

**An exploration of Black carers' experiences of their relative/loved one's detention
under the Mental Health Act.**

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:



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Overview

Black people in the UK are more likely to be detained under the Mental Health Act, compared to their White counterparts. However, little is known about the impact of compulsory detention on the relatives and carers who provide support to their loved ones.

Part I includes a conceptual introduction exploring the impact of caring for a loved one with psychosis and the ethnic disparities in coercive mental health interventions. This chapter also considers the wider context of ongoing racial trauma and structural racism and how this affects how marginalised groups interact with mental health services. Lastly, this introduction outlines how services can address ethnic disparities in the treatment of people affected by psychosis and the rationale for the current study.

Part II is an empirical paper exploring ten Black carers' experiences of their loved one's detention under the Mental Health Act. Interpretative phenomenological analysis (IPA) of the interview transcripts revealed that the experience of compulsory detention is traumatic for carers and they felt let down by services. Reclaiming their power in carers groups and relying on their faith helped them to manage. It was challenging for some Black carers to speak about their experience of racism, in relation to their caregiving role while their loved one was compulsorily detained. Clinical and research implications are discussed.

Part III is a critical appraisal of the research process, including the researcher's reflections on how her background and personal characteristics informed the conception of the topic and the impact of interviewing the participants.

Impact Statement

There has been increasing evidence that Black people continue to be disproportionately detained under the Mental Health Act. Carers of service-users are encouraged to be actively involved in the treatment and care of their loved one(s) and to work in collaboration with mental health services. However, carers can feel dismissed and silenced by mental health professionals. Furthermore, there is a paucity of research specifically exploring the needs of Black African and Caribbean carers, despite this community being one of the largest caring communities in the UK. Therefore, this study aims to give voice to Black carers and understand their experiences of their loved one being compulsorily detained.

This thesis addresses a clinically meaningful topic, which has received little research interest to date. Gaining in-depth knowledge about Black carers' experiences when their loved one has been compulsorily detained, is crucial to identifying their needs and how services can be best placed to support them during this challenging time. Furthermore, this insight can inform the development of appropriate clinical interventions, including cultural adaptations that may need to be considered. Increasing our understanding of how Black carers interact with health professionals and how they feel others perceive them in ward environments, can also generate hypotheses about how staff and services can be supported to ensure they are providing person-centred care and acting with cultural humility. This could lead to training recommendations and service development, improving outcomes for staff, service-users and their support networks.

Crucially, speaking to members of the Black community about their experiences, serves to amplify underrepresented voices in existing literature. This has wider social implications by showing how services may start to address existing health inequalities and disparities. Engaging in conversations about racism and discrimination can help services understand what the most appropriate way may be to respond to these instances. This provides services

the opportunity to convey to oppressed groups that they are committed to dismantling the effects of institutional racism. This could help to build trusting relationships between Black people and services, ultimately improving outcomes for these communities.

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Part I: Conceptual Introduction

Why we need to talk to Black carers of people with psychosis

Introduction

Although evidence suggests that African-Caribbean people appear to show elevated rates of prevalence across most severe mental illnesses, the most striking disparity is often evident in 'psychosis' diagnoses (McKenzie & Bhui, 2007). Therefore, this conceptual introduction will largely focus on the literature that refers to psychosis. The prevalence rates of psychosis among individuals of Black African and Caribbean heritage in the United Kingdom (UK) are significantly higher than rates of psychosis for White British populations (Qassem et al., 2015). Elevated rates of psychosis appear to be associated with migration, social disadvantage and stronger identification with an ethnic group (Morgan et al., 2008; Morgan et al., 2019; Reininghaus et al., 2010). Furthermore, evidence has consistently shown that Black African and Caribbean service-users are significantly more likely to be detained under the Mental Health Act compared to their White counterparts (Davies et al., 1996). This highlights the racial inequalities that exist for this psychiatric condition and the need for services to address the impact of this on the service-user and their supporting networks.

Many individuals diagnosed with psychosis tend to live with or be in close contact with family members, friends or "informal carers" (Birchwood, 1992; Onwumere et al., 2016). Informal carers are often parents, partners or siblings of service-users and are mostly female (Onwumere et al., 2018). These carers play a crucial role in identifying a deterioration in mental health of their loved ones and helping them to access services (Morgan et al., 2006b). However, the experience of caregiving is associated with emotional exhaustion and feelings of inadequacy (Onwumere et al., 2018).

Although there is a considerable body of research exploring the various impacts of caregiving, little research has specifically investigated the experiences of Black African and Caribbean carers. This is despite the likelihood that Black carers have increased contact with mental health services due to the disproportionate rates of compulsory detention for

Black service-users. This chapter outlines the urgent need for the views of Black carers to be heard to address the health inequalities that have been evident for decades.

Section 1: Caregiving in psychosis

1.1 Caregiving impact

The experience of caring is complex with some reporting positive experiences of caregiving, whereby providing support to their loved one helps them to feel valued and provides a purpose in their life (Nolan & Lundh, 1999). Caring for an individual with a severe mental illness can have a rewarding effect and help carers to feel more understanding of others with mental health problems and recognising one's own inner strength (Kulhara et al., 2012).

However, it is important to consider the context and other factors that may relate to the overall caregiving experience. The model of stress appraisal and coping provides a useful framework to predict how caregivers perceive their caring responsibilities (Haley et al., 1987). In this model, the service-user's illness, behaviours and perceived disruptions are identified as the stressors, while mediating factors such as the carer's personality and levels of social support may impact the appraisal. It is the interaction between the carer's appraisal and their coping strategies that may determine the carer's general wellbeing (Lazarus & Folkman, 1984). Pickett et al., (1997) found that parent's positive appraisals of their caregiving relationships were significantly associated with lower levels of caregiver burden. Additionally, family-carers negative appraisals have been found to be a strong predictor of psychological distress, with factors such as the duration of the service-user's illness and levels of their functioning influencing caregivers' appraisals (Harvey et al., 2001). Moreover, caregiving appraisals are associated with their social isolation and relationships with their loved one and services (Kuipers et al., 2010).

Caring for a loved one with a severe and enduring mental illness is also associated with negative consequences including increased burden and poorer psychological well-being (Awad & Voruganti, 2008; Martens & Addington, 2001). Furthermore, research has shown the impact of caregiving even in the early stages of psychosis (Addington et al., 2003). Caregivers report experiencing a mixture of emotions including guilt and the need to adjust to the unpredictable nature of psychosis (McCann et al., 2011). Carers who support a loved one suffering with first-episode psychosis report feeling emotionally exhausted and a lower sense of accomplishment (Onwumere et al., 2018). Together, these factors contribute to the overall burden that caregivers experience and the need for supportive social networks to alleviate increased stress (Loukissa, 1995). However, accessing support from others can be challenging in light of the stigma felt by many carers (Angermeyer, 2003).

Caregivers report their friends gradually reducing contact with them and having misconceptions about the service-user's illness (Schulze & Angermeyer, 2003). In addition to dealing with their own psychological distress due to the demands of caregiving, carers are often also faced with instances of discrimination and being socially excluded (Schulze & Angermeyer, 2003). Given that psychosis is an enduring mental health problem, the impact of caring for service-users with a chronic illness is associated with higher levels of time dependence, physical burden and social burden (Sagut & Duman, 2016). Caregivers describe that providing support for a long-term mental health condition negatively affects their finances, social life and sense of freedom ultimately leading to feeling overwhelmed and hopeless (Brain et al., 2018).

A longitudinal study found that carers of individuals with psychosis experienced social isolation, psychological distress and poorer quality of life when compared to the general population (Poon et al., 2017). Furthermore, caregivers may have felt forced into the position of providing support and placed into a "caring" role because of their relationship to the service-user and therefore been left with no choice but to take on the associated

responsibilities of being a caregiver (Kuipers, 2010). Many relatives or friends who support individuals diagnosed with a severe mental health problem often don't identify themselves to be a "carer" or "caregiver and feel uncomfortable with this term.

This highlights the long-term impact of caring for a loved one diagnosed with psychosis and the need for services to not only be aware of this, but to extend interventions to the family unit and support network of the service-user.

1.2. *The crucial role carers play in the person's care and wellbeing*

Delays in accessing treatment for psychosis can have negative consequences, with a longer duration of untreated psychosis (DUP) shown to be a strong predictor for worse recovery outcomes (Harrigan et al., 2003). Furthermore, it is anticipated that service-users who display a larger delay between the onset of their psychotic symptoms and accessing treatment are less responsive to treatment and require more intensive input from services (Black et al., 2001; Drake et al., 2020). Therefore, it is important for those presenting with psychosis symptoms to access services and receive treatment as early as possible.

Family carers provide essential care to their loved ones to ensure their basic and functional needs are met, bridging the gap between recognition of deterioration in mental health and lack of services (Fleury et al., 2008). Carers play a crucial role in their loved one accessing mental health services, facilitating help-seeking for their loved one (Morgan et al., 2006b; O'Callaghan et al., 2010). Fridgen et al., (2013) found that almost half of all the participants in their study sought help from family members or friends first for their psychotic symptoms, before presenting to mental health services. Furthermore, qualitative interviews with service-users engaged in an early intervention program highlighted the barriers to seeking-help and the value of significant others to overcome these barriers and initiate the help-seeking process (Anderson et al., 2013).

The presence of family involvement has been shown to significantly reduce the length of DUP for individuals presenting with first-episode psychosis (Compton et al., 2008). Data from the Aetiology and Ethnicity in Schizophrenia and Other Ethnicity in Schizophrenia and Other Psychoses (AESOP) study found that participants who had family involved in seeking help displayed a DUP median of 5 weeks, compared with a median of 12 weeks for those who did not have family involved (Morgan et al., 2006b). This reiterates the value that family-carers play in identifying individuals in need of support to the appropriate services.

The value of family support continues even after carers have supported their loved one to access services. Service-users who had a supportive family network available showed better treatment adherence and recovery outcomes in comparison to service-users with no family involvement (Glick et al., 2011). Additionally, service-users who had more carer contact had shorter hospital stays than service-users who had more infrequent contact with their carers (Schofield et al., 2001). Importantly, service-users state that they value services that incorporate family support within their treatments and appreciate when services work jointly with their carers (Lester et al., 2011).

Family engagement has been shown to reduce relapse rates through the use of better detection of early warning signs (Herz et al., 2000). Furthermore, the association between increased family involvement and reduced relapse appears to be maintained over a long-term period (Hultman et al., 1997). Norman et al., (2005) investigated 113 service-users engaged in a Prevention and Early Intervention Program for Psychoses and measured their social support, psychotic symptoms and hospital admission over a three-year period. Findings showed that higher levels of social support correlated with fewer positive symptoms and less hospitalisations at follow up (Norman et al., 2005). Furthermore, when service-users feel that they have the emotional support from family, they are more likely to show better recovery outcomes (Tempier et al., 2013).

Despite the clear evidence showing the value of carer involvement in their loved one's treatment and recovery, carers consistently report feeling undervalued and ignored by health services (Jones, 2009). Carers report wanting to be involved in their loved one's care and to feel supported by services (Lloyd & Carson, 2005). In practice, however, carers' experience of this appears to be mixed with some reporting feelings of being dismissed and lied to by mental health professionals (Clarke, 2006). Qualitative research of carer's experiences of acute psychiatric wards highlight themes of powerlessness and isolation (Wilkinson & McAndrew, 2008). In this study, carers reported feeling a "divide" between themselves and the healthcare professionals in the wards, perceiving the ward staff to hold all knowledge and control. Importantly, findings of this study also portrayed that all the participants expressed a desire for working in partnership with the ward staff.

Section 2: Ethnicity, coercive mental health interventions and their impact

2.1 Brief review on evidence of disproportionate admissions

It has been observed that there appears to be higher incidences of psychosis among migrant and minority ethnic groups (Morgan et al., 2010). The AESOP study in the United Kingdom aimed to investigate these high incidence rates and consistent with previous research, concluded that there indeed is a "genuine and marked excess" of psychosis in Black African and Caribbean populations in the UK (Morgan et al., 2006a). It has been suggested that this increased risk of psychosis among both first- and second-generation migrants, suggest that socio-economic factors play a pivotal role in the development of the illness (Coid et al., 2008). This supports previous research which found that social disadvantage appears to partly explain excess rates of psychosis among African Caribbean groups in the UK, however the authors conclude that more research is needed for this to be confirmed (Brugha et al., 2004).

A recent meta-analysis highlighted that being ethnic minority status correlated with elevated risk of psychotic symptoms and experiences, and this risk increased in groups challenged with deprivation and discrimination (Leaune et al., 2019). This raises the issue regarding the role of socio-economic factors in the prevalence of psychosis among minority groups. Furthermore, Kirkbride et al., (2008) found in their study that all Black and minority ethnic groups continued to show increased rates of psychosis even after factors such as age, gender and socio-economic status were controlled for. This suggests that there must be more going on for these groups to explain the higher prevalence rates.

Proposed explanations include misdiagnosis of psychotic symptoms from practitioners unfamiliar with how African Caribbean individuals may present to services. For example, Western approaches to psychiatry may be inappropriate when it comes to understanding non-European expressions of distress (Sashidharan, 1993). Racism and discrimination experienced by ethnic minorities is also likely to affect their social, physical and psychological environments and thus can lead to behaviours similar to psychotic symptoms (Sharpley et al., 2001). Discrimination perceived by ethnic minorities has been found to contribute to the increased risk of schizophrenia in these groups (Veling et al., 2007). Indeed, there does appear to be a relationship between experienced and perceived racism and the development of common mental health problems and psychosis (Karlsen et al., 2005). A recent review concluded that discrimination does appear to play an important role in the presence of psychosis and suggested that there may be a dose-response relationship between exposure to discrimination and the likelihood of reporting psychotic experiences (Pearce et al., 2019).

In addition to higher rates of psychosis among Black communities, there also appears to be significant differences in their pathways to care, when compared to White populations. Research has consistently shown that African Caribbean population are more likely to be detained under the Mental Health Act than their White counterparts and are consequently

over-represented in inpatient services (Mann et al., 2014; Morgan et al., 2004). A meta-analysis reported the odds ratio for compulsory detention in Black patients to be 3.83 times higher than White British patients (Singh et al., 2007). Despite the acknowledgment of these disparities, these issues continue to persist with a recent review highlighting that there has not been any change in the rates of compulsory admission for Black African and Caribbean service-users (Odula et al., 2019).

Furthermore, evidence suggests that pathways to care for Black service-users are more likely to include contact with the police and criminal justice system involvement compared to White service-users (Halvorsrud et al., 2018). When followed up over a 5-year period, Black patients increased contact with the police did not appear to be consistent with any deterioration in their functioning or illness severity (Ajnakina et al., 2017). Although the presence of violence may partly explain why police contact is more common for some first-episode psychosis patients, it does not fully explain the ethnic differences in these criminal justice pathways (Bhui et al., 2015). It is also crucial to consider the psychological impact of these pathways to care.

2.2.1 Trauma impact- PTSD associated with treatment

Interviews with service-users who have been admitted to hospital against their will reveal a mixed experience of being able to build supportive relationships with ward staff, but conversely experiencing loss of their competence (Hughes et al., 2009). Many service-users identify the decision to be admitted involuntarily as necessary and beneficial (O'Donoghue et al., 2010). However, there may have been a high risk of bias given that service users were interviewed by the ward's psychiatrist, and therefore likely failed to reveal the full range of service-users experiences about the admission, given the likely power imbalance. The process can be a conflicting experience for service-users having to navigate both positive and more challenging aspects of involuntary admission.

Murphy et al., (2017) interviewed 50 service-users who had experienced involuntary hospital admission and found that although there were reports of positive, person-centred care from staff, many reported that they had felt coerced and unsupported with long-term detrimental effects on their well-being. Emotional responses to involuntary admission also include feeling angry, powerless and fearful (Meehan et al., 2000). Involuntary hospital admission can leave service-users feeling disempowered and stigmatised impacting on their self-esteem and overall quality of life (Rusch et al., 2014). Service-users report feelings of humiliation and this is more common when they have experienced verbal or physical force (Svindseth et al., 2007). Strong negative reactions are reported by some service-users, with some making references to “feeling “imprisoned” when recounting their experiences of involuntary admission (Nyttingnes et al., 2016).

The experience of being locked in secure care with limited freedom and away from significant others can be traumatising in itself (Cohen, 1994). In light of this, it is not surprising that the psychological impact of involuntary admission leaves some service-users with symptoms of Post-Traumatic Stress Disorder (PTSD) (Morrison et al., 1999). Service-users report perceived traumatic experiences following hospital admission and treatment (Paksarian et al., 2014). The trauma that occurs within psychiatric admissions include physical assaults, sexual assaults and witnessing traumatic events (Frueh et al., 2005). In addition to the impact of hospital admission for the service-user, family members are often equally affected.

Compulsory detention and treatment against a patient’s will, can have a huge impact on the relatives of the patient (Boydell et al., 2014). For many carers, involuntary admission of their loved one can be a conflicting emotional experience as a common initial response is a sense of relief, followed by worries and guilt (Jankovic et al., 2011). While quantitative data show that family carers often report positive and favourable experiences of involuntary treatment, this does not appear to be the case for many families (Giacco et al., 2012).

In-depth interviews with carers highlight that the emotional conflict associated with involuntary admission can be confounded by carers not wanting to disrespect their loved one's autonomy while maintaining their human dignity (van den Hooff, & Goossensen, 2015). An involuntary hospital admission often carries with it, feelings of sadness and grief for family members, leading to significant distress and potential threats to family relationships (Wyder et al., 2018). Unfortunately, however, there is a paucity of research investigating the varying impact of compulsory detention on family carers, despite them being an integral part of the service-user's recovery.

2.2.2.2 The context of ongoing racial trauma/ structural racism and adversity for both service users and carers

When discussing the impact of trauma as a response to psychiatric admission, it would be remiss not to do so without acknowledging the context within which this occurs in relation to ongoing racialised trauma experienced by oppressed groups. Racial trauma, also referred to as race-based stress describes minority ethnic groups' responses to danger and real or perceived experiences of racial discrimination (Comas-Diaz et al., 2019). Racial trauma includes threats of harm and injury, police incidents, and humiliating and shaming events (Smith, 2010). Evidence suggests that the psychological effects of racial trauma are consistent with symptoms of PTSD, however race-based stress is often not considered during the assessment of PTSD (Butts, 2002). Despite oppressed groups of society experiencing severe traumatic events, their needs may be neglected by services and they continue to be exposed to different forms of racial attacks.

Although the effects of racial trauma can mirror the symptoms observed in PTSD, it is slightly different as the victims are also subject to continual racial microaggressions (Comas-Diaz, 2016). Racial microaggressions refer to common verbal, behavioural or environmental

slights towards ethnic minority groups that communicate hostile, belittling or negative racial insults (Sue et al., 2007). Racial microaggressions are associated with poorer mental health and symptoms of depression and negative affect (Nadal et al., 2014). In a study using 187 Black women, Donovan et al., (2013) highlighted the difference in impact between racial micro-aggressions and macro-aggressions. Macro-aggressions referred to instances of overt, purposeful racial discrimination and although less common than micro-aggressions had more detrimental effects to participants' mental health. Their findings highlight the high prevalence of subtle forms of racism and the dangerous impact this can have on everyday life for Black individuals.

Furthermore, race-based stress is made more complex due to ways it is maintained throughout society, perpetuated in the same systems that should operate to help these vulnerable populations (Hardy, 2013). Structural racism has been defined as the normalisation and legitimising of historical, institutional and interpersonal processes that strategically advantage White people, while producing persistent harmful outcomes for Black and minority ethnic groups (Lawrence & Keleher, 2004). Structural racism works on the macrolevel of social and environmental factors and therefore can influence outcomes more than at an individual level (Gee & Ford, 2011). For example, within mental health, structural racism predicts which groups of people can and will access and receive treatment by mental health services (Mensah et al., 2021). This is evident in the disparities seen by how treatments and pathways to care differ according to racial groups, which appears to confirm the presence of institutional racism (McKenzie & Bhui, 2007).

Furthermore, Black communities in the UK represent one of the most socially disadvantaged groups of the population (Morgan & Hutchinson, 2010). In addition to the higher rates of psychosis seen in Black communities partly explained by greater social disadvantage, Black people often attribute their disadvantage to racism (Cooper et al., 2008). This shows that the experience of racism, whether at an interpersonal or structural level, is perceived to be a

significant factor by the communities affected by it. Therefore, it is vital that services not only name these inequalities, but actively work to dismantle the structural components of racism.

2.2.2. Racial inequalities and the impact on relationship with services

Existing racial inequalities have an understandable impact on marginalised groups' interaction with services. Previously, these groups would often be classified as "hard to reach", based on the recognition of their social, geographical or economic disadvantage presenting as a barrier to accessing care (Shaghagi et al., 2011). However, this term not only implies that this is a homogenous group with similar needs, but also places the problem within the vulnerable population rather than as a consequence of mental health services needing to do more.

Access to mental health services is often lower for people from Black and minority ethnic backgrounds (Commander et al., 1997). Using qualitative methodology, Memon et al., (2016) aimed to explore what the perceived barriers to accessing mental health services were for people from Black and minority ethnic groups. Participants reported issues such as stigma and waiting times as barriers, and some also discussed that they did not trust healthcare services to adequately recognise and attend to their needs. This is consistent with previous research highlighting that Black people may fear they will not be treated equally and with dignity by services (Jamdagni, 1994).

Experienced discrimination is associated with lower engagement with services, with mistrust in services playing a key mediating role in this relationship (Clement et al., 2015). Specialist services targeting minority groups tend to improve trust and engagement, however this does not take away the need for mainstream services to be more skilled in cultural humility (Suresh & Bhui, 2006). The wider implementation of early intervention services seems a promising way to bridge this gap aiming to reduce inequalities and achieve improved

outcomes for Black and minority ethnic service-users, while utilising early detection of psychotic symptoms. These services are often perceived to be accessible and supportive holding acceptable levels of cultural awareness (Singh et al., 2013). However, engagement within these services still appears to vary depending on ethnic and racial groups.

Despite input from early intervention services, Black African service-users still show greater chances of being compulsorily detained and admitted to hospital (Mann et al., 2014).

Furthermore, Black African and Caribbean service-users appear to engage with community and primary health care services significantly less than their White counterparts (Ghali et al., 2013).

Conversely, there does not appear to be differences in engagement of psychological interventions when delivered in the setting of an early intervention inpatient ward (Reynolds et al., 2018). This suggests that there can be learning taken from inpatient settings regarding engaging with groups, who may be less inclined to take up services in the community.

As mentioned earlier, service-users consistently report family members and caregivers being key in facilitating access to services (Memon et al., 2016). Therefore, maintaining and fostering relationships with family members of service-users can be critical in improving engagement and trust in services.

Section 3: How can services address ethnic disparities in care for people with psychosis?

3.1 Legislative/ governmental initiatives

Given that existing health inequalities have now been well documented and established, it poses the question of how these areas can be addressed. In response to this, the UK

Government has set out policies and action plans aiming to reducing the inequalities in accessing and engaging with mental health services for people from Black and minority ethnic backgrounds. The National Service Framework for Mental Health; Delivering Race Equality in Mental Healthcare Action Plan (2005) was also written following the inquiry into the tragic death in custody of David Bennett, who died in a medium secure psychiatric inpatient unit after being physically restrained by staff (Duxbury et al., 2011).

Some of the key objectives outlined in this report included to reduce the fear of mental health services within Black and minority communities and to reduce the disproportionate rates of compulsory detention of Black and minority ethnic patients in psychiatric wards (Department of Health, 2005). Recommendations of this report include mandatory training for all staff of cultural awareness and institutional racism and the implementation of a more ethnically diverse workforce in mental health services. Although this report highlights the importance of engaging with Black and minority ethnic communities, there is no specific mention of what needs to be done to better support the families and carers from these communities.

Following this, the Government published a later document, which built on previous policies and action plans. This report aimed to build on The National Service Framework ultimately hoping to achieve improved mental health outcomes for all and reduce the inequalities of care (Department of Health, 2009). The value and key role of families and carers was acknowledged and a pledge to not only include families more in the treatment of their loved one, but also to support the well-being of carers themselves. This expands on previous legislation, recognising carers and identifying their rights under the Carer Recognition and Services Act (Department of Health, 1995). This includes essential responsibilities afforded to carers, such as the entitlement to a carer's assessment. Such legislative initiatives aim to support local authorities to provide necessary help for carers, however it has been argued

that the use of carer assessments does not go far enough to appreciate the crucial and multi-faceted position carers play in supporting their loved ones (Repper, 2009).

NICE Guidelines appear to address this issue by making specific recommendations emphasising the need for all mental health services to highlight the impact of culture, race and ethnicity in psychosis and schizophrenia presentations (NICE, 2014). Furthermore, NICE guidelines recommend that carers should not only be offered a carer's assessment but should be involved in the decision-making of care for their loved one and offered a carers-focused education and support programme (NICE, 2014). Despite legislation and clinical guidelines, there are still barriers to including carers as partners of care.

3.2 Are existing interventions suitable and effective for Black service-users and their carers?

Services have a duty and responsibility to ensure that the interventions they provide not only involve carers but also appropriately serve the needs of Black and minority ethnic groups. Family interventions aim to improve communication and quality of relationships for service-users and carers and can significantly reduce relapse and hospital admission rates (Pilling et al., 2002). The positive effects of family interventions are apparent not just in the service-user, but also the carers. Berglund et al., (2003) compared the effectiveness of a structured, manualised family support programme with standard family support and findings showed that the structured family intervention reduced carer burden and improved carers' attitudes toward services.

NICE guidelines recommend family interventions as a first-line treatment for psychosis and schizophrenia; however, the implementation of these interventions appears to be low (Haddock et al., 2014). Barriers to implementation include lack of knowledge and skills felt by staff and competing workload demands (Berry & Haddock, 2008). Qualitative research

show that staff report difficulties engaging families for family work due to issues such as challenges motivating clients and choosing appropriate families (Nilsen et al., 2015). This would also suggest that there may be variability in recruiting and selecting families that are deemed more “appropriate” to engage in a family intervention. For example, families that have a history of greater treatment compliance tend to be more likely to engage and complete family interventions (Nugter et al., 1997).

However, there is a lack of research investigating whether family interventions are equally effective treatments for Black and minority ethnic groups. Only a small number of studies evaluating the effectiveness of family interventions actually include samples of Black and minority groups (Onwumere et al., 2011).

3.2.1. Validity of fundamental models of caregiving in psychosis

When thinking about the feasibility of interventions for Black and minority ethnic communities, it is worth considering the evidence-base that inform these interventions. Existing literature strongly points to the influence of high expressed emotion (EE) as a key indicator for relapse and well-being in service-users diagnosed with psychosis and schizophrenia. Expressed emotion describes the way relatives of a patient talk about the service-user (Butzlaff & Hooley, 1998). Levels of expressed emotion are measured by the Camberwell Family Interview (CFI) and family members are categorised as being high in EE if they reach the specified cut-off for number of critical comments or display hostility or marked emotional overinvolvement (Vaughn & Leff, 1976).

High EE has been shown to be a strong predictor of patient’s relapse, suggesting that family members’ attitudes and behaviour towards their loved one can have a detrimental effect on the service-user’s recovery (Linszen et al., 1997). Furthermore, high EE has been observed even in relatives of patients at the early stages of the psychotic illness (Sadath et al., 2017).

However, although EE consistently predicts relapse irrespective of the chronicity of the patient's illness, there is a greater association between EE and relapse in samples containing more chronically ill service-users (Butzlaff & Hooley, 1998).

When exploring the mechanisms involved in the relationship between high EE and relapse, evidence suggests that carers beliefs and controlling behaviour can undermine service-user's sense of self-worth and increase their stress (Barrowclough & Hooley, 2003). Furthermore, high EE is associated with low carer self-esteem and poorer carer coping strategies (Kuipers et al., 2006). We know that carers with low self-esteem can feel hopeless and place more pressure on services to help their loved one, indicating that professional support can be crucial particularly for this group of carers (Kuipers et al., 2010). This suggests that psychosis interventions should include carer-focussed strategies to reduce criticism, hostility and encourage more adaptive coping skills. Effective family interventions reduce relapse of psychosis patients and show significant improvement in levels of EE, particularly in emotional over-involvement (Mari & Streiner, 1994).

Although the construct of EE has been well established, the data is less clear in non-White and non-Western groups. A recent review highlighted that the experience of EE is not a universal construct and there are cultural differences in the scoring and interpretation of EE scoring (O'Driscoll et al., 2019). An example of this can be seen in more collectivist cultures where there tends to be greater emphasis on maintaining family and community relationships (Singh et al., 2013). Conversely, in Western cultures, personal independence is often the norm so criticism can be perceived as more detrimental compared to African caregiving relationships where criticism can be viewed as a sign of care, warmth and support (Rosenfarb et al., 2006).

Therefore, this calls for the importance of mental health services to have cultural awareness about different caregiving behaviours, which can then lead to appropriate adaptations for diverse communities.

3.2.1. Cultural adaptations of psychosocial interventions

There have been some attempts to address this issue with increasing efforts to culturally adapt evidence-based interventions for psychosis. Cognitive Behaviour Therapy for Psychosis (CBTp) has a strong empirical basis and is commonly used in clinical practice, reducing distress and symptoms for service-users (Gould et al., 2004; Wykes et al., 2008). In light of this, it is recommended as a first-line treatment for psychosis in conjunction with anti-psychotic medication (NICE, 2014). However, it has been suggested that cultural differences may impact the effectiveness of CBTp (Hays & Iwamasa, 2006).

Qualitative interviews conducted with service-users, carers and health professionals in Pakistan highlighted that patients often utilise the support of family members and spiritual leaders when seeking help for mental health problems (Naeem et al., 2016). Similar themes were identified during semi-structured interviews with patients, carers and mental health professionals in China highlighting the value of family involvement and religious attributions of illness (Li et al., 2017). In light of this, Habib et al., (2015) made cultural adaptations of CBTp integrating a bio-psycho-spiritual-social model used within the Pakistani community. Their findings showed that culturally-adapted CBTp was effective in reducing psychotic symptoms and improving insight (Habib et al., 2015).

This suggests that there is an unmet need for interventions to be adapted for Black and minority ethnic populations, to improve access, engagement and recovery for these individuals (Beck & Naz, 2019). Furthermore, in the UK, patients of Black African and

Caribbean heritage express the need for CBT to be culturally adapted in order to be an appropriate treatment for these populations (Rathod et al., 2010). When these adaptations are made, Black and minority ethnic service-users show reductions in psychotic symptoms and report greater satisfaction with treatment (Rathod et al., 2013).

However, when it comes to family interventions for psychosis, there is a lack of research investigating the efficacy of this. In a promising study, Edge et al., (2016) explored the feasibility of culturally adapted family intervention for African-Caribbean service-users and showed that proactively involving family members and community leaders could increase engagement with mental health services and result in improved outcomes for minority groups. Evidence suggests that culturally adapted interventions can be more efficacious than standard treatments, however no firm conclusions can be made due to the lack of established research in this area (Degnan et al., 2018). Further research is needed to understand the specific adaptations required to support the needs of Black service-users and their carers.

Section 4: Rationale for focussing on the views of Black carers of people with psychosis

4.1 Importance of qualitative research to build an understanding and inform development of interventions

Carers report that they sometimes feel excluded from the care of their loved one and that health professionals do not have the time to talk to them (Askey et al., 2009). Furthermore, despite greater emphasis on the importance of involving carers in the decision making and care planning, there is a general consensus among carers that they are pushed out of processes determining care for their loved one and their caring roles are underappreciated by health professionals (Cree et al., 2015).

Unfortunately, carers often do not feel supported by the mental health services providing support to their loved one, which results in increased psychological distress and built-up feelings of resentment (Sin et al., 2005). However, it seems that carers tend to have positive experiences when their loved one is under the care of an early intervention service. This may be due to the social recovery and outreach model used within early intervention services, which aims to actively involve carers in the treatment of service-users (Fowler et al., 2009). Lavis et al., (2015) interviewed 80 carers of young people with first-episode psychosis engaged in early intervention services and carers provided positive feedback of feeling involved in their loved one's care and recognised as key contributors to the safety and recovery of service-users. The authors conclude that listening to the needs of carers should be a priority across all mental health services, to ensure they are appropriately supported.

When thinking about how to address the needs of carers, it is beneficial to hear the experiences of what has worked well to inform the development of successful interventions. The importance of a strong therapeutic relationship with healthcare professions appears to be key in what is valued by carers (Allard et al., 2018; Loughlin et al., 2020). Furthermore, carers describe wanting to have clear written and verbal information about their loved one's illness as well as increased access to developing a network of carers in similar circumstances (Sin et al., 2005).

If services are to be genuinely responsive to the needs of families and service-users, it is vital that they consult with carers regarding the implementation and facilitation of carer-focused initiatives (Sin et al., 2005). This includes listening to the voices of all carers, from all backgrounds and ethnicities. However, the needs of Black Afro-Caribbean carers remain a largely under-studied and unheard focus of research.

4.2. Unheard voices of Black carers of people with psychosis

Keating and Robertson (2004) conducted in-depth interviews with African and Caribbean service-users and carers about their experiences of mental health services. Their findings highlighted that Black families and carers were reluctant to be involved in services, due to fears that this would negatively impact on the treatment their loved one was receiving. In this study, Black carers spoke about the power imbalance between themselves and professionals, leading the carers to feel 'silenced' and less likely to challenge professionals. Research has also found that families from African and Caribbean populations perceive mental health services to misinterpret cultural modes of self-expressions highlighting a gap in professionals' awareness and understanding of their different cultural needs (McLean et al., 2003).

Black patients tend to be significantly less satisfied with their treatment, especially if they have experienced multiple hospital admissions (Parkman et al., 1997). This poses the question of why are we not speaking to this group of people, to better understand where services are falling short and what needs to be done? Despite the disproportionate rates of Black African and Caribbean compulsorily admitted in psychiatric and the well-documented impact this has on carers and relatives' well-being, their needs continue to be poorly researched.

Little research has specifically explored the experiences of Black African and Caribbean carers when their loved one has been detained under the Mental Health Act. If we are genuinely committed to engaging in anti-racist practice and reducing racial health inequalities, we must identify what minority and oppressed communities need from services.

4.3 Important to focus on their experiences of inpatient care

Furthermore, given the heightened responsibility that some Black carers may feel to protect their loved ones from coercive traumatic practices, it would be beneficial to hear from these carers after their loved one has experienced a psychiatric admission. Keating and Robertson (2004) conducted focus groups and semi-structured interviews with Black service-users and carers and identified that “circles of fear” are maintained in the Black community through processes of mistrust, discrimination and stigma associated with use of mental health services.

Their findings also highlighted that staff in inpatient psychiatric services do not feel adequately equipped or aware of the specific needs of members of the Black community. The authors conclude that these vicious cycles of fear can only be broken through concerted efforts by mental health services to bridge the gap between the Black community and mental health services.

This project is an attempt at building this bridge. Specifically, this project will explore Black carers’ perceptions of how services regarded their involvement in their loved one’s care. This project aims to explore carers experiences throughout all stages of the compulsory detention process, including the initial decision to detain, the service-users’ hospital admission and carer’s reflections following this. By gaining an in-depth insight to the experiences of Black carers, this knowledge can then be used to inform appropriate interventions to ensure that carers feel that they are partners with services in the care of their loved one.

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Part II: Empirical Paper

**An exploration of Black carers' experiences of their relative/loved one's detention
under the Mental Health Act.**

Abstract

Aims: Compulsory admission can have a devastating impact on the service-user and their families. Black people continue to be disproportionately detained under the Mental Health Act; however, little is known about the impact of this on their support network. With greater emphasis now on involving carers in the treatment of service-users, it is therefore important to consider their views to inform service development. This study aims to understand the experiences of Black carers, when their loved one has been detained under the Mental Health Act.

Method: Ten Black carers of African and Caribbean heritage were recruited online from non-NHS carer organisations across the UK. Semi-structured interviews were conducted online as well as demographic details and the Brief Experience of Caregiving Inventory (BECI) for descriptive purposes. Interview transcripts were analysed using Interpretative Phenomenological Analysis (IPA).

Results: Five superordinate themes emerged. Black carers reported that the compulsory detention of their loved was traumatic. They were fearful about how services would treat their loved one and felt let down and unappreciated by health professionals. Black carers valued attending carer groups and relied on their faith for coping. The subjective experience of racism was felt by some Black carers, but it was difficult to articulate.

Conclusions: Compulsory detention of a loved one, is a traumatic and frightening experience for Black carers. Clinical implications include the need for trauma-focussed interventions and services working in partnership with Black carers.

Introduction

The important role of carers

Psychotic disorders can be particularly distressing and destabilising for individuals and those around them (NICE, 2014). People with psychosis often require long-term treatment and support across many different areas of life, including emotional support, and financial and practical assistance (The Schizophrenia Commission, 2012). In most cases, it is family members who provide this care and support (Jones, 2009). More broadly, “informal carers” include parents, partners, siblings or friends who live with or are in regular contact with service-users (Onwumere et al., 2018). Carers play a vital role in the wellbeing and recovery of their loved one (Jones, 2009; Sin et al., 2021).

This highlights the importance of informal carers who are often the first to notice a deterioration in their loved one’s mental health and successfully initiate contact with services (Connor et al., 2016). Family involvement significantly reduces the length of DUP for individuals presenting with first-episode psychosis (Morgan et al., 2006). Furthermore, once patients have accessed services, the benefits of family support continue. Greater social support is associated with lower levels of psychotic symptoms and fewer hospital admissions (Norman et al., 2005). Social support is also a protective factor which reduces the risk of the negative outcomes associated with psychosis (Bjornestad et al., 2017). This may be linked to evidence that suggests individuals presenting with psychosis without family support, are more likely to disengage from services (Schimmelman et al., 2006). Conversely, service-users who perceive more positive affect from their family are less likely to relapse in first-episode psychosis (Lee et al., 2014).

The value that carers bring in supporting the recovery of service-users is now well established, however the experience of caregiving is complex.

The impact of caregiving

Caregivers report that caring for a loved one with psychosis can be rewarding, stating that they feel they have become more “understanding” and “patient” due to supporting their loved one in managing their difficulties (Chen & Greenberg, 2004). Caregiving gains also include carers recognising their own inner strengths and feeling clearer about their values and priorities (Chen & Greenberg, 2004). However, the majority of the sample in this study identified as being White (98.2%), therefore it is unclear whether the findings of this study can also be generalised to carers of African-Caribbean descent. Furthermore, carers describe positive aspects of the relationship with the service-user outdo the negative aspects (Kulhara et al., 2012). Carers appear to experience satisfaction from helping their loved one to overcome difficulties, which helps carers feel wanted and valued (Nolan & Lundh, 1999).

However, caring for a loved one with a severe mental health problem is also associated with increased stress and burden (Awad & Voruganti, 2008; Martens & Addington, 2001). Carers of people with psychosis experience poorer mental health (Sin et al., 2021). The consequences of caregiving include high levels of worry and financial burden (Gonçalves-Pereira et al., 2013). Carers supporting a loved one with a psychotic disorder experience poor quality of life and high levels of anxiety and depression (Stanley et al., 2017). Furthermore, this experience of carers appears to remain consistent over time, and in some cases gets worse (Poon et al., 2017). A high proportion of carers experience “burnout” including emotional exhaustion and a lower sense of accomplishment (Onwumere et al., 2017). There is evidence to suggest that carer burnout is higher for those supporting loved ones who have experienced psychosis for longer. Carers of chronic psychosis patients display higher levels of burden compared to first-episode psychosis carers (Sagut & Duman,

2016). It may be that patients with chronic psychosis experience more hospital admissions, which is a significant factor for caregiver burden (Gutiérrez-Maldonado et al., 2005).

Carers of people with psychosis display Post-Traumatic Stress Symptoms (PTSS) due to experiencing and witnessing stressful life events related to their role as caregivers (Barton & Jackson, 2008; Kingston et al., 2016). Furthermore, the exposure to the unpredictable nature of psychosis and aggression of service-users can result in carers displaying symptoms consistent with Post-Traumatic Stress Disorder (PTSD) (Loughland et al., 2009). The effects of trauma can include flashbacks or intrusive memories of the traumatic events, hypervigilance and avoidance of reminders about the traumatic incident (American Psychiatric Association, 2013).

Qualitative research exploring the experience of carers of young adults with first-episode psychosis highlighted that not only do carers go through a “rollercoaster of emotions”, but they do so while balancing life’s competing demands such as parenting and work (McCann et al., 2011). The emotional distress associated with caregiving is often linked to carers sense of guilt and blaming themselves for their loved one’s illness (Ferriter & Huband, 2003). In light of this, carers find support from family members and self-help groups particularly beneficial (Ferriter & Huband, 2003). However, a limitation of this study is that all participants were White, with the authors describing the decision to not include minority ethnic participants as due to “controversy regarding diagnosis in Black communities”. Although this may have reduced confounding factors in the results of this study, it does not provide experiences from communities that are already silenced and marginalised. Furthermore, this study focussed solely on parent caregivers. Therefore, it would be beneficial for future research to establish whether similar themes are apparent in other caregiving relationships.

Carers experience of mental health services

Increasingly over the past few decades, the need for carers to be viewed as a valuable resource in mental health services has been emphasised, with policies stating that carers should be partners with clinicians in the care and treatment of their loved one (Repper, 2009). Psychiatric hospitals can be a frightening and confusing place for service-users, therefore it is understandable that carers may experience an increased urge to protect and support their loved one during their hospital admission (Fenton et al., 2014). Additionally, carers report wanting to be involved in their loved one's care and to feel supported by services (Lloyd & Carson, 2005). In practice, however, carers' experience of this appears to be mixed with some reporting feelings of being dismissed and lied to by mental health professionals (Clarke, 2006). Large quantitative data suggests that overall, carers experiences of involuntary hospital admission are generally positive (Giacco et al., 2012). However, more in-depth and subjective analysis of carers' experiences tends to show a highly contrasting picture.

Qualitative research of carers' experiences of acute psychiatric wards highlight themes of powerlessness and isolation (Wilkinson & McAndrew, 2008). In this study, carers reported feeling a "divide" between themselves and the healthcare professionals in the wards, perceiving the ward staff to hold all knowledge and control. Importantly, findings of this study also portrayed that all the participants expressed a desire for working in partnership with ward staff. Although this was a small study utilising 4 participants, it provided rich information about the experiences of carers' interactions with psychiatric services. It would be valuable for further research to build on this existing data with a possible larger sample size to explore whether these findings may be consistent with other carer participants.

Greater staff presence and working in collaboration with patients and their networks improves the culture on the ward for both patients and staff (Hamrin et al., 2009). It can be difficult for carers to maintain and respect their loved one's autonomy, while also feeling that they have to make important decisions about their care while they are

compulsorily detained (van den Hooff & Goossensen, 2015). Furthermore, carers' involvement in the compulsory detention process often leads to them feeling responsible for their loved one and can put a strain on their caregiving relationship (Sugiura et al., 2020). Carers often feel that compulsory hospital admission is the most appropriate way for their loved ones to be in a place of safety and is often perceived to be a "last resort"; however, carers are left feeling anxious about the potential of re-admission and they find it challenging to access support form services following discharge (Ranieri et al., 2018).

When their loved ones are compulsorily detained, many carers feel let down by services due to the lack of information sharing and not feeling valued (Hickman et al., 2016).

Unfortunately, carers report that they are excluded from decision-making processes and their knowledge and expertise is not appreciated by professionals (Cree et al., 2015). These feelings may have been further amplified in the past year due to the Covid-19 pandemic, with carers not able to visit their loved ones during their hospital admission (NHS England, 2020). A recent systematic review concluded that in order for carers to feel that they are partners in care, it is essential they feel able to build trusting relationships with staff and they need timely and accessible information related to the wellbeing of their loved one (Stuart et al., 2020). Furthermore, this review highlighted the paucity of research specifically investigating the experiences of Black and Minority ethnic carers, despite these groups being overrepresented in psychiatric services (Stuart et al., 2020).

Disproportionate rates of psychiatric admissions

It has been well-known for decades that the African Caribbean population are more likely to be detained under the Mental Health Act than their White counterparts and are consequently over-represented in inpatient services (Mann et al., 2014; Morgan et al., 2004). With Black service-users and their families more likely to be in contact with services due to being

overrepresented in psychiatric hospitals, it is important that we understand their experiences and needs.

Black carers interactions with mental health services

Racially minoritised groups of people who already experience prejudice and discrimination in their everyday lives, are also faced with the added stigma of mental health within their own communities, which can create a barrier to utilising services (Gary, 2005). Minority ethnic carers endorse higher levels of shame and the need to conceal their loved one's illness compared to their White counterparts (Wong et al., 2009). In this small study with carers of early-onset psychosis, families reported that talking with others, their religion and faith served as a protective response against the negative impact of stigma (Wong et al., 2009). Furthermore, religion is an effective coping strategy for carers and is associated with lower levels of psychological distress (Fortune et al., 2005). However, little research has explored whether Black carers feel that services are equipped to meet their spiritual needs.

African and Caribbean carers state they are also hesitant to engage in services, due to worries that their involvement may negatively impact their loved one's treatment (Keating & Robertson, 2004). Furthermore, findings from this qualitative study highlight that Black carers experience a power imbalance between themselves and professionals, which leads to them feeling "silenced" and unable to challenge professionals. Semi-structured interviews and focus groups with Black service-users, their carers and professionals identified "circles of fear" that are perpetuated in the Black community, through mechanisms of mistrust, discrimination and stigma associated with use of mental health services (Keating & Robertson, 2004). Participants in this study were asked about their experiences of mental health services in general. It is unclear whether these findings specifically relate to Black carers experiences during the sectioning and compulsory hospitalisation.

The experience of Black carers is poorly researched, despite what we know about the distressing and traumatic impact hospital admissions have on service-users and their families. Little research has specifically explored the experiences of Black African and Caribbean carers when their loved one has been detained under the Mental Health Act. If there is to be a serious attempt to deliver services that are committed to tackling the effects of institutional racism, then the needs of these marginalised groups need to be understood (Bhui & Sashidharan, 2003). Conducting in-depth interviews with Black carers, gaining an insight into their subjective experiences is a step in addressing these issues.

Aim

This study aims to understand the experiences of Black carers when their loved one has been detained under the Mental Health Act, with a view to identify their needs and how they feel their contribution was perceived by services including whether their perspective on whether race may have impacted on their experience. The broad research question of the study is to investigate what are the needs, attitudes and experiences of Black carers when their loved one has been compulsorily detained throughout all stages of the process, including the initial decision to detain, the hospital admission and the aftermath.

Method

Design

The study utilised a qualitative design involving semi-structured interviews with Black people who had experienced a family member/loved one being detained under the Mental Health Act. A qualitative approach was deemed to be appropriate, given its usefulness in uncovering in-depth, meaningful and subjective data (Britten, 2006).

Ethics

Approval for the study was gained through the UCL Ethical Department (Reference: 18775/001). All data was obtained and stored in accordance with UCL Data Protection policies. Please see Appendix A for the official letter of ethical approval.

Participants

Participants were carers who identified as being of Black African or Caribbean heritage. Inclusion criteria for this study were that participants were caring or had cared for individuals with a severe mental illness who had been detained under the Mental Health Act. To establish carer ethnicity, carers had to self-define their ethnicity to be of African or Caribbean heritage. For the purpose of this study, “carer” was defined in the following way: a family member, spouse or partner of a service-user who lives with the service-user and provides them with support; or an individual who lives with the service-user and has been identified or self-identifies as their loved one’s carer; or an individual who is regarded as a carer living separately from the service-user but in close contact with their loved one for at least 3 months prior to admission (Kuipers et al., 2006; Onwumere et al., 2008).

The Good Practice Guidance for Involving Carers, Family Members and Close Friends of Service Users in Research (Simpson & Repper, 2011) note that the term ‘carer’ should be inclusive and recognise that friends as well as family can be in this role (including a parent, spouse, partner, family member, friend or other informal carer).

All participants were required to have a sufficient command of English language and had to be over the age of 18.

Thirteen carers expressed an initial interest in the project, of whom 10 took part. Two were excluded because they identified as being White, and one was excluded due to being a full-time paid carer.

Measures

Information was collected on carers' socio-demographic characteristics via a questionnaire completed by the carer. This included: age, gender, ethnicity, relationship to the service-user and whether the carer lived with the service-user. In addition, information such as the age, gender and diagnosis of the person they were caring for was collected. Please see the Appendix for all measures.

Participants completed the Brief Experience of Caregiving Inventory (BECI) for descriptive purposes. The BECI is a reliable and valid measure and has been found to consistently measure the subjective psychological distress and well-being of carers (O'Driscoll et al., 2018). The BECI is a 19-item measure assessing caregivers experiences and relationship to services. The items are rated on a Likert scale (0 = never; 1 = rarely; 2 = sometimes; 3 = often; 4 = nearly always). Participant scores were entered into a BECI database which generates composite scores for 3 negative subscales comprised of: Difficult behaviours (e.g. service-user being unpredictable and irritable); Problems with services (e.g. health professionals do not understand my situation) and Stigma/effects on the family (e.g. the illness causing a family breakup). There is one positive sub-scale - Positive personal experiences (e.g. I have discovered strengths in myself). The combined scores yield a total BECI score (range 0 – 76), with the negative subscale being reverse scored. A greater score on the BECI indicates greater levels of distress.

Interview schedule

Phase I: Item generation from reviewed literature

The researcher reviewed existing literature to inform the development of the interview schedule. Given the scarcity of research specifically exploring the needs of Black African and Caribbean carers, the researcher drew on literature that described more widely patient and carer experiences of mental health services (Mann et al., 2014; Islam et al., 2015; Weich et al., 2012). Particular attention was paid to studies that included samples of Black and minority ethnic individuals and the conclusions that were identified. Interview questions were generated based on the recommendations from the evidence base. The researcher was able to access the interview schedule used in a study exploring the experiences of African Caribbean carers in the UK (Pelle, 2013). This served as a useful framework to establish key questions that had already been asked and gaps in research. This enabled the researcher to generate the first few key items for the current study's interview schedule.

Phase II: Expert consultation/ review

The initial draft was reviewed by Dr Miriam Fornells-Ambrojo, the Chief Investigator, a Clinical Psychologist, and a Professional Lead for Psychological Services for First Episode Psychosis in NELFT NHS Trust. Dr Kat Alcock, an expert in qualitative research, was consulted to provide feedback and guidance on the styles of questions used to meet the aims of the study and address the research questions. On the basis of her comments on wording, question order, and interview style, changes were made to the interview schedule. The interview schedule was further refined with experts in the field. Consultations with Dr Juliana Onmuwere, an expert in carer research and race-relations research, and Dr Claire Williams, Consultant Clinical Psychologist and Clinical Lead in an Inpatient service provided feedback on the focus of the questions in the interview schedule. Specifically, the feedback helped to ensure that the topics discussed in the interview were relevant and fully addressed

the aims of the study. A Black carer consultant, who also met the inclusion criteria for the current study, reviewed the interview schedule checking the content and wording felt appropriate for the target sample. This feedback was incorporated to generate the next version of the interview schedule.

Phase III: Piloting

A pilot interview was conducted with a fellow clinician to understand the flow of the interview questions. This pilot also provided an opportunity for the researcher to estimate the length of time needed for the interview and whether the questions would provide rich and valuable, in-depth data. Following feedback from the clinician, the interview was amended to ensure that questions were asked in a meaningful yet sensitive manner.

Final version of the interview schedule

Based on the recommendations and feedback from the experts in the field and experts by experience, the final version of the interview schedule was developed, please see Appendix E.

The interview schedule included a brief introduction and reminder about the study, allowing the opportunity for participants to ask any questions before the interview commenced. This was followed by an orientation section to check language. This enabled participants to state how they would like to be referred to during the interview and the terms they would prefer the researcher to use.

The interview schedule covered sections about the compulsory detention process; hospital admission; reflections and the impact of personal characteristics on their experience. The interview included questions about the carer's experience of the compulsory detention process and prompts such as where they were on the day and how involved they felt during the process. The interview also included questions about the carer's experience of the

hospital admission. Example questions from this section included “How would you describe your experiences with staff on the ward?” and “Can you please tell me about the decision for your loved one to be discharged from hospital?”. Participants were asked about their reflections of the compulsory detention process and hospital admission. An example question from this section included “How has your experience of your loved one’s detention under the Mental Health Act, influenced your view of mental health services and health professionals?”. Lastly the interview schedule included questions about the participant’s individual characteristics such as race and gender and participants’ views on whether these characteristics made any difference to their overall treatment.

Procedure

Participants were recruited via online advertisement through the use of flyers and liaising with wider carer and Black African and Caribbean non-NHS organisations. The study was advertised within the carer organisations’ own webpages and blogs in addition to social media platforms including Twitter and Instagram. The researcher also attended online carer forums to recruit participants.

Potential participants were asked to share their contact details with the researcher. Potential participants were contacted by the researcher and emailed a Participant Information Sheet detailing the study and Consent form, in order that they could provide informed consent. From the point of receiving the information sheet, carers were given at least 24 hours to make a decision about taking part in the study and again reminded that they were under no obligation. If, after this time, carers provided informed consent, a date and time was arranged at the convenience of the carer for the interview to take place.

At the interview session, the researcher explained the study again and offered the opportunity for any further questions to be asked. Written consent forms were completed online prior to the interview. Most interviews lasted between 45 - 120 minutes, with a few

lasting longer than 120 minutes. All interviews were audio-recorded and conducted online, due to Covid-19 restrictions. Participants were given a gift voucher worth £20 for their participation. Carers were provided with debriefing sheets at the end of each interview and asked if they were happy to be contacted at a future date to take part in validity checks.

Analysis

Demographic and clinical data was analysed using SPSS to produce descriptive statistics of the sample.

Anonymised interview transcripts were analysed using interpretative phenomenological analysis (IPA). In IPA, the researcher aims to investigate how the participant makes sense of their experience (Pietkiewicz, & Smith, 2012). IPA uses an idiographic approach, entailing in-depth analysis of single cases and examining individual perspectives of study participants, in their unique contexts (Pietkiewicz, & Smith, 2012). This approach was in line with the study's research question.

In line with the ethos of IPA, it was empirical for the researcher to become immersed in the data, through the reading and re-reading of all interview transcripts. The researcher initially read through the first transcript, while searching for themes that emerged. Connections between these themes and superordinate themes were then established. This process was replicated for the remaining transcripts, with the researcher identifying patterns to develop master themes for the sample.

The transcription and analysis of data were completed by the researcher. A research volunteer assisted in reviewing the accuracy of the transcripts. The interview transcripts were transferred to an Excel spreadsheet, where the researcher created a left-hand column to make initial notes. These notes were to highlight any initial thoughts and interpretations of

the data. A right-hand column was then used to record emergent themes that were generated from the transcript. Following this, the researcher clustered the emergent themes in an effort to pool the themes together. This process was repeated for each subsequent transcript, with the researcher looking for similarities and connections between themes, while remaining attentive to the development of any new themes.

Validity checks

Once the master table of themes was generated, this was independently checked by the chief investigator and carer consultant. This triangulation of the data aimed to increase the validity of the qualitative findings. A proportion of the sample were also offered the opportunity to conduct member checks of the results of the study to ensure that the themes extracted resonated and accurately reflected the experiences of the participants.

Epistemological position

When conducting qualitative research, it is important that researchers understand that the knowledge generated from their research, can be influenced by their own assumptions and views about the world (Willig, 2012). Therefore, it is crucial that qualitative researchers acknowledge their epistemological positions and how this may have influenced the research study. For this current study, the researcher's epistemological position was 'phenomenological'. A phenomenological position aims for the researcher to capture the subjective reality of the participants' experience, listening empathically without judgment and without questioning the accuracy of the experience described (Willig, 2012). Furthermore, qualitative researchers are encouraged to disclose their perspective including information on their personal characteristics, as this transparency helps the reader to evaluate the conclusions drawn (Barker & Pistrang, 2005).

The researcher remained mindful that being a Black woman with caring responsibilities, had largely influenced the conception of this research project as an initial idea. Furthermore, the researcher's clinical experiences of working alongside carers shaped how the researcher approached participants and interacted with them during the interview. For example, the researcher adopted a compassionate and flexible stance, taking into consideration the context of participants. The researcher reflected upon the impact of being a Black woman and hearing and connecting with Black people's pain and distress during the research interviews with the supervisor.

The researcher is a Trainee Clinical Psychologist, who has experience working in NHS mental health settings. This had largely influenced the researcher's choice to target family members and carers for this research study. This was further enhanced during the researcher's psychologist training and experiences on clinical placements, where family involvement had not felt like an embedded part of therapeutic recovery.

The researcher aligns herself with community psychology approaches, which value the importance of context and social justice (Prilleltensky, 2001). The researcher has an awareness of the inequalities that exist for marginalised and oppressed groups. In light of this, the researcher was keen to utilise qualitative approaches to ensure that Black people were given a space to have their voice and stories heard. Considering the evidence suggesting that Black individuals tend to be less satisfied with mental health services (Boydell et al., 2012); the researcher was open to the possibility of hearing more difficult or negative experiences from participants. This influenced the questions that were included in the interview schedule, with the researcher endeavouring to show curiosity for both positive and negative experiences.

Results

Participants

Demographic information about participants and their loved ones were collected and are displayed in Table 1. The sample included a slightly higher number of female than male carers, with a mean age nearing 60 years old. There was variety in how participants described their ethnic identity, however “Black British” had the highest number of endorsements. Most participants identified as being of Christian faith. The sample included parents, children, siblings, partners and a friend of service-users, with half of the sample representing parents of loved ones.

The majority of the loved ones described in the sample were male, with a mean age nearing 42 years old. When it came to their loved one’s ethnic identity, slightly more participants described their loved one as being “Black British”, representing half the sample. The most common mental health diagnoses of loved ones reported by carers were Psychosis and Schizophrenia. The vast majority of loved ones had been in contact with services for more than two years and been compulsorily detained multiple times. Most of the carers in this sample did not live with their loved one. At the time of the interview, only one carer reported that their loved one was currently detained under section. A slightly higher proportion of the sample had most recently been detained under the Mental Health Act, over a year ago.

Table 1
Participant demographic characteristics

Demographics of carer (n=10)		Descriptive n (%)/ Mean (SD) [Range]
Gender	Female	6 (60%)
	Male	4 (40%)
Age		58.8 (16.27) [28 - 87]
Ethnic identity	African	2 (20%)
	Afro-Caribbean	1 (10%)
	Black	1 (10%)
	Black British	3 (30%)
	Black Caribbean	2 (20%)
	Black South American	1 (10%)
Faith/ belief system	Christian	7 (70%)
	None	3 (30%)
Relationship to loved one	Parent	5 (50%)
	Child	1 (10%)
	Sibling	2 (20%)
	Partner	1 (10%)
	Friend	1 (10%)
Demographics of loved one (n=10)		
Gender	Female	3 (30%)
	Male	7 (70%)
Age		42.2 (13.91) [24 - 64]
Ethnic identity	African	2 (20%)
	Afro-Caribbean	1 (10%)
	Black	1 (10%)
	Black British	5 (50%)
	Black Caribbean	1 (10%)
Mental health diagnosis	First episode psychosis	1 (10%)
	Bipolar disorder	2 (20%)
	Psychosis	3 (30%)
	Schizophrenia Paranoid	3 (30%)
	schizophrenia	1 (10%)
Length of contact with mental health services	Less than 6 months	1 (10%)
	More than 2 years	9 (90%)
Living with carer	Yes	3 (30%)
	No	7 (30%)
Detained under MHA more than once	Yes	9 (90%)
	No	1 (90%)
Currently detained under MHA	Yes	1 (10%)
	No	9 (90%)

Most recent time detained under MHA	Less than 1 year ago	4 (40%)
	More than 1 year ago	6 (60%)

Brief Experience of Caregiving Inventory (BECI)

Participants' scores in these domains are displayed in Table 2. The mean BECI score for this sample was 39.2, which is a slightly higher compared to the mean total of 33.2 seen in the sample used by O'Driscoll et al. (2018). The highest score in the current sample was seen in the negative subscale of difficult behaviours, followed by problems with services.

Table 2
Caregiving scores on the BECI (n = 10)

BECI Domains	[range]	Mean (SD)
Stigma/effects on the family	[0 – 16]	8.2 (2.78)
Positive personal experiences	[0 – 16]	12.6 (3.81)
Problems with services	[0 – 20]	13.0 (3.83)
Difficult behaviours	[0 – 24]	14.6 (6.02)
Total BECI score	[0 – 76]	39.2 (10.29)

Qualitative analysis

10 interview transcripts were analysed, and five superordinate themes were generated: *painful emotions; being let down by services; always a carer; building resilience and it's not racist, but...* Each superordinate theme had 3 -4 themes. The master table of themes for all participants is displayed in Table 3. All superordinate themes were endorsed by each participant interview.

Table 3
Master table of themes

Themes	Quotes from interviews
1. Painful emotions	
1.1. Impact of trauma	"You just go into auto-pilot" - P006 "I used to have...flashbacks" – P009
1.2 Self-blame	"I should have done something" – P001 "Did I actually put him in hospital?" -P002
1.3 Bearing witness to distress	"I live with it" – P008 "I was in the middle of it" – P005
1.4 Cycles of fear	" I was absolutely terrified" – P003 "I didn't want them to choke or suffocate him" -P006
2. Being let down by services	
2.1 Not heard or seen	"They didn't listen" – P009 "My input had no value" – P007
2.2. Emotional disconnection from staff	"It was a bit more cold" – P002 "It was a tick box" – P006
2.3 A constant battle	"They were against us" – P006 "It felt like a battle" -P007
2.4 Hurdles to reach help	"It is hard to get in" – P004 "They were waiting for a crisis" – P009
3. Always a 'carer'	
3.1 Being the bridge between loved one and services	"he carried on calling me...nobody had got back to me" - P001 "we're the nurses" – P009
3.2 Life's competing demands	"I had to get on with life" – P001 "significantly affected my grades" – P002
3.3 The breakdown of family relationships	"She kicked me out the house" – P004 "We would have issues in the family" – P002
4. Building resilience	
4.1 Assertiveness	"I decided I'm having a break" – P001 "wasn't just going to say yes" – P003
4.2 Liberation	"I was able to speak" – P009 "I was delivering...value" – P002
4.3 Faith and connection	"we're very religious people" – P006 "I cannot rely on human institutions" – P008
5. It's not racist, but...	
5.1 Challenges naming racism	"It is covert" – P006 "Maybe it is because he's Black" – P010
5.2 Working harder	"how I presented" – P003 "had to work very hard to overcome" – P006
5.3 Resisting racism	"I haven't allowed it to" – P008 "It's about my strength" – P001

1. Painful emotions

This superordinate theme emerged from participant accounts detailing the overwhelming and complex emotions across all stages of the sectioning and compulsory hospitalisation process. Four sub-themes arose:

1.1 Impact of trauma

Participants' accounts revealed that the sectioning process and hospital admission was a traumatic and distressing experience for carers, often leaving them no space to process their own emotions. Carers described having automatic responses of shock and being left no choice but to delve straight into action for the sake of their loved one.

"You just go into auto-pilot" (Participant 006)

"I used to have...flashbacks" (Participant 009)

Carers explained that they had to focus on action and ensuring they were supporting their loved one, which meant that they had to detach from their own pain and emotion in order to carry on. Although not all participants used the word "trauma", when recounting their experiences, the descriptions of "flashbacks" and detailed sensory information during the interview supported the generation of this theme. For some participants, the experience of the sectioning process was a painful reminder of previous incidents, not just with the loved one in question, but other family members. Carers described the impact of inter-generational narratives of pain and distress.

"The story of my brother being in hospital is not really the story of my brother. It's like the story of my family because actually, my dad, um, was also sectioned at one point...for schizophrenia." (Participant 002)

1.2 Self-blame

Carers crucial involvement in helping their loved one access treatment often carried with it a sense of blame that carers located within themselves. Participants described the conflict of prioritising the safety of their loved one, while also feeling guilty for placing them in “the system”. Carers worried about the impact this would have on their relationship with the loved one and some spoke about having to “overcompensate”, by always remaining available to responsive to the loved one in an effort to reduce the guilt they felt.

“I became aware that it was me. It was me. So, it was me that called the police. It was me that called the ambulance. It was me that had to take him to the hospital. So, I'm...it's all my fault.” (Participant 007)

Carers were left wondering about their role in the decision for their loved one to be compulsorily detained and whether there was more they could have done to prevent the loved one ending up in hospital.

“I should have done something” (Participant 001)

“Did I actually put him in hospital?” (Participant 002)

1.3 Bearing witness to distress

All carers described the triggers and build-up of symptoms that they noticed prior to the compulsory detention of their loved one. Therefore, this theme reflects the impact that was felt witnessing the deterioration of a loved one’s mental health. Carers were often one of the first people to notice the change in behaviour of their loved one, due to being in close proximity or

living with their loved one. Carers described that this gradual change in the loved one's behaviour felt like a loss of the person they knew as a family member or a friend.

"I live with it" (Participant 008)

"It's quite, it's quite terrible to be honest with you and quite stressful. Because you know the person as a friend. As someone who is capable of doing his own thing." (Participant 010)

Many carers described that they were present during the sectioning process of their loved one. Participants shared that their loved ones were reluctant to be voluntarily admitted to hospital, resulting in their compulsory detention. As carers were often the ones to communicate their concerns with services, this placed them in the position of having to negotiate between their loved one and health professionals. This was done in an environment where the behaviour of the loved one escalated and for some this occurred in public spaces, adding to the distress of the overall experience.

"I was in the middle of it" (Participant 005)

1.4 Cycles of fear

Carers described fears about whether their loved one would be treated unfairly by services, often linked to the appearance of their loved one, for example being "big" and "Black". These fears were then perpetuated by the loved one's behaviour and how this may be perceived by professionals interacting with them. Carers were fearful that acts of violence and force would be used against their loved one, as a means of trying to de-escalate the situation.

"I was absolutely terrified." (Participant 003)

"I didn't want them to choke or suffocate him." (Participant 006)

It is important to note that many carers described police involvement as part of the sectioning process, and this came with specific fears linked to narratives surrounding police interactions with Black people. Fear continued to persist throughout the process, even once the loved one had been discharged from hospital, with carers fears then turning to how the experience of being detained will impact the loved one's life. Some carers also described fears about the illness seeming never-ending and worries about the loved one ending up being detained again.

“Just the thought of having to phone the police. Um, this is where, as I say, when this interview that you're doing, you know, coming from a Black person with a Black child, the thought of having to call the police with him, having a mental health. I think the dilemma is, how's he gonna be treated? You know, is he gonna be angry?” (Participant 001)

2. Being let down by services

An overarching theme that was prevalent across all participant accounts, was the sense that they felt neglected, failed and let down by services. Under this superordinate theme, the following themes emerged:

2.1 Not heard or seen

Participants felt that the knowledge they brought as carers was neither recognised nor valued by health professionals. This led to many carers feeling they were dismissed when trying to liaise with professionals. Carers spoke about the desire to feel respected by health professionals and this was particularly difficult, when they felt their presence was not felt by others.

“My input had no value.” (Participant 007)

“They didn’t listen.” (Participant 009)

Due to this, many carers spoke about the need to make themselves visible on the wards to ensure that it was known that their loved one had family support. However, even when carers tried to make themselves visible on the wards, they described that they felt “cast to the side” and ignored.

*“I’d go to the office. So, the staff would be in the office and they’d pretend that I wasn’t there.”
(Participant 005)*

2.2 Emotional disconnection from staff

When carers did interact with staff, they reported that they felt a lack of compassion and empathy shown towards them and their loved one. During the interviews, carers showed awareness of the pressures of an NHS environment, and how this in turn may impact on the staff’s capacity to be more emotionally engaged. However, this meant that carers were often met with what they described as “cold” and “hostile” responses.

“It was a bit more cold.” (Participant 002)

“It was a tick box.” (Participant 006)

This emotional disconnection was also prevalent in the perception of how the loved one was treated in hospital, with the focus appearing to be on medication maintenance. Many carers expressed a desire for a more holistic view of treatment, incorporating therapeutic input and a focus on social recovery.

2.3 A constant battle

Participants view of services reflected a “battle” that made it feel that health professionals not only abandoned them but were actively working against them. Often this was confounded by limits of confidentiality, whereby carers felt there was a lack of communication from services regarding the wellbeing of their loved one. This theme also reflects the power imbalance between carers and the health professionals. Carers described a sense of powerlessness and that decisions were made regarding their loved one, without the carer’s input. Carers expressed a wish to work together with services to support their loved one, but unfortunately, for many, this was not their experience.

“They were not willing to listen. They were against us. There was a brick wall. They were not cooperative.” (Participant 006)

“It felt like a battle.” (Participant 007)

“But that’s my one little voice against the professionals” (Participant 009)

2.4 Hurdles to reach help

Many carers felt this “battle” began even before their loved one had accessed services. Participants described the challenges it took for services to take action and listen to their concerns about their loved one’s deterioration in mental health. For some, this involved having to call different services, prior to their loved one being detained.

“They were waiting for a crisis.” (Participant 009)

“Because it was from custody that they arranged for him to be taken into a unit. That was the only...that was the only way...we could get help, to get him arrested.” (Participant 006)

These hurdles continued once their loved one was admitted to hospital, with carers feeling it was difficult to be with their loved one on the ward and to access information. Some carers spoke about their loved one being transferred to a hospital far away from their home, and the additional challenge this presented for them.

"It is hard to get in." (Participant 004)

3. Always a 'carer'

This superordinate theme represents the pervasive role that being a carer entails. Participants described the responsibility of remaining a reliable source of support to their loved one and this often meant prioritising the needs of the loved one over their own. Under this superordinate theme, the following themes emerged:

3.1 Being the bridge between the loved one and services

Carers were often the first ones to notice the loved one's early warning signs of illness, which subsequently placed them in the position of being the bridge between services and their loved one. This was done, almost intuitively from the carer's point of view in order to ensure that their loved one was in a place of safety. Carers described that they maintained constant communication with their loved one during the sectioning and compulsory detention process. This communication occurred for various reasons. For example, some carers stated that they became the container for the loved one's fears and worries. Other carers reported that they would have to encourage the loved one to engage with services and their treatment, if they had absconded or were distrusting of services.

"He carried on calling me...nobody got back to me [during sectioning process, prior to hospital]." (Participant 001)

Furthermore, participants also described being placed in the position of being the beacon of support for others who also presented with mental health difficulties. Due to participants' active involvement, some of those in the community were relying on the support of these carers as opposed to accessing services.

“Right now, I'm involved with two other people. Two other young women who have mental health difficulties. And they were referred to me. And I become their big auntie, you know?”
(Participant 005)

“We're the nurses.” (Participant 009)

3.2 Life's competing demands

In addition to being a crucial source of support for their loved one in hospital, carers spoke about the context out of which they provided this support. Carers discussed having to continue duties such as caring for others in the family and the detrimental impact this had on other areas of their lives.

“I had to get on with life.” (Participant 001)

“...significantly affected my grades.” (Participant 002)

This was often done without professional support from NHS services and with the added challenge of feeling stigmatised among friends and more specifically, within the Black community. One carer used the term “sympathy fatigue” in relation to how she felt her friends would feel, if she continued to share with them her woes about her loved one being compulsorily detained.

“It's not something I could even share...in the congregation. My daughter is...my 2 daughters...were supportive. But then they were also suffering as well. They were having to deal with their own issues.” (Participant 006)

3.3 The breakdown of family relationships

The impact of being involved in the decision for their loved one to be detained led to disruptions in the relationship between carers and their loved one. Participants reported that their identity of being a family member or friend and also ‘carer’ put a strain on the caregiving relationship. Loved ones may have felt that their carers were to blame for them being in hospital, which would sometimes result in the loved ones trying to distance the carers from their care. This was particularly difficult, depending on the relationship between carer and loved one. For example, roles would reverse when carers were the children of the loved one and were placed in positions of making important decisions about the care of their parent.

“She kicked me out the house at some point, and then I started to try live nearby because she was in the care of my brother, who had Autism...he has autism, and he can't speak. And he became really sick himself. So that caused all sorts of issues.” (Participant 004)

Participants added that the disruption of relationships would also occur between different family members. With the system only allowing one person to be registered as a next of kin, the responsibility of sharing information to others in the support network about the wellbeing of the loved one, would often fall on this named individual. However, if there were tensions in the family, this sharing of essential information would be placed in jeopardy. This could lead to carers’ sense of isolation, having a negative impact on their mental health.

“a big domino effect of that would be, we would have issues within the family. So, there was a time...there was actually months where I wasn't speaking to my mum. Or I wasn't speaking to my brother, my older brother.” (Participant 002)

4. Building resilience

It was apparent across all participant accounts, that the lived experience of supporting a loved one with a mental health problem highlighted strengths that the carers possessed. Therefore, this superordinate theme reflects the resilience that was portrayed within all the interviews. The following sub-themes were generated:

4.1 Assertiveness

Participants highlighted that they had to be persistent to ensure that their loved one could access the appropriate support and treatment. This persistence was shown during interactions with professionals, where carers described they had to stand their ground, despite being in intimidating environments with health professionals.

“I think they perceived me as somebody who...wasn't going to just say yes and no to whatever they're saying.” (Participant 003)

The act of being assertive was mostly shown during interactions with health professionals. However, carers also had to be assertive towards themselves to engage in self-care. A few carers accessed formal support from services, such as individual counselling to look after their mental health. However, this represented a minority of the participants, with most having to use their own techniques to provide themselves with respite.

“I decided I'm having a break. I'm not calling anyone. Not chasing anything.” (Participant 001)

4.2 Liberation

Resilience of the participants was also built through reclaiming their power in different settings. For some, this was when they felt their voice was heard during discussions with members of staff or being actively involved in joint meetings. These instances of feeling valued felt even more meaningful in a context where they experienced many power imbalances and were often bound by the authority of professionals.

“I was delivering...value.” (Participant 002)

“That’s why I found the ward round was very good for me. Because I...gave me a lot of information. And I was able to speak...you know...as I felt.” (Participant 009)

Many carers spoke about their drive to continue using their voice or platform to support others by taking up roles within NHS trusts informing others of the value of carers’ lived experience. Most carers also described that just by sharing their story in this research interview, it felt liberating and therapeutic, as they had not previously been given the space or opportunity to process these events.

“History is about him writing about us, we have to write about ourselves. Yeah, we own it. And if we don’t own it, somebody else is always gonna be writing about our experience.” (Participant 007)

4.3 Faith and connection

A key part of the participants’ strength came from feeling supported by others in their network. This support sometimes came from key professionals who carers had been able to establish

trusting relationships with. Carers spoke about using their own initiative to find others who were going through or had been through similar experiences. Many spoke about the effect of connecting with other carers and how comforting it was to share experiences, knowledge and stories. In a context where many participants alluded to the stigma of mental health and not feeling able to be open with friends and family about their loved one's illness, it is not surprising that carers groups provided such valuable support.

"You know the carers group? I can't remember who introduced me to it. I really can't. But it was one of the best thing that happened to me." (Participant 009)

Others also spoke about their religious practice as a means of comfort and holding on to their faith as a source of strength. This theme was included, because although not all participants spoke about their religion as a protective factor; religion and spirituality are often given very little space in relation to carer support. Furthermore, for the carers who did openly speak about their religion, they did not feel that their religion was considered in the treatment of their loved one. Therefore, it feels important that this theme is generated, in order to reflect these concerns and to amplify an area that, for some carers, has felt overlooked by services.

"You know, we're very religious people...and when we have difficulties...the natural thing for us, to do would be to pray." (Participant 006)

"I cannot rely on human institutions" (Participant 008)

5. It's not racist, but...

This superordinate theme reflects participants' responses during the interview when asked about race and other individual characteristics, such as their gender, age and religion. It was apparent that being asked about race in particular, felt unfamiliar and for some, this was

shown in their initial responses to deny that race was a factor during their experience. Conversely, it appeared that some carers felt more confident externalising the impact of racism to their loved one, rather than speaking about their own personal experiences. Under this theme, the following sub-themes were generated:

5.1 Challenges naming racism

Once participants were able to reflect and use the opportunity to think about the impact of race, it revealed a nuanced picture that was difficult to express in words. This was made more complex when carers described that the nursing staff, for example were predominantly Black. For these carers, they drew on rarer occasions interacting with non-Black staff, where they felt they had been judged negatively. Some participants were left questioning whether the treatment they had received was due to their race being a factor and tentatively alluded to racism.

“It is covert” (Participant 006)

“Maybe it is because he’s Black.” (Participant 010)

For some carers, the challenge was naming specific examples where racism had occurred, however they were able to describe more subjective feelings of being discriminated against or treated differently due to their race. Others more explicitly described examples where race had been a factor, and this was more prevalent where loved ones had been hospitalised in less diverse areas.

“Being an articulate Black woman was...was the barrier for me to getting additional support with the mental health services.” (Participant 007)

"I can't give you a particular example. Because as far as...discrimination is a covert thing. It is done in such a...sometimes it is not open. And...you know in your heart it's that."

(Participant 009)

5.2 Working harder

Some participants drew on the extra effort they had to take in order to avoid the possibility of racism occurring. For some, this meant having to present particular versions of themselves with health professionals to avoid being labelled with a negative stereotype. Some carers spoke directly about "working harder", such as trying to appease staff or having to think more strategically as a family unit about how to approach staff. For example, one carer spoke about buying food and trying to "befriend" the staff on the ward, in an effort to appear less threatening to them.

"how I presented" (Participant 003)

"I tried to think through it and research it before I open my mouth." (Participant 005)

"Like I said before, there's that stereotype that goes on in their mind like, Ah..big Black equals trouble maker, you know? So...I was very mindful of that, and it added an extra layer of difficulty and barriers that I worked...had to work very hard to overcome." (Participant 006)

5.3 Resisting racism

When participants were asked their perspectives on whether race had been a factor during their experience, many carers drew on their own personality characteristics that they felt had helped them to resist racism. This portrayed an individualised ability to fight racism, which

may reflect a protective function needed to survive living as a Black person in the UK experiencing racism on a regular basis.

"It's about my strength." (Participant 002)

"Um, maybe because I just communicate slightly differently and I've learnt...I don't know what it is." (Participant 002)

"Well, I haven't allowed it, because otherwise I would...I would probably be in hospital with her myself, wouldn't I?" (Participant 009)

Discussion

Main findings

For many Black carers, experiencing a loved one being compulsorily detained is traumatic and emotionally conflicting. Carers feel guilty about initiating the support of services for their loved one, despite knowing that a hospital admission may be the most appropriate option at that time. Furthermore, Black carers witness their loved one unwell and in distress, with little support from others, and reported feeling stigmatised from their own friends and community.

Most Black carers reported they were frustrated and disappointed with mental health services, as they felt they were ignored and dismissed by health professionals. Black carers experience professionals as lacking in warmth and empathy, and they are confronted with barriers in accessing information about their loved one. Regardless carers still -while balancing other responsibilities and duties- play a crucial role in mediating between services and their loved one,

Black carers report they are sometimes treated worse due to their race and ethnic identity, but this subjective experience is difficult to describe to others. To avoid the possibility of being a victim of racism and discrimination, Black carers state they have to work harder so that they are not labelled with negative racial stereotypes and are forced to draw on their own abilities to resist the painful impact of racism.

Caring for a loved one who has been compulsorily detained has negative knock-on effects on the caregiving relationship and wider family dynamics. In spite of the difficulties that are faced by Black carers, seeking connections with others and finding spaces where they feel empowered enables them to build on their resilience. Finding sources of strength from their faith and religion helps carers to restore their hope during such a challenging period.

Impact of caring

Black carers described the multi-faceted impact that comes with supporting a loved one who has been detained under the Mental Health Act. Many carers reported the impact of trauma, which is consistent with previous research suggesting that carers may display PTSS (Barton & Jackson, 2008; Kingston et al., 2016). However, in this current study, Black carers also described the impact of inter-generational trauma (Dekel, & Goldblatt, 2008). This came from witnessing other family members, such as parents, previously experience compulsory detention.

As inter-generational trauma in caregivers has received little research interest, it is unclear whether the impact of this may be more prevalent in the Black population. Given what we know about the disproportionate rates of involuntary admission for Black people, it is plausible that Black families may be more likely to witness a greater number of relatives or loved ones experience compulsory detention. Cumulative trauma can cause detrimental effects, including greater PTSD symptoms (Martin et al., 2013). Furthermore, the cognitive

appraisal of these events, is likely to influence the associated trauma symptoms (DePrince et al., 2011). For example, if carers experience fear witnessing a parent be compulsorily detained, this is likely to impact how they may also experience their loved one undergo the same process. More research is needed to further understand this relationship and the mechanisms that may be involved.

Some Black carers reported that their religion served as a useful coping method while their loved one was compulsorily detained. This is in line with existing research that suggests that Black families may be more likely to rely on their faith, while supporting a loved one diagnosed with Psychosis (Wong et al., 2009). Black and Asian families' spiritual beliefs influence how they make sense of their loved one's illness and they are more likely to access support from faith-based organisations (Singh et al., 2013). Despite this, therapists report they feel "overwhelmed" when faith or spirituality is brought up by families, thus they tend to avoid talking about it when supporting individuals presenting with psychosis (Rathod et al., 2010). Our findings highlight that Black carers do not feel that services take into consideration their religious beliefs and show a limited understanding of the importance of spiritual expression for them and their loved ones. This suggests that a core part of Black family's identities may be overlooked by services.

Sectioning of a Black loved one: justified fears

One of the key findings from the current study, was the fear that was prevalent throughout all carer's accounts. In their qualitative study utilising semi-structured interviews and focus groups, Keating and Robertson (2004) identified "circles of fear" that exist within Black carers. They conceptualised these "circles of fear" into the sources and consequences of these fears. The present study builds on this further, as this theme emerged in its own right by carers more explicitly detailing their associated fears linked to their involvement in the sectioning decision and loved one's treatment in hospital.

Carers were fearful about how their loved one would be perceived and treated by professionals interacting with them, with some carers making reference to violent acts or use of force possibly resulting in fatal outcomes. These extreme fears may be particularly unique to the experience of being a Black carer. Some carers described the appearance of their loved one – “big” and “Black” as possible reasons why they felt they may be more vulnerable to physical attack by professionals. This appears to be consistent with research that describes the phenomena of Black males in particular (more than Black females), often perceived to be “big, Black and dangerous” (Walker, 2020). This links back to historical deaths in custody of Black males, who were all diagnosed with Schizophrenia and died after excessive use of restraints and tranquillising medication (Walker, 2020). Furthermore, the intergenerational trauma of colonialism and racism is evident (Graff, 2014). In light of this, it is understandable that for many Black carers, the prospect of their loved one being detained against their will, carries with it, fears about what this could lead to.

Black individuals are more likely to have police involvement in their pathway to psychiatric care (Commander et al., 1999; Halvorsrud et al., 2018). The current study was able to capture the subjective experience of danger associated with this well-known statistic. Not only do Black carers have to deal with the distress of a loved one being compulsorily detained, but they also have to manage their fears about police brutality and the potential of fatal restraints. Keating and Robertson (2004) highlighted that possible consequences of the “circles of fear”, include limited trust and engagement in services. However, the current findings suggest that the impact of these fears may run deeper than that for some Black families. These findings suggest that Black families remain traumatised by the stories of fellow Black people losing their lives at the hands of those who were in positions of power and authority.

The feelings of self-blame and guilt when a loved one has been compulsorily detained are not exclusive to Black carers (Jankovic et al., 2011; Sugiura et al., 2020). However, these feelings

may be more complex for Black carers, who may also feel the additional weight of feeling responsible, if anything catastrophic were to happen to their loved one during the compulsory detention process and hospital admission.

Carer commitment to support and fight to improve services

One thing that was prevalent from this sample of carers was their drive to support others and improve mental health interactions for other carers. Most carers were actively involved in their NHS trusts or had taken leadership roles within carer groups. Some spoke about independently researching and studying further to increase their own knowledge about mental health care and systems. This finding is consistent with previous research, highlighting that carers report their caregiving role allows them to recognise their own strengths and be clearer about their priorities and values (Chen & Greenberg, 2004).

However, the current study highlighted that this sample of Black carers held a commitment to action to ensure that services were improved. It could be hypothesised that the experience of supporting a loved one who has been compulsorily detained, forces carers to be in positions where they feel “powerless”. This creates an urge for carers to be in spaces where they not only feel heard but feel empowered to be in positions where they can effect change. Given that many carers in this study, had felt let down by services, it is understandable that they may be motivated for a change to occur.

Limitations

This study has addressed a gap in the literature, by exploring the subjective experiences of Black carers after their loved has been sectioned under the Mental Health Act. This is an area that has been largely under-studied, and the findings have provided valuable insight into what it is like to be a Black carer. However, some limitations should be noted.

Given that many of the participants in this study were recruited via the same online carers' forum, this presents a potential selection bias. This is further emphasised, by the fact that many carers in the sample had some involvement with NHS trusts and were active in this area of research. This means that the sample may not be representative of other Black carers, who have less capacity or ability to be as actively engaged with services. However, qualitative research does not aim to have samples that are necessarily 'representative' of a particular population. This study reflects the themes of ten carers who were actively involved in helping others. Furthermore, the current sample included a good proportion of males and carers with a range of relationships to their loved one, which is often not reflected in the existing carer literature (Onwumere et al., 2018). Additionally, by recruiting via non-NHS organisations, this study was able to recruit participants who may have been missed by standard NHS services, particularly enabling the voices of Black men in caring roles to be heard, which is often not seen in mental health research.

A methodological limitation of this study is the absence of a bracketing interview. Bracketing is a method used in qualitative research that aims to reduce the impact of unconscious biases and assumptions during the research process (Tufford & Newman, 2012). Furthermore, bracketing interviews allow the researcher to reflect upon how their personal and professional experiences may impact the conception, design, data collection and findings of their research (Rolls & Relf, 2006). By not conducting a formal bracketing interview, it is possible that the researcher may not have been aware of preconceptions that could have led the design of the current study. However, the researcher actively reflected upon her identity throughout the research process and kept a reflective journal. Additionally, the researcher had regular discussions with her supervisor about the impact of conducting such emotionally challenging and meaningful interviews. It is recommended that future research includes the use of a bracketing interview to fully ensure that researchers aim to acknowledge and set aside their biases.

Another potential limitation of this study was that there was no time limit specified regarding how long carers had been supporting a loved one or whether they were still in a caring role.

Therefore, this could have influenced the experiences that were shared by carers and posed a possible recall bias if carers were speaking about events that occurred a long time ago. Despite this, participant accounts did resonate with each other and findings were consistent with previous research.

All interviews were conducted online, due to Covid-19 restrictions. Therefore, this raises the issue of possible recruitment bias and whether the use of this method may have excluded participants who were unable to access digital technology. Despite this, the current study was able to recruit a range of ages, with the oldest participant being 87 years old. Furthermore, conducting the interviews online as opposed to face-to-face may have impacted the findings of the results, including how the researcher may have interacted and responded differently to participant responses and vice-versa. For example, the conceptualisation of non-verbal information may have been a particular reflection point. It is unclear to accurately depict what may have been the difference conducting the interviews in a face-to-face setting, however future research could build on this and further explore this.

It is a limitation to group all Black carers together, when they are not a homogenous group (Swan, 2016). There are huge differences in every Black person's lived experience and so it can be invalidating to not recognise this (Louis, 2020). However, a strength of the current study is that participants were able to name their ethnic identity, without any fixed categories presented to them. Although all participants were 'Black', there was variation in how participants self-identified and chose ethnic identities for their loved one. Further research may want to utilise this method, to acknowledge the differences in how Black people may choose to identify. This also carries further implications about other categories that are sometimes used in clinical and research settings, such as 'BAME'.

Clinical implications

Carers showed an understanding of a busy NHS environment, but felt that ward staff were emotionally disconnected and lacked warmth. The environment on a psychiatric ward can be stressful for staff with a high number of aggressive and violent incidents between patients and towards staff (Tuveesson et al., 2011). If the staff on the ward are supported through the use of safe spaces and reflective groups, this may increase their capacity to show compassion and empathy to the families they come in contact with.

Barriers to accessing information about their loved one, contributed to carers feeling that services were working against them. It is recommended that inpatient services actively include carers in the care plans of their loved one, so that they are kept informed about their loved one's recovery. Furthermore, practitioners should not only be mindful of the power imbalance that exists between professionals and families but should actively work to reduce it. For example, carer and service-user voices should be prioritised and given more space during joint meetings such as ward rounds. The findings of the current study highlight that Black carers want to be involved in the treatment of their loved one and want to share their knowledge with health professionals. Therefore, carers should be included in joint care planning regarding their loved one.

Black carers were offered little support from the hospital where their loved one was compulsorily admitted, despite the experience being traumatic and extremely distressing. Clinicians need to be trained to understand the context in which a compulsory admission and the decision to support loved ones might mean for a Black carer. This includes the associated distress of the compulsory detention process and the paralysing fear that many Black carers may feel. It would be beneficial for services to offer trauma-focussed interventions to carers. Holding in mind the carer's context of possibly feeling stigmatised from friends and experiencing intergenerational trauma, it may be suitable for cultural adaptations to be made to these interventions to meet the needs of these populations. Furthermore, it is recommended that the value and expertise that Black carers bring, should

be celebrated and any interventions that are designed for these populations need to be co-produced with them. There have been promising findings from culturally adapted family interventions for psychosis, suggesting that specific adaptations of interventions could improve outcomes for marginalised groups (Edge et al., 2016).

Future research

It was apparent from the interviews, that many Black carers were initially unsure how to respond when asked their perspective on whether race had been a factor during their overall experience. This suggests that this question may have been difficult to answer and this difficulty may have been reduced by re-wording of the question. Although the interview schedule was reviewed by a Black carer expert by experience and fellow clinician, future research may want to further co-produce and develop the aims and questions in collaboration with Black individuals (Clark, 2015). This would allow researchers to further understand or identify how best to ask questions about the impact of race.

This study highlighted the value of faith and spirituality as a way of coping for Black carers. Further research may want to build on this, exploring the impact of religion and spirituality for caregivers and whether this is more prevalent in the Black community. Furthermore, it may be useful to explore perspectives from health professionals regarding how they view faith and whether they feel equipped to incorporate it in interventions (Codjoe et al., 2019; Codjoe et al., 2021).

Conclusions

This qualitative study explored Black carers experiences when their loved one had been detained under the Mental Health Act. The findings highlighted that this experience is traumatic for Black carers and they feel a range of emotions, including self-blame and guilt. Black carers are particularly fearful about how professionals may interact with their loved one, and how this

may impact on caregiving relationships. Black carers value feeling heard and want to work together with professionals, to improve the wellbeing of their loved one. This presents implications for clinical practice and future research, including how services can ensure that services are safe and supportive environments for Black carers, where their ethnic identity and aspects of their culture are acknowledged and appreciated.

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Part III: Critical Appraisal

Introduction

This chapter is a critical appraisal of my experience conducting the current research study. It begins with an outline of my background and how this influenced the development of the research topic. I then share my reflections throughout various stages of the research process and theoretical underpinnings and challenges I encountered. Finally, I detail some of my personal reflections regarding the impact of conducting the interviews and meeting the participants, before offering my final conclusions.

Background

Prior to gaining a place on clinical training, I worked as an assistant psychologist in an Early Intervention in Psychosis Service (EIP). The recovery model of EIP utilises the support of family carers, through the use of carer-focused interventions and family therapy (Fowler et al., 2009). I appreciated this way of working, which acknowledges the strengths and expertise that exists within family units.

During my time working at this service, I built on this further by co-facilitating carer groups and training in family therapy approaches. Working clinically in these settings, I was humbled hearing the stories of pain, distress and triumph that carers shared with myself and others. I was struck by the resilience that was shown by all carers and their persistence to continue supporting their loved one by any means possible. I noticed that many carers would sacrifice their own wants and needs, prioritising the wellbeing and safety of their loved one. It appeared that carers valued feeling involved in their loved one's care and I noticed that feedback from carers groups would often highlight that carers wanted longer and more frequent sessions. This suggested that carers appreciated safe spaces to share with others their worries and experiences.

This felt like a contrast to previous clinical experience I had, working as an honorary assistant psychologist in an acute mental health ward. Although family members were invited to ward rounds, it did not feel that carers were actively included within the recovery model. Some carers spoke about having to take on additional responsibilities such as picking up their loved one's children from school, while they were involuntarily detained. This made it challenging for them to attend ward rounds or to visit their loved one during the allocated visiting hours. Furthermore, there was a high turnover of staff and it did not feel like the professionals were adequately equipped or resourced to appropriately meet the needs of service-users and their families.

I witnessed the gap in services for family carers and how this made it difficult for some families to engage in the treatment of their loved one, in the way they wanted to. Furthermore, the majority of patients admitted in the ward were of an African or Caribbean heritage, which made me wonder how suitable services were to meet the needs of these populations.

The conception of a project

When it came to selecting a topic for my doctoral thesis, I knew I wanted to do something that aligned with my passions and interests. Being one of only two Black females in my cohort, I was also driven to do a project that amplified the voices of marginalised groups. When potential projects were presented to us, although they all seemed interesting and meaningful, unfortunately I did not feel that any of the topics matched the vision I had for a research project. Therefore, I thought it may be best if I could present my own ideas to supervisors who were open to accepting novel research ideas.

I came up with a number of ideas including the possibility of exploring Black female Psychologists in leadership positions. However, I wondered whether it may be more

valuable to draw upon my clinical experiences. In light of this, I approached my current supervisor, Dr Miriam Fornells-Ambrojo with the idea of exploring family carers experiences when their loved one had been compulsorily detained. Initially, I thought about focussing on carers from Black and minority ethnic backgrounds, however after discussion with my supervisor, together we decided it would be best to focus solely on the experience of Black carers. This was in order for the project to have a clearer focus and it reflected the disproportionate rates of psychiatric admissions for Black people over other minority ethnic populations (Mann et al., 2014; Singh et al., 2007).

Choosing a qualitative approach

I knew that in order to do the research topic justice and to gain the deeper insight into Black carer's experiences, utilising qualitative methodology would be the best fit. However, I had little experience of using qualitative methods, as my research experience from my undergraduate and master's degrees had both involved quantitative approaches. Therefore, I found it helpful drawing on the qualitative teaching I had received during clinical training and discussing approaches with my supervisor.

We agreed that conducting semi-structured interviews would be the best way to gather in-depth information about participants' subjective experiences and perspectives, in line with the research question. My aim was to immerse myself in the reality of the participants and to uncover the meaning behind their stories, therefore interpretive phenomenological analysis (IPA) was chosen for the qualitative analysis. In IPA, the researcher aims to investigate how the participant makes sense of their experience (Pietkiewicz & Smith, 2012). This approach was in line with the study's research question.

The researcher's position and prior assumptions

Qualitative researchers are encouraged to reflect upon and declare their personal and epistemological position, as prior assumptions can influence the research study throughout all stages (Willig, 2012). I adopted a 'phenomenological' position, as I was keen to step into the realities of the participants, hearing their narratives and truths. My position was also influenced by community psychology principles, which seek to give voice to the underrepresented and be sensitive to the contexts of individuals (Prilleltensky, 2001).

During my time working in EIP, there were fewer Black families engaged in the service, compared to White families. Of the small number of Black families who were accessing the service, they tended to experience more frequent hospital admissions and the service-users presented with more severe symptoms of psychosis. These families often wanted more input from services and were less satisfied with the treatment their loved one was receiving. With this in mind, I assumed that I would hear more negative experiences and complaints from participants.

Although I choose not to identify as a 'carer', I do hold caring responsibilities, supporting family members diagnosed with Sickle Cell Anaemia. I acknowledge that there are various differences supporting relatives with physical health problems as opposed to mental health problems. Furthermore, I do not intend to state that I can even begin to imagine the difficulties faced by those who experience their loved one being detained under the Mental Health Act. However, drawing upon my own personal experiences of being a relative and having loved ones in hospital, I have felt cast to the side and that there was a lack of information and support available to me. This further contributed to my expectation that I would hear more negative experiences from carer participants.

While I expected to hear more negative experiences in general about carers' interactions with mental health services, I was unsure of how carers would respond when asked their views on whether race was a factor in how they were treated. Part of me assumed that carers would automatically speak about their subjective experiences of racism and discrimination. This was based on my knowledge of institutional racism and how it is maintained through structures, such as mental health services (Mensah et al., 2021). However, reflecting upon my daily life as Black woman living in the UK, I feel if I were asked a similar question about the impact of race, I would find it difficult to answer. This is because the subjective experience of racism and discrimination can be extremely hard to process and express using words. A lot of the time, it is something that is felt and only fully understood by others who have gone through similar experiences. Furthermore, I was conscious that within the NHS, individuals from Black and minority ethnic populations, tend to be employed in lower-grade roles (Sprinks, 2012). Therefore, I assumed that it may be the case that a lot of the interactions the carer participants had, were likely to also be with Black people. I wondered how this may impact on the data I would collect.

Although the influence of a researcher's personal background is not necessarily "problematic", it is important for the researcher to own their position and to actively reduce the possibility of bias during their research (Barker & Pistrang, 2005). In light of this, I tried to hold in mind my prior expectations and assumptions, without letting them drive the direction of my research. I found it helpful to keep brief reflective notes throughout the process and to use space with my supervisor as discussion and reflection.

Impact of Covid-19 on recruitment

Given my supervisors' links with EIP's and inpatient wards, the original plan was to spend time in these clinical settings to recruit potential participants. However, we were stopped in our tracks when the pandemic hit. The original plan had to be amended due to Covid-19

restrictions. The restrictions meant that it would not be possible for me to visit any services in person or conduct interviews face-to-face. At the peak of the pandemic, I was preparing my documents for submission to NHS Ethics. However, this was also affected, as at the time, all NHS research was put on hold and only Covid-related research was being prioritised. This presented a unique challenge to everyone at the time and I felt disappointed and saddened that I would not be able to interview participants in the way I had envisioned. Particularly, given the sensitive nature of the topic, I wondered how this may impact my ability to respond to participants' distress during interviews.

In light of this, and after discussion with my supervisor, we thought carefully about how we could amend the project so that it still reflected my interests and produced meaningful data. We agreed that the best course of action would be to recruit from non-NHS organisations and to conduct all recruitment and interviews online. Although this process caused a significant delay, it forced me to think creatively about how I could recruit participants. Instead of applying for NHS ethics, ethical approval was gained from the UCL Ethical department.

I searched online for non-NHS organisations that I felt were relevant to the research project. This included local and national carer organisations, groups specifically targeting Black and minority ethnic groups and charities. Due to the pandemic, many organisations were not based at their offices, meaning most contact was via emails. I was fearful that communicating in this way would result in me not successfully recruiting my target number, due to the busy nature of people's work. I was afraid that my emails would end up being overlooked or ending up in junk mail. Although I did not hear back from some organisations, I was pleasantly surprised that generally people were receptive.

One of the most valuable connections I made while recruiting, was through a Black male who wrote an online blog about his caring experiences. He had great knowledge and

expertise in the field and was kind enough to invite me to online carer forums that he facilitated. The majority of the participants were recruited from these forums. In hindsight, I believe that going to these forums was a more successful way of recruiting, as it was possibly the closest thing I had to attending face to face carer groups. I think that by seeing that I was a Black woman interested in issues affecting the Black community, this may have made carers more willing to engage in the project. I was also able to answer questions that carers had and take their contact details as soon as they expressed interest. Importantly, however, by attending these carers groups, I was reminded of the purpose of the research as I listened to carers' struggles and challenges.

Interviewing participants

Given that I had no prior experience of conducting qualitative research interviews, I was slightly nervous about doing the interviews. I also felt the responsibility of ensuring that the interview served as a safe space for the carers to share their stories. I adopted a compassionate and curious stance, aiming to build rapport and a good relationship within the time available. I was mindful that the majority of participants were older than me, and I wondered how they would perceive me being a younger female asking about such personal and sensitive topics.

Drawing on my cultural values and personal experience of the Black community, respect towards older people is emphasised. I was conscious that the questions could feel intrusive and I did not want participants to feel I was being disrespectful. In light of this, I took every effort to ensure that the participants were happy with the language and terms I used. I also made sure that I allowed enough time for participants to freely talk about their experiences, without interruption. The first interview I conducted lasted for nearly three hours (average interview length was between 45 and 120 minutes) and I was struck by how much the carer had to say about her experiences. This made me wonder about how little space is given to

carers to sufficiently process the events they have gone through and give voice to their stories.

I used the interview schedule as a guide, rather than sticking rigidly to every single question. However, I tried to ensure that all relevant areas were sufficiently covered. I found that participants would naturally end up following the flow of the schedule, without me having to ask the questions or prompts, which I perceived to be a good sign that the schedule was able to accurately reflect participants' experiences. Despite this, I was still worried about whether the information I had gained would provide rich enough data.

In the future, I would like to spend more time reviewing my interview technique after each transcript as I feel this would have allowed me to critique and develop my interview skills. At the end of each interview, I asked participants their feedback on how they had found the process of speaking with me. Many carers described the experience as "therapeutic" and I was moved that some also shared words of encouragement and motivation about completing the project and my studies. It appeared that carers held a strong desire for there to be more Black psychologists in the field.

Analysis and interpretation of the results

The process of IPA was new to me, so I found it helpful using the literature as a guide and leaning on the support of other trainees who were also using IPA. The process of the analysis involved reading through the first transcript and systematically searching for themes that emerged within it. After this, I tried to form connections between these themes, before eventually, superordinate themes were established. This process was then repeated for the remaining transcripts, identifying patterns between participants in order to develop master themes for the sample (Smith & Osborn, 2015).

Findings highlighted carers' frustrations and disappointment with services, in addition to the impact the compulsory detention had on the caregiving relationship. This was consistent with what I expected to hear from participants, but I also did not want to miss out on all the different aspects that had been revealed during the interviews. When considering the themes, I thought about the key messages that were apparent from the data and what had resonated with me. Given that this area of research, is largely under-studied, I felt pressure to capture all that had been said from participants to the best of my ability. However, it is merely impossible to capture every last detail from interviews and I found it helpful to be reminded of this by my supervisor.

Although many participants shared negative encounters, they had with mental health services, they also recognised and were understanding of the restraints affecting many health professionals. This may also reflect that this sample of participants, included carers who had active roles within carer groups and NHS trusts. Therefore, they may be more exposed to the structures and pressures of NHS environments. They may also have a greater ability to mentalise the perspectives of health professionals, due to forming working relationships with some of them. I wonder if I had been able to recruit more carers who were less involved in services, how this may have impacted on the data that was produced. I was informed by a couple of carers that they had friends who they had spoken to about the research, but who had such traumatic experiences, they were not in a place to share their story. This highlights an issue of the potential of selection bias in the sample. It also poses the question of how researchers can hear the stories of those who have been most deeply affected by their experiences, to ensure that they are provided with the most appropriate support.

Personal reflections

When I initially came up with this research project as an idea, I knew that it would be meaningful and incredibly valuable. However, I underestimated how powerful it was to hear the trauma and distress of fellow Black people. Listening and reading through the interviews was a painful reminder of the difficult experiences families endure, without little or no support from the services who are in place to safeguard them. I found it emotionally challenging being immersed in the data and I had to actively engage in self-care and remind myself to take breaks from the data. I found it particularly painful hearing when carers spoke about their interactions with police and their associated fears. In a context where the past year has seen the re-generation of the Black Lives Matter movement, the visibility of Black trauma has felt more live than ever. For this reason, I felt even more personal pressure to empower Black voices and ensure that they were not sharing their pain in vain. In essence, I became a witness to their distress, which is a privilege and humbling position to be in.

Furthermore, I was taken aback by the sheer strength and resilience that the carers displayed. That they endured so much and still held the drive to support others and improve services for all. I was keen that this was highlighted in my findings, as it inspired me and helped me to reconnect to the purpose of my research. Given the emotional connection I felt to the participants' stories, it poses the question of how truly impartial I may have been throughout the research process. I found it helpful to have open discussions with my supervisor about these issues, and for her to be able to point out any areas that I may have missed from my own lens. I also feel that being genuine in my approach and being open with participants about my desire to improve outcomes for Black individuals, served as an advantage and enabled the participants to begin to trust me.

When asking participants about the impact of race and other individual characteristics, I was met with various responses. From some carers initially denying it had been a factor to others

whole-heartedly stating it had been a detrimental factor during their experience. Regardless of the content of participants' responses, it was apparent that this was not a question that these participants were used to answering. This makes me wonder what we are missing out on, by not asking service-users and their families about possible instances of racism and discrimination. While it may be an uncomfortable subject to broach, services may be maintaining the mechanisms that perpetuate the impact of institutional racism by completely ignoring this subject. On the other hand, given how traumatic it may be for some carers to relay instances of racism and discrimination, it may be that more research is needed first to explore the most appropriate way for health professionals to respond to disclosures of racism.

One of the main challenges I experienced, was conducting and writing up the research during a global pandemic. I was forced to adjust to the changing restrictions and continue as normal to complete the research I had originally envisioned. As someone who benefits from studying outside of the home, I found it particularly difficult to write the thesis from home and deeply missed the physical connection and support from others. In light of this, I am proud of the thesis I produced and feel fortunate that I was able to meet such admirable carers.

Conclusions

Reflecting back on the process of undertaking this research, I have gained a greater understanding of qualitative methods and approaches. I remain happy that I was motivated to see the project through to the end, from conception to write up. I am optimistic that the findings of the project will be disseminated in relevant spaces to ensure that these voices are heard and ultimately, services can better meet the needs of Black carers and their networks.

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Appendix A: Official letter of ethical approval

16th November 2020

Professor Miriam Fornells-Ambrojo
Research Department of Clinical, Educational and Health Psychology
UCL

Cc: Nifemi Ajala

Dear Professor Fornells-Ambrojo

Notification of Ethics Approval with Provisos

Project ID/Title: 18775/001: An exploration of Black carers' experiences of their relative/loved one's death under the Mental Health Act

Further to your satisfactory responses to the Committee's comments, I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **16th November 2021** subject to the following provisos:

- If substantial changes are made to the questionnaire following piloting please inform the REC as an amendment request form might need to be completed.
- Please provide evidence of social media platform permission for advertising purposes if indeed permission is required. Please ensure that you abide by the platforms Terms and Conditions as a minimum

Ethical approval is also subject to the following conditions:

Notification of Amendments to the Research

You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'

<http://ethics.grad.ucl.ac.uk/responsibilities.php>

Adverse Event Reporting – Serious and Non-Serious

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information

Office of the Vice Provost Research, 2 Tavilton Street
University College London
Tel: +44 (0)20 7679 8717
Email: ethics@ucl.ac.uk
<http://ethics.grad.ucl.ac.uk/>

sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report

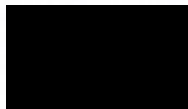
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: <https://www.ucl.ac.uk/srs/file/579>
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely



Professor Lynn Ang
Joint Chair, UCL Research Ethics Committee

Appendix B: Participant Recruitment Flyer

Study Title: An exploration of Black carers' experiences of their relative/loved one's detention under the Mental Health Act

Are you a caregiver providing support for someone with a severe and enduring mental health problem?

Has your loved one been detained under the Mental Health Act?

Do you identify as being Black?

If you answered