to offer services tailored to cultural, political, and social contexts. Implications for clinical practice, service delivery, strengths, and limitations as well as future research directions are discussed within these contexts.

key words: ‘African-Caribbean’, ‘forensic carers’, ‘Psychosis’

Glossary List

Race: Race is a classification system that has been used to categorise groups of people based on common descent, physical appearance or heredity (Senior & Bhopal, 1994), as there is an assumption that genetic heritage is evident in physical characteristics. However, the concept of race has little scientific value as there is greater genetic variation within a group as opposed to between groups (Agyemang et al., 2005; Sheldon & Parker, 1992). Therefore, the division of humans, including caregivers, by race is flawed. Furthermore, the concept of race is related to slavery, racism, eugenics and Nazism, leading to discrimination (Essed, 1991; Fernando, 2017). Racial discrimination can be understood in the context of racialisation (Hughey & Jackson, 2017), this is whereby certain race / ethic identities (e.g., 'black race') are ascribed meaning which is shaped through history and politics.

Culture: Fernando (2014) described culture as "a flexible system of values and worldviews that people live by, and through which they define identities and negotiate their lives" (p. 12). Hence, culture is dynamic and difficult to define. Furthermore, it is no longer seen as something individuals and groups take on passively; instead, it is a product of the people (Fernando, 2014). Therefore, caregivers should not be categorised by their culture as the concept is changeable.

Ethnicity: An alternative way to categorise caregivers is through 'ethnicity' This concept offers more dimensions to a person's identity than their culture and racial background. Hall (1992) argued that ethnicity recognises, language, the place of history and culture in identity development. Thus, the definition of ethnicity also changes over time.

Psychosis: Psychosis is a term used to describe a range of serious MH conditions. These can be broadly categorised into non-affective and affective. The National Institute of Clinical Excellence (NICE; 2014) has separate guidelines for non-affective and affective psychosis, which have different treatments and psychological interventions. Non-affective psychotic disorders include ‘schizophrenia’, ‘schizoaffective disorder’, ‘schizophreniform disorder’ and ‘delusional disorder’. Symptoms are often termed as positive (hallucinations, delusion, thought disorder) and negative (social withdrawal, self-neglect, apathy; NICE, 2014). The diagnosis that is most representative of psychosis in Western psychiatry is schizophrenia.

Abbreviation

BAME: Black, Asian and Minority Ethnic

BPS: British Psychological Society

CaFI: Culturally adapted family interventions

CoP: Counselling psychology

DoH: Department of Health

FMHH: Forensic Mental Health Hospital

FMHS: Forensic Mental Health Services

FT: Family Therapy

IPA: Interpretative Phenomenological Analysis

MH: Mental Health

NHS: National Health Service

NICE: National Institute for Clinical Excellence

ONS: Office for National Statistics

SU: Service User

UEL: University of East London

UK: United Kingdom

WHO: World Health Organisation

Chapter 1 - Introduction

Chapter Overview

Carers from a Black, Asian and Minority Ethnic (BAME) background have been described as a 'hidden population' in the UK (Afiya Trust, 2008; Greenwood, 2018). This term is used the literature to refer to individuals who might not want to be found or contacted (Shaghaghi et al., 2011). Furthermore, BAME carers tend to face unequal opportunities, financial difficulties, social exclusion, discrimination (Beresford, 2008; Greenwood, 2018) and mental health (MH) inequalities (Nazroo et al., 2020).

This study focuses on carers of individuals detained in an NHS forensic mental health hospital (FMHH), most specifically on the experience of carers from racialised communities such as carers with African-Caribbean heritage. This is because carers from this community are likely to care for SUs in this setting since this group of SUs are overrepresented in forensic mental health services (FMHS; Coid et al., 2007; Landsberg & Smiley, 2001) and have increased incidents rate of psychosis across all major psychotic disorders (Fearon et al., 2006; Tortelli et al., 2015).

To date, few studies have focused on forensic carers. The majority of research into caregivers' experiences supporting a SU with psychosis in forensic settings has focused on caregivers who were white European parents, mostly mothers, and therefore the evidence base is built on a particular political, economic and social and cultural context (Dilworth-Anderson et al., 2002).

In the studies exploring the journey of forensic carers, their experiences seemed to vary from one caregiver to the next. For example, some of Ridley et al.'s (2014) participants reported their journey of being a carer started prior to the person they cared for accessing forensic services, others described stumbling into the role, and for some this role was "thrust upon" (Ridley et al., 2014, p., 37) them by services once the individuals were in FMHH.

Furthermore, the nature of the role has been described as something that is difficult to define as it was neither constant nor fixed but has instead changed over the years and for some became a lifetime role (Ridley et al., 2014). The role requires caregivers to be responsive not proactive as they endeavour to meet the needs of their relative. The role involves both offering practical support (visits, taking items such as food, advocating for the relative by accessing legal services) and providing emotional support (Ridley et al., 2014; Greenwood, 2018). However, researchers clearly agree that the role of caregiver within forensic setting is demanding and the degree of burden experienced due to stress is multidimensional. This is because caregivers in this setting might be considered vulnerable because in addition to dealing with MH difficulties, they are exposed to violent behaviour or deal with criminal offences (Copeland, 2007; Maclnnes & Watson, 2002).

The impact of the role, often referred to as caregiving burden (objective and subjective), has been the primary focus within the literature (Askey et al., 2009). Objective burden includes physical illness and financial burden related to difficulties maintaining employment (Ridley et al., 2014). Subjective burden considers the psychological impact of the role including managing difficult emotions. The degree and intensity in which these emotions are experienced vary depending on the caregivers' circumstances, such as, outset of the illness, receiving a diagnosis of schizophrenia, and managing violent behaviour and SU's referral to FMHS (Nordström et al., 2006). Caregivers reported feeling shock, anguish, loss, anxiety, confusion, anger, and self -blame (Ferriter & Huband, 2003; Maclnnes et al., 2013; Maclnnes & Watson, 2002; Ridley et al., 2014).

In addition, caregivers experienced increased rates of MH difficulties, suicidal behaviour and fatigue compared to non-carers (Kuipers et al., 2010; Stansfeld et al., 2014) and these stressors may be understood as "secondary trauma" (Wyder & Bland, 2014, p., 181).

The Department of Health (DoH) recognised the burdensome nature of the role and the inequalities forensic carers from African and African-Caribbean background are facing and suggested in its policies and guidelines that we must understand and address their needs (DoH, 2005, 2009, 2011; NHS England, 2018). The purpose of this study is to explore the experiences of caregivers of African-Caribbean heritage who are supporting individuals with a diagnosis of psychosis in an NHS FMHH.

Organisation of this Research

The first part of this chapter will provide a critique of relevant terminology. The context of being a BAME carer in the UK is discussed before presenting the rationale for focusing on carers of African-Caribbean heritage. This group's social and political history within the UK is reviewed as well as the benefits of family involvement, the challenges of caring for a SU with a diagnosis of psychosis, and the challenges arising when the SU is in FMHS. Furthermore, the roles that families play in SU's recovery are presented, alongside the inconsistencies within FMHS' guidelines and policy related to families in SU's care.

The second part of the chapter critically reviews the literature on caregivers' experience of supporting a SU in FMHS. It also critiques literature on differences in caregiving between ethnic groups. The rationale for this research and its potential contribution to clinical practice, counselling psychology (CoP) and allied professionals are also discussed.

Key Concepts and Terms

Terms used within this research will be explained and critiqued in this section.

Carers, Forensic Carers or Family Members

Various terms are used to describe the sample population for this study (NHS England, 2018; Ridley et al., 2014), including 'carers', 'informal care', 'caregiver', ‘relatives’, and in more recent years ‘forensic carers’ (Ridley et al., 2014). The term ‘forensic carer’ was coined to refer to families and friends of SU detained in secure units (McKeown et al., 2019) to highlight the SU’s setting in which carers provide support. NHS England described forensic carers as “relatives and friends who play a role in the care of those who use secure mental health services” (2018, p. 9). The term ‘carer’ is tied to legislation of the Care Act (2014), which protects carers’ rights.

However, there is proposal for the term to be replaced as it fails to assist those who need it (Molyneaux et al., 2011), given it does not encompass the emotional and relational factors that motivate individuals to provide care (Netto, 1998). For instance, some carers may prefer to describe themselves with their relational roles, such as parent or friend, (McKeown et al., 2019). Others have argued the term ‘carer’ is culturally bound and, therefore it might mean different things for people of differing heritages (Gunaratnam, 1997).

Additionally, in some cultures and languages, the term does not necessarily translate, causing confusion (Afiya Trust, 2008; Greenwood, 2018). The implication for caregivers not identifying with the title of ‘carer’ is that they might not utilise available services (O’Connor, 2007; Greenwood, 2018). Therefore, the DHSC (2018) has revised the definition of carer to, “those who care for and support another regardless of whether they identify as a carer” (p. 758).

The terms ‘carers’, ‘forensic carers’, and participants’ relational descriptions, such as grandparent, are used interchangeably in this study. Those who are accessing services are described as ‘SU’ and ‘family member’ using their relational role instead of ‘patient’. SU’ was chosen as it captures individuals who are in the community but have resided in FMHS in the past year as their caregivers are included in this study.

Black Caribbean or African-Caribbean Heritage?

Participants in this study have been defined by various terms, including ‘Black and Minority Ethnic’ (BME), 'Black, Asian and Minority Ethnic (BAME)', ‘Afro-Caribbean’, ‘African-Caribbean’ and ‘Black’. In the current study caregivers were not identified (where possible) according to their race as defined by the Office for National Statistics (ONS; such as ‘Black Caribbean’) as the concept of race is considered flawed with no scientific base (Agyemang et al., 2005; Sheldon & Parker, 1992). Further, the term has political connotations and is attached to a history of racist oppression, both during slavery and British colonialism, when individuals’ culture, heritage and beliefs were overlooked. Researchers suggest using precise, descriptive terms such as ‘first generation African-Caribbean’ (Agyemang et al., 2005).

The term ‘African-Caribbean’ is used to describe people who are now living in the UK with African ancestral origins who migrated via the Caribbean islands or parents, or had grandparents born in the Caribbean. However, in the studies conducted in the UK, this term has been applied inconsistently and interchangeably as it included those of West African descent. However, West African and African-Caribbean people differ in their languages, diets, beliefs and migration histories (Agyemang et al., 2005), which has been recognised by the UK census (ONS, 2011). This research included forensic carers, who identified as having African-Caribbean heritage. When citing literature, the authors’ terminology was used.

Schizophrenia or Psychosis?

FMHS within the NHS are organised around psychiatric diagnostic frameworks such as the International Classification of Diseases - version 10 (ICD-10: World Health Organisation, 1992). Psychosis is a term used to describe a range of serious MH conditions. These can be broadly categorised into non-affective and affective.

The National Institute of Clinical Excellence (NICE; 2014) has separate guidelines for non-affective and affective psychosis, which have different treatments and psychological interventions. Non-affective psychotic disorders include ‘schizophrenia’, ‘schizoaffective disorder’, ‘schizophreniform disorder’ and ‘delusional disorder’. Symptoms are often termed as positive (hallucinations, delusion, thought disorder) and negative (social withdrawal, self-neglect, apathy; NICE, 2014). The diagnosis that is most representative of psychosis in Western psychiatry is schizophrenia.

However, the reliability and validity of these classifications has been questioned (Boyle 2002; Read, 2013; Timmi, 2014). The UK's Critical Psychiatry Network (CPN) advocates for diagnosis of psychotic disorders to be abolished, suggesting that it is not scientific, but rather harmful, as it leads to stigma (CPN, 2011) particularly for those within African-Caribbean communities due to institutional racism (Fernando, 2017). This will be discussed in detail in the section titled ‘Experiences of carers of African-Caribbean heritage are more challenging’.

Due to the limitations of schizophrenia classification systems, the term ‘psychosis’ is commonly used to reduce the emphasis on diagnosis. However, it is used in conflicting ways in the literature.

Some authors have highlighted the term psychosis has been described as a generic, broader classification of schizophrenia (Boyle, 2006; Longden et al., 2012), as per the NICE guidelines, while others defined it as something that comes before a diagnosis of schizophrenia or even as an independent concept (Boyle, 2006). However, the term psychosis carries the assumptions and medical language associated with schizophrenia and is used commonly in MH services (Boyle, 2002).

In the present study, the NICE guidelines (2014) description of psychosis are used (NICE, 2014), which refer to non-affective psychotic disorders including ‘schizophrenia’, ‘schizoaffective disorder’, ‘schizophreniform disorder’ and ‘delusional disorder’. The limitations of these diagnoses as well as the concept of psychosis are acknowledged.

Context

The purpose of this section is to discuss the importance of BAME carers in the UK and their experience of providing care. It provides the rationale for focusing on forensic carers with African-Caribbean heritage who are caring for a relative with diagnosis of psychosis. This group’s social and political history within the UK is reviewed. It will outline the impact of caregiving in psychosis before providing an overview of FMHS, and the circumstances in which SUs are admitted. Lastly, policy, guidelines, provision for forensic carers involvement and support will be discussed and evaluated.

BAME Carers in England

The 2021 census analysis identified 5.0 million people in England and Wales provide informal care (ONS, 2021). Surprisingly, the number of unpaid carers in England and Wales has reduced from the last 2011 Census (5.8 million). This might be because the number of caregivers providing lower hours of care have reduced (Carers UK, 2023). However, Carers UK research estimated the number of informal carers could be as high as 10.6 million (Carers UK, 2023). Furthermore, there is an apparent surge in the number of carers providing extended hours of care in the recent 2021 census (Carers UK, 2023). For instant, a quarter of a million unpaid carers provide 20-49 hours of care (Carers UK, 2023). These figures are concerning because of the negative impact the role has on the overall life of caregivers including their physical health, mental health, and their ability to manage their role and work.

According to Carers UK Census, there were almost 600,000 BAME carers in 2012, a 20% increase from 2001. This was more rapid than for the general carer population (Carers

UK, 2013). The rise might be understood in the context of better record due to improved definitions and awareness (Chemerynska et al., 2021). Some 56% of BAME carers spent 20 or more hours per week caring compared to 47% for White equivalents (Carers UK Policy Briefing, 2015; NHS Information Centre, 2010). Hence, caregivers make a vast economical contribution to the UK (DoH, 2010; Guberman et al., 2003), saving the government £132 billion per year (Carers Trust, 2015).

In the past, policies have positioned carers as co-workers, clients and, in recent years, resources (Glendinning & Arksey, 2008). Viewing carers as a resource means services and government are concerned about their wellbeing so they can maintain their role (Glendinning & Arksey, 2008). To better support carers, we must recognise that their circumstances and needs are diverse; there is no such thing as a ‘typical carer'. Individual differences such as age, gender, sexuality, disability, ethnicity, culture, beliefs, and the condition of the care recipient must be considered (Beresford, 2008; Glendinning & Arksey, 2008).

BAME carers are described as the hidden population of UK carers as there is limited understanding of their experience (Afiya Trust, 2008). What is known is this group tended to face some challenges including, financial difficulties, unequal opportunities, social exclusion, racism, discrimination, and MH inequalities (Afiya Trust, 2008; Carers UK, 2011; Greenwood, 2018). Furthermore, BAME carers are less likely to access services despite having greater needs than their White counterparts (Greenwood, 2018). Barriers to accessing services faced by this community include cultural expectations, stereotypes, language barriers and stigma when providing support for MH difficulties (Carers UK, 2011; Greenwood, 2018).

In summary, although the population of BAME carers in the UK is increasing, this group is described as unseen and hidden, and facing many challenges including MH inequalities. To help contextualise the latter, the next section will outline the incidence of MH difficulties and rate of admission to MH hospitals among different ethnic groups.

African-Caribbeans, Psychosis and UK MH Services

The prevalence of MH disorder in the public is high (McManus et al., 2016), however in the UK, around 2% of the adult population will have a diagnosis of psychosis and up to half of these people will have caregivers (Kuipers, 2010). Carers of SUs with psychosis are a neglected group (Kuipers, 2010). This is especially true among BAME populations, who are less likely to access evidence-based treatment for psychosis, such as family interventions (Edge et al., 2016).

African-Caribbeans in the UK have the highest psychosis incidence with many authors reporting a significantly higher rate of psychotic disorders among Black populations (Cantor-Graae & Selten, 2005; Fearon et al., 2006; Kirkbride et al., 2012). Researchers have found a 6-18-fold elevated rate of psychosis diagnosis among the UK Black population (Hickling, 2005). Aetiology and Ethnicity in Schizophrenia and Other Psychoses study (ÆSOP) found a ninefold increase in the risk of developing schizophrenia for Black people of Caribbean heritage in the UK, along with an increased risk of 5.8 incidence rate ratios in Black African people and 1.4 in South Asian people, when compared with White British people (Fearon et al., 2006). Furthermore, Tortello et al. (2015) found that Black Caribbean people tended to have higher incidences of all major psychotic disorders. However, research with carers in these communities is limited (Boydell et al., 2014).

This research focuses on African-Caribbean caregivers because not only they have increased incidences of psychosis compared to other BAME groups, but also carers of African-Caribbean heritage are likely to support individuals who have negative experiences of services, poor access to MH care and poor clinical outcomes compared with other ethnic minorities in the UK (Edge et al., 2016; Fearon et al., 2006). This is because individuals from this community experience delayed access to treatment despite numerous efforts to access help (Morgan et al., 2004). This means prolonged periods of untreated symptoms, so that illness is more acute on contact with services (Marshall et al., 2005). This lack of timely support means disproportionately high numbers of African-Caribbean family members involve the police before their relative accesses treatment (Shefer et al., 2013).

Hence, the care pathway of SUs from this community are less likely to involve a general practitioner (GP) and more likely to involve the police and criminal justice system (Morgan et al., 2004), and specialist MH services such as forensic services (Bhui et al., 2018; Morgan et al., 2005; Kirkbride et al., 2012). Delayed access to services also impacts carers via tension, conflicts and high levels of burden, possibly resulting in family breakdowns (Edge et al., 2018; Mallett et al., 2002; Morgan et al., 2007).

In the recent ONS (2022), the report outlined the rate of detention under the Mental Health Act in England during 2021-22 amongst different ethnic groups. The rates of detention for the 'Black or Black British' group were 341.7 detentions per 100,000 population, which were over four times than those of the White group 72.4 per 100,000 population. Furthermore, this group ('Black or Black British') were over eleven times more likely to be placed under the Community Treatment Order (CTO) compared to the white group. Moreover, this group have the second highest percentage (20.8 %) of being detained more than once, as well as being detained the longest in hospital.

Research has shown BAME people are significantly over-represented in British prisons and forensic settings (Landsberg & Smiley, 2001). Black men have the highest rates of admission to FMHS and are considered to have high risk of dangerous and criminal behaviour, leading to more admissions and increased levels of security (Bhui, 2002; Codi et al., 2001). Some 40% of patients in high secure hospitals are of African-Caribbean origin and their average stay is more than nine years longer than for White patients (The Black Manifesto, 2010; Walker, 2020).

Furthermore, people of African and African-Caribbean heritage form the largest minority group within medium secure units, make up 58% of the BAME populations (Landsberg & Smiley, 2001). Hence, African-Caribbean carers are more likely to support individuals in forensic and prison settings and possibly for extended periods, yet there is no literature exploring the experience of forensic carers from these communities.

In summary, among BAME communities, carers with African-Caribbean heritage within the UK might be dealing a two-fold MH inequality; higher incidences of psychosis rates and over-representation within FMHS.

Social, Political and Historical Context of African-Caribbeans Living in the UK

In this section a brief overview of the migration history, and social, political and historical context of African-Caribbeans living in the UK will be provided in order to understand their experience of caregiving and their relationship with MH services.

Black Caribbean people make up 1.1% of the UK population (ONS, 2011). The migration history of this group can be traced between the 16-19th centuries when the Tri-Continental Slave Trade occurred. Between 1948 and 1950, there was mass migration of people from the Caribbean to the UK, following the UK government's drive to rebuild Britain after World War II. Most were from Jamaica, although others came from Trinidad and Barbados (Arnold, 2011). Collectively, they became known as the Windrush Generation. They settled in many cities in England, particularly Birmingham, London, Nottingham and Wolverhampton (Arnold, 2011).

Decades after the mass migration of the Windrush Generation, the over-representation of Black Caribbean people within MH services began to be reported (Sharpley et al., 2001;

Walker, 2020). Since then, explanations for the high rates of psychosis within this community have been discussed in depth. Although these discussions are important, this is beyond the remit of this literature review. Some of the explanations put forward included migration (Morgan, et al., 2010), socioeconomic disadvantage (Morgan et al., 2008), genetic predisposition, cannabis use and social disadvantages such as racism (Sharpley et al., 2001).

Furthermore, the lower rate of diagnosis in various Caribbean islands (Bhugra et al., 1996; Mahy et al., 1999) compared to the UK suggests that discrimination on both an institutional and personal level may contribute to this prevalence factors (Morgan et al., 2006; Morgan et al., 2009). Hence, factors such as, social isolation, socioeconomic status discrimination and institutional factors may explain the poor MH of this community (Bhui et al.,2018; Fung, 2009; Nazroo et al., 2020; Walker, 2020). These factors might also be relevant for caregivers from this community, not only in their caregiving role but also in their own lives. Therefore, these caregivers are vulnerable to more stress than White families, increasing their vulnerability to MH difficulties (Greenwood, 2018).

In a contemporary society, critical race theory (CRT) has served as a theoretical framework to study racism and social inequalities. In the mid-70s, CRT was founded by lawyers, activists, and legal academics in America as they collectively agreed and recognised that the advancement made through the civil rights era of the 1960s was stalling and in many respects being reversed.

The theory was later popularised by Crenshaw and Bell in the 1980s, the authors highlighting the lives of African Americans had not improved despite the civil right legislation. Some of the reasons for understanding the lack of progress included the idea that positive change only occurs for marginalised communities including the racialised communities when it benefits those in power. CRT's main principle is to give a marginalised people, including those with lived experience of racism, a voice. The framework offers a way of understanding the influence of racism in shaping government policy, health services and society in general. Furthermore, CRT highlights the nature of racism at both the institutional and in individual level. As well examining how the current political and economic structure promotes white supremacy and white privilege.

Bonilla- Silva (2015) argues that racism is more than an individual prejudice, it is systemic and deeply ingrained in social structures. This means often racism is mistakenly accepted as a natural process rather than a consequence of racial domination. The Implications of this is, for instant the unequal distribution of resources. Since race are constructed into hierarchies, resources are also distributed across these hierarchies. Hence, although race is not the only factor to explain social inequalities but is one of the factors that is relevant in contemporary society and CRT encourages a discussion of systemic racism at the core of addressing racism and promoting antiracism practice both at society and service level. However, despite, the framework being useful one of the limitations of the framework is not considering the role of other factors such as religion, education, class and ethnicity, sexuality and gender in understanding social inequality within society.

Caregiving for an Individual with a Diagnosis of Psychosis

Impact of Caregiving in Psychosis.

Since SUs with psychosis maintain close contact with their caregivers and families (Onwumere et al., 2014), those caregivers play a key role in accessing MH services (Jansen et al., 2015; Tanskanen et al., 2011), influencing SUs' treatment adherence and reducing relapse rates (Dixon et al., 2000).

However, caring for a family member with psychosis can be demanding, prolonged and distressing (Kuipers & Bebbington, 2005; Roick et al., 2007). In the literature on the impact of caregiving, the concept of carer burden is often discussed (Askey et al., 2009). This refers to both ‘objective’ burden, e.g., a financial hardship, absence from work due to caregiving responsibilities or poor physical health, and ‘subjective’ burden, e.g., psychological impact (Askey et al., 2009).

In relation to subjective burden, a third of carers suffer post-traumatic stress disorder (Barton & Jackson, 2008), experiencing a sense of loss similar to bereavement (Patterson et al., 2005). Researchers exploring the positive aspects of caregiving found that carers who were ‘coping’ reported increased self-confidence and life experience (Bauer et al., 2012; Kuipers et al., 2010).

Expressed Emotion and Family Intervention in Psychosis.

While family involvement can be helpful, some caregiver reactions can harm both SUs’ recovery and caregiver outcomes. Expressed emotion (EE) is a pioneering theory which was generated by Brown et al. (1962). This is an influential theory as it highlighted the course of schizophrenia is linked not only to biological factors but also to social factors. Research related to this theory has influenced the development of family intervention for psychosis (López et al., 2004), as recommended by NICE (2014). The term EE describes “a global index of particular emotions, attitude, and behaviour expressed by relative about a family member diagnosed with schizophrenia” (Nirmala et al., 2011, p119).

According to EE, some caregivers interpersonal interactions with SUs, such as critical comments, hostility and emotional over-involvement (known as high EE), are associated with increased relapse (Weintraub et al., 2017). The relapse of SU’s might mean caregivers taking on greater responsibility for the care of their relative, possibly resulting in increased level of stress expressed in heightened EE (Nirmala et al., 2011). Authors have also found that caregiver burden is linked to high EE and poorer carer outcomes such as stress, distress, low self-esteem and avoidant coping style (Kuipers et al.,2010; Raune et al., 2004). Therefore, there is growing interest in understanding the caregiving process and researchers now consider caregiver outcomes independently from SU outcomes (Onwumere & Kuipers, 2017a).

Despite these findings, researchers have overlooked the role culture plays in how families and psychosis interrelate (López et al., 2004). For instance, Jenkins and Karno (1992) suggested that EE may reflect caregiver-generated meanings for behaviours that are endorsed, or that violate social norms. Thus, culture might define which behaviour warrants criticism.

Furthermore, there is variation across different cultural groups regarding what is considered emotional involvement and the meaning of caring and appraisal of relatives' difficulties (Bhugra & McKenzie, 2003; Rosenfarb, 2006). Hence, to have a better understanding of caregiver processes and outcomes, insight into the experience of particular communities of caregivers, such as African-Caribbean carers, is needed because values and norms endorsed in the context of caregiving roles might influence caregiver outcomes.

FMHS, SUs and Forensic Carers

Forensic Services.

This section will present a brief overview of FMHS and explain the circumstance surrounding the admission of SU's.

FMHS are commissioned by NHS England as part of an integrated care pathway, which includes high, medium and low secure inpatient and outpatient services in the community (NHS Confederation, 2012). In England, there are 57 medium secure units and 3 high secure hospitals (Holley et al., 2020). According to guidance for FMHS' commissioners (2013), there are approximately 6,000 inpatient beds commissioned (680 in high, 2,800 in medium and 2,500 in low secure units). Therefore, most carers in these settings are supporting SUs in medium and low secure units. These services tend to discharge SUs within 18 months of their arrival. However, half of these SUs are detained for much longer, in some cases even for 10 or 20 years (Rutherford & Duggan, 2007). Therefore, carers in these settings support SUs for extended periods, greatly impacting their lives and psychological wellbeing (Sampson et al., 2019).

SUs.

SUs tend to be admitted into inpatient forensic services from prison, general MH services or other forensic MH (inpatient) services (NHS Confederation, 2012). The main reason for admission is risk of absconding (Ministry of Justice, 2010) and violence to others (McKeown et al., 2019), with carers and partners often being victims (Nordström & Kullgren, 2003), which can leave them with lasting trauma symptoms (Hanzawa et al., 2013). Additionally, SUs tend to have enduring MH difficulties, with one or more diagnoses, including psychosis and personality disorder. Approximately 50-60% of SUs are diagnosed with schizophrenia (Jansman-Hart et al., 2011), although others argue this figure may be over 70% (McKeown et al., 2019).

Forensic Carers.

There is no data available on the number of forensic caregivers within inpatient forensic services. While findings from staff surveys indicate that approximately 70% of family members continue to have contact following SU's admission (Absolom et al., 2010; Ridley et al., 2014), services and professionals are likely to underestimate contact, as family members might not be considered 'carers' (Ridley et al., 2014). In this setting, parents, mostly mothers, tended to be carers rather than siblings or spouses (Ridley et al., 2014).

Authors have argued that families supporting a SU with a diagnosis of schizophrenia in forensic services are more likely to experience burden than families caring for similar individuals who are not in forensic services (Maclnnes & Watson, 2002; Tsang et al., 2002). Caregivers in this setting might be considered vulnerable because in addition to dealing with MH difficulties, they are exposed to violent behaviour (Copeland, 2007). The degree of burden experienced by forensic carers appears to be related to several factors. Tsang et al.'s (2002) model of the stress and burden experienced by forensic carers highlights four dimensions of burden (symptom-specific, social, emotional and financial). The main sources of stress included criminal offences and managing the SU's MH difficulties, with secondary sources of stress relating to the criminal offences (dealing with police, court,media and admissions to forensic mental health hospitals; Tsang et al., 2002). Therefore, caregivers in forensic services might be dealing with multiple stressors, making them vulnerable to distress.

Despite this, family members play a significant role in SUs' recovery. SUs in forensic settings have limited opportunities to sustain social networks (Barksy & West, 2007). Therefore, having positive interactions and staying connected with family members may help SU's recovery (Clarke et al., 2016; Roe & Davidson, 2005; Shepherd et al., 2016) and contribute to shorter admission and successful discharge (Castro et al., 2002). Furthermore, family involvement might be a protective factor for SUs and can be considered a risk management strategy in risk assessment tools, such as HCR-20 v3, which assess the risk of violence (Douglas et al., 2013).

Despite the contribution of forensic carers in SU's recovery, services have failed to evaluate carer support in a systematic manner (Ridley et al., 2014). In England and Wales , only a small proportion of the medium secure hospitals provide family therapy (FT; Cormac et al., 2010; Davies et al., 2014), which is a vital intervention in forensic services given its contributions to case risk management and formulation (Nagi & Davies, 2010, 2015; Sturmey & McMurran, 2011). Other benefits of this intervention include increasing caregivers' understanding of MH difficulties (Absalom et al., 2012; Nagi & Davies, 2015), processing traumatic experiences related to violence and, improving the expression of difficult emotions (Ridley et al., 2014; Robinson et al., 1991). Additionally, FT has been shown to alleviate caregiver burden and associated health problems

(Lobban et al., 2013). Despite these benefits, families of African and African-Caribbean heritage are less likely to access evidence-based treatments such as family interventions (Edge et al., 2016).

The regulations of the Care Act (2014), government MH strategies (DoH, 2011), clinical guidelines (NICE, 2014) and the triangle of care (Worthington et al., 2013) advocating for carer and family involvement, they are only partially relevant here as they were written for carers of non-offending SUs. Thus, there has previously been less clarity for services and professionals in terms of their responsibility for supporting and involving caregivers in this setting.

However, family involvement is not a new concept in this setting, as some policies outline the best practice guidelines for it in inpatient forensic services, including a Health Offender Partnership (2007) and the Royal College of Psychiatrists (RCPsych, 2017). The most recent guidelines by NHS England (2018) highlight that services have a responsibility for supporting caregivers and prioritising the maintenance of family relationships. Although these guidelines are important for meeting forensic carers' needs, they lack detail on how services can implement these strategies.

Chapter 2 - Literature Review

Chapter Overview

This section will review existing literature exploring the caregivers' experience of supporting an individual with psychosis in forensic settings. Given the limited literature on African-Caribbean caregivers within this setting, the review draws on literature that has explored this group in non-forensic settings, highlighting its findings, epistemological underpinning and type of knowledge that was generated, to gain a better understanding of the lived experience of caregivers of African-Caribbean heritage supporting a SU in forensic services. The importance of this research topic is highlighted by considering its relevance to theory, research and clinical practice, and underlining the lack of empirical evidence examining caregiver experiences from African-Caribbean descent in forensic settings in the UK. Finally, a rationale and research question of the proposed study will be outlined.

Search Strategy

It is important to note some studies discussed in this study and the figures on BAME carers are not up to date figures, highlighting the lack of research and interest in this topic. To conduct a comprehensive literature search, several databases (Science Direct, EBSCO, PsycARTICLES, PsycINFO, Scopus, PubMed, Psych Net) and websites (Google Scholar and ResearchGate) were searched to identify key papers, books, government and health policies. The keywords used for search included: 'Black and Minority Ethnic' (BME), 'Black, Asian and Minority Ethnic (BAME)', 'Afro-Caribbean', 'African-Caribbean', 'Black Caribbean', 'Black', 'Black British', 'carers', 'informal care', 'caregiver', 'relatives' and 'forensic carers', 'Psychosis', 'schizophrenia', 'schizoaffective disorder', 'schizophreniform disorder' and 'delusional disorder', 'Forensic Mental Health Services', 'Forensic Mental Health Hospital', 'Forensic Services', 'Medium secure units', and 'Low secure units. These keywords were combined using ‘OR’ and ‘AND’, creating a new set of terms to filter results and identify relevant studies.

Provision of Support for BAME Forensic Carers

Canning et al.’s (2009) cross-sectional survey of healthcare professionals on the provision of support for caregivers across high and medium (NHS and private) hospitals in England and Wales highlighted the benefits of supporting caregivers. Most units provided support; however, the frequency and type of support varied. Of those units that responded, 57% stated that they provided specific provisions for BAME groups such as having a diverse workforce, access to Black advocates, and facilitating equality and diversity groups to lessen non-discriminatory practices. However, most services did not have specific provisions for BAME carers, despite stating that services should provide culturally appropriate support for this group (Canning et al., 2009).

A subsequent postal survey focusing on forensic psychiatric facilities’ (medium and low secure) provision for carers was undertaken by Cormac et al. (2010) who reported similar findings to those of Canning et al. (2009); services varied in the support and provision offered to BAME carers. The lack of support from services to BAME carers was explained, among others, by the assumption that BAME carers have wide support networks and, therefore, do not need support from outside the family (Parveen et al., 2011; Pound & Greenwood, 2016). Consequently, services tend to overestimate the ability of Black families to provide informal care (Adamson & Donovan, 2005).

While these findings are useful for understanding the support BAME carers might be receiving in forensic services, they do not provide insights into how this community of caregivers may feel and think about their role in forensic NHS settings (Canning et al., 2009;

Cormac et al., 2010). Having insights into this might help services to develop strategies and plans for supporting this group, thus indirectly aiding the recovery of SUs.

Ridley et al. (2014) directly explored forensic carers' experiences about the support they receive and their experiences of being caregivers across FMHS throughout Scotland using mainly qualitative methods. Nineteen carers were interviewed and were found to be the primary source of support for SUs. The impact of being a forensic carer was profound, impacting all areas of carers' lives, including their physical and MH (Ridley et al., 2014). The authors reported inconsistencies both within and between FMHS in Scotland regarding the provision of carer support (carers support group and family interventions) and the degree with which this was accessed. Carers also spoke about difficulties accessing and exchanging information with professionals, with barriers including SUs' right to confidentiality and service culture (Ridley et al., 2014).

Although Ridley et al.'s study (2014) provided insight into forensic carers' experience, the authors recognised that all of their participants were White British or Scottish. Thus, little is known about the experiences of caregivers from BAME backgrounds. The authors highlighted that future researchers should seek to understand the difference in social-cultural views of caring, recognising that BAME forensic carers might be dealing with additional stress than those faced by White British/Scottish carers. Having insight into BAME forensic carers' experiences may help inform the provision of services to this group.

Notably, Ridley et al. (2014) did not stipulate whether forensic carers were recruited from NHS, private hospitals or both, although provision of support might vary between these services. Family intervention might be underused in the NHS as it is costly and time intensive (Haddock et al., 2014). This then possibly impacts caregivers' experiences. Ridley et al.'s study (2014) also explored caregivers' experiences across different levels of security and for SUs with various MH difficulties.

However, Tsang et al. (2002) suggested that these caregivers tend to deal with symptom-specific burden. Hence, caregivers supporting a person with psychosis might have different experiences than carers of people with other MH difficulties; Kuipers (2010) highlighted that caregivers of SUs with a diagnosis of psychosis tend to deal with both positive (e.g., delusional thinking) and negative symptoms (e.g., lack of motivation). Hence, viewing all forensic carers' experiences as one homogeneous group might conceal important differences (Glendinning & Arksey, 2008). Nonetheless, the present study will address this limitation by looking specifically at forensic carers who are supporting a SU with a diagnosis of psychosis within the NHS.

Impact of Caregiving in Forensic Services and for People Living with Schizophrenia

Acknowledging the double burden of those whose relatives are diagnosed with schizophrenia and accessing forensic services, Nordström et al. (2006) explored the experiences of 14 parents who had an adult son diagnosed with schizophrenia within forensic services in Sweden. Using a grounded theory approach, they highlighted four events were important for all parents: the onset of MH difficulties, the schizophrenia diagnosis, violent behaviour or criminal offence, and the referral to forensic services. The onset of psychosis triggered guilt, helplessness, anxiety and fear. Parents reported that news of their sons' diagnoses evoked grief and loss.

Furthermore, when parents found out that their son had been referred to forensic services, this elicited relief, as the responsibility of care was transferred to services. Similar findings were reported by Ridley et al. (2014), with forensic carers in Scotland describing their initial response to the same news as shock and relief. Nordström et al.'s (2006) study showed that caregiver experiences might change depending on the phase the SU is in. Although findings are relevant to forensic carers in the UK, the legal and medical systems differ, meaning the systems with which families must interact and as a result their experiences are also likely to differ.

Solely focusing on parents' experiences of caregiving for those with a diagnosis of schizophrenia who accessed NHS forensic services in the UK, Ferriter and Huband (2003) interviewed 22 parents to explore their emotional burden and the helpfulness of others in coping with that burden. They used a Likert scale to measure burden and asked parents to endorse items from a list of problem behaviours. However, parents raised additional difficulties outside of those items, indicating the limitations of using discrete measures.

The authors analysed the interview data for emotional content. All parents reported stress, but this was not explored in detail. Other emotions included fear (77%), grief (73%), confusion (50%) and loss of what might have been (91%; Ferriter & Huband, 2003). Half of the parents expressed guilt, blame and failure for doing, or not doing something that could have contributed to the SU receiving a diagnosis of schizophrenia, and regret for not detecting early warning signs. Self-blame was sustained despite the absence of blame from others and reassurances being offered. Additionally, parents reported financial stressors and difficulties accessing information from services, which left them feeling neglected and angry.

These studies are useful for illuminating parents' experiences of supporting an adult child with a diagnosis of schizophrenia in secure settings. However, they provide little insight into the experiences of BAME forensic caregivers. While one study failed to provide information on caregivers' ethnicity (Nordström et al., 2006), others only had White participants (Ridley et al., 2014).

Some deliberately excluded BAME groups from their UK studies, even though SUs from these communities are over-represented in forensic services (Ferriter & Huband, 2003). Ferriter and Huband (2003) stated that including this group of caregivers would have introduced confounding factors such as the controversial issue of over-diagnosis of schizophrenia in Africa and African -Caribbean communities. The authors also recognised the experience of racism can contribute to the development of mental health difficulties,its negative impact on accessing appropriate and timely treatment, and the differences in cultural perceptions of mental illness (Aiyebbusi, 2000; Patel & Fatimilehin, 1999), suggesting that culture and ethnicity might influence caregivers' experiences.

These are important elements to consider, as researchers have shown that how families appraise their relatives' experience of psychosis can influence carers' reactions, leading to a range of carer behaviour toward relatives and services and different carer outcomes (Kuipers et al., 2010). Thus, the lived experiences of BAME forensic caregivers are unknown.

However, when considering the influence of ethnicity and culture on caregivers' experiences in this setting, it is important to begin by addressing the analytical clumsiness of conceptualising all BAME carers as an undifferentiated, homogeneous group of people. The term 'BAME' includes Asian, South Asian and Black subgroups (i.e., African and African-Caribbean) of people. There are several problems here with understanding caregiver experience, which will be discussed in detail further on.

However, relevant for this section of the literature review is the notion that homogenising ethnic groups conceals important differences between them such as disparities in pathways to care (including admission to FMHS), incidences of psychosis and inequality within MH services. Thus, the current researchers propose to focus on one group of BAME forensic carers which is forensic carers of African-Caribbean heritage given Black Caribbean individuals have higher incidences of psychotic disorders (Tortello et al. 2015) and are overrepresented in FMHS compared to other ethnic groups (Black Manifesto, 2010; Codi et al., 2001; Landsberg & Smiley, 2001). Yet, little is known about the experience of carers of this group of individuals. Having insight into their experiences might help services to provide care to meet their specific needs (NHS England, 2018).

Experiences of Carers of African-Caribbean Heritage are More Challenging

Greenwood (2018) argued that the experiences of BAME carers are more difficult and challenging than those of their White counterparts given this community is more likely to struggle financially and to care for longer periods. These increased hours of caring may leave carers more vulnerable to poor health, difficulties in keeping paid employment and social exclusion (Carers UK, 2011). Furthermore, carers of African-Caribbean heritage might find that ethnocentrism and racism form part of their experience within services (Afiya Trust, 2008; Beresford, 2008; Greenwood, 2018).

For more than six decades, African-Caribbean communities have faced MH inequalities in the UK (Nazroo et al., 2020). These inequalities can be understood in the context of institutional racism; that is, systematic bias which operates against Black people in the UK criminal justice and MH systems (Fernando, 2017; Walker, 2020). For instance, Black people’s responses to oppressive psychiatric circumstances have been pathologized, whilst social, political, economic and interpersonal contexts have been ignored. An early example of this is the label of ‘drapetomania’ being given to a runaway slave (Fernando, 2017). Since then, associations have been made between race and illness. For example, Fernando (2017) in the UK and Metzl (2009) in the USA have explored the notion that embedded racism has resulted in schizophrenia becoming a ‘Black disease’.

Stereotypes about Black men being ‘big, bad and dangerous’ are held within FMHS (Angiolini Report, 2017; Prins et al., 1993; Walker, 2020). Authors have reported that SUs with African-Caribbean heritage experience restricted care, including higher rates of seclusion, restraint, and higher doses of medication than other ethnic groups (Bhui et al., 2003; Morgan et al., 2004). Hence, these stereotypes are not only dehumanising but also create the risk of excessive force being used on vulnerable individuals who might be viewed as a threat (Walker, 2020). This prejudice within FMHS is not new (Angiolini Report, 2017). It first came to light after an inquiry was carried out after the death of three Black men (Michael Martin in 1984, Joseph Watts in 1988 and Orville Blackwood in 1991) who had all been diagnosed with schizophrenia and were killed in Broadmoor hospital (INQUEST, 2015; Prins et al., 1993). However, such incidents are not unique to this period or hospital, with other deaths including David 'Rocky' Bennet's in 1998 at a secure psychiatric unit, and Sean Rigg's in 2008 after being restrained by police whilst experiencing a MH crisis (Walker, 2020).

This experience might have profound impact on the community including SU's and their families. Studies have described the experience of SUs' and families with African-Caribbean heritage of MH service involved a vicious 'circle of fear' with delayed engagement or non-engagement, negative care pathways, and poor outcomes for SUs. Thus, this experience and perceiving services as institutionally racist reinforces the fear, mistrust and avoidance of MH services by African-Caribbean families (Keating & Robertson, 2004; Keating et al., 2002).

Despite this, no researchers have explored the experience of forensic carers from this community whilst considering their social, political and cultural context. Hence, the voices of forensic carers from this community are absent from the literature.

A qualitative methodology would be ideally placed to explore what caregivers from this community feel and think about caregiving in this setting, which might provide insight into their relationship with services and professionals. Having insight into carers' experiences might help professionals and services to reduce racial inequalities and challenge ideologies that perpetuate racism within services (Ahsan, 2020; Combs, 2019).

Additionally, Keating and Robertson (2004) also argued that the fear expressed by this community in relation to MH services was related to the stigma and shame associated with MH. The experience of stigma is not just relevant to Black caregivers; however, the sense of shame might be more acute within these communities due to racism and stereotypes (Keating & Robertson, 2004; Kinouani, 2021). The authors argued that there is no political will to address the concerns of this community, calling for a systemic change.

Forensic Carers, Stigma and Culture

Stigma has been identified as the main stressor and challenge for carers in forensic settings across various cultures (McCann et al., 1999; Pearson & Tsang, 2004; Ridley et al., 2014).

Rowaert et al. (2017) used thematic analysis to explore relatives' experience of supporting family members who are in forensic services following a criminal offence. Families described experiencing a 'double stigma' and double burden, as SUs were seen as both 'bad' and 'mad'. Some caregivers also perceived that these views were held by the professionals caring for their relatives, leading to concern for their relatives' safety. While some caregivers take on the identity that is defined by their relationship with the stigmatised SU (Ridley et al., 2014), others can resist the stigma (Rowaert et al., 2017).

The impact of stigma on forensic carers includes a loss of support network, withdrawal from others, including family members, and feeling isolated (Pearson & Tsang 2004; Ridley et al., 2014). This may be partly because stigma is a societal phenomenon which is reflected in negative media coverage (Pearson & Tsang 2004). Caregivers in forensic services might have to deal with the media (McCann et al., 1996), while relatives have described being 'outed' by the media over the SU offence (Person & Tsang, 2004).

In contrast, Maclnnes and Watson, (2002) found that forensic caregivers were less likely to report stigma-related burden than non-forensic caregivers. The authors suggested that forensic carers might be more concerned with specific severe burdens (such as violence) rather than stigma. However, other researchers argued that the degree of stigma experienced by caregivers in forensic settings may vary depending on cultural values and societal expectations (Pearson & Tsang, 2004).

Furthermore, authors have argued that mental health services and national programmes that address stigma in the UK do not consider that particular communities might be dealing with multiple forms of stigma, including racism and disempowerment (Eylem et al., 2020). It can therefore be argued that there is a gap in knowledge about the experiences of stigma in African-Caribbean carers supporting someone with psychosis in forensic settings.

Carers of African-Caribbean, African American Heritage and Perceived Burden

Alongside cultural values and ethnicity possibly influencing caregivers' experiences of stigma, authors have also found a difference between ethnic groups regarding stress and perceived burden in non-forensic populations of carers supporting an individual with psychosis (Rosenfarb et al., 2006; Stueve et al., 1997). However, these findings are mixed.

Caregivers of people with a diagnosis of psychosis experience a high degree of burden, such as meeting the highest clinical threshold for distress and depression (Boydell et al., 2014; Kuipers et al., 2006; Yusuf & Nuhu, 2011). However, there is some evidence that ethnicity appears to affect carers' burden. Rosenfarb et al. (2006) proposed a "social-cultural stress and coping model of subjective burden and family attitude toward patients with schizophrenia" (2006, p. 157).

These authors built on a theoretical framework and evidence from dementia research (Knight et al., 2000) which proposed that cultural factors might influence variations in how patient's symptoms and behaviour, the caregiving role and coping style are appraised. Knight et al. (2000) argued that this, in turn, impacts the level of burden experienced by caregivers and how they behave toward their relatives.

Rosenfarb et al. (2006) found White American family carers (N=79) were significantly more likely than African Americans (N=92) to feel burdened by their caregiving role and to reject their unwell family member, even after taking into consideration the severity of the illness and sociodemographic variables (Rosenfarb et al., 2006). One the limitation of this study was the authors have relied on self-identified ethnicity as a proxy for cultural group membership. However, findings were in line with Knight et al.'s (2000) finding that race or ethnicity may moderate stress appraisal in caregivers of people with dementia. Lefley (1998) attributed African Americans' reporting of low levels of caregiving burden to larger social networks and mutual aid systems compared to White families. Furthermore, among African American families, religious involvement has been identified as a coping resource, which offers emotional and practical support that can increase the self-esteem of caregivers (Lefley, 1998).

Similar findings were reported by Stueve et al. (1997), who compared the perceived burden among African Americans, Hispanic and White caregivers of adults with serious MH difficulties, including those with a diagnosis of schizophrenia and those admitted to psychiatric inpatient units.

Despite similar findings, the authors argued it should not be assumed that Black caregivers are less distressed by the demands of caregiving. Instead, they acknowledged that study results can be explained methodologically, such as through the selection process, outcome measurement and reporting effects. The authors argued that research on racial and ethnic differences raises questions about reporting bias and psychological distress, which might be experienced differently from one cultural group to another.

Although these studies are from the USA, they provide useful insight into ethnicity and caregiving (Rosenfarb et al., 2006; Stueve et al., 1997). Nevertheless, findings might not be fully relevant to African-Caribbean caregivers in the UK, as these caregivers provide support in a different context. Therefore, they may face different social, economic and political challenges, including accessing public services such as the NHS, which might impact their caregiving roles and coping strategies.

The only study conducted in the UK that compared carers' levels of distress and burden across ethnicity, using a cross-sectional design, was conducted by Boydell et al. (2014), who explored whether Black Caribbean and Black African groups report different experiences of caregiving than the majority group (White British) and whether this was related to levels of compulsory treatment. Carers reported high levels of distress and burden which did not differ based on ethnicity, social class or social support. These findings are not consistent with those from the USA, indicating that evidence of an ethnic difference in perceived burden is mixed.

However, Boydell et al. (2014) inquired whether ethnicity or social factors influenced long-term burden, as their study only involved caregivers who were supporting a relative with their first episode of psychosis. Furthermore, carers of patients who had been detained against their wishes were significantly more likely to report burden in terms of having problems with the service. This effect was stronger in the Black Caribbean groups. This finding might be relevant for caregivers of African-Caribbean heritage in forensic settings as SUs detained under the Mental Health Act 2007 are more likely to experience coercive treatment and have extended admissions.

While Boydell et al. (2014) could quantify carers' burden using clinical outcome measures, data was collected for this study between 1997 and 1999, meaning carers' experiences of MH services and treatment pathways may have changed significantly since then (Boydell et al., 2014). Therefore, the experiences and opinions of forensic carers from these communities are missing from the literature, with carers having to manage symptoms of psychosis, violent behaviour and antisocial behaviour (MacInnes & Watson, 2002). A qualitative phenomenological focus could help provide a richer understanding of caregiver experiences. This is because authors (Boydell et al., 2014; Rosenfarb et al., 2006; Stueve et al., 1997) have approached caregiving from a limited scope, focusing on distress and perceived burden.

Therefore, exploring caregivers’ experiences from a more holistic perspective might provide further insights, including potential gains from caregiving. It is possible that these understandings may contribute to a broader conceptual framework for understanding caregivers' experiences (Milne & Chryssanthopoulou, 2005).

There is a further advantage to the current study exploring caregivers’ lived experience and meaning-making around caregiving, since most existing studies have taken a post-positivist approach, using race (Black Caribbean and Black African) and ethnicity (African or Caribbean and African American) as a proxy for cultural group membership to assess ethnic and cultural differences in the caregiving process. Therefore, issues pertaining to race, ethnicity and culture within the caregiving role have not been fully explored and underlining meanings are not fully conceptualised (Dilworth-Anderson et al., 2002). Hence, exploring the caregiver experience means that the possible impacts of socio-political and cultural contexts can be considered (Janevic & Connell, 2001), rather than overlooking these aspects and so effectively excluding BAME groups from research (Milne & Chryssanthopoulou, 2005).

There are also clinical implications for exploring the experiences of caregivers from these communities as MH professionals might be able to discuss caregiving from a broader perspective. This, in turn, can shape the assessment tools used when working with caregivers, thus enabling the identification of caregivers' needs and resources. Additionally, if services include perspectives and ideas that resonate with specific groups, this can improve caregiver engagement and clinical outcomes (Seabrook & Milne, 2004).

Although the studies that explored African and African-Caribbean caregivers in the UK are important for informing clinical practice (Boydell et al., 2014; Keating & Robertson, 2004), they have amalgamated caregivers from two communities into one ethnic group, assuming homogeneity. This is despite these communities' differences in culture, language, dialect, religion and traditions (Agyemang et al., 2005). The UK census referred to these groups as 'Black Caribbean' and 'Black African' (ONS, 2011), perhaps acknowledging that they are culturally and ethically distinctive.

However, health researchers continue to combine them. Problematically, this may conceal important inter-ethnic differences in terms of caregiver experiences as their differing heritages may impact their caregiving process. Studies that do not take account of this might be considered unrepresentative or even meaningless (Gerrish, 2000). This is because, by grouping ethnic communities, their needs are left unexplored. This has a significant impact on our understanding of the experiences of carers from BAME communities. Therefore, the current research will explore the lived experience of forensic carers with African-Caribbean heritage solely. While this includes people from many islands, they form a homogenous group as they share a common migration history, culture, and numerous injustices in UK society.

The Lived Experience of Forensic Carers

Only Finlay-Carruthers et al. (2018) examined parents' lived experience of supporting an adult son or daughter diagnosed with psychosis who is receiving treatment in medium secure NHS FMHS. They offered a detailed exploration of how parents make sense of their world and an insight into parents' experiences of managing the onset of mental distress, difficult experiences with services and professionals and their feelings about providing care. If services viewed parents as forensic carers, this might improve their engagement, making services more respectful of their concerns and needs (Finlay-Carruthers et al., 2018). Thus, to enhance inclusive practice, it is essential that policymakers and MH services encourage high-quality family involvement.

This study has many strengths, one of them is the impact and importance in helping professionals and services to have an enhanced understanding of the lived experience of forensic carers. Other strengths included the authors recruitment process was carried out with sensitivity and care. For instance, prior to approaching SU's parents, SU's consent was sought by research team and only then information about the research was sent to their caregivers and potential participants must directly contact the research team. Furthermore, the author has also engaged in personal and methodological reflexivity. For instance, the first author reflected on her connection to the research topic (e.g., her experience working in forensic service) this adds to the rigour and transparency of the research as the author was able to recognise her potential biases.

A limitation of Finlay-Carruthers et al.'s study (2018) was the lack of racial and cultural diversity among the participants, as all parents were White British. The authors acknowledged that caregivers from BAME backgrounds might have appraised caregiving in this setting differently. Hence, they suggested future studies should explore cultural differences in caregiving.

Potential barriers that impacted the inclusion of caregivers of African-Caribbean caregivers within this study was the selection process of caregivers in the study. Ethically, SUs had to consent to the study, which may have excluded caregivers who had difficult relationships with the people they were supporting. This may have been a barrier to including

African-Caribbean caregivers, given the high rate of disruption and estrangement that is reported amongst African-Caribbean SUs and their families (Mallett et al., 2002; Morgan et al., 2007).

Moreover, caregivers of African-Caribbean heritage in forensic settings might be considered ‘hard-to reach’ communities who have a long history of mistrust of MH services (Keating & Robertson, 2004), and so might be less likely to be involved with research conducted by such services. However, some research suggests that groups that are considered 'hard-to-reach' should be considered 'easy to ignore’ instead (Lightbody, 2017). This is because it might be easy for governments and services to overlook this group due to the complexity of their situation, because solutions are often difficult to devise, and because they lack understanding of the community needs (Lightbody, 2017). Therefore, Caregivers from this communities need to be reached in a different way which respects confidentiality and is acceptable to ethics panels, so that their voices can be heard. This includes recruiting from charities.

Present Research

The review of existing quantitative and qualitative studies has highlighted several gaps in the research. To date, most research into caregivers’ experiences of supporting a SU with psychosis in a forensic setting has been with White European parents, mostly mothers, with an emphasis on their experience of burden (Ferriter & Huband, 2003; Finlay-Carruthers et al., 2018; Ridley et al., 2014). However, while the title of forensic carer is inclusive of friends and other family members who are involved in SU care, little is known about other caregivers’ experiences in this setting.

Furthermore, researchers are yet to explore the experiences of BAME forensic carers supporting a SU with psychosis in an NHS forensic setting. Amongst the BAME community, individuals with African-Caribbean heritage have higher rates of psychosis and are overrepresented in forensic services. Hence, research that gives voices to this community of forensic carers is needed. Having insight into their lived experience and the meaning prescribed to it might help services to design and offer support that meets their needs. This is especially valuable given that this group of carers have a history of mistrust, fear and avoidance of MH services (Keating & Robertson, 2004).

Furthermore, in the limited UK studies that explored the experience of African-Caribbean and African caregivers, these groups of caregivers were grouped together. Therefore, the current research is with caregivers of African-Caribbean heritage only who share a common migration history, culture and numerous injustices in UK society.

Relevance to Counselling Psychology

Exploring the lived experience of forensic carers of African-Caribbean heritage is in line with national clinical guidelines. NICE (2009) advocates for the development of specific psychosocial interventions to meet the needs of SUs of African-Caribbean heritage diagnosed with psychosis, such as offering culturally adapted family interventions (CaFI) to enhance engagement and access to evidence-based care (Edge et al., 2016). This is particularly relevant for the forensic population, as these SUs are likely to lose contact with their relatives. Thus, offering SUs CaFI could be a significant step in helping them to reconnect with their communities and families (Edge et al., 2018).

NHS England (2018) has also highlighted the requirement for further understanding of the needs of BAME carers in FMHS since SUs from this community are over-represented. Furthermore, the Division of Clinical Psychology (DCP) of the BPS, has been criticised on its specific guidelines ‘understanding Psychosis and Schizophrenia’ first issued in November 2014 (Cooke, 2014), which provide information on carers for psychosis, for its lack of meaningful engagement with issues related to ethnicity, race and schizophrenia (Kalathil &

Faulkner, 2014), including a lack of recognition of the over-representation of African-Caribbean people with a diagnosis of schizophrenia (Fernando, 2017).

This resulted in part of the guidelines being rewritten (BPS, 2017). The DCP of the BPS have since published separate guidelines for family intervention in psychosis (BPS, 2021). Although the information on culture and diversity is provided, it is brief. Therapists were encouraged to move away from "dominant understandings of distress, wellbeing and healing" (DCP BPS, 2021, p. 42) and to consider families' cultural contexts and norms.

However, the guidelines do not provide information on specific BAME cultures. Thus, the aforementioned gap in literature remains. The current research is intended to contribute to the evidence base. Exploring the lived, subjective experience of forensic carers of African-Caribbean heritage might enable CoPs to understand caregiving within secure settings.

In addition , focusing on the meaning of caregiving might enable CoPs to better understand a community that might be considered 'hard-to-reach' and that has a negative experience of MH services. This knowledge and insight can then inform assessment, formulation and intervention as well as services that meet this community's needs. Furthermore, this understanding can enhance CoPs knowledge of how caregiving in secure settings is currently understood in the African-Caribbean community. No previous authors have considered these elements, meaning this is novel research. The current study aligns with CoP values, as there is a focus on individual experience and knowledge that addresses social justice (BPS, 2005; Tribe & Bell, 2018). The study is focused on culture and ethnicity, which CoP advocates (BPS, 2005). Perhaps caregivers' experience of MH services could improve if they are supported by professionals and services who meet their needs and are sensitive to their culture, political and social contexts.

Research Question

What is the experience of carers of African-Caribbean heritage supporting an individual with psychosis in an NHS forensic mental health hospital (FMHH)?

Chapter 3 - Methodology

Chapter Overview

This chapter includes a reflection on my epistemological stance, the rationale for using interpretative phenomenological analysis (IPA), and an overview of the research process which includes data collection and analysis. Additionally, I conclude this chapter with an account of my reflexivity. In this chapter, I demonstrate my commitment to reflexivity and my involvement in the research process by using first person tense.

Research Aims

The aim of this research was to explore the experience of carers of African-Caribbean heritage supporting individuals with psychosis under a forensic service NHS. Given the lack of research exploring this topic my hope was to provide insight into their experience by adopting a phenomenological perspective.

Research Questions

What is the experiences of carers of African-Caribbean heritage supporting an individual with psychosis in an NHS forensic mental health hospital?

Research Paradigms

Research paradigms are sets of ideas that influence the research; different paradigms embrace differing standpoints. However, researchers use various terms to refer to the nature of reality (ontology), the nature of knowledge (epistemology) and the role of the researcher in the scientific process (axiology; Ponterotto, 2005).

Traditionally, psychology has been dominated by quantitative, empirical methodology with a positivist stance (Camic, et al., 2003). The assumption within a realist ontology is that a single reality exists which is observable, measurable and verifiable (Camic, et al., 2003).

Therefore, behaviour and experience can be measured objectively, using a quantitative approach to verify the existence of a phenomenon (Blair, 2010). However, proponents of the positivist paradigm fail to recognise individuals' subjective experiences and the meaning given to those experiences. Nevertheless, the positivist paradigm has been challenged by relativist researchers, who argue that it is impossible to fully grasp 'true reality' (Willig, 2013).

The social constructionist paradigm is associated with an ontological position of relativism. This stance presumes that reality and all human experience, including the construction of social and psychological knowledge, is influenced by various factors such as culture, ethnicity, social factors and political, with a focus on power structure (Ponterotto, 2005; Willig, 2013). It is suggested that multiple realities exist (Ponterotto, 2005).

The tension between these two paradigms allows for the alternative ontological stance of critical realism, to which I subscribe. In this stance, it is assumed that there is a real, knowable world that exists behind the subjective world (Braun & Clarke, 2012). Therefore, the critical realist assumes that there are multiple, equally valid realities. Thus, I recognise and accept an independent reality that is distinct from my views; yet through observation and the application of my beliefs, perceptions and analysis, I can construct my reality (Maxwell, 2012). My ontological stance fits well with interpretative phenomenology which aims to understand individuals' subjective experiences by considering their broader meaning-making in relation to the social, cultural and psychological context (Willig, 2013).

The role of a researcher's influence in the research process has been debated mainly using the work of two philosophers, Husserl and Heidegger. Husserl (1927 as cited in Smith et al., 2009) argued that researchers can put aside (bracket) their assumptions, values and experiences so that phenomena speak for themselves (Langdridge, 2007). In contrast, Heidegger (1962 cited in Smith et al., 2009) argued that it is difficult for researchers to position themselves outside of the phenomenon under investigation and fully bracket their pre-existing views, assumptions and experiences. Instead, researchers are encouraged to be aware of their biases to minimise their impact on the research process by focusing on the research data (Langdridge, 2007).

As a researcher I subscribe to Heidegger's view, since I believe my pre-existing views could influence the research process. Therefore, it was important that I acknowledge and consider how my values, experiences and assumption have shaped the research and that I use my understanding to enhance the phenomenon being studied (Langdridge, 2007). Therefore, my epistemological and ontological positions are consistent with my CoP identity, where individuals are viewed as the experts in their own experiences. Furthermore, subjective experiences and the meaning-making that is involved in human experience are valued and explored within CoP (BPS Division of Counselling Psychology, 2005).

Rationale for IPA and the Perspective it Underpins

IPA was deemed to be the most appropriate methodology, given my research aimed to explore in detail the lived experience of participants and uncover the meanings they ascribe to the phenomenon being studied.

IPA is based on three key principles: phenomenology (the study of experience), hermeneutics (the theory of interpretation) and idiography (in-depth analysis of a single case; Pietkiewicz & Smith, 2014). Phenomenology is a philosophical approach to studying experience and existence (Larkin & Thompson, 2012). Phenomenologists are concerned with individuals' experience of a phenomenon and the meanings that are assigned or hidden within those experiences (Larkin & Thompson, 2012).

This is also relevant to my research question, as I am interested not only in exploring the lived experience of carers of African-Caribbean heritage supporting individuals with a diagnosis of psychosis, but also their interpretations of their experiences in a social, political and cultural context. It is hoped that knowledge gained in this study will contribute to the evidence-based practice and aid counselling psychologists and other allied professionals in their clinical practice when supporting caregivers from this community within forensic services.

IPA also draws on the hermeneutic theory of interpretation (Smith & Osborn, 2015). This means the researcher interpretatively engages in the research process by making sense of the participants' making sense of their experience, which is referred to as a double hermeneutic within IPA (Smith et al., 2009). Smith et al. (2009) argued that knowledge could not be reached outside of an interpretative stance as is entwined with the individual's relationship, culture and language. Given the IPA stance on bracketing (Langdridge, 2007), this analysis will reflect my relationship with the data (Willig, 2013).

IPA also relies on idiography, that is an in-depth analysis of all cases within its context before generating a general statement (Pietkiewicz & Smith, 2014). To facilitate this in-depth analysis, a small sample is recommended. This is also in line with the current research intending to explore each carer's subjective experience and account of caring for someone with psychosis within forensic services before identifying common themes across the cases.

Additionally, the notion of idiography also aligns with my identity as a CoP, where the individual unique view is valued over broad, general statements. Due to these three core concepts of IPA, it was deemed an appropriate methodology for this study.

Prior to selecting IPA, I considered other qualitative methodologies, including Foucauldian discourse analysis (FDA) and grounded theory (GT). FDA was considered as it has an interest in the social, political and psychological characteristics of phenomena (Smith & Osborn, 2015). This appeared relevant to my research due to the discourse of oppression and inequality within the literature on carers of African-Caribbean heritage (Landsberg & Smiley, 2001; Nazroo et al., 2020).

However, as FDA aims to produce knowledge on how participants' social and psychological realities are constructed and negotiated using language (Willig, 2013), it was incongruent with the aim of the study. Although I am interested in participants' use of language, this is only in the context of viewing language as a tool used by participants to describe their experiences and meaning making (Smith & Osborn, 2015). Therefore, FDA was discarded.

I also considered Thematic Analysis (TA) for studying the experience of carers of African-Caribbean heritage supporting individuals with psychosis under a forensic service NHS. TA was considered as it is accessible, systematic, and rigorous in coding and in the development of theme to describe the phenomenon in the data (Braun & Clarke, 2012). This appeared to be pertinent because it would help describe the phenomena of the experience of carers of African-Caribbean heritage supporting individuals within forensic services. However, although TA might be able to generate themes it does not pay attention to the meaning caregiver prescribed to their experience, therefore it was disregarded.

I also considered GT which aims to systematically gather, integrate and analyse data to develop a framework for understanding a phenomenon (Willig, 2013) or a theory or model for contextualising social processes (Starks & Trinidad, 2007). While GT might be able to answer a question about the subjective experience of caregivers within forensic services, the aim of developing a theory was incongruent with this research. Therefore, GT was not suitable for this study.

Ethical Consideration

This research is exploring a subject that could be considered as sensitive and the sample population might be considered a ‘hard-to-reach’ group (Shaghaghi et al., 2011). Thus, careful ethical consideration was required to ensure participants’ well-being and safety without overlooking their autonomy and voice.

I obtained ethics approval from the University of East London (UEL) research ethics committee (Appendix A). To protect participants’ welfare, the UEL Code of Practice for Ethical Research (2013) and the British Psychological Society's (BPS, 2018) guidelines were strictly followed.

Each participant was asked to sign a consent form before the interview (Appendix F). Participants also received an information sheet (Appendix G) that facilitated an informed decision about participation (BPS, 2018). The information sheet also highlighted participants’ right to withdraw at any point during the study up to three weeks after the interview, at which point it was estimated that data analysis might have begun.

Participants were informed that all details relating to their identity and the individual they cared for would be anonymised by employing pseudonyms and changing details such as locations in the thesis extracts (BPS, 2018). All paper documents related to participants were stored in a secure cabinet, while all data was password protected (BPS, 2018). Participants were informed that personal information would be destroyed once the research and ethical obligations have been addressed.

In addition, during the interview if participants became visibly upset and found it difficult to talk during the interviews, I paused the interview and asked how they were. We then discussed further action collectively. Participants were supported with any decisions, including the option of withdrawing from the interview (BPS, 2018). Upon completion of the interview, a debrief support and helpline information sheet was provided (Appendix H). Since caregivers were supporting relatives in forensic services, risk was closely examined. Participants were informed of the limitations of confidentiality. Furthermore, interviews were conducted during working hours, so I could contact my supervisor if needed.

To further address the impact of power imbalance at this initial stage, participants were given a minimum of one week between receiving the information sheet and being invited for an interview so they could consider the implications of participating (BPS, 2018).

Challenges and Amendments to Ethics

In the initial ethics application, participants were going to be recruited across London and Greater London area. The population of forensic carers of African-Caribbean are vulnerable to experience discrimination and stigma and may mistrust mental health services due to cultural, economic and social factors (Kayrouz et al., 2016), which makes this group ‘hard-to-reach’ (Ellard-Gray et al., 2015). Thus, to help overcome this barrier, the recruitment process was amended to include forensic carers of African-Caribbean across the UK (Appendix C) and I used both traditional recruitment strategies and social media (Kayrouz et al., 2016). This will be discussed in detail in the section titled ‘Recruitment Strategies’ section.

Further, an ethical amendment was sought, since I initially intended to recruit caregivers who had supported a relative for at least six months within an FMHH within NHS. This would ensure that participants understood caregiving within these settings. However, participants who had a longer experience of caregiving but who’s relative had been discharged to the community were not initially considered.

According to Rutherford and Duggan (2007), half of the service users in medium secure forensic mental health units are detained for less than five years, while 18% are held for between ten and twenty years. Therefore, it was felt that including caregivers who had had a relative discharged in the past year would greatly enhance the data and provide a deeper understanding of caregiving in these settings (Appendix C). However, participants were reminded during the research interview to focus only on their experience of caregiving for the relative whilst they were inpatient in a forensic service.

Further, ethical amendment was requested to allow for some interviews to take place remotely due to COVID-19 restrictions (Appendix D). Although these video interviews were virtual, I was able to remain attentive to verbal and non -verbal cues much the same as I would during a face-to-face interview. Lastly, ethical amendment was sought to amend consent form (Appendix B) and to change the research title from it working title (Appendix E).

Research Sample

The study is based on data gathered from carers of African-Caribbean heritage supporting an individual with a diagnosis of psychosis under an inpatient forensic service within the NHS. Seven participants met the inclusion criteria (see below) and were interviewed. This number fits well with recommended sample size for professional doctorate IPA research (Smith et al., 2012), given it was sufficient to provide a rich narrative and allowed for a comprehensive analysis within the project timeline (Braun & Clarke, 2012).

Participant Inclusion and Exclusion Criteria

A homogenous sample is essential in an IPA study (Smith et al., 2009), thus the following inclusion and exclusion criteria were applied. Participants had to self-identify as a carer of African-Caribbean heritage supporting a relative within FMHH within the NHS (medium secure or low secure units). The relative needed to have a functional psychiatric diagnosis of psychosis-schizophrenia, schizoaffective or another psychotic disorder given by a consultant psychiatrist.

Caregivers were expected to have been actively involved in the relative's care for at least six months. Participants also had to be proficient in English to share their experience and the meaning that was assigned to their caregiving role. Participants needed to be aged over eighteen, although there was no specific requirements for gender, no upper age limit, and no restriction on the type of relationship to the relative (as the role of carer can be adopted by any family member regardless of the above factors).

Caregivers were excluded if they were under eighteen, involved in an index offence of the relative or currently experiencing mental health difficulties. Participants who were involved in an index offence were excluded as this experience might have been traumatising and discussing this in a research context might have been re-traumatising. Participants were assessed for these characteristics through the UEL's risk assessment and pre-screening questions.

Recruitment Strategies

Participants were recruited via purposive and opportunistic sampling. I used multiple recruitment strategies in this study. I secured agreement to advertise this study from two third-sector mental health charities (Rethink Mental illness and African-Caribbean Community Initiative; Appendix I and Appendix J). Rethink Mental Illness agreed to disseminate the recruitment advert within their services and recipients were asked to contact me directly.

In contrast, at the African-Caribbean Community Initiative service, potential participants were first contacted by the lead carer support workers, who sent information about the research (Appendix G & K). I was also invited to carers' monthly meetings to discuss the research with group members. Further, the research poster (Appendix K) was shared via social media sites including Facebook, Twitter and Instagram.

Data Collection and Participant Selection

Potential participants who were interested in the study contacted me via my university email address or telephone number. Following this, I offered a face-to-face meeting or telephone conversation for a preliminary discussion. All potential participants chose to have the preliminary meeting over the phone. I provided them with further information on the study, assessed their suitability (using the pre-screen questionnaire, inclusion and exclusion criteria) and readiness to participate in the study, focusing on their mental health, if relevant (Appendix L).

Several people who came forward were not included in the study, either because the individuals they were supporting were not receiving care at an FMHH within the NHS or because they did not identify as having African-Caribbean heritage. Anyone who was excluded from the study was provided with a rationale for this decision to minimise feelings of rejection.

All those who met the inclusion criteria and were willing to proceed received an information sheet and had the opportunity to ask questions. Individual interviews were carried out either at the charity's premises, a local library or a UEL meeting room, and remote interviews were held via Microsoft Teams. Participants were sent an email or text message to confirm interview arrangements.

Assessing Validity and Quality

Yardley (2000) proposed four principles for assessing reliability and validity in qualitative research.

Sensitivity to Context

Yardley (2000) recommended the need for sensitivity to context in qualitative research. I considered this in the current study by appreciating the context of being a caregiver within forensic services for individuals with a mental health diagnosis. From the initial stage of the research, I approached potential participants with sensitivity and care. During recruitment, participants were able to discuss confidentiality, while information was provided on the procedures for ethically protecting their data and safety.

Additionally, I was aware of the need to be flexible when scheduling interviews to prioritise participants' needs. Thus, the participants were provided with the opportunity to choose the day, time, and location for the interviews in order to avoid conflicts with their roles and responsibilities. Interviews were carried out in private, quiet environments, demonstrating sensitivity toward the difficult experiences participants were sharing.

Additionally, during interviews, participants were reminded to only discuss information they felt comfortable sharing and to ask questions if they were unsure about the research process in the hope to address the power dynamic that might exist between participants and the researcher. Furthermore, participants were given the opportunity to ask questions throughout the interview and to add anything important to them ensuring that their voices were heard.

Commitment and Rigour

Yardley (2000) argued that extensive engagement with both the research topic and method can demonstrate rigour and commitment. I have attended workshops on carers, completed extensive reading on forensic carers and caregiving among African-Caribbean communities, and written a research proposal and a literature review. I have attended workshops and lectures on IPA and participated in IPA research groups to better understand the data collection and analysis processes. Additionally, I have taken a module on research integrity and ethics.

Being a novice qualitative researcher, I read widely and engaged in peer discussions on IPA. Additionally, I used supervision sessions to discuss the various stages of analysis. Verbatim quotes are used to support the selected themes in the analysis chapter. Furthermore, engaging in personal and methodological reflexivity added to the rigour of the research.

Transparency and Coherence

Smith et al. (2009) stated that, within IPA, transparency refers to showing the stages of the research process, as demonstrated in the upcoming sections of this chapter. Reflexivity, which is included in this chapter, also demonstrated transparency as it enables the reader to follow the research process. Finally, coherency was achieved by ensuring that the research was aligned with the theoretical assumptions of IPA.

Impact and Importance

Yardley (2000) claimed that the validity of a study is entwined with the production of knowledge that is interesting and beneficial. This study aimed to enhance our understanding of the experience of forensic carers of African-Caribbean heritage supporting individuals diagnosed with psychosis, since there is a dearth of literature in this area. This qualitative research facilitated a deeper, rich understanding of the experiences of these carers.

Furthermore, previous authors grouped caregivers of African and African-Caribbean heritage together despite their differences (Agyemang et al., 2005). Therefore, I included only

African-Caribbean participants to avoid concealing important inter-ethnic differences in terms of caregiving experiences, thus creating novel data.

Moreover, it is hoped that the understanding gained from the study will help clinicians facilitate discussions with caregivers during clinical meetings and interventions with families.

The Seven Participants

Seven participants were recruited creating a homogeneous sample (Smith et al., 2009). They all identified as forensic carers of African-Caribbean heritage who had held that role for more than six months. If the person they cared for had been discharged, this was less than a year ago. The person they cared for had a diagnosis of psychosis and had accessed services within FMHH in the NHS. Table 1 displays participants' demographics.

Table 1.

Participants' Demographic Information

	1	2	3	4	5	6	7
Pseudonym	Samantha	Cedella	Chadice	Devan	Winston	Tianna	Helen
Age	58	62	54	86	65	60	63
Gender	Female	Female	Female	Female	Male	Female	Female
Ethnicity	African Caribbean	African Caribbean	African Caribbean	African Caribbean	African Caribbean	African Caribbean	African Caribbean
Relationship to service user	Mother	Mother	Sister	Mother	Father	Grandparent	Mother

	1	2	3	4	5	6	7
Length of time being a carer	5 years	20 years	1 year	20 years	10 years	4 years	10 years
Type of service the service user accessed	Low secure unit	Low secure unit	Medium secure unit	Medium secure unit	Medium secure unit	Low secure ward	Medium secure unit
SU's diagnosis	Paranoid schizophrenia	Paranoid schizophrenia	Paranoid schizophrenia	Schizophrenia	Schizophrenia	Schizophrenia	schizophrenia

Semi-Structured Interviews

IPA researchers aim to elicit rich, detailed, first-person accounts of the experiences and phenomenon under investigation (Pietkiewicz & Smith, 2014). A semi-structured interview schedule with open-ended questions (Appendix M) was developed to achieve these aims.

During the interviews I adopted active listening, attempting to comprehend what was being shared and what meaning was being ascribed to experiences. When required, I offered prompts and verbal encouragement to further explore what was being said. The interviews were conducted with empathy, a non-judgmental attitude, and responsiveness. This supported participants to engage fully and feel valued as well as building rapport (Pietkiewicz & Smith, 2014). Each interview lasted between 75 and 150 minutes. Interviews were audio-recorded.

I practiced the interview with my peer to verify that the questions elicited rich data. Furthermore, the first participant's interview acted as a pilot, as discussed below. It is important to highlight that this interview schedule was used flexibly to facilitate authentic conversation (Pietkiewicz & Smith, 2014). The schedule included warm-up questions (e.g., "describe your ethnicity") to ease participants into the interview and build rapport before asking more sensitive questions (Smith et al., 2009).

Furthermore, the interview schedule included key questions to initiate the discussion about participants' caregiving experience within forensic services. This enabled an exploration of any thoughts and ideas that were unanticipated. It was also beneficial to have prompt questions ready if participants found questions too general or abstract. Prompts were also useful for further exploring participants' perceptions, thoughts, emotions and individual interpretations (Pietkiewicz & Smith, 2014). Lastly, the interview schedule concluded by asking participants if they had anything else to add to the interview.

The Interview

A pilot interview was carried out and recorded to assess whether the schedule elicited data that was relevant to the research questions. I then transcribed this interview and reviewed it with the help of my supervisor. This process demonstrated that the interview schedule elicited relevant data. However, I could have asked follow-up questions to further explore the meanings participants attributed to their experiences. Thus, this process enabled me to reflect on ways I could improve my interviewing skills. I completed additional reading on qualitative interviewing techniques and practiced skills with my peers. Hence, undertaking this pilot interview was beneficial.

The pilot interview was included in the final analysis as it provided somewhat rich data. The interview schedule used for the pilot was also used for the subsequent interviews. However, I amended my interview technique by asking participants to reflect on their experiences in more detail and attend to the meaning behind those experiences.

Transcriptions

Following the collection of data, I transcribed each interview verbatim. I then reviewed the transcript several times, including against the recording, to ensure its accuracy. Pseudonyms were used to protect participants' privacy, and personally identifiable information was altered or removed. As Smith and Osborn (2015) proposed that, within IPA, transcriptions should include semantic details (such as pause, laughter and sighs) as these might be meaningful in the analysis, they were therefore included to ensure the richness of the data. Nevertheless, I removed some "ums" and "errs" from the data (Langdridge, 2007) where they did not add meaning, thus facilitating the easier reading of the analysis chapter.

Analytic Strategy and Procedure

IPA was employed to analyse the data, following the stages proposed by Smith et al. (2009) as guidelines. My refection of this will now be discussed.

Stage 1: Reading and Re-Reading

To facilitate the process of becoming immersed with the data, transcripts were read whilst listening to each recording. This enabled me to remember the voice of the participants for the subsequent reading of the transcript, thus ensuring a more comprehensive analysis (Smith et al., 2009). During this stage, I read the reflective notes I had written after each interview for any held ideas and beliefs. The transcript was re-read several times to fully engage with the data and start the process of understanding participants' experiences.

Stage 2: Initial Noting

This detailed, lengthy stage examines the semantic content and use of language in an exploratory manner. As I worked through this stage, I remained open-minded and noted anything that came up, particularly the way participants described, understood and thought about their experiences. Initially, I found this stage challenging as there were no specific rules or expectations regarding how comments should be made during an analysis. However, being familiar with the guidelines was useful.

The objective of this step was to produce comprehensive notes and comments on my reflection of the data. My notes consist of descriptive (red ink), linguistic (purple ink) and conceptual comments (green ink). Descriptive comments focused on relationships, places, events, principles and processes. Linguistic remarks were concerned with how language was used and why participants might have used particular descriptive comments. Conceptual annotations were concepts or ideas that gave a broader understanding of the participant's experiences.

The process of writing these comments required the double hermeneutic, since I was interpreting the participants' sense-making of their experiences. The transcript was then reviewed after some time, and any new comments were included (Appendix N).

Stage 3: Developing Emergent Themes

This phase of the analysis involves reducing the level of detail while retaining the level of complexity. This may involve using the notes rather than just the data. The goal at this stage is to identify emerging themes (recorded in the right-hand margin) that are closely related to the subsections of data.

During this stage, I broke down the narrative flow of the data and re-organised it whilst incorporating my interpretation. Hence, the analysis became the product of both the participants' experience and my interpretation (Smith et al., 2009).

Stage 4: Searching for Connections Across Emergent Themes

During this stage, I initially arranged the themes in the order they arose within the data. To help me map out and think about how the themes fit together, I then printed out and cut up the themes to search for patterns and connections. To facilitate this process, Smith et al. (2009) suggested grouping related themes according to abstraction (when a new label is assigned to common themes), polarization (when themes with oppositional relationships are clustered together), subsumption (when an emerging theme is elevated above another to unite other related themes) and contextualization (identifying narrative and contextual aspects within an analysis). During this process, overlapping themes were discarded. I recorded these decisions for tracking purposes.

Stage 5: Moving to the Next Case

The same steps were then repeated for the other six participants. Each interview was looked at individually. It was important to try to bracket emerging themes from previous interviews to maintain the new interview's idiosyncrasy. Following the outlined steps ensured the emergence of new themes for each interview (Smith et al., 2009). The number of major themes that emerged for each interview ranged from 6 to 10 (Appendix N).

Stage 6: Looking for Patterns Across Cases

In this step, patterns were searched for across all participants. To facilitate this, I colour-coded each participant's emerging themes, laid them out on a large desk and searched for connections. During this process, several questions were considered (Smith et al., 2009). These included: what connections are there across interviews? How do one transcript's emerging themes help to illuminate another transcript? Which themes are most potent?

This process also involved rearranging and relabelling themes. To begin with, I identified 11 super-ordinate themes, condensed them to four using subsumption and contextualization. The super-ordinate themes contained 2 to 3 sub-ordinate each. Finally, a Word document was created that included all quotes for each super and sub-ordinate theme whilst identifying the corresponding participant and line numbers. This was useful when writing up as I could find the relevant quotes easily.

Reflexivity

Reflexivity is imperative in IPA since there is a recognition that the researcher shapes the research process. An essential component of reflexivity is being aware of how one's beliefs, emotions, assumptions and motivations influence the research process, including the analysis (Langdridge, 2007). My methodological and personal reflections are discussed below, as they will enable the reader to evaluate the extent to which my experiences, beliefs and assumptions may have influenced the research and interpretation.

Methodological Reflexivity

Growing up in London which has a high percentage of African and African-Caribbean communities, I was exposed to comments made by community members who mistrusted being involved in research. This mistrust was mainly attributed to the inequalities and racial discrimination which these communities have been subjected to. Therefore, whilst planning the research, I anticipated that recruitment might be an issue. I was also aware that these communities might be considered a hard-to-reach population (Kayrouz et al., 2016).

This knowledge made me feel under pressure as I had to complete the research within a specific time frame. I addressed this by developing working relationships with gatekeepers, firstly by attending workshops and networking with relevant third-sector charities. While this was time-consuming and costly, as I had to travel to Birmingham on a few occasions, it also opened up opportunities for me to talk about my research to the charities in their monthly carer meetings, thus enabling me to access potential participants.

Furthermore, my background as a British Ethiopian might have hindered or aided both recruitment and building rapport with participants during the interviews. Potential participants often enquired or made comments about my ethnicity and heritage. I felt my background might have benefited me because I found it easy to relate, connect to and communicate with potential participants as we were all people of ethnic minorities living in the UK and sharing a race.

However, this could have also prevented participants from taking part, given the shame, secrecy, and embarrassment amongst African-Caribbean communities and families living in the UK around discussing mental health difficulties, especially with someone who is not part of their family or is outside their community (Singh et al., 2013). However, several participants said that it was helpful and therapeutic to speak to someone close to the community as they were able to discuss topics related to their race and culture within their caregiving experience, as they felt I could understand and relate to these subjects.

Personal Reflexivity

My interest in this area is related to both my experience of working in inpatient forensic services and my lived experience of supporting a family member with mental health difficulties. My experience of being a caregiver has given me insight into the difficulties and the emotional pressure of the role both on myself and the rest of my family.

Being a first-generation Ethiopian living in the UK, I am aware that my experiences, including caregiving, are influenced by my culture as well as the social, historical and political context of the UK.

For instance, coming from a household with a collectivist culture and Christian values, I was raised with the strong view that caring for a family member or anyone who needs support was a privilege and duty. Therefore, I felt a tremendous pressure to continue caring for my relative, even when I struggled to juggle the role with my other responsibilities.

This pressure was compounded by other social and political issues such as inequality within mental health services and the overrepresentation of people from my communities within services, including forensic services.

Furthermore, in my clinical work within forensic services, I noted that there is little opportunity to work with caregivers and for them to be involved in SU’s care. This mirrored my lived experiences as a caregiver when my relative accessed mental health services. Therefore, I believed that caregivers from African and African-Caribbean communities may face barriers due to their social and political context.

My beliefs, personal and professional experience might have influenced my decision to research this topic and analysis process. Although I cannot be completely impartial as an IPA researcher, I tried to limit my biases by keeping a reflective journal and by utilising research supervision and personal therapy to ensure the themes reflected participants’ experiences.

Chapter 4 - Analysis

Chapter Overview

As discussed in chapter one, the aim of the study is to explore the lived experience of carers of African-Caribbean heritage supporting a relative with psychosis, who is in an FMHH within the NHS.

Prior to discussing the analysis, it is essential to highlight the crucial characteristics of reflexivity and IPA. In IPA, the meaning of subjective experience is co-constructed between the researchers and the participants(Smith, et al., 2009), meaning different researchers may select different themes. Given the subjective nature of the research Yardley's recommendation (2000) was observed, as explained in the methodology chapter. An essential component of sustaining the quality of the analysis was to remain reflexive, which I did by making notes in response to participants' data throughout the analysis process.

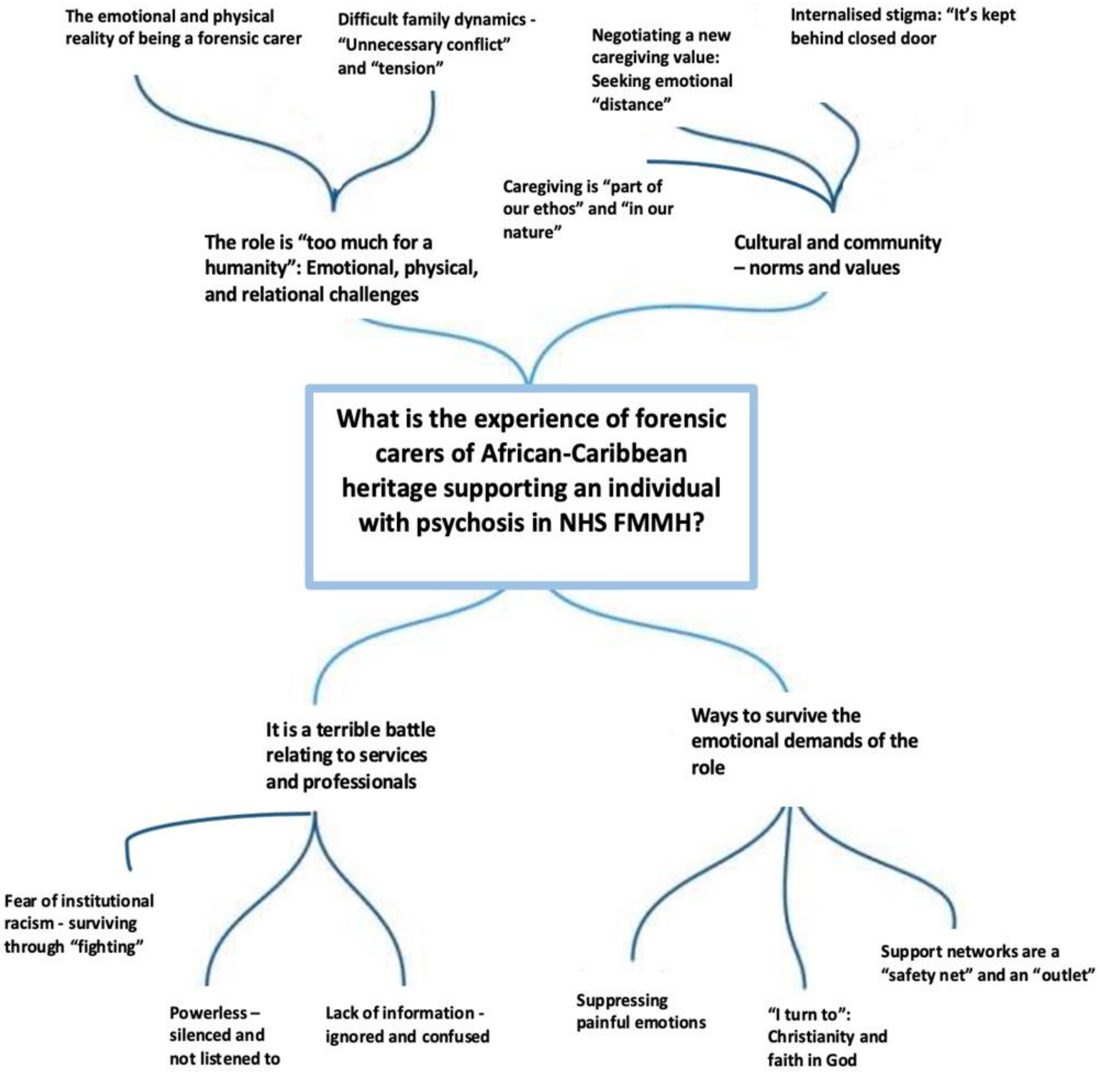
The IPA analysis in this study led to the generation of four superordinate and eleven subordinate themes (Figure 1). These themes highlight the experience of forensic carers of African-Caribbean heritage supporting an individual who has received a diagnosis of psychosis and is an FMHH within the NHS. The themes are organised to capture participants' experiences, including their psychological responses to their role, the person being cared for, their family, culture, community and healthcare professionals.

Key for Participants' Quotes

Consistent with IPA principles, participants' quotes are central to this chapter. Quotes are italicised and a line number reference is provided alongside their pseudonym, i.e. [Samantha, 500-555]. Furthermore, in cases where I have added additional words to make the quotes more readable, I have used square brackets to highlight this. Additionally, words that were emphasised by participants were underlined. Lastly, ellipses within square brackets (i.e.

[…]) signify words and phrases that have been excluded to focus on more relevant narratives for the interpretation.

Figure 1.
A graphic representation of the four super-ordinate and the related sub-ordinate themes.



Superordinate Theme One: The Role is “Too Much for a Humanity”: Emotional, Physical, and Relational Challenges

This theme is concerned with the burden and pressure of being a forensic carer for a relative with a diagnosis of psychosis within forensic services. Many participants described the emotional, physical and financial burdens related to the role. Additionally, participants described difficult family dynamics. There are two subordinate themes: ‘The emotional and physical reality of being forensic caregiver’ and ‘Difficult family dynamics - “Unnecessary conflict” and “tension”’.

Subordinate Theme One: The Emotional and Physical Reality of Being a Forensic Carer

This theme reflects the emotional and physical demands of being a forensic carer supporting an individual with a diagnosis of psychosis. Participants discussed the impact of the physical demands (e.g., feeling exhausted) of the role on their psychological wellbeing, and vice versa.

Emotional responses to their relatives’ difficulties included sadness, fear, guilt, self-blame and hopelessness, and some were close to accessing mental health services for themselves. Several participants described sadness when discussing their relative’s diagnosis. Chadice described her experience:

> *“So it just makes me feel really sad that he’s not been able to fulfil his potential. And I really much doubt that he will now”. (Chadice 646-647)*

Chadice may be describing a loss of hope and anticipated future for her brother. Perhaps she was mourning her brother’s aspirations and dreams, as he was the “brightest” in her family.

Others reported guilt and self-blame. Helen said:

> *"What probably brings on my guilt, because [...] I kind of feel that there might be some truth in the fact that you know that he might have carried that gene or the- that- that ehm that susceptibility to- to ehm schizophrenia or mental health. (R: OK, yeah.) That might have been triggered because of the environment, (R: Yeah.) kind of volatile relationship I had with- and how he felt about my partner, (R: OK.) my children's father" (Helen, 930-939).*

> *"it does impact on me as a mother. I feel that you know I've not ehm done- maybe- maybe I failed in some way you know" (Helen, 1082-1082).*

Helen seemed to partially blame herself for her son's diagnosis. Perhaps, as his mother, she believed her role was to provide a stable home for her son. She tentatively considered whether she had "failed" in this task in quote two. Later, Helen stated more certainly that she "felt like a failure, […] like as a mother I'd failed". She then described having to "live with a certain amount of guilt", despite the absence of blame from others.

Many caregivers were worried about their relative's safety in inpatient forensic services. Samantha's son had been physically assaulted by his peers in hospital settings.

> *"I'm scared for him every day. Because they're not safe, they're not safe places [hospital wards] [...] I'm just frightened for him [...] I don't want anything to happen to him again. Because I think that would be the end of it then" (Samantha, 637-652).*

Samantha reported living her life with the constant anticipation of her son being harmed or in danger of physical violence. Perhaps she felt helpless, unable to protect her son. Furthermore, her phrase "end of it then" may refer to both her and her son's experiences. Perhaps she fears her son might die in this setting. Since Samantha was already stretched emotionally, this news might result in her emotional breakdown, possibly being the "end of it" for her.

Almost half the participants expressed worry about what their relative's future would hold, especially after discharge. Winston worried about his daughter's future after he and his wife had passed away.

> *"I worry that when her mum's gone (R: Yeah.) I'm gone (R: Yeah.) and there'll- because I've seen mental people on the road. (R: Yes.) And I've seen mental people who don't get visits. (R: OK.) And that's what frightening me, with [daughter] deteriorating- [sighs] you've seen them on the bus talking and- or not carrying themselves properly (R: Mm.) not dressed prop- and that's what at the back of my mind I don't want to happen, alright?" (Winston, 747-751).*

Winston's fear that his daughter won't cope without her parents' support is exacerbated by the chronic nature of her psychosis, which makes her vulnerable to neglecting herself and being lonely. Almost all participants defined the role as being "challenging", "difficult" and leaving them with no hope. Cedella said:

> *"so much challenges and difficulties[...] Even though you have your faith there's times when it seems ehm- a tunnel seems so black, there's no- there's no light in it. And it seems as if the light has been extinguished, you have no light in your life, no hope concerning this family [...] And that's not a very nice place to be ehm. (R: Yeah.) I wouldn't wish that on anyone"*
> *(Cedella, 320-325).*

Cedella saw the role of forensic carer as burdensome. Although her faith provided some protection, she was still vulnerable to distress. Her use of elaborate metaphors may signify an absence of hope, meaning and purpose for her life and son, leaving her in despair. She experienced the role as unbearable, as indicated by her words "wouldn't wish that on anyone".

Most participants found engaging with their relatives when they were acutely unwell especially challenging. Cedella described having contact with her son when he was unwell:

> *"having phone calls with someone that's not well is not an easy phone call. (R: Yeah.) Because some of the things that they come out with that they really believe are true*

> *(R: Yeah.) or some of the damming things that they say about you that they really believe that are true [...] ehm send you backwards. Mash up your whole day, mash up your whole week. (R: Yeah.) Sometimes your whole month, you know? (R: Yeah.) So it's not easy to have, and my son's very unwell." (Cedella, 485-491).*

Cedella use of the phrase "mash up" portrays an emotional world in which she felt crushed and distress following interactions with her son. Her emotional wellbeing was not considered in these interactions; perhaps there was no space for it, given his mental health.

Furthermore, there was a sense that she could not challenge her son regarding the "truth". Even though his words hurt her, she had to accept this is his reality. Perhaps Cedella was aware that she could not reason with her son as he was fixed in his beliefs. This could leave her feeling helpless, although she emphasised that her son was "unwell", reminding herself that her emotional responses do not matter as her son does not know he is hurting her.

Many participants discussed the physical demands of the role, such as not having enough time to rest, which harmed their psychological wellbeing. Like others, Tianna described having to negotiate this role alongside her other responsibilities, including full-time work.

> *"it's kind of exhausting really because you feel like you're always on the go [...] you know it's just never ending; it was like oh, give me a break! [...] But you still have to do it" (Tianna, 770-776).*

Tianna's phrase "always on the go" illustrates her juggling various overwhelming caregiving responsibilities. Tianna also described missing her own medical appointments to care for her grandson. Her word "exhausting" suggested being physically and/or emotionally drained. Tianna's frustrated tone of voice and her comment "give me a break" might indicate that the demands of the role are unrealistic, leaving her vulnerable. However, she perseveres with the role despite its difficulties, as indicated by her words “still have to do it”.

Cedella echoed the emotional and physical demands of the role and, adding more context, perceived her son’s behaviour as demanding:

> *“It’s too much for a- ehm humanity to fulfil his demands” (Cedella, 753).*
>
> *“my son pulling from- demanding from me, pulling my last ehm, ehm mental and emotion and physically and- and spiritualist- spiritual strength from me. And not leaving anything for me. And that’s a very, very fragile and vulnerable place to leave* a person” (Cedella, 723-725).

The first of these quotes indicates that Cedella’s son’s demands are inhuman, perhaps indicating the enormity of his demand on her emotions, body and spirit. In the second quote, Cedella’s description of her son “pulling” her resources out of her feels almost demonic. His demands are experienced as forceful and intense. Hence, her caregiving role was draining her of emotional, physical, mental and spiritual resources. Perhaps when Cedella said she was “very fragile” and in a “vulnerable place”, she was highlighting that her mental, physical and spiritual health were at risk, leaving no space for her own care. She went on to say:

> *“my son’s condition used to bring me close to ehm not being unwell [...] I’ve come close to going under the home treatment team and going into hospital” (Cedella, 538-541).*

Cedella’s mental health deteriorated due to the stress of the caregiving role. Her repetition of “close” may indicate the degree and number of times her mental health was at risk due to her role. Her history of mental health difficulties might have left her more vulnerable to stress.

Subordinate Theme Two: Difficult Family Dynamics - "Unnecessary Conflict" and "Tension"

Most participants described how family members, including siblings, sisters-in-law, children, grandparents and partners, helped to provide emotional and practical support for the family member with the diagnosis of psychosis. This involvement often caused tension within families. Chadice described conflict with her brother Lloyd:

> *"my brother has refused to- he's refused to go halves with me with the passport [...] And he was like no- and I was so angry with my brother[...], like £40 each, what is that? [...] So I felt really angry, we didn't speak for ages" (Chadice, 1194-1200).*

Chadice may have assumed that Lloyd should share caregiving responsibilities for their unwell brother, including the finances. Chadice's rhetorical question "what is that?" indicates confusion over Lloyd's decision to not collaborate. She later made sense of this by suggesting that Lloyd held different views about their brother's care, as he commented that he is "in the best place". Chadice might have perceived Lloyd's refusal as his attempt to postpone or hinder the discharge process for their brother. Perhaps this indicates a power struggle between the siblings over their brother's care. Chadice's repetition of "angry" might indicate the frequency and intensity of her experience of feeling unsupported by her brother. The relationship was harmed by this tension, perhaps leaving her alone in caring for her brother.

Tianna described conflict with her husband and grandson when he stayed overnight from the hospital:

> *"You start arguing because I might- I might want to do it this way, my husband might want to do it another way and [grandson] might want to do it another way. It- it-*

> *sometimes it just causes a lot of conflict. […] Just even an extra person being in the house. […] Not that he's doing anything, but just him being there, is a stressful thing. […] like my husband will say, oh for instance, have you given him his medication? […]- and I said yes, I've done it, and then it will cause an argument because I said, oh what, you think I don't know what I'm doing?! […] [small laugh] Which I'm you know, which is not normal but because of the situation. You know there's- it just causes conflict. (R: OK.) Unnecessary conflict sometimes and it's nobody's fault, it's nobody's fault, it just happens" (Tianna, 741-750).*

Tianna attributed the cause of this "conflict" to several factors. One is the conflicting views between her husband, grandson and herself. Perhaps this includes her caregiving behaviour. The phrase "lot of conflict" signifies difficulty negotiating these aspects with her grandson and husband, reflecting high adrenaline, dispute and tension.

Furthermore, Tianna reported having to share her space and consider her grandson's needs. Perhaps this is "stressful" because there is an internal conflict around having an "extra person" in the house, which requires adjustments and interferes with her routine.

Lastly, Tianna attributed the cause of the "conflict" to her perception that her husband was criticising or doubting her caregiving abilities. Her laugh might indicate awareness that her response to her husband might be an overreaction. Perhaps she feels insecure about her caregiving role, indicated by "you think I don't know what I'm doing?". Tianna might have displaced her frustration onto her husband, thus impairing her marriage, as indicated by her later comment that she "took it out on my husband in more ways than one […], that impacts on your marriage".

Tianna's phrase "it just happens" indicates that these conflicts are an impulsive, inevitable reaction to this stressful context. Hence, she appears compassionate, blaming neither herself nor the rest of her family.

Samantha also described tension following a disagreement with her sister about her son’s legal affairs.

> *“My family didn’t- my sisters don’t really come and see me that much, I don’t know why. I think since [son’s] got into trouble, the family’s split as well. (R: OK.) Yeah, there’s been tensions in the family” (Samantha, 866- 868).*

Although uncertain about the source of the difficult dynamics within her family, Samantha tentatively attributed them to her son getting “into trouble”. Perhaps she is tentative so as not to exacerbate this dynamic. Samantha’s phrase “family’s split as well”, indicates being not only physically separated from her son but also a rupture in her relationship with her sisters, leaving her isolated in her caregiving role.

Superordinate Theme Two: Cultural and Community – Norms and Values

This theme explores the influence of Caribbean culture on expectations and norms surrounding caregiving behaviour and attitudes. Participants considered these values throughout their caregiving experiences. Negotiations of the new caregiving values or attitudes, which contradicted the norms and expectations of the Caribbean culture, are discussed.

This theme also includes participants’ perceptions of their community, by whom they felt stigmatised, rejected and discriminated against. There are three subordinate themes: ‘Caregiving is “part of our ethos” and “in our nature”’, ‘Negotiating for new caregiving values: Seeking emotional distance’ and ‘Internalised stigma: “It’s kept behind closed doors”’.

Subordinate Theme One: Caregiving is "Part of Our Ethos" and "In Our Nature"

Most participants referred to cultural values and norms when discussing their perceptions of caregiving. Perceptions were underpinned by family and gender norms as well as parental responsibilities. Most participants saw caregiving as part of life. They described witnessing family members caring for each other and other community members. Indeed, caregiving was so embedded in their lives that the decision to care was not debated – when the time came, care was provided, often alongside feelings of guilt. They saw caring for their family deeply rooted in Caribbean culture; participants saw the role as a "responsibility", a "duty" and "natural" despite its difficulties. Thus, perceptions of culture and family norms meant there was no sense of choice over whether to care for their relative.

Tianna described the community expectations she perceived regarding caring for her family.

> *"I think in a Caribbean community, family is very important. Family is key actually. You know because we always say family comes first, so that's what we do, we look out for our families [...], if they have a need, then we as a family will help to meet that need. (R: OK.) Yeah, no matter what it is, the good, the bad, the ugly, we try to help, yeah. Not that we uphold wrongs or anything like that but you know if you as a family cannot support, no matter what the person's done, (R: Yeah.) or who the person is, then [...] You don't really have anybody, do you?" (Tianna, 80-87)*

Tianna's language ("family", "comes first", "key") highlights that caregiving responsibilities are valued in the Caribbean community. Perhaps there is pride in caring for a family. It seems that Caribbean attitudes include commitment, dedication and allegiance to the relative being cared for. She may be worried that if she does not put her family first, she and her grandson could end up isolated.

Helen also spoke about the norms of caregiving within the Caribbean community, which were underpinned by her gender and parenting status:

> *"innately as a Caribbean mother, we are quite- we're care- caregiving is in our nature [...] I see that also in an African mother, we are the glue [...]you don't let your child go, no matter what they've done" (Helen, 1071- 1077).*

Helen saw caregiving responsibilities as intertwined with her cultural heritage, and parental and gender roles. Helen's use of the phrase "innately" and "in our nature" suggest in her view, mothers within the Caribbean community are hardwired for caregiving. Helen's metaphor of "glue" might indicate that caregiving in this context means holding on to her role and son despite his alleged sexual offence. Perhaps the script for Caribbean mothers is that care for a "child" is unconditional.

Samantha also spoke about caregiving responsibilities in the context of her Caribbean culture and parental role:

> *"it's just part of our ethos. It's part of the culture I suppose" (Samantha, 549-550).*
>
> *"So caring is something that- it's within us [Samantha and her mother], so, it's something that we do, we just have to get on with it, you know. So ehm my experience of caring for [son] is ehm it's something that I just get on with it, you know. It's difficult but it doesn't matter how difficult something is, you just have to get on- he's my only child, like I said" (Samantha, 484-488).*

Samantha's phrases "our ethos" and "part of the culture" suggest that caregiving values and norms are embedded within Caribbean culture. In addition, caregiving qualities and attitudes may be ingrained in Samantha's family identity ("it's within us"). Furthermore, Samantha's repetition of the phrase "get on with it" might highlight the degree of pressure she experienced. She chose to persevere with the role despite it being "difficult" as she wanted to care for her son no matter what, reflecting resilience. Not persevering might be perceived as going against the "ethos" of the culture and possibly her identity.

Subordinate Theme Two: Negotiating a New Caregiving Value: Seeking Emotional "Distance"

Participants explained that being a forensic carer supporting a relative with a diagnosis of psychosis can be an enormously pressured and stressful experience, especially in the context of long-term caregiving. Some participants described trying to gain either emotional or physical distance from this emotional, physical and financial burden. However, these negotiations created tension and conflict for participants given the norms and expectations around caregiving values within the Caribbean community.

Participants explained that this "distance" served different functions on different occasions, such as being able to protect and preserve their mental health, prioritising their needs and to promote independent behaviour in their relatives. This appeared to facilitate participants' ability to maintain their difficult roles.

Chadice described tension following her decision to create some distance from her caregiving responsibilities:

> *"living where I live was a- unconscious decision to move away from family because it was done in gradual steps, it was [place] and then it was even further and further away from family (R: OK) even my mum made a comment that, oh you're moving further and further away from the family [spoken with Jamaican accent], but that was a conscious decision [...]I think (R: Yeah.) because I wanted that distance. And I'm really glad that I still have that distance because I think if he was living near to me, I would throw myself into it [...] I would get very, very, very sad and low about it all, just the whole situation, and I would feel put upon" (Chadice, 1174-1182)*

Chadice may have used the term "distance" either to refer to geographical and physical distance from her brother or to an emotional distance where she became disengaged from their relationship – or, perhaps, both meanings.

Chadice made sense of this “distance” as an attempt to set boundaries. Her laughter, use of the Jamaican accent and conflicted narrative around her decision being “conscious” or “unconscious” can be interpreted as Chadice’s awareness that having “distance” might be considered to be going against family and cultural norms of caregiving.

Perhaps Chadice had to negotiate tension and conflicts when prioritising her needs over the norms. Setting internal boundaries might have been difficult; external boundaries might also have been needed, indicated by having moved away. Perhaps the function of the “distance” might be the removal of external pressure from family and internal pressure from herself to visit her brother often, indicated by her comment “feel put upon”. This helped to reduce her experience of feeling “very sad”, therefore “preserving” her overall mental health so that she could continue to provide care for her brother.

Cedella also spoke about setting boundaries to preserve her mental health:

> *“he wants to push you into your own illness. He’s- I’m not prepared until you give up your sanity for him. And there was times when I would- was prepared to do that for him, I loved him that much. But now I won’t, that’s one thing I won’t do for him. (R: OK.) I refuse to do for him and the time before that I was and my daughter said no mum, you shouldn’t give up your sanity for no one mum, that’s where you should draw the line” (Cedella, 746-750).*

Cedella’s account of being “prepared” to give up her “sanity” might be understood as her response to the perceived view that, as a Caribbean mother, she should be offering “unconditional love” and care to her son.

However, her phrases “now I won’t” and “refuse” may indicate a shift in her perception and caregiving attitude. She might be redefining her ideas about what is reasonable and possible whilst preserving her psychological wellbeing. Cedella recalling her daughter’s comment of “draw the line” could be interpreted as her attempt to validate her courageous decision, which may have caused her tension and conflict, as it challenged her family as well as community norms and expectations around caregiving.

Cedella also described various occasions where she set boundaries, one of which was limiting her hospital visits due to finances.

> *"I said no, I can't afford to pay cabs and I can't afford to come to [institution] and back on public transport with my disability. (R: Yeah.) I said you're gonna have to pay. And ehm he paid in the end, not willingly" (Cedella, 482-484).*

Cedella described setting boundaries around the conditions in which she would make visits outside of her plans to meet her son's requests. The repetition of "can't afford" highlights the financial burden of the role, which was possibly exacerbated by her physical disabilities and the distance to the hospital. Perhaps Cedella also "can't afford to risk her health with these journeys. Cedella assertively communicated her needs to her son, which possibly facilitated her son taking on responsibility, even if reluctantly. Setting those boundaries might have saved her money and avoided putting pressure on her physical health.

Similarly, Winston described his experience of trying to limit the phone calls he was receiving from his daughter "every ten minutes". He found the calls demanding, interfering with his daily life:

> *"I'm getting a bit stronger, like I will say [daughter] I'm- when she'll phone I'll answer and say don't phone me back, and the- and the only thing what frightens me (R: Yeah.) is because the couple of times when I don't answer the phone (R: Yes.) [daughter] set fire to the place" (Winston, 609-612).*

Like Cedella, Winston set some boundaries. He might be seeking emotional distance from his daughter, who appears overly dependent on him. Winston's phrase "bit stronger" suggests he was developing his confidence and becoming more assertive by setting limits on the phone calls. This new approach might have created some tension. Winston appears uneasy about setting boundaries as he assumes his lack of response might result in his daughter setting fire at the hospital.

Throughout the interview, Winston revealed continued growth in confidence; he described setting limits in other areas of caregiving behaviour, such as the number of visits to the hospital, indicated by his comment "I know that I have to say no […] I don't visit her for a week". Winston hoped this decision would help his daughter develop her resilience and possibly sense of autonomy, indicated by his comment "it will make her a bit stronger I hope".

Meanwhile, other participants felt that saying "no" to any caregiving responsibilities might be perceived as rejecting and abandoning their relative – and perhaps as undermining the family and cultural norms of caregiving, thus threatening family harmony. Helen described her experience of persevering with the role despite its challenges:

> *"emotionally you know it's- it takes a lot out of you [...] you never think of I should abandon this [...] I don't think that comes in the- that's not in any- any Caribbean mother's book, no. (R: Book, OK.) No, that's not in our- that's not in our- in our nature, in our culture, in our- in our- it's not in our DNA" (Helen, 1099-1106).*

Helen's words "Caribbean mother's book" and "DNA" suggest that caring values are prescribed and culturally embedded. The ultimate affront to her community and possibly her family members might be abandoning her caregiving role. Perhaps saying "no" to any caregiving responsibility would be unacceptable, disturbing social and family harmony, or even being perceived as her rejecting her son. Perhaps reminding herself of this collective value might help her to persevere in the role, despite it being experienced as emotionally burdensome.

Subordinate Theme Three: Internalised Stigma – "It's Kept Behind Closed Door"

Stigma around mental health difficulties and accessing mental health services might be a deep-rooted issue within the Caribbean community. Although participants recognised mental health difficulties, they assumed that most people in the Caribbean community either do not believe mental health difficulties exist or tend to minimise or overlook distress. Additionally, participants perceived that the norm in the African-Caribbean community is not to speak about a relative's mental health difficulties outside of the family. Themes of stigma and prejudice were common, taking the form of internalised negative assumptions and judgments toward themselves and their family, including the individual being cared for.

Chadice described how mental health difficulties were perceived in her community and family:

> *"it's kept in the family it's kept behind closed doors [...] but I don't know if that's a generational thing or cultural thing (R: Yeah.) but everything was just swept under the carpet" (Chadice, 546- 549).*

Chadice's metaphors "behind closed doors" and "swept under the carpet" might indicate that mental health difficulties were perceived as embarrassing and wrong within the community. Chadice later reflected on the reasons for these negative attitudes in the context of her own mental health difficulties. She thought these difficulties might be "another thing to add to being Black!", saying "It's another thing to add that's a negative thing to your sense of self". Perhaps forensic carers with African-Caribbean heritage are at risk of dealing with multiple stigmas around racial and mental illness. Chadice may have internalised these views, harming her self-perception.

Chadice felt concerned about disclosing to others due to the stigma attached to having relatives with a diagnosis of schizophrenia:

> *"there's not many people that I know that's got a brother in a forensic psychiatric hospital! [...] there's a little bit of shame as well- ehm that- that I've got two siblings with schizophrenia, because I- because the way I see it is that when you tell people that, they're going to think, oh my God what went wrong in your family?! [laughs] For you to have two siblings that like, you know- so I kind of feel that people will kind of look down on me (R: OK.) and think, oh my God what- what the hell happened in your family?" (Chadice, 1242- 1251).*

Perhaps Chadice felt isolated. She was dealing with double stigma, feeling ashamed not only of being a forensic carer but also of having two siblings with a schizophrenia diagnosis. Disclosing to others could mean that she and her family would be criticised and stigmatised. Perhaps disclosing her family's mental health challenges would mean that she and her family lose the respect of their community, a fear that reinforced her worries and sense of isolation.

Similarly, Helen felt scared about disclosing her son's difficulties to others, anticipating stigma:

> *"I feel like I'm living in- in different segments. I- I have a life with my- I have my two children, so that's one segment. I go to work- I can't tell anyone about it because I feel the stigma and the- the shame and the embarrassment, I don't talk to anyone, no, I don't tell anyone about it" (Helen, 392-395).*

Helen hid parts of herself and her experience of being a forensic carer from others outside of her family. She feared being stigmatised and discriminated against. She might be silencing herself to avoid the "shame" and "embarrassment" that come with stigma. Helen may have internalised negative assumptions about being a forensic carer.

She later explained why she held these views as well as her decision to remain silent:

> *"within the Caribbean community we get- within certain cultures like African cultures, the stigma of mental health, the way they- ehm they relate to it is sometimes*

> *worse than keeping it to yourself, you know? (R: Yeah.) They don't- they brush it off as if it's nothing and you know as you- get over it, what's the problem" (Helen, 456-459).*

Helen feared that being stigmatised might involve community members dismissing the distress associated with mental health difficulties. This could leave Helen and her son invalidated, misunderstood and shunned. Perhaps being rejected by her community might be more distressing than being isolated with her problem.

Helen also perceived that stigmatizing views were held by professionals of African heritage working within forensic mental health services:

> *"I have noticed [...] there's certain staff in there, and it's particularly the African staff because of their stigma about certain things, rape- ehm mental health, they are very horrible to him [son] [...] Yes, and he tried to take his life [short pause] at the end of last year" (Helen,647-650).*
>
> *"they don't like him, they treat him like that, they treat me like that. When I go in there, they're rude" (Helen, 662-663).*

Helen suggested that, due to her son's sexual offence and mental health difficulties, he was stigmatised, particularly by professionals of African heritage. Helen's son was mistreated, "abused" and discriminated against, which she perceives as having contributed to the deterioration of his mental health and suicide attempt. Helen explained how the stigma has impacted her life. She thinks these professionals' perceptions of her son had a direct influence on how they relate to her. She saw professionals of African heritage being "rude" to her as relating to their negative view of her son, due to his offence. Perhaps as a forensic carer, she is experiencing stigma by association.

Superordinate Theme Three: It is a Terrible Battle Relating to Services and Professionals

This superordinate theme explores participants' experiences of relating to services and professionals within forensic mental health services. Most participants perceived racial inequality within forensic services and, therefore, feared that their relatives would encounter institutional racism. Participants also faced challenges when accessing and receiving information. Moreover, they reported power imbalances within services and professionals. The superordinate theme contains three sub-ordinate themes: 'Fear of institutional racism - surviving through "fighting"', 'Powerless'-Silenced and not listened to and 'Lack of information'-Ignored and confused .

Subordinate Theme One: Fear of Institutional Racism - Surviving Through "Fighting"

This subordinate theme is about the racial inequalities that most participants reported facing or perceiving within forensic mental health services. Furthermore, this sub-theme also explores participants' experiences of services' institutional racist treatment of their relatives.

These experiences elicited fear, mistrust and suspicion towards NHS FMHS. In response, caregivers developed survival strategies such as needing to "work hard", "fight" and "pull" up a relative so that those relatives were not overlooked, discriminated against or even forgotten within services.

Chadice described her perception of racial inequalities within UK society before explaining their influence on her caregiving behaviour:

> *"it was no Blacks, no Irish, no dogs, you know, so- and there was a lot of abuse that she [mother] suffered as well. (R: Yeah.) So- so I think when you hear those sort of stories as well as a child, it stays with you." (Chadice, 105-107).*

Chadice used the term “it stays with you” to indicate how hearing about her mother’s experience of racial discrimination and trauma growing up had a lasting influence on her. This might have left her with the implicit understanding that racial inequalities within UK society mean a lack of access to resources and services.

Chadice also elaborated on her perceived view of racial inequalities within forensic services, potentially resulting in inadequate care for her brother. She also reflected on how this informed her caregiving behaviours and attitudes:

> *“I do remember my mum sort of ehm [short pause] she did used to say [...], that if- if she [mother] don’t fight for my sister, people are gonna walk over her because she’s Black! [...] maybe that’s instilled in me [from her mother] that if I don’t do something [short pause] the authorities gonna forget about him because he’s Black. (R: OK.) [...] if I don’t do something (R: Mm.) the authorities are gonna take the piss out of him more, excuse my language, because he’s* <u>*Black*</u>*, do you know what I mean? (R: Mm, that’s OK, yeah.) And that might not be the case (R: Mm.) but I just think that’s the case, that they’re gonna treat him badly because he’s Black” (Chadice, 1485-1492).*

Chadice might have been socialised by her mother to learn survival strategies for dealing with racism. For instance, her strategy for education was “work[ing] hard”, while her strategy for caregiving was “to fight”. Chadice’s account revealed her fear that her brother might encounter institutional racism. Perhaps she anticipated him receiving inadequate care, being overlooked, neglected and/or disrespected.

The repetition and tone of her words “if I don’t do something” might indicate her lack of trust, fear and suspicion toward services. Chadice’s question “do you know what I mean?” might signify that she was seeking validation for her thoughts and fears, perhaps leaving room for doubts about her perception of racial inequalities within services. However, this was short-lived, as Chadice's use of "I" may indicate her reclaiming her view that services are institutionally racist.

Similarly, Tianna described how her personal experience of racism might have shaped her caregiving attitude, behaviour and perception of services:

> *"I became- yeah, I became aware that people can be treated differently just because they're Black [...] So I became aware and it kind a [short pause] it changed me as a person because I ... now, I'm having to fight for my rights [...] So for me, if I'm looking after my grandson now, I'm fighting for him now. (R: Mm.) Because I know what he's got to put up with, not only because he's Black but because he's got a mental illness, yeah? (R: Mm.) Because he's quite big in body. So I'm working harder now, I'm working overtime for my grandson because I want him to get the best" (Tianna, 197-204).*

Tianna's phrase "treated differently" might refer to her experience of racism, which included being othered and marginalised. Her false start and repetition of "become aware", as well as her use of the term "change me" may indicate the significance of her newfound insight that racial discrimination occurs within UK society.

Tianna's decision to "fight", "work harder" and "work overtime" could be interpreted as her adopting a survival strategy for dealing with racial discrimination in not only her caregiving role but also her personal life. Tianna suggested that she might be hypervigilant within her caregiving role as she anticipated her grandson being stigmatised and stereotyped, not only due to his "Black" race but for other reasons too. Perhaps, by describing her grandson as "big in body", she might anticipate him being stereotyped as violent or as dangerous, while he might experience stigma for having mental health difficulties.

Tianna perceives the compound effect of being Black, "big in body" and having mental health difficulties, means her grandson might be even more likely to experience discrimination. Additionally, the repetitions and tone of "working" might indicate the burden of trying to access the "best" for her grandson, as she might be dealing with a triple stigma and stereotypes as a forensic carer.

Similarly, Devan perceived that services were institutionally racist and an unsafe setting for her son:

> *"Once you enter in those places [hospital], you like you're going into the shark mouth. [...] Well to the time- from the time he enter into the mental ill system, I have to try myself all the while to help pull him up. If I had left him, it would swallow him up already" (Devan, 805-819).*

> *"from the moment they entered into the system [...] they see them as Black, big and dangerous [ ] So ehm, I mentioned that they say, and the consultant said to me- asked me, have you heard it here? I said no, I haven't heard it here but it's in the underground system here" (Devan, 1205-1211).*

Devan used the vivid metaphor of "going into the shark mouth" to illustrate how she perceived her son entering mental health services including forensic services. This indicated the significant risk, danger and threat she perceived for her son in this setting. Perhaps a "shark" symbolises the position of power services hold, whilst also suggesting that services could destroy and annihilate her son. This might signify that Devan feels mistrusting and fearful of services.

Similarly, to Tianna's, Devan also highlighted how her son's race and physical stature makes him even more vulnerable to experience discrimination from professionals. This is indicated in the second quote, Devan's phrase "they see them as Black, big and dangerous", which further illustrates and contextualises her distrust and fear. Her comment "it's in the *underground* system" suggested that institutional racism might have become a hidden or covered-up issue; her distrust in service was deep rooted.

Devan later posed a rhetorical question in her interview, stating "You know how many of our Black boys [hitting table] die in the institution [ ]?". Devan nonverbal response of hitting the table might indicate her anger and perceived view that their lives, in this setting, are not valued.

In the first quote, above, Devan highlighted that her role as a caregiver was to continually "help pull [her son] up". Her assertive tone indicated that she was embodying a fighting spirit. She assumed that the alternative might be her son being "swallow[ed] up" or left to "rot in the institution", suggesting that her son would be neglected without her input.

Helen also described adopting a survival strategy of "fighting" within her caregiving role.

> *"my ancestors who fought to survive [slavery]"(Helen,119)*
>
> *"I come from strong women who- who- who fight back, you know, and not necessarily with their fists but with their, you know, the knowledge of what they have, you know (R: OK.) you have to sometimes take on institutions, take on you know [short pause] situations. For example, in the- in the- where my son is in the [unit] you know (R: Yeah.) I've had to have some struggles and battles with them, and I've had to be fighting back all on my own, you know" ([Helen, 260-265).*

Helen might have internalised a survival strategy of "fighting back" thanks to her female family members and ancestors. She used this strategy in her caregiving role. This survival strategy might be deeply rooted within Helen's heritage, indicated by her comment about how her ancestors "fought to survive" slavery. The implicit message for Helen might be that racial discrimination and systemic oppression, including those within forensic services, are survived through fighting as a form of resistance. This "fight" is not necessarily fought physically but psychologically and intellectually. Helen appeared to have a difficult relationship with services and professionals. This “battle” and “fight” with services might have been experienced by Helen as lonely and isolating.

Subordinate Theme Two: Powerless – Silenced and not Listened to

Although each participant described their relationship with professionals in a unique, idiosyncratic manner, the majority revealed an imbalance of power in those relationships. This imbalance was attributed to several causes, such as racial inequalities, difference in knowledge and expertise, or both. Participants explained that this left them feeling silenced, intimidated and ignored. Chadice shared her experience:

> *“I find it very difficult to- to sometimes get through to them [White professionals] about what I’m feeling, and sometimes I don’t really say (R: Mm.) I don’t really say everything that I want to say, sometimes I feel a bit like they’re better than me sort of thing (R: OK.) so maybe that is a part of feeling oppressed (R: Mm.) by a White society, I feel that they might [laughs] that because they’ve got this ‘doctorate’ [air quote] or whatever, you know, ehm that they might know better- know more than me, so sometimes I won’t speak up (R: OK.) and say certain things. But I’m trying to change that now, I’m trying to speak up a bit more” (Chadice, 1589-1595).*

Chadice’s phrases “get through” and “very difficult” might refer to her struggle to be understood by White professionals. There was a sense of Chadice silencing herself, possibly due to feeling inferior to White professionals. This may reflect the power imbalance that comes with racial inequalities, indicated by the word “oppressed”.

Additionally, Chadice’s experience of power imbalances can be understood through her perception that professionals may be more knowledgeable than her, indicated by her comment “*know better- know more than me*”. Chadice may have used nonverbal communication (laughter and the use of air quotes) to indicate that she did not value – or perhaps even mocked – professional qualifications. This may be her attempt to address the power difference in their relationship and so find her voice in this meeting.

Tianna also reported power imbalances during clinical meetings with professionals:

> *"how I experience it is as if people are just talking at you, they're not waiting to hear your opinion or how you feel or what you want, they're just telling you what you have to do and what happens and how it goes, which I didn't like at all. [...] You know or speaking down to you because they think you don't have the knowledge and the know-how, yeah?" (Tianna, 210-214).*

Tianna's account suggests that her experience of interacting with professionals included not being listened to and have been experienced as uncollaborative when providing care for her grandson; there is a sense that she felt dismissed, her input not valued.

Tianna made sense of professionals "speaking down" to her as their perception that she lacked knowledge or understanding. Tianna might have perceived that professional attitude prizes medical knowledge over her knowledge of what her grandson wants and needs. Perhaps this signified a power imbalance between professionals and caregivers, leaving her feeling disrespected and powerless.

Tianna later elaborated on her experience of power imbalances in interactions with professionals in a clinical meeting:

> *"I didn't agree but you don't feel as if you can question it because there's ten- you know there's ten professional people sitting around you, (R: Mm.) and you kind of feel a little bit out of your depth" (Tianna, 236- 239).*

Tianna felt intimidated in a clinical meeting due to the number of professionals in the room. Perhaps she was outnumbered and therefore, was unable to express her disagreement by challenging or "question[ing]" professionals over her grandson's care. Perhaps this left her feeling powerless and helpless.

Devan echoed a sense of being intimidated by professionals:

> *"Like you're walking on eggshell. (R: Yes.) Or you're walking a tightrope" (Devan, 1321).*

Devan's use of vivid metaphors to describe her relationships with professionals might signify that she felt uneasy in those interactions. Perhaps she worried about causing offence, leaving her overly concerned with the professionals' reactions. This may indicate the power professionals hold over caregivers, as she altered her behaviour towards them.

In contrast, Helen reflected on her experience of speaking up to voice her grievances with professionals even though the outcome was being ignored.

> *"I've complained about them [professionals], written complaints and nothing happens. (R: Mm.) This is a big -NHS institution. (R: Mm.) They don't want lawsuits, so they- I- I should be honest, I think they lied- they lied to cover up their bad behaviour and the mis- the- the negligence of their staff" (Helen, 439-443).*

Helen's decision to complain about the professionals might indicate her ability to recognise her own power and autonomy. However, she was met with no response from the services, meaning her negative experiences were not validated and her voice was not heard.

Helen felt that she was not listened to due to the power discrepancy between her and services, indicated by her comment "big NHS institution". Helen might have believed that, as the services had the power, they would go to any length to "cover up" and protect their interests. This may have left her to feel powerless and ignored.

Subordinate Theme Three: Lack of Information – Ignored and Confused

Participants reported that accessing information from professionals and services was a challenge at times, as they felt virtually ignored despite being their relatives' main supporters. This exclusion and the lack of information contributed to caregivers' feelings of isolation and left them feeling disconnected. Chadice explained her experience of trying to access information:

> *"I just feel like I've just got to battle with the- with the- with the hospital for instance and the social workers. I'll email the social worker, no one will get back to me. I'll make a phone call to the hospital and- just to ask for just a general update (R: Mm.) and it will be like, oh the doctor's not here, or I don't know [name] very well or can you ring back later? […] So it just feels like a fight, battle, and ringing up- and it's- I can never get a straightforward answer"* (*Chadice*, 1448-1454).

Chadice's words "a fight, battle" gave a graphic illustration of her relationship with professionals and services, which was not an effective partnership for sharing information. Rather, she perceived that there were obstacles to accessing information within forensic services. These included individual professionals failing to respond to her inquiries. Perhaps this left Chadice feeling overlooked.

Other barriers included a lack of protocols for accessing information, including a "general update". Perhaps this required Chadice to put in additional effort when trying to locate the appropriate professional. Her frustrated tone of voice signified that this task might be laborious.

Participants reported that attending clinical meetings at forensic services was one of several ways to gain information on their relative's progress. However, there were challenges involved in both accessing and being involved in these meetings. Helen stated the difficulties of accessing both verbal and written information:

> *"in the- in the forensic unit (R: Yeah.) they don't tell me anything. That's one of the problem I have with them" (Helen, 582-583).*

> *"some wards he's been on, are running through the CPA [meeting] they've involved me. (R: OK.) There are other ones where they've left me outside sitting. (R: OK.) Sitting outside for two hours while I could have been at work and then they call me in and they say, do you have any questions? And I said to them, how can I have questions if I've not been a party to the discussions that you're having? (R: Yeah.) They'll say to me, they'll give my son the report, they never do. (R: Mm.) And we got- we get tired of having to ask for them because they give you the impression that they don't want you to have them" (Helen, 753-759).*

Helen highlighted how the lack of access to information had strained her relationship with services. Her involvement with her son's care across the unit appears variable, from being included to being ignored, despite being her son's main supporter. Perhaps involvement in her son's care, including seeking information, is unpredictable. Helen's phrase "left me outside" portrayed her isolation and disconnection from professionals. She stated the exact time she was left outside, suggesting that she assumed her time and input were not valued by professionals. Helen's question to the professionals suggested that she want to see this meeting to be collaborative, but it might be frustrating they are not. Furthermore, professionals' failing to share written information might have reinforced her feeling of being excluded and isolated.

Helen elaborated on her experience of being declined information by professionals:

> *"He [ward manger] says to me, ehm- oh something has happened, but ehm- ehm I'm not in a position to tell you about it. So I got angry [raised voice]. [...] I said, well if*

> *my son had died- he's dead, what are you going to do, wrap him up in a black bin bag? And I said and then you will tell me about it. (R: Mm.) I said, <u>I sincerely hope</u> that if he dies, you're able to tell me something because I don't know at what point you're able to tell anyone anything. [...] I put the phone down, so all kinds of things- and then I started crying" (Helen, 861-869).*

Helen highlighted the significant strain that a lack of information has had on both her relationship with professionals and her emotional wellbeing. Being declined information might have left her on an emotional roller coaster of anger, confusion and tears. This may have left her vulnerable to distressing, catastrophic thoughts, indicated by her comment "if my son had died -he's dead".

Her phrase "wrap him up in a black bin bag" gives a graphic illustration of her perception that services could dehumanise service users – and possibly caregivers too. This might have left her feeling helpless, frustrated and devalued. Perhaps she perceived that professionals might not have compassion for her very human distress.

In contrast, Tianna reflected on the value of psychoeducation:

> *"I think what would have helped if they [professionals] had given me, you know some information or study- you [...] I don't know how to care for him as being schizophrenic. (R: Mm.) I don't know that side of it. (R: Mm.) So maybe that would have helped me relax a little bit and not have so much anxiety" (Tianna,886-890).*

It appears that Tianna sought psychoeducation for forensic carers of people living with schizophrenia. Her lack of knowledge and understanding left her less confident, unsure of how to support her grandson. Tianna assumed that the provision of information by professionals would aid her role as a forensic carer. Perhaps she hoped this would alleviate her "anxiety" and help her meet her grandson's specific needs.

The quotes above illustrate a lack of information have been harmful to caregivers in numerous ways and participants suspected that more information would have been helpful, Cedella quote shows the benefit of having extra information.

> *"when they started to explain things to us […] I think then there began to be a light. (R: Mm, OK.) It was a dim light that shone brighter. (R: OK.) […] I think that's when the hope came back (R: OK.) for my family member, loved one, for us as a family […] the hope began to come back because we began to be enlightened people instead of unlight- unenlightened people"* (*Cedella*, 338-347).

Cedella's use of the metaphors of "light" and "dim light that shone brighter" might signify how having an increased understanding of her son's circumstances restored her and her family's "hope" for his recovery. The repetition of "hope" might highlight the importance of this for her caregiving role. Perhaps the professionals explaining her son's circumstances brought a shift in her perspective, leaving her optimistic about his future.

Superordinate Theme Four: Ways to Survive the Emotional Demands of the Role

This superordinate theme explores how participants coped with the emotional demands of the role. It includes three subordinate themes: 'Suppressing painful emotions', '"I turn to" –faith in God and Christianity' and 'Support network is a "safety net" and "outlet".

Subordinate Theme One: Kept Going by Avoiding and Suppressing Painful Emotions

This subordinate theme looks at how participants maintained caregiving responsibilities by suppressing and avoiding the distressing emotions associated with the role. Participants felt this was the only way to continue caregiving. Samantha explained how she coped:

"I just try to push it away [...] That's the only way I can keep going" (Samantha, 849-851).

Her phrase "try to push it away" suggested that she was trying to suppress the difficult emotions and thoughts that come with the role. Perhaps she was deliberately trying to forget or put aside painful and unwanted thoughts. This strategy might make overwhelming thoughts and emotions more manageable when providing support.

In contrast, Chadice described avoiding various practical aspects of the caregiving role:

"I'm trying to avoid the practical things of it because it- [short pause] because it's hard- stressful and hard work" (Chadice, 1020-1021).

Chadice's phrase "avoid" might refer to her ignoring some aspects of caregiving responsibilities, such as cleaning her brother's flat. Such behaviour might prevent feelings of overwhelmingness and stress, perhaps allowing her to focus on other aspects of the role, such as providing emotional support by visiting her brother regularly.

Furthermore, Chadice described not only avoiding aspects of the role but also using this approach to cope with distressing emotions. She explained that visiting her brother was "stressful" and left her "tearful". She also described experiencing "mental exhaustion" due to overwhelming thoughts related to her role. Chadice explained how she managed this:

"I'll just go to bed [sleep] [...] to block it all out" (Chadice, 1323-1324)

"I have to drink [alcohol] [...] to get drunk! [laughs] [...] It just helps me to forget about the whole situation" (Chadice, 1299-1331).

Chadice's attempt to "block it all out" and "forget" might indicate her attempt to disconnect from difficult thoughts and emotions. Drinking alcohol and sleeping may bring about a temporary escape and relief from difficult emotions. Her laugh might indicate her awareness that drinking alcohol might have been a maladaptive away to deal with the pressure of the role, leaving her possibly embarrassed.

Chadice described feeling “fine” after waking up, indicating an improvement in her emotional state as she has fewer worrying thoughts; she said she “still think[s] about it but not as bad”. Perhaps this meant she was able to carry on with her other responsibilities and focus on her daily activities following her sleep.

Devan also described avoiding reflections on her past caregiving experiences:

> *“Looking back (R: Mm.) [short pause] it carries me back [short pause] to the sense [short pause] of being bitter. […] it makes me be angry […] So, I don’t look back”. (Devan, 463-464).*
>
> *“you don’t run the race looking back. [R: Mm mm.] This race, I’m running it forward”(Devan, 455-456).*

The phrase “looking back” might refer to Devan recalling memories of her caregiving experience. These memories might transport her back to feeling “bitter” and “angry”: painful, distressing emotions. Perhaps this approach might help create distance from emotional pain, enabling her to “run the race”. This may mean she can fulfil her caring responsibilities without being consumed by these difficult emotions. Perhaps, her use of the metaphor “run the race”, might suggest caregiving in this context is tiring, pressurised and requires her full attention.

Subordinate Theme Two: “I turn to”: Christianity and Faith in God

More than half of the participants mentioned a belief in God and used prayer to manage their difficult emotions within caregiving roles, enabling acceptance of their circumstances. Several spoke about their hope for miracles:

> *"Well my faith ehm- when things seemed* too daunting *for me and feel that- ehm too challenging and difficult ehm I turn to my faith, I pray and I ask my Christian friends to pray for me. […] it always brings a break- a breakthrough" (Cedella, 165-167).*

Cedella tended to "turn to [her] faith" to deal with the emotional burden of caregiving. Her repetition of "I" indicates a proactive choice to manage her difficult emotions through prayer. Cedella later defined "breakthrough" as detrimental feelings and situations being "removed very quickly". She perceives that prayer has the power to alleviate distress.

Similarly, Devan's belief in God helped her to manage difficult emotions:

> *"And if [son] wasn't ill, which I am not question- questioning God, (R: Yes.) why him or why me have to go through this process […] Because he promise he'll give me the grace to go through the darkness, the storm." (Devan, 541-545).*

Devan stated that she would not question God, but goes on to ask questions, suggesting a tension between what she wants to do (not question God) and what happens in reality. Devan appears to bear her fate as a caregiver, reluctantly accepting her difficult circumstances. The word "promise" indicates an agreement with God for his favour so she can undergo these difficult experiences as illustrated through her vivid metaphor of "darkness and storm".

Devan also described a belief that God could do miracles in her son's life.

> *"Lazarus died and God raised Lazarus back from the grave. Lazarus came back and he lived twenty-five years […] So what he done for Lazarus as a dead person (R: Yeah.) he will do for my son as a live person as well." (Devan, 1677-1681).*

Devan retold a Biblical story about one of God's miracles. Devan's language demonstrates her certainty that God will intervene, heal her son and change his circumstances. Perhaps her confidence in her son's recovery is in God instead of his treatment.

Similarly, Winston discussed how his faith helped him to manage difficult emotions.

> *"God knows everything, understands things, so even [daughter] (R: Yeah.) you know suffering here (R: Yeah.) if somehow God brings her back you know, it'll be for eternity. (R: OK.) So the little short time what she's been suffering (R: Yeah.) is nothing compared to everlasting life" (Winston, 1204-1207).*

Winston's repetition of "suffering" might indicate the degree of emotional distress he anticipated his daughter experiencing. Although Winston is uncertain if God can heal his daughter or return her to her formal self ("if somehow God brings her back"), his faith offers him hope of his daughter returning to her former self in the afterlife and the belief that her distress on this earth is temporary.

Subordinate Theme Three: Support Networks are a "Safety Net" and "Outlet"

This subordinate theme looks at the role of support networks on caregivers' experience within forensic services. This included professionals (NHS mental health services and external charities), family members and partners.

Half of the participants described a helpful support network, using words like "outlet", "safety net" and someone you "can cry out to". Devan explained how a mental health charity that solely supports African and Caribbean communities supported her:

> *"You get one to one support. Somebody who'd listen. [...] They have time for you, to listen. (R: Mm.) Those places [forensic mental health services] don't have no time, they don't listen. (R: Yeah.) That somebody you can cry out to. [...] can call you see at any time, [...] I get support, I get a word of encouragement. (R: Yes.) At all times."* (*Devan*, 1393-1398).

Devan's phrases "can cry out to" and "encouragement" might indicate that professionals in the charity provided her with emotional support. "One to one support" indicated that support was tailored to her needs.

Devan described that charity representatives attended clinical meetings (tribunals and CPA meetings) with her and also visited her son when she was not available. Perhaps this practical support eased some of the stress of the role. Devan's repetition of the word "listen" might highlight she highly valued being heard. Perhaps this provided her with a sense of being understood by the charity professionals since the forensic mental health services did not listen. Furthermore, her words "have time for you" and "any time" suggest that care and support were reliable and easily accessible.

Cedella described getting support from multiple support networks:

> *"my son's condition used to bring me close to ehm not being unwell but if my team and my daughter and her husband and [partner] and my true close friends (R: Mm.) have got me through it"* (*Cedella*, *537-539).*

> *"So I spread it around (R: OK, so you-) and it works for me. [...] If I didn't have all those things, I wouldn't manage it. I spend a lot of time in hospital"* (*Cedella*, *770-773).*

Cedella described how multiple support networks have provided her with emotional and practical support, aiding her mental health. This support might have been vital as Cedella may be more vulnerable to stress due to her existing mental health difficulties.

Additionally, Cedella's phrase "spread it" and her later comment about not wanting to use her "friends as a Marjorie Proops" (agony aunt) might indicate that having multiple support networks was more effective as it did not overburden one individual. Perhaps each support network brought different skills and resources, thus helping her “manage” and preventing prolonged hospital admissions.

Cedella also explained how her mental health team supported her.

> *“I’ve worked through [self-blame] that with my community mental health team and my CPN. (R: Mm mm.) And ehm I know I’m not to blame for it. My son had choices and opportunities [ ] he veered more to the [short pause] male influence outside the home and wasn’t a good influence. They weren’t leading him on the right path” (Cedella, 279-286).*
>
> *“I had my team [mental health professionals] as back-up, if I have a hiccough or trauma I can self-refer myself to them (R: Mm.). (R: Yes.) So I’m not exactly out there with no safety net at all” (Cedella, 545-547).*

Cedella’s first quote suggested that professionals within the NHS, yet outside of forensic services, might have supported her in processing difficult emotions. This might have changed how she relates to herself, indicated by her comment “not to blame”. Perhaps she felt less critical of herself and, in return, may have placed more responsibility onto her son for the “choices” that led to him accessing forensic services. Perhaps this shifted how she related to her son and her caregiving behaviour. For example, she refused to give him money in case he bought drugs indicated by her comment, “I’m not giving you money to support a drug dealer”

In quote two, Cedella described professionals as “back-up” and a “safety net”, suggesting she planned to seek support from professionals when experiencing setbacks.

Chadice also explained how multiple support networks provided her with an “outlet”:

> *“I’ve got family, I’ve got grandchildren, I’ve got a full-time job Mm. And a boyfriend! [laughs] […] It’s just another outlet”* (Chadice, 1212-1220).

Chadice’s word “outlet” might refer to an emotional “outlet” or a way out of the practical problems of the role. Perhaps the multiple support systems, including her job, met her needs in different ways. For example, she described her boyfriend providing her with financial support, which her family could not do, thus alleviating the financial stress of the role. Furthermore, her repetition of “I’ve got” and her laugh suggest that it’s important for Chadice to have something that is hers, as caregiving can be consuming.

Summary

The current study explored the experiences of seven carers of African-Caribbean heritage supporting individuals with psychosis within NHS FMHH . Four superordinate and eleven sub-ordinate themes emerged. These provided an in-depth understanding of the emotional reality of being a forensic carer, including difficult relationships with the person being cared for and other family members, in the context of managing caregiving responsibilities. The analysis explored how participants’ culture and community informed their caregiving attitudes, values and behaviour. An in-depth understanding of caregivers’ relationships with professionals and services was provided. Finally, an understanding of how caregivers manage and maintain their roles was given.

Chapter 5 - Discussion

Chapter Overview

The purpose of this study was to explore the experiences of caregivers of African-Caribbean heritage who support individuals with a diagnosis of psychosis in an NHS FMHH. This group is described as a 'hard-to-reach', hidden populations when they should be considered as 'easy to ignore' as as facing social exclusion, discrimination, and MH inequalities (Beresford, 2008; Greenwood, 2018; Nazroo et al.,2020), while their subjective experiences have remained unexamined (Stevens et al., 2017). The findings of this study illustrate that although forensic carers of African-Caribbean heritage share some experiences with White forensic carers, several unique social and cultural factors influence their caregiving experience.

Four super-ordinate themes emerged: 'The role is "too much for a humanity": Emotional, physical and relational challenges', 'Cultural and community – norms and values', 'It is a terrible battle relating to services and professionals' and 'Ways to survive the emotional demands of the role'. These themes will now be discussed with reference to previous research. The study's potential contribution to the evidence and clinical practice of counselling psychology will also be considered. In addition, the study will be critically evaluated, and future research directions will be suggested.

The Role is "too much for a humanity": Emotional, Physical and Relational Challenges

Most participants discussed the burden of being a forensic carer for a relative with a diagnosis of psychosis. Participants described the role as emotionally demanding, physically exhausting, financially costly and impacting their relationships with other family members.

Participants discussed the impact of the carer role on several aspects of their lives. These included the time of the SU's diagnosis, their legal affairs and admission to FMHH.

Hence, participants experienced multiple simultaneous stressors, meaning their burdens were multi-dimensional. This finding relates to Tsang et al.'s (2002) model for understanding forensic carers' stress and burden. Four dimensions of burden forensic carers might experience have been posited – symptom-specific, emotional burden, financial burden and social burden – with managing SUs' MH difficulties named as a core stressor.

Secondary sources of stress were related to the offence and included managing the police and media, attending court and admission to FMHH. Hence Tsang et al. (2002) argued that forensic carers might be dealing with additional, cumulative burdens. Similarly, MacInnes and Watson (2002) stated that forensic carers supporting individuals with a diagnosis of schizophrenia reported higher levels of burden than non-forensic caregivers for those with the same diagnosis. In relation to objective burden, Stansfeld et al. (2014) argued that caregivers of people living with psychosis experience higher levels of fatigue than the general population. Indeed, participants in the current study reported being physically exhausted, with some negotiating the role alongside full-time work and the support of other family members.

Furthermore, forensic carers have reported financial stressors (Ferriter & Huband, 2003). MacInnes and Watson (2002) argued that forensic carers are more likely to experience financial burdens than caregivers supporting someone with a non-offending history. Most participants in the current study reported financial stress. Information that adds to literature was uncovered, demonstrating that financial burden is also experienced by forensic carers of African-Caribbean heritage, a group neglected by researchers. For instance, Chadice reported borrowing money from her partner to pay for her brother's passport, which would facilitate his discharge from hospital. Considering that BAME communities are likely to experience poverty and higher unemployment rates (Institute of Race Relations, 2019), this financial burden might leave caregivers from this community financially vulnerable.

Additionally, evidence suggests that both social and economic factors might place people of African-Caribbean heritage at greater risk of MH difficulties such as anxiety and depression (Browne, 2013). Hence, although objective and subjective burdens are separate concepts, they crossover, as the objective burden of financial difficulties might result in the subjective burden of depression and anxiety.

Regarding subjective burden, caregivers in this study reported an impact of the role on their MH. Samantha described being depressed, while Cedella reported being “close to” accessing MH services. These findings align with previous literature, where caregivers have reported increased rates of MH difficulties including depression, post-traumatic stress (Kuipers et al., 2010) and suicidal behaviour (Stansfeld et al., 2014) compared to the general population.

However, adding to this picture, several participants in the current study had MH difficulties before taking on the role. Chadice had previously avoided caregiving to “preserve” her MH as she feared that taking on the role would result in her “end[ing] up in hospital”. Perhaps forensic carers with a history of MH difficulties experience additional stress given their need to preserve their own health.

Furthermore, in relation to subjective burden, forensic carers, mostly parents of SUs, frequently express guilt over their relatives’ MH difficulties (Ferriter & Huband, 2003; Ridley et al., 2014; Rowaert et al., 2017). Similar findings emerged in this study, as parent participants sometimes felt fully or partially responsible for their offspring’s difficulties.

Ferriter and Huband (2003) found that parents’ self-blame was maintained despite the absence of blame from others and reassurances being offered. In this study, Helen’s guilt and self-blame persisted, whilst Cedella worked through these emotions with the support of her MH team. Hence, Helen’s experiences are in line with existing research, whilst Cedella’s adds to the picture, offering some hope that these emotions can be processed.

Nordström et al. (2006) argued that families' emotional experiences can reflect the phase of the journey their relative is in, and it is through this lens that the difference between Helen's and Cedella's experiences can be understood. At the time of the interview, Helen's son's MH was fluctuating, and he had attempted to take his life. In contrast, Cedella's son had been discharged from the low-secure ward, indicating stable MH. This demonstrates that forensic carers' emotional support needs may vary depending on the SU's mental state.

Furthermore, this study shows that professionals have an important role in supporting caregivers who are processing difficult emotions. Similarly, Kuipers (2010) argued that services need to tailor support to suit caregivers' needs. Evidence shows that family interventions can significantly improve caregivers' wellbeing over time (Claxton et al., 2017).

In addition to the emotional and physical demands of this role, participants discussed difficult family dynamics. This is in line with the literature stating the whole family is impacted when a relative experiences psychosis (BPS, 2021). This finding could be explained using EE theory. The theory highlighted the importance of focusing on the stress level of household of caregiver's and SU's, as this has great implication of SU's and caregiver wellbeing (Kuipers et al., 2010).

Critical comments, hostility and families' emotional involvement with SUs have been found to correlate with adverse outcomes such as increased risk of SU's relapse (Birchwood & Cochrane, 1990). However, this is not a simple cause-and-effect relationship, as EE might vary depending on a family's circumstances and SU's levels of mental illness (Birchwood & Cochrane, 1990).

In this study, Tianna described conflict in her household when her grandson was on overnight leave from the hospital. She attributed this to several factors and described displacing her frustration onto her husband, which impaired her marriage. Samantha echoed this, describing that conflict within her family left her isolated in her caregiving role. This finding supports existing evidence that caregiver burden is strongly related to high EE.

Additionally, poor care outcomes such as stress, distress and low self-esteem strongly correlate with high EE (Kuipers et al.,2010; Raune et al., 2004). Hence, awareness of how SU's MH affects the whole family has risen including caregiver outcome (Onwumere & Kuipers, 2017a). NICE guidelines recommend that all SUs who are experiencing psychosis and in touch with their families should receive family intervention. However, these interventions are not offered routinely by most services (BPS, 2021), and families from African-Caribbean groups are less likely to access them due to their lack of awareness and understanding of such interventions (Edge, 2016).

In summary, the unique contribution of this study to the evidence based included highlighting forensic carers of African-Caribbean heritage are financially vulnerable because they likely to experience poverty as well as financial burden within the role. Therefore, this group of caregivers might be a greater risk of MH difficulties such as anxiety, depression and at great risk of accessing mental health services due to their social and economic factors. This in turn means they might not be able to carry on with their roles. Furthermore, this study adds to evidence base by highlighting how professionals play significant role in supporting caregivers to process difficult emotions such as self-blame. This then offering the hope that distressing emotions can be alleviated and processed. Additionally, this study highlights the tension and conflicts within a caregiver's household might be linked to when supporting SU's in their recovery, including having them for an overnight leave. This at times means caregivers having an extra responsibility giving their relative their medication and managing the risk of absconding whilst they are under their care.

Cultural and Community – Norms and Values

The unique finding of this research within the forensic carer literature was this study highlighting the influence of culture, community norm and values on caregiving experience. In this study most participants discussed caregiving values and norms embedded within Caribbean culture, especially in the context of caring for family members.

Adamson and Donovan (2005) explored what it meant to be a carer for people from BAME communities who have a relative with dementia. These carers, including those of African-Caribbean heritage, located their caregiving experience within the context of culture. Caregivers portrayed caring for a family as virtuous, yet also viewed their role as an expected responsibility. These findings could be understood in the context of cultural value of familism – this refers to "strong identification and solidarity of individuals with their family as well as strong normative feeling of allegiance, dedication, reciprocity and attachment to family members, both nuclear and extended" (Knight & Sayegh, 2010, P.7).

Another novel finding of this study within the forensic carer literature is it might be that due to these cultural values, forensic carers with African-Caribbean heritage are likely to be a family member, including extended family (e.g., grandparents), whereas the literature with forensic carers states parents, mostly mothers, tended to be carers rather than siblings or spouses (Ridley et al., 2014).

Furthermore, Adamson and Donovan (2005) found that most caregiving was an extension of participants' previous responsibilities, such as being a spouse, son or daughter-in-law. Hence, carers viewed caregiving role as a "duty related to love, reciprocity, position in the family or a combination of these factors" (Adamson & Donovan, 2005, p. 46). Hence, caring was already integral to participants' sense of self, meaning some caregivers did not view themselves as carers.

Similarly, some participants in the present study recognised their role as an extension of their previous role of mother, grandmother or father, which is a novel finding within the forensic carer's literature. Specifically, in the current study, several participants reflected on their relational role when discussing their experiences, highlighting their commitment regardless of their relatives' behaviour, including involvement in criminal offences. For instance, Tianna stated that, in the Caribbean community, families support each other through the "good, the bad, the ugly". This can be understood as a cultural, familial obligation of providing support in times of need (Chakrabarti, 2013). Others, like Samantha, reflected on the mothering role and the Caribbean outlook on caregiving, explaining why she persevered with the role despite finding it "difficult". This highlighted the influence of culture on participants' resilience when caregiving.

Another novel finding within this study was some participants in the current study had adopted new caregiving values due to the pressure of the role. This involved creating emotional and physical distance from the SU to preserve their own MH and maintain their caring role. This is because the new caregiving value offered them distance from these emotional, physical and financial burden. However, the new set of caregiving values caused tension, as setting boundaries appeared to go against Caribbean values of caregiving. It is possible both the internal and external pressures due to these changed values might have impacted participants' sense of self, especially regarding the mothering role. For instance, Cedella perceived that, as a Caribbean mother, she should be offering "unconditional love" to her son. However, setting boundaries enabled her to redefine what it meant to be a Caribbean mother whilst caring for a son with MH difficulties in forensic services. Perhaps her attitude had shifted from a collectivist to an individualistic cultural value of caregiving (Arnold, 2011; Willis, 2012).

Milne and Chryssanthopoulou (2005) argued that, in the context of caregiving, the concepts of culture and ethnicity vary across countries, places, communities, families and individuals. Additionally, these concepts vary according to circumstances, are contested, diverse and subject to change. Collectivistic cultures focus on the needs of the extended family, whilst individualistic cultures focus on autonomy and independence (Reher, 1998; Willis, 2012). Collectivism and individualism are attached to specific cultures and countries (Willis, 2012). For instance, Britain is a highly individualistic country, whilst Caribbean culture is considered collectivist (Arnold, 2011). However, it is important to highlight that, due to migration, a single country can have a variety of cultures, and that compliance with cultural values may differ within countries, ethnic groups and even one's family (Willis, 2012).

Participants also spoke about stigma within their community. In the literature, stigma has been considered a psychological and social phenomenon (Mantovani et al., 2017) which occurs at three inextricably linked levels: self-stigma, social stigma and structural stigma.

Social stigma refers to community members who are hostile toward individuals with certain traits (such as MH difficulties) because they feel those traits contradict community norms. Social stigma is caused by collective and individual beliefs among dominant members of society and often impacts oppressed groups. It is thought to lead to self and structural stigma. For instance, the belief that people of African-Caribbean heritage who have MH difficulties are "Black, big and dangerous" might encourage coercive MH interventions, contributing to structural stigma. While this conceptualisation of stigma is valuable (Mantovani et al., 2017), it fails to recognise the stigma families and caregivers experience due to having a family member with MH difficulties. This is referred to as 'courtesy stigma' (Goffman, 1963) or 'associative stigma' (Mehta & Farina, 1988).

In this study, Chadice reported that her sibling’s MH difficulties were kept “behind closed doors” within her family. She attributed this decision to culture, indicating that MH difficulties were perceived as embarrassing and wrong in the Caribbean community. This suggested social stigma. Similarly, Mantovani et al. (2017) found that African and African-Caribbean faith leaders, outreach workers and church members living in London held stigmatizing ideologies around mental illness. This included viewing mental illness as a “moral failing or weakness” (p.377), indicating social stigma.

Additionally, Mantovani et al. (2017) argued that families tended to avoid disclosing relatives’ MH difficulties to maintain an “idealised social identity” (p.378). Likewise, Chadice described her anticipation of associative stigma due to having a relative in a forensic psychiatric hospital, stating that having two siblings with schizophrenia would mean she and her family lost their community’s respect. She also reflected that having a MH difficulty as an individual of Caribbean heritage is “another thing to add to being Black”. This indicated that forensic carers of African-Caribbean heritage are at risk of dealing with the triple stigma of race, mental illness and a family member accessing forensic services.

Keating and Robertson (2004) argued that the sense of shame-related stigma for African-Caribbean caregivers might be more acute due to racism and stereotypes. A novel finding of this study is that one participant described experiencing associative stigma from professionals of African heritage working within forensic services, indicating structural stigma (Mantovani et al., 2017).

It is a Terrible Battle Relating to Services and Professionals

Institutional racism is a term coined by Carmichael and Hamilton (1967) to highlight that racial inequalities are not a natural phenomenon but are the result of actions taken within established institutions. Researchers have argued that discrimination and racism can shape the provision of MH services (Fernando, 2004; Nazroo et al., 2020). Institutional racism operates through the process of racialising, in which racial meaning is attributed to people's identities (Miles & Brown, 2003). Furthermore, Song (2014) argued that racism can be viewed as a form of racialisation as it operates by excluding, marginalising and demeaning groups based on their skin colour, culture and symbolic differences.

The unique contribution of this study to the evidence based included highlighting that most forensic carers of African-Caribbean heritage perceived NHS FMHS as institutionally racist, eliciting deep mistrust, fear and suspicion. This shaped their caregiving attitudes and behaviour. Some participants in this study described instances of institutional and interpersonal racism they and their relatives experienced within forensic services. For instance, Devan described her son entering mental health services including forensic services as "going into the shark mouth". This indicating the significant risk, danger and threat she perceived for her son in this setting. Therefore, she highlighted that her role as a caregiver in this setting was to continually "help pull [her son] up". She assumed that the alternative might be her son being "swallow[ed] up" or left to "rot in the institution", suggesting that her son would be neglected without her input.

Furthermore, Chadice described hearing about her mother's experience of interpersonal racism, while Tianna had experienced interpersonal racism at work. Both women feared that their relatives might encounter institutional racism. This finding can be understood in the context of Virdee's (1997) suggestion that individual experiences of racism are not only considered personal attacks but also attacks on the community.

Further, Karlsen and Nazroo (2004) argued that individuals do not need to experience racism directly for it to elicit a sense of threat, given it reflects historical legacies of oppression, thus reinforces a lack of security for those with racialised identities (Nazroo et al., 2020).

Additionally, CRT might be a useful theory to hold in mind when trying to understand racism and social inequality within contemporary society (Bonilla- Silva, 2015). The theory highlights the nature of racism, which is racism experienced at both an institutional and an individual level, which is echoed by the finding within this study. For instance, most of the forensic carers in the study referred to systemic racism and one participant spoke about her own experience of interpersonal racism at work. CRT also offers frameworks to understand the influence of racism in shaping government policy, health services and society in general. This study's finding complements this theory, as participants spoke about the racial inequalities they faced or perceived within forensic mental health services and, therefore, feared that their relatives would encounter institutional racism.

Adding to this, participants in the current study reported that institutions' previous treatment of community members might influence their perception of services and caregiving behaviour. Devan posed a rhetorical question, asking "You know how many of our Black boys die in the institution?" She perceived Black men's lives, in this setting, were under threat and that institutionally racist services were an unsafe setting for her son. Devan's concerns are in line with the literature, such as the Prins Inquiry (1993) investigating the deaths of three Black males diagnosed with schizophrenia who were killed by physical and chemical restraint in Broadmoor hospital. In recent years, authors of the Angiolini's review found a disproportionate number of deaths of Black men in police custody amongst those with MH problems (Angiolini, 2017).

Further, some caregivers in the current study perceived that their relative had been stereotyped and stigmatised within forensic services due to skin colour, physical stature or both. For instance, Devan stated that when SUs of African-Caribbean heritage access services, healthcare professionals "see them as Black, big and dangerous". This exact phrase was reported in the Prins Inquiry as being openly used by nursing teams; the report highlighted staff's lack of response to signs of distress from Black SUs (Prins et al., 1993).

Although this inquiry is almost 30 years old, this issue remained for Devan and other participants. Devan's beliefs and concerns coincide with the existing literature on institutional racism within MH services (Bhui, 2002; Fernando, 2008; Nazroo et al., 2020). While racial injustice and oppression are acutely felt by Black and Asian SUs in FMHS (Fernando, 2004), these racist stereotypes have been longstanding in the UK, with institutional racism being an issue within institutions such as the police service (Angiolini, 2017).

Furthermore, CRT also offers a possible explanation for the lack of progress in addressing racism within contemporary society. Again, this is also a point echoed within this study, specifically with Devan's account. Crenshaw and Bell (1980) argued that the lives of African Americans had not improved despite passing of civil rights legislation. The authors argued that one reason for understanding the lack of progress was that positive change only occurs for marginalised communities, including the racialised communities, when it benefits those in power. Additionally, the theory also highlights the role of current political and economic structures in promoting white supremacy and white privilege, thus maintaining social inequalities. Hence, at its core CRT advocates for a discussion around systemic racism and the promotion of antiracism practice within services is essential in addressing racism (Bonilla-Silva, 2015).

In this study, participants also reported that the impact of perceived institutional racism within forensic services resulted in fear, mistrust and suspicion. Similarly, Keating and Robertson. (2004) found that families of African-Caribbean heritage supporting SUs in non-forensic populations perceived services as institutionally racist. Families experienced MH services as a vicious 'circle of fear', reporting delayed or non-engagement, negative care pathways and poor outcomes for SUs. Thus, the fear, mistrust and avoidance of those services by African-Caribbean families were reinforced (Keating & Robertson, 2004; Keating et al., 2002).

However, the novel finding of this study was caregivers in the current study did not avoid services but were active in their role. In some cases, carers “worked hard” so that their relatives were not overlooked or discriminated against within services. Furthermore, most caregivers adopted a survival strategy of fighting back to deal with discrimination and systemic oppression within forensic services. Some described this strategy as deeply-rooted in their heritage.

As well as institutional racism, participants identified a lack of involvement in SU care as another factor contributing to problematic relationships with services. Guidelines developed specifically for carers supporting an individual within inpatient MH settings, such as the triangle of care (Worthington et al., 2013) and the secure carers toolkit (NHS England, 2018), advocate for meaningful involvement and support for carers. The triangle of care describes a three-way partnership between clinicians, SUs and caregivers. Crucially, carers should be “active partners” (Worthington et al., 2013, p. 6) in providing care to SUs in hospitals. This includes professionals seeking carers’ views and knowledge to inform SUs’ treatment plans. However, for this collaboration to be effective, professionals and caregivers must be willing to participate and engage. To aid SU’s recovery and meet carers’ needs, all stakeholders must be heard and allowed to influence treatment decisions (Worthington et al., 2013).

Machin et al. (2022) argued that forensic carers were too often not heard; instead, there was an “illusion of inclusion” (Sampson et al., 2019, p. 309) within forensic services. Sampson et al. (2019) reported that forensic carers saw themselves as an untapped source of information for services due to their knowledge about their relatives.

One forensic carer in Sampson et al. (2019) study described the triangle of care as being like “a three-legged stool with two long legs and one-half leg, which is the carer’s” (Sampson et al., 2019, p. 309). The current study's findings are consistent with those of Sampson et al. (2019). For instance, Devan described her experience of interacting with professional as “Like “walking on eggshell” and “walking a tightrope”.

Additionally, participants in the current study also discussed barriers to their involvement as forensic carers of African-Caribbean heritage. Most participants reported participating in ward reviews and care programme approaches (CPA) despite their busy schedules and distance from the hospital.

Caregiver participants also reported that a barrier to effective partnership was the power imbalance between themselves and professionals due to racial inequalities, differences in knowledge and expertise between professionals and carers, or a combination of both. For instance, Devan and Tianna reported feeling intimidated by professionals during ward reviews, resulting in feelings of helplessness and powerlessness. This was also seen in Keating and Robertson’s (2004) study, where a similar group of caregivers described a power imbalance between themselves and MH professionals. Caregivers reported being afraid to challenge professionals’ decisions and felt that their concerns were not taken seriously.

Furthermore, caregivers tailored their behaviour toward professionals by remaining silent in meetings so that their relatives would not experience negative outcomes (Keating & Robertson, 2004).

In the current study, Chadice reported silencing herself in ward review as she felt inferior to White professionals. Reports of forensic carers being intimidated by healthcare professionals were also found by Ridley et al. (2014), although caregivers attributed this to the nature of caregiving in secure hospitals.

Ridley et al. (2014) also found that forensic carers reported their perspectives about their relatives' care were not considered by staff. Similarly, Tianna described a lack of collaboration from professionals when caring for her grandson. Hence, the power imbalance between professionals and caregivers might prevent forensic carers from being effective 'active partners' within the care team (Worthington et al., 2013).

Another essential aspect of carers' involvement is their ability to access information from professionals (Ridley et al., 2014). In the current study, some carers experienced barriers in their attempts to access information, which elicited negative feelings, further straining carers' relationships with professionals. Similarly, other authors have found that caregivers have reported frustration, anger and despair when they were denied access to information due to confidentiality or other issues (Ferriter & Huband, 2003; Morrissey et al., 2017; Ridley et al., 2014).

Confidentiality has been seen as a barrier due to professionals' and services' tendency to be over-cautious and the desire to balance SU's privacy with carers' rights (Sampson et al., 2019). The present study captured the value of providing caregivers with confidential and non-confidential information such as psychoeducation and their relatives' prognosis. Cedella's experience of receiving information resulted in her and her family feeling "enlightened", leaving them optimistic about their relative's future and perceiving professionals as supportive and caring. Similarly, MacInnes et al. (2013) found that providing information to forensic carers was associated with greater satisfaction with services.

Ways to Survive the Emotional Demands of the Role

In the Lazarus and Folkman's (1984) stress, appraisal and coping model, caregivers' experiences of psychological distress depend on their subjective appraisal of stressors and perception of their ability to cope. Several stress-coping models have been developed based on this framework, such as the socio-cultural stress and coping models (Knight et al., 2000), which emphasise the influence of culture on role appraisal and coping resources, such as social support and coping styles.

Optimal coping responses for caregivers supporting an individual with psychosis have been discussed. Caregivers' distress has been related to both illness-related difficulties and coping styles (Kuipers et al., 2010). Coping involves cognitive and behavioural changes (Cotton et al., 2013). Researchers have argued that active, 'problem-focused' coping strategies are more effective than avoidant strategies for reducing carer burden (Raune et al., 2004). Caregivers engaging in this coping style tended to report higher levels of personal accomplishment. Hence, these coping styles have been encouraged and endorsed within family interventions (Kuipers et al., 2010).

Novel findings of this study was few forensic carers of African-Caribbean heritage in the current study used avoidant coping strategies. For example, Chadice drank alcohol to "forget" difficulties related to caregiving and slept during the day to "block" out worrying thoughts. Although avoidant coping strategies are rarely used by caregivers supporting individuals with their first episode of psychosis, they are more likely to be used when supporting individuals with chronic psychotic disorders within a non-forensic population (Gerson et al., 2011). This finding aligns with the current study since forensic carers are likely to support SUs with longstanding MH difficulties who have prolonged hospital admissions.

This research unique contribution to existing literature is by showing the context in which forensic carers use avoidant coping styles. In this study, avoidant coping provided for one participant with a temporary escape from emotional distress after a difficult visit. Other caregivers in this study suppressed their distress, perhaps to have distance from painful emotions. For instance, Devan described to fulfil her caring responsibilities without being consumed feeling of "bitter" and "angry" she has decided to "run the race" of caregiving by "running it forward*"* instead of looking back. Perhaps this approach might help her create distance from emotional pain, enabling her to continue care for her son.

The evidence base on this coping style is mixed, as some authors argue this coping style can be beneficial when caregivers are dealing with acute stress (McGorry & McConville, 1999), as illustrated in this study and others argue it can be harmful (Onwumere et al., 2011).

Gerson et al., (2011) argued use of avoidant coping strategies leads to greater fatigue and burden over time. However, regardless of the duration of SU's MH difficulties (Onwumere et al., 2011), caregivers using this coping style reported increased levels of distress, meaning it is associated with poorer overall functioning (Raune et al., 2004).

Perhaps, this coping style can be helpful for forensic carers to deal with acute stress, but the longer-term impact is something that can be explored in future studies. Similarly, active coping strategies such as acceptance and religion are associated with less caregiving burden and distress for caregivers of SUs with chronic MH (Huang et al., 2007; Fortune et al., 2005).

The present study revealed that many participants' belief in God and Christianity influenced their lived experiences as forensic carers in various ways. These included the role of prayer in coping with difficult emotions, the influence of faith in accepting their circumstances and the role religion had in restoring health and wellbeing.

Many African-Caribbean communities in the UK consider religion a core aspect of their cultural identity given faith plays a significant role in the lives of many BAME carers (Carers UK, 2022). As such, shared religious values might lead to shared understanding. For instance, organised religions such as Christianity are viewed by many Black British

Caribbean community members as a coping mechanism is highly valued resource during times of distress and hardship as it is rooted in their ethnocultural coping strategy (Edge, 2013; McKenzie et al., 2011).

Findings from ethnographic studies with African American and Black Caribbean communities have indicated that high levels of religious involvement can improve overall MH (Chatter et al., 2008). Additionally, Singh et al. (2013) found that caregivers of Black Caribbean heritage living in the UK and supporting a SU with the first episode of psychosis, rely on their spiritual beliefs and church support network to meet their psychosocial needs.

Although existing literature has explored the link between culture, religion and caregiving in first episode psychosis to an extent (Singh et al., 2013), the current research added to the existing literature by showing that this is also the case for forensic carers of African-Caribbean heritage, a group that tends to care for SUs with enduring MH difficulties.

For example, Cedella reported that when things were “too daunting”, she prayed and asked others to pray for her as she perceived that prayer could alleviate her distress. Furthermore, faith in God enabled a few participants to accept their difficult circumstances as forensic carers. Hence, caregiver faith and religious practice had a role in how they coped with distress.

Implications for Counselling Psychology and Clinical Practice

Service Level

An aim of the present study was to inform clinical practice for CoPs and allied MH professionals working with forensic carers of African-Caribbean heritage, who are caring for individuals diagnosed with psychosis.

This research is well-timed, as issues of structural racism and racial injustice have resurfaced recently, capturing the attention of a new generation. This is evidenced by the support for the global Black Lives Matter movement.

In addition, although COVID-19 impacted individuals across different communities within the UK, deaths were disproportionately high among BAME communities (Public Health England, 2020). This opened a societal discussion around racial inequality and its links to health inequality.

FMHS are not exempt from interpersonal and institutional racism (BPS, 2021) which was an important aspect of participants' lived experiences in the current study. These experiences elicited fear and mistrust of NHS FMHS while also shaping caregiving behaviour so that participants' relatives were not overlooked or discriminated against within services.

The UK government has previously attempted to address racial inequality, raising the issue of institutional racism in MH services and poor access to services (DoH, 2005). The government proposed a five-year plan entitled 'Delivering race equality in mental health care: An action plan for reform inside and outside services' (DoH, 2005).

However, no improvements in race inequalities relating to MH care have been found since the end of the programme (Nazroo et al., 2020). This may be because services are not thoroughly assessing the role of racism in generating MH inequalities (Nazroo et al., 2020).

Nazroo et al.'s (2020) framework for understanding the role of structural, interpersonal and institutional racism in generating and reproducing MH inequalities may benefit individual services when addressing racial inequality whilst working with forensic carers of African-Caribbean heritage. Further barriers to addressing racial inequalities within MH services include limited resources for funding relevant projects as well as a lack of prioritisation and thoughtful, progressive action by services (Bhui et al., 2018).

Despite this, authors of a recent independent review of the Mental Health Act (UK Government, 2018) recommended that NHS England develop a Patient and Carer Race Equality Framework (PCREF) to address racial disparities in relation to access, experience and outcome for African and African-Caribbean communities. It is hoped that this will improve relationships by increasing carers' and SUs' trust in services. This framework is currently being piloted in four NHS trusts across the country (NHS England, 2022).

CoPs and allied MH professionals can help to implement this framework and other projects that promote antiracism and discrimination in MH by developing working groups to address the racial inequalities that carers experience within services. They can also work in partnership with other forensic services and community organisations that are committed to this work. This would help to keep services accountable for prioritising racial inequalities. This is especially relevant for CoPs and allied professionals, who must engage in issues related to social justice, allowing them to be "agent[s] for social changes" (Lee et al., 2018, p. 33) when working with marginalised communities.

Furthermore, services could offer training addressing structural stigma, social stigma and the triple stigma faced by forensic carers of African-Caribbean heritage, and a reflective space to enable MH professionals recognise their own biases and challenge ideologies that perpetuate racism.

FMHS can also improve relationships with carers of African-Caribbean heritage through consultation and community engagement work (Tribe & Bell, 2018). This might involve services hosting regular coffee mornings for carers in and outside churches, allowing them to meet the professionals working with their relatives, thus building a therapeutic alliance with carers and take steps in addressing health inequalities (WHO, 2020). This is key as forensic carers in the current study identified a power imbalance as a barrier to partnership when providing care for SUs.

Clinical Level

Family interventions are recommended for individuals living with a diagnosis of psychosis (NICE, 2014), including those who are accessing forensic services (BPS, 2021). Furthermore, the NICE guidelines recommend practitioners should deliver culturally appropriate interventions, seek specialist supervision and work in partnership with community members (NICE, 2014).

The aforementioned PCREF advocates supporting more BAME communities to access FT (BPS, 2021; NHS England, 2022). Crucially, FT training should be provided for practitioners from diverse workforces (BPS, 2021). Thus, training for CoP working with BAME forensic carers needs to be considered carefully.

Findings from this study can help inform clinical practice in this area given forensic carers faced distressing emotions and difficult family dynamics. Participants coped using various strategies, including avoidant coping. Family interventions could address these difficulties (Kuipers et al., 2010).

However, there are potential barriers for forensic carers of African-Caribbean heritage who wish to access family interventions such as a lack of understanding and service location (BPS, 2021; Edge, 2016). While forensic services cover large geographical areas, and it can be difficult for carers and their families to attend sessions (BPS, 2021), they could be offered information on, and the intervention itself, remotely.

Cultural nuances that influence how forensic carers of African-Caribbean heritage appraise, cope with and shape their caregiving behaviour were found in the current study. Whilst participants discussed sensitive issues, they did so in the safe, confidential setting of the research interview. This indicates that when forensic carers of African-Caribbean heritage can discuss their experiences in a safe space, they are prepared to discuss issues of culture and race as well as their influence on caregiving behaviour and relationships with FMHS.

Therefore, when working with forensic carers of African-Caribbean heritage, attention must be given to creating a safe clinical setting. For instance, creating opportunities to build a strong therapeutic rapport with carers outside of clinical meetings could enhance the development of safe spaces within family interventions, which would facilitate this exploration. Further, practitioners could engage in open discussions about cultural differences and express their willingness to engage with topics related to culture and ethnicity if forensic carers of African-Caribbean heritage are keen to do so.

This study's novel finding on the values related to caregiving in Caribbean culture, such as the findings that carers break away from those values in order to become more individualistic and protect their own mental health, could offer professionals insight into the experiences of forensic carers of African-Caribbean carers and inform assessments, formulation and family interventions. For instance, relevant psychoeducation could be co-produced and facilitated with community members.

Faith and prayer have been recognised as important methods of coping among the UK's African-Caribbean community (Singh et al., 2013), which was confirmed by caregivers in this study as helpful for managing distress, reluctantly accepting difficult circumstances and providing hope. Hence, CoPs and other MH professionals conducting family interventions could encourage forensic carers of African-Caribbean heritage to discuss religion to maintain and improve caregivers' psychological wellbeing. However, given that professionals often struggle to incorporate spirituality into therapy (Holmberg et al., 2017), training in the necessary skills to facilitate such discussion is essential.

Strength and Limitations

The present study has several strengths and limitations. As noted, counselling psychology distinguishes itself from other disciplines by focusing on the experiences of individuals in addition to the meanings given to those experiences. Thus, CoPs can provide interventions tailored to individuals' needs (Rennie, 2007). This was one reason for employing a qualitative approach, which allowed for an in-depth exploration of forensic carers' of African-Caribbean heritage lived experiences.

Few studies have focused on forensic carers' experiences and either excluded or failed to recruit forensic carers of African-Caribbean heritage. However, this study has been able to capture the voices of this 'hard-to-reach', 'hidden' population of carers contributing significantly to the literature. Additionally, this study has highlighted the impact of the role on these carers, the cultural norms and values that influence their caregiving experiences and coping strategies and their problematic relationships with service providers and professionals.

Another strength of this study is that the researcher shares a race with the participants (Black African), having Ethiopian-British heritage. The researcher recognised this aided both recruitment and building rapport with participants during interviews. Given forensic carers' mistrust of forensic services, participants may have felt more at ease speaking to a researcher who shares their race. However, these similarities could also be a barrier as due to MH stigma in both African and African-Caribbean communities in the UK, some participants might not have shared information about their relative's offence or MH difficulties for fear of being judged by the researcher. Hence, the research data might not reflect the participants' views in their entirety. Authors of future studies can address this limitation by exploring these factors with participants at the initial stage of recruitment and, where possible, match researchers and participants according to their preferred ethnicity to obtain rich data. However, the research has provided insights into the lived experience of forensic carers of African-Caribbean heritage.

In this study, the researcher's personal and professional knowledge of literature could have influenced the interview questions and interpretation. If another researcher with different experiences had conducted this IPA study, their interpretation of the data may have been different and resulted in different themes. However, IPA researchers recognise that the meaning ascribed to experience is co-constructed (Smith et al., 2009). Hence, this researcher took steps to minimise biases throughout the research process, including the analysis process by being reflective, using supervision and increasing her knowledge and understanding of IPA. Thus, the study's quality can be assured.

Furthermore, it is important to highlight that forensic carers of African-Caribbean descent come from many islands. This might be considered a limitation as forensic carers from various islands might hold different views about caregiving. Since this population is considered 'hard-to-reach' and hidden, focusing on one island of carers would have increased recruitment barriers.

Crucially, the objective of qualitative research is 'theoretical transferability' (Smith et al., 2009). To support the study's transferability, the role of the researcher is to provide rich, comprehensive contextual information so that the readers can make an informed decision whether findings apply to them. However, given this study novel finding around the influence of culture on caregiving, future studies should explore the experience of forensic carers from specific islands. Given there is a lack of research among forensic carers with African-Caribbean heritage, this is still an area that can be better understood to further improve the delivery of service and the need of this community.

Summary and Conclusion

In this study, the lived experiences of forensic carers of African-Caribbean heritage caring for a relative with psychosis were explored. Seven participants were recruited and interviewed. Interviews were analysed using IPA. The analysis revealed four super-ordinate themes and eleven subordinate themes.

Study findings were consistent with the wider literature on BAME carers and some evidence on forensic carers. However, this study also provided novel findings around the norms and expectations of Caribbean culture held by forensic carers and their attempts to negotiate new caregiving values due to the demanding nature of the role.

Furthermore, this study revealed how perceived institutional and interpersonal racism informed caregiving attitudes and behaviours. Participants identified barriers to effective and complete partnership with services and professionals as a power imbalance and lack of information. Additionally, the study revealed ways forensic carers coped with the role.

These findings can inform the clinical practice of CoPs and the delivery of forensic services. These findings respond to NHS guidelines (2018) calling for further understanding of BAME carers' needs within forensic services. The study has both strengths and limitations.

A limitation is the grouping of forensic carers from different Caribbean islands as they might hold different views, which could bring into question the homogeneity of the sample. Furthermore, the researcher's heritage and race might have impacted the extent to which information was shared.

However, a strength of the study was the rich, valuable data obtained through semi-structured interviews, which provided insight into carers' experiences of discrimination from services. This information could inform assessment, formulation, intervention and the delivery of culturally appropriate services.

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Appendices

Appendix A: Ethics Approval Form

Department Of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants

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

REVIEWER: Rachel Tribe

SUPERVISOR: **Stelios Gkouskos**

STUDENT: Timnit Teccola

Course: Professional Doctorate in Counselling Psychology

Title of proposed study: What are the experiences of African-Caribbean carers supporting an individual with psychosis in an inpatient forensic service?

DECISION OPTIONS:

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

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

2

Minor amendments required *(for reviewer)*:

The trainee has a very experienced DoS, so I am sure any issues I raise or any others that arise will be dealt with quickly and efficiently. The topic is important and relevant. The student has not completing the section relating to additional ethical permissions, it would appear that either NHS or ethical permission from the two organisations who are going to assist in finding participants might be necessary or at least good practice. This is mentioned in a later section though. I realise that the participants will be the carers and not the person receiving help under a forensic service.

I was unclear how social media is being used to obtain participants. I would like to see a definition of how a carer is defined in this study, even if this is self-defined. I also think some clarity relating to 'under forensic services' would be helpful.

There is a typo in appendix 6, it currently states- Time you spoke your family member. I wondered if the word interview could be helpfully changed to meeting in the letter to participants, it carries less judgemental connotations.

I would like the trainee to tell someone when the interviews are taking place and starting and to inform them when they are completed, as a safety protocol.

I wish the candidate success in conducting this study.

Major amendments required *(for reviewer):*

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

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

Student's name *(Typed name to act as signature):* Timnit Teccola
Student number: u1723773

Date: 06.08.19

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

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

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

YES / NO

Please request resubmission with an adequate risk assessment

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

☐ HIGH

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

☐ MEDIUM (Please approve but with appropriate recommendations)

☒ LOW

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

Reviewer *(Typed name to act as signature)*: Professor Rachel Tribe

Date: 25.7.19

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

RESEARCHER PLEASE NOTE:

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

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

Appendix B: Request Form for an Ethics Amendment-Edit a Consent Form

UNIVERSITY OF EAST LONDON

School of Psychology

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & 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 impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Tim Lomas (Chair of the School Research Ethics Committee. t.lomas@uel.ac.uk).

HOW TO COMPLETE & SUBMIT THE REQUEST

1. Complete the request form electronically and accurately.
2. Type your name in the 'student's signature' section (page 2).
3. 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 Tim Lomas at t.lomas@uel.ac.uk
5. Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
6. Recruitment and data collection are not to commence until your proposed amendment has been approved.

REQUIRED DOCUMENTS

1. A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
2. Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
3. A copy of the approval of your initial ethics application.

Name of applicant: Timnit Teccola

Programme of study: Doctorate of Counselling Psychology

Title of research: Experience of Carers of African-Caribbean heritage supporting an individual with Psychosis in forensic settings: An Interpretative Phenomenological Analysis (IPA)

Name of supervisor: Dr Stelios Gkouskos

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

Proposed amendment	Rationale
I have edited the consent form in the original ethics application. Please see the attached consent form.	I have edited my consent form in order to make the information clearer and more accessible for participants.

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	x	

Student's signature (please type your name): Timnit Teccola

Date: 22. 06.2020

TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	YES	
Comments		

Reviewer: Tim Lomas

Date: 22.06.2020

Appendix C: Request Form for an Ethics Amendment - To Recruit Participants Across UK and to Included Forensic Carers of SU who have been Discharge in the Past Year

UNIVERSITY OF EAST LONDON

School of Psychology

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & 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 impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Tim Lomas (Chair of the School Research Ethics Committee. t.lomas@uel.ac.uk).

HOW TO COMPLETE & SUBMIT THE REQUEST

- Complete the request form electronically and accurately.
- Type your name in the ‘student’s signature’ section (page 2).
- When submitting this request form, ensure that all necessary documents are attached (see below).
- Using your UEL email address, email the completed request form along with associated documents to: Dr Tim Lomas at t.lomas@uel.ac.uk
- Your request form will be returned to you via your UEL email address with reviewer’s response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
- Recruitment and data collection are not to commence until your proposed amendment has been approved.

REQUIRED DOCUMENTS

1. A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
2. Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
3. A copy of the approval of your initial ethics application.

Name of applicant: Timnit Teccola

Programme of study: Doctorate of Counselling Psychology

Title of research: Experience of Carers of African-Caribbean heritage supporting an individual with Psychosis in forensic settings: An Interpretative Phenomenological Analysis (IPA)

Name of supervisor: Dr Stelios Gkouskos

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

Proposed amendment	Rationale
In the original ethics application, the researcher outlined that potential participants will be contacted after gaining permission from the third-sector mental health charities, such as "Rethink Mental Illness" across London and Greater London area. However, researcher is now proposing amendment to recruit participants from all parts of the UK, such as Birmingham and Manchester after gaining permission from the third-sector mental health charities.	In order to allow the researcher to to reach wider segments of the population, researcher will need to recruit participants across different cities in the UK. As along as participants meet the inclusion criteria geographical location should not be barrier to participating in the research. Although participants might be living in different parts of the country, they all share something in common, that of supporting someone with psychosis in an inpatient forensic setting within the NHS. Participants will be recruited through charities (Rethink Mental Illness, Mind etc.) and via social media. Participants will be interviewed at either at the charity's premises or at a local library as stated in the previous ethics application.
Inclusion criteria –	The research expects to elicit subjective stories that will enable the exploration of the participant's lived experience of the

In the original ethics application under recruitment, the researcher outlined that carers who are supporting a service user under secure forensic inpatient service (Medium secure unit and low secure wards) for at least six months will only be included within the research. However, the researcher is now proposing amendment to include Carers of service users who have been discharge to the community in the past year will also be included in the research.	phenomenon under investigation. To ensure that the phenomenon would have been experienced for some time, the minimum period a carer should have experience of the forensic services is 6 months. However, the rationale to include participants that might not be supporting someone within this setting currently, but have done so in the last year, is based on the rationale that participants might have supported someone within an inpatient setting for many years prior to the patient being discharged. Therefore, these participants might have a longer experience of caregiving within this setting as the average stay in this setting is two years or more. Including these participants will enrich the research data and enable a deeper understanding of participant perceptions of caregiving within these settings.

Please tick	**YES**	**NO**
Is your supervisor aware of your proposed amendment(s) and agree to them?	x	

Student's signature (please type your name): Timnit Teccola

Date: 20.11.2019

TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	YES	
Comments		

Reviewer: Tim Lomas

Date: 6.12.19

Appendix D: Request Form for an Ethics Amendment - To Carry Interview Online via Microsoft Teams

UNIVERSITY OF EASTLONDON

School of Psychology

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & 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 impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Tim Lomas (Chair of the School Research Ethics Committee. t.lomas@uel.ac.uk).

HOW TO COMPLETE & SUBMIT THE REQUEST

1. Complete the request form electronically and accurately.
2. Type your name in the 'student's signature' section (page 2).
3. 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 Tim Lomas at t.lomas@uel.ac.uk
5. Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
6. Recruitment and data collection are not to commence until your proposed amendment has been approved.

REQUIRED DOCUMENTS

1. A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
2. Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
3. A copy of the approval of your initial ethics application.

Name of applicant: Timnit Teccola

Programme of study: Doctorate of Counselling Psychology

Title of research: Experience of Carers of African-Caribbean heritage supporting an individual with Psychosis in forensic settings: An Interpretative Phenomenological Analysis (IPA)

Name of supervisor: Dr Stelios Gkouskos

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

Proposed amendment	Rationale
In the original ethics application, the researcher wanted to meet all participants face to face for the interview. However, the researcher is now proposing ethical amendments to carry out interviews online via a secure video platform called Microsoft Teams and phone	Due to COVID-19 there has been lot of uncertainty this has impacted the research process as government guidelines have been changing daily this then impacting the research and recruitment process mainly due to social distancing. Therefore, upcoming interview had to be rescheduled. I am hoping to apply for ethical amendment in order to accommodate remote interview for participants that meet the inclusion criteria therefore overcoming barrier of social distancing in participation of the research . All participants would be required to meet the inclusion criteria sharing a similar experience in order to explore the same phenomena. when possible, a video

	interview will be offered as I will be able to pick up on verbal and non -verbal cues which is comparable to face-face interview. However due to research population (older adults caregivers) online interview might not be feasible for all potential participants due to not having access to computers and skill to use the computer. In this circumstance I will offer phone interview. Both online and phone interview might ease potential anxiety of participating in the research as they will be in an environment whereby, they are comfortable in. Risk issues will be followed as described in my original ethics application. Also, in relation to current situation with COVID-19 both when arranging the interview and on interview date I will check with participants if they are in good health to complete the interview.

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	x	

Student's signature (please type your name): Timnit Teccola

Date: 28.03.2020

TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	YES	
Comments		

Reviewer: Tim Lomas

Date: 2.4.20

Appendix E: Request Form for an Ethics Amendment - Change of Research Title

School of Psychology Ethics Committee

University of East London

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): j.lemoine@uel.ac.uk
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.	YES ☒

Details

Name of applicant:	Timnit Teccola
Programme of study:	Prof. Doc. Counselling Psychology
Title of research:	Experience of Carers of African-Caribbean heritage supporting an individual with Psychosis in an adult

	medium secure unit: An Interpretative Phenomenological Analysis (IPA)
Name of supervisor:	Dr Jeeda Alhakim

Proposed title change

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

Old title:	Experience of Carers of African-Caribbean heritage supporting an individual with Psychosis in an adult medium secure unit: An Interpretative Phenomenological Analysis (IPA)
New title:	The lived experience of UK forensic carers of African-Caribbean heritage caring for someone with Psychosis: An interpretative phenomenological analysis.
Rationale:	I have added UK to study title as all participants recruited for this study lived in the UK. The term forensic carers were used to describe the sample population which consists of caregivers who are caring for individuals with psychosis within forensic services, either within medium secure unit and/or low secure unit.

Confirmation

Is your supervisor aware of your proposed change of title and in agreement with it?	YES ☒	NO ☐
Does your change of title impact the process of how you collected your data/conducted your research?	YES ☐	NO ☒

Student’s signature

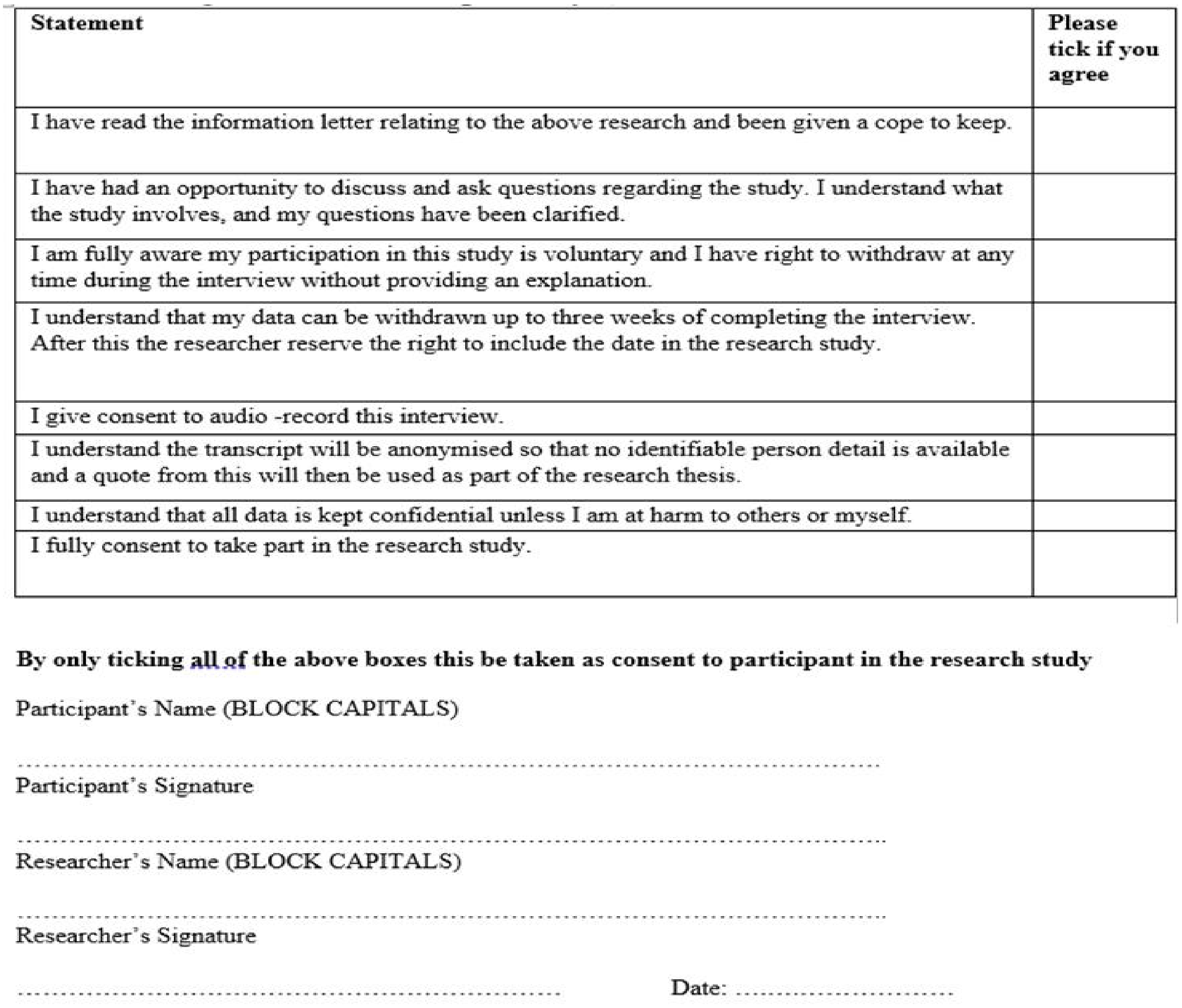
Student: **(Typed name to act as signature)**	Timnit Teccola
Date:	27/10/2022

<table>
<tr><th colspan="3">Reviewer’s decision</th></tr>
<tr><td>Title change approved:</td><td>YES
☒</td><td>NO
☐</td></tr>
<tr><td>Comments:</td><td colspan="2">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.</td></tr>
<tr><td>Reviewer:
(Typed name to act as signature)</td><td colspan="2">Dr Jérémy Lemoine</td></tr>
<tr><td>Date:</td><td colspan="2">28/10/2022</td></tr>
</table>

Appendix F: Consent Form

Consent form

Experience of Carers of African-Caribbean heritage supporting an individual with Psychosis in a forensic service: An Interpretative Phenomenological Analysis



Statement	Please tick if you agree
I have read the information letter relating to the above research and been given a cope to keep.	
I have had an opportunity to discuss and ask questions regarding the study. I understand what the study involves, and my questions have been clarified.	
I am fully aware my participation in this study is voluntary and I have right to withdraw at any time during the interview without providing an explanation.	
I understand that my data can be withdrawn up to three weeks of completing the interview. After this the researcher reserve the right to include the date in the research study.	
I give consent to audio -record this interview.	
I understand the transcript will be anonymised so that no identifiable person detail is available and a quote from this will then be used as part of the research thesis.	
I understand that all data is kept confidential unless I am at harm to others or myself.	
I fully consent to take part in the research study.	

By only ticking all of the above boxes this be taken as consent to participant in the research study

Participant's Name (BLOCK CAPITALS)

....

Participant's Signature

....

Researcher's Name (BLOCK CAPITALS)

....

Researcher's Signature

.... Date: ....

Appendix G: Information Sheet

Researcher: Timnit Teccola, Counselling Psychologist in Training,
University of East London, E15 4LZ
E-mail: U1723773@uel.ac.uk, Tel: 07943822391

Supervised by Dr Stelios Gkouskos, Counselling Psychologist
University of East London, E15 4LZ
E-mail: s.gkouskos@uel.ac.uk, Tel: 020 8223 4993

Consent to participate in a research study

I would like to invite you to take part in a research study. Before you decide I would like you to understand why the research is being done and what it would involve for you. I am happy to go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask me if there is anything that is not clear. The project is being conducted as part of my Professional Doctorate in Counselling Psychology at the University of East London. My research has been approved by the School of Psychology Research Ethics Committee. This means that my research follows the standard of research ethics set by the British Psychological Society.

Project Title

Experience of Carers of African-Caribbean heritage supporting an individual with Psychosis in a forensic service: An Interpretative Phenomenological Analysis

Project Description

Health professionals would like greater involvement of, and support for, carers of people with mental illness. However, to date there have been no studies which have explored the personal experience of carers of African-Caribbean heritage of supporting an individual with psychosis under a forensic service. The purpose of this study is to extend existing knowledge and specifically to:

A) Understand the experience of carers supporting individuals who have a psychosis diagnosis, who are under secure forensic mental health care

B) Explore the care-giving experience from the carer’s perspective

C) Consider the carer’s experience of professional care for their family member.

Who can take part?

I am looking for participants who are of African-Caribbean heritage and self-identify as a carer of a service user with a diagnosis of psychosis, who has accessed a forensic service in at least the past 6 months. They must have regular contact with the service user. Carers should be willing to discuss their experience with me.

What will you be required to do?

After reading this information sheet, please contact the lead researcher, Timnit Teccola, if you would like to participate in an interview. Contact details are at the end of this information sheet.

Once you contact me, you will be offered an option to have a preliminary discussion over the phone or in person to discuss the nature of the research including the research inclusion criteria and any question you might have about the research.

During this phone call, I will seek your verbal consent to participate and arrange a time that is convenient for you to be interviewed. Interviews will take place at UEL or a more convenient library where we will have a face-to-face interview lasting approximately 60-90 minutes. The interview will be recorded and transcribed by me, and all data will be anonymised and stored securely.

During the interview you will be asked about your views and experiences of a range of your experiences of personal involvement in the care of the service user, as well as your experiences of mental health professionals. You do not have to answer all the questions and will not be forced to discuss anything you feel uncomfortable with. The discussion will be audio recorded to enable me to transcribe it afterwards. You will not be paid to participate in the study. However, I will arrange the interview at a time and date to suit you, so that you do not incur any unnecessary inconvenience by participating.

Benefits

I cannot promise the study will benefit you directly, although you may find it helpful to tell your account in your own words. The insights gained from this study may help improve mental health professionals' understanding of what carers' face, and the findings may provide new suggestions about working with this community within forensic services.

Risk

There are no foreseeable risks or harm that may result from the interview. If there are questions which you find uncomfortable, you do not have to answer them. You can request to break or end the interview at any time. However, in case of you experience distress I will be able to direct you to appropriate service for emotional support. This list is also at the end of this information sheet. I will only contact the emergency services if there is an immediate danger to yourself or others.

Confidentiality of data

Your responses will be treated with full confidentiality and any information that could identify you as an individual will be removed. You do not have to answer all the questions if you do not want to and will have the choice to withdraw at any time with no explanation required during the study.

You can also withdraw up until 3 weeks after the interview. In this case your data will be destroyed and will not be included in my research. If you wish to withdraw after this period, your anonymous data will be retained in the study as by that point data analysis will have already started. After the study has been completed, the data will be kept in a secure computer in a folder that is password.

Appendix H: Debrief Sheet

Thank you for taking part in my research project.

As discussed, the aim of my research was to explore your experience of providing a care and support to an individual with psychosis under a forensic service. It asked about your subjective experience of proving care for individual within forensic service.

If you found the interview uncomfortable or distressing in any way, please feel free to discuss this with me. Following this interview, if you would like to access more support, please contact the following agencies

Rethink Mental Illness

https://www.rethink.org/advice-information/living-with-mental-illness/

Support care-01215227007
Advice service -0300500827
mailto:info@rethink.org

Mind
https://www.mind.org.uk/information-support/helplines/
15-19 Broadway, Stratford, London E15 4BQ
T: 020 8519 2122, F: 020 8522 1725
E-mail: supporterrelations@mind.org.uk

Improving Access to Psychological Therapies (IAPT)
https://www.nhs.uk/Service-Search/Psychological%20therapies%20(IAPT)/LocationSearch/10008

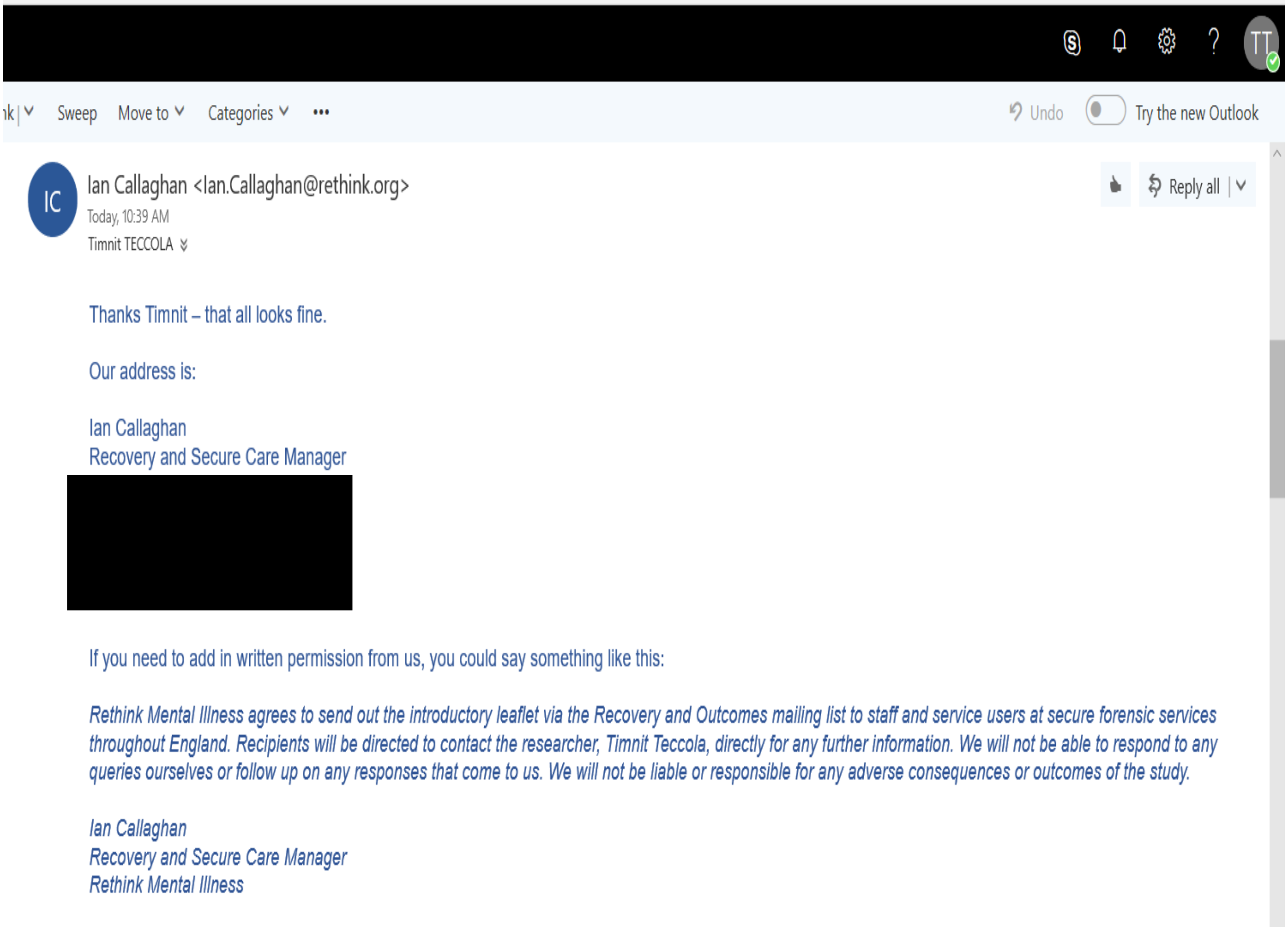
Samaritans
08457 90 90 90 / 116 123
Email: jo@samaritans.org
https://www.samaritans.org/

If you have any further questions and wish to get in touch please do so:

Timnit Teccola, Counselling Psychologist in Training,
University of East London, E15 4LZ
E-mail: U1723773@uel.ac.uk, Tel: 07943822391

Supervisor: Dr Stelios Gkouskos,
Programme Director
Professional Doctorate in Counselling Psychology
University of East London, E15 4LZ
E-mail: s.gkouskos@uel.ac.uk, Tel: 020 8223 499

Appendix I: Permission Email from Services 1



Ian Callaghan <Ian.Callaghan@rethink.org>
Today, 10:39 AM
Timnit TECCOLA

Thanks Timnit – that all looks fine.

Our address is:

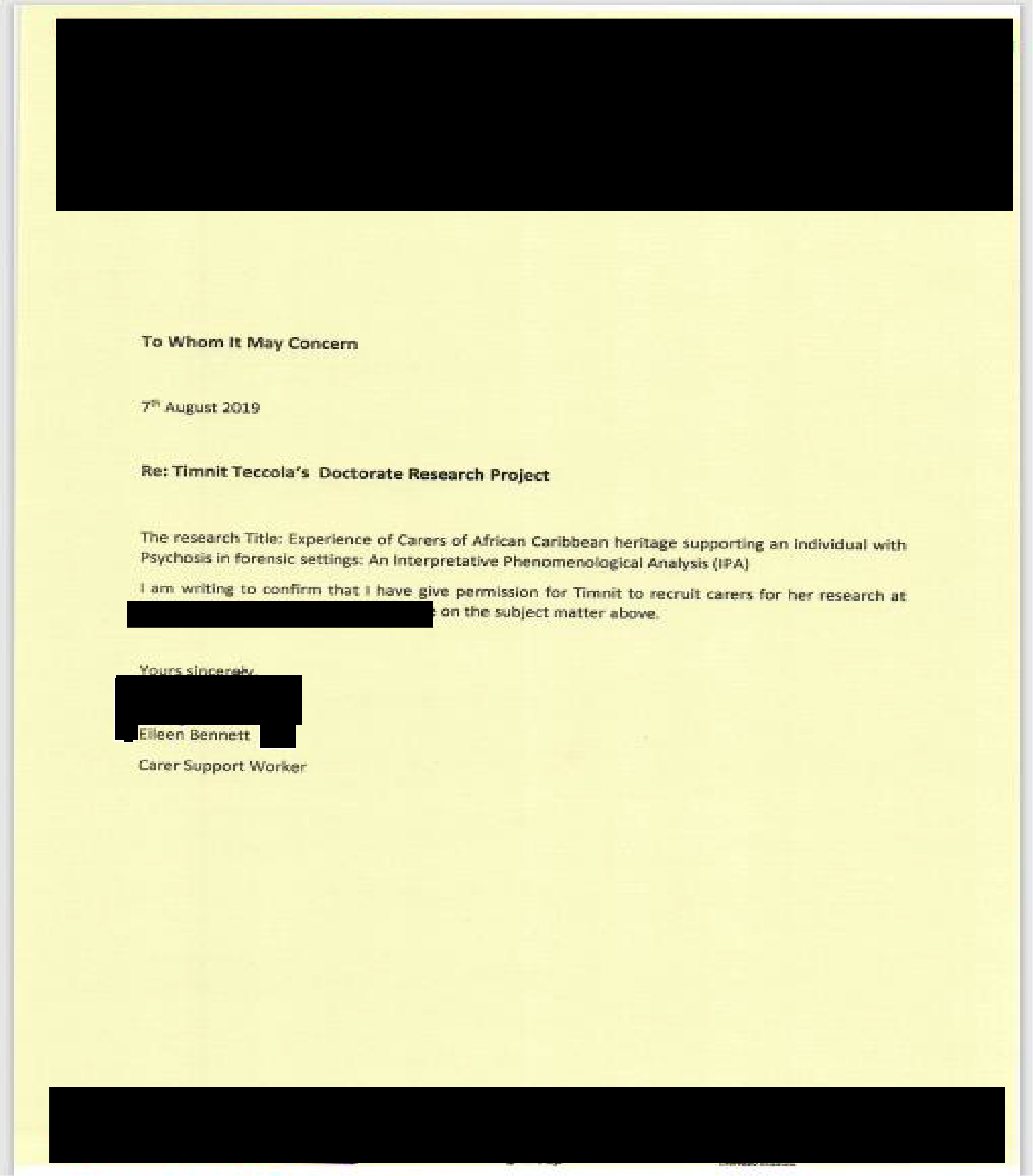
Ian Callaghan
Recovery and Secure Care Manager
[redacted]

If you need to add in written permission from us, you could say something like this:

Rethink Mental Illness agrees to send out the introductory leaflet via the Recovery and Outcomes mailing list to staff and service users at secure forensic services throughout England. Recipients will be directed to contact the researcher, Timnit Teccola, directly for any further information. We will not be able to respond to any queries ourselves or follow up on any responses that come to us. We will not be liable or responsible for any adverse consequences or outcomes of the study.

Ian Callaghan
Recovery and Secure Care Manager
Rethink Mental Illness

Appendix J: Permission Letter from Services 2



[redacted]

To Whom It May Concern

7th August 2019

Re: Timnit Teccola's Doctorate Research Project

The research Title: Experience of Carers of African Caribbean heritage supporting an individual with Psychosis in forensic settings: An Interpretative Phenomenological Analysis (IPA)

I am writing to confirm that I have give permission for Timnit to recruit carers for her research at [redacted] on the subject matter above.

Yours sincerely

[redacted]

Eileen Bennett [redacted]

Carer Support Worker

[redacted]

Appendix K: Research Poster

Are you a carer or a family member with African-Caribbean heritage supporting an individual with mental health difficulties within forensic services in the NHS?

If you answered YES then please get in touch! So, we can discuss further about the project and your suitability to participant in the study.

Timnit Teccola, counselling Psychologist in Training
Email:

I am in my final year of Doctorate Counselling Psychology at UEL. I am interested in learning about your experience of supporting a family member who accesses forensic services. Carers would need to identify as having **African-Caribbean heritage** and be caring for an individual with mental health difficulties within inpatient forensic service.

Appendix L: Pre-Screening Questionnaire

Pre-Screening Questionnaire

Title of research: The lived experience of UK forensic carers of African-Caribbean heritage caring for someone with Psychosis: An interpretative phenomenological analysis.

Demographic Information

Name	**Gender**	**Age**

1. How would you describe your ethnicity?

2. Are you a forensic carer?

3. Are you currently providing care and support to the person you care for?

4. What is the length of time you have been a carer?
    - less than 6 months
    - less than 1 year
    - 1-5 years
    - 5-10 years
    - In any other case, please specify
5. What is your relationship to the person you care for?
    - Parent
    - Partner/spouse
    - Son/daughter
    - Sibling
    - Friends
    - In any other case, please specify

6. Does the person you are supporting have functional psychiatric diagnosis of psychosis – schizophrenia, schizoaffective or other psychotic disorder, for a minimum of six months, established by a consultant psychiatrist?

7. Is the person you are supporting in, or was in, Forensic Mental Health Hospital within the NHS for a minimum of six months?

8. What type of forensic mental health service within the NHS was the person you are supporting in or is currently in?

    - Medium secure units
    - Low secure units
    - Other

9. Please can you tell me if you were involved in the index offence of the person you care for?
10. Please could you tell me if you have any current mental health diagnoses?

11. In the past 6 months have you been admitted to inpatient mental health services?

12. In the past two weeks have you had any suicidal thoughts?

13. Are you currently under the care of community mental health services?

Appendix M: Interview Schedule

Research question - What are the experiences of African-Caribbean carers supporting an individual with psychosis in an inpatient forensic service within NHS?

1. As you know I am interested in getting a better understanding of the experience of carers with African-Caribbean heritage. So, can I please first ask you how would you describe your heritage/ethnicity?

2. Can you tell me when you first started being a carer for someone suffering from psychosis who was admitted to an inpatient forensic service in the NHS?

Prompts

- What happened? When?
- How was it decided that you will be the carer?
- Tell me about this process.
- Where you involved in caring for this person before they were admitted? (How, for how long, did they have the diagnosis before they were admitted, etc.)
- How did you feel during this time?

3. Can you please tell me about your role as a carer for an individual that has been diagnosed with psychosis and is an inpatient forensic service?

Prompts

- What does it involve? / Frequency of contact and type of contact.

4.What does ‘caregiving’ for someone who suffers from psychosis mean in the context of your heritage?

Prompts

- What is your understanding of psychosis from the context of your heritage? If so, how did this impact your caregiving role?
- What is your understanding of caregiving from the context of your heritage? If so, how did this impact your caregiving role?
- How do you feel about your role?

4. What is you experience as an African-Caribbean carer of the NHS Forensic Service?
   Prompts
   - How the context works/supports
   - Relationship with mental health professionals
   - Difficulties/Challenges
   - Positive aspects

6. Has ‘caring’ affected your life? If so, in what respects? (Personal life, work, relationships with person caring for and with others, etc.)

7. Has your experience as a carer changed over time? If so, how? When? How does it impact you?

   - Self
   - Areas of life
   - Relationship with the person you care for
   - Relationship with professionals/context

8. Is there anything else that you consider it would be important to talk about your experience as an African-Caribbean carer, who is supporting an individual with psychosis in an inpatient forensic service within NHS?

Appendix N: Example of Transcript Analysed

Descriptive comments The role of being a forensic carer is challenging, difficult and daunting. The role leaves the carer emotionally vulnerable despite her faith and resilience. Caregiver wellbeing is intertwined with her caregiving role and the SU's circumstance and situation - no hope. **Linguistic comments** **So black there is no light in it seems as if the light has been extinguished** – a use of metaphor to highlight her emotional world of hopelessness, daunting. A sense of being alone and no meaning for her life. There is a sense of loss as she is mourning for her son. **Not a very nice place to be in wouldn't wish that on anyone-** a sense the role is unpleasant and is unbearable. Conceptual comments The role is emotionally and psychologically demanding. Emotional impact of caregiving includes hopelessness and negative outlook in life. Caregiving role is unbearable and undesirable and helplessness.	**caring (R: Mm.) for a family member or a loved one. (R: Mm.) And so much challenges and difficulties which I've explained to you, and daunting. (R: Daunting, mm.) Even though you have your faith, there's times when it seems ehm- a tunnel seems so black, there's no- there's no light in it. (R: Mm.) And it seems as if the light has been extinguished, you have no light in your life, no hope concerning this family and loved ones' life and situa- circumstance and situation. (R: Yeah.) And that's not a very nice place to be ehm. (R: Yeah.) I wouldn't wish that on anyone.**	Emotionally and psychologically demanding. Caregiver psychological wellbeing is intertwined with SU. Emotional impact of caregiving includes - hopelessness, loss, daunting. Caregiving role is unbearable, undesirable.

Appendix O: Example of Major Themes

Major theme	Emergent themes
The role is demanding in nature	• Financially burdensome • The role is physically exhausting • The role takes away normality. • Difficult family dynamic
The role is psychological and emotionally demanding	• Anxious • Sense of loss and morning what relative could been • Guilty for finding the role burdensome • Sitting with confusion and uncertainty
Caregiving values and responsibility	• The script for caregiving in Caribbean culture • Stigma
Relating with professionals and services	• Power imbalance • Mistrust of service and professionals • Professionals are an obstacle to caregiving. • Race of the professional's matter - relating with professionals
Relating with services	• Lack of information and support • Treatment and protocol at services are unpleasant. • Being a Black caregiver is another struggle
Coping style	• Families offer emotional and financial support • Avoidance coping strategy • Prayer

Appendix P: Overview of Themes

Superordinate themes	**Sub-ordinate themes**
The role is "too much for a humanity": Emotional, physical and relational challenges	• The emotional and physical reality of being a forensic carer • Difficult family dynamics - "Unnecessary conflict" and "tension"
Cultural and community – norms and values	• Caregiving is "part of our ethos" and "in our nature" • Negotiating a new caregiving value: Seeking emotional "distance" • Internalised stigma: "It's kept behind closed doors"
It is a terrible battle relating to services and professionals	• Fear of institutional racism - surviving through "fighting" • Powerless – silenced and not listened to • Lack of information - ignored and confused
Ways to survive the emotional demands of the role	• Suppressing painful emotions • "I turn to": Christianity and faith in God • Support networks are a "safety net" and an "outlet"

Appendix Q: Theme recurrence Table

Superordinate Themes	Superordinate Theme One	1 Cedella	2 Tianna	3 Chadice	4 Helen	5 Winston	6 Samantha	7 Devan
The role is “too much for a humanity”: Emotionally, physically and spiritually demanding	The emotional and physical reality of being a forensic carer	✓	✓	✓	✓	✓	✓	✓
	Difficult family dynamics - “Unnecessary conflict” and “tension”	✓	✓	✓	✓	✓	✓	
Cultural and community – norms and values	Caregiving is “part of our ethos” and “in our nature”	✓	✓	✓	✓		✓	✓
	Negotiating a new caregiving value: Seeking emotional “distance”	✓		✓	✓	✓		
	Internalised stigma: “It’s kept behind closed doors”		✓	✓	✓	✓		✓
It is a terrible battle relating to services and professionals	Fear of institutional racism - surviving through “fighting”		✓	✓	✓			✓
	Powerless – silenced and not listened to		✓	✓	✓			✓
	Lack of information -	✓	✓	✓	✓			

	ignored and confused							
Ways to survive the emotional demands of the role	Kept going by avoiding and suppressing painful emotions	✓		✓			✓	✓
	“I turn to”: Christianity and faith in God	✓	✓		✓	✓		✓
	Support networks are a “safety net” and an “outlet”	✓	✓	✓		✓		✓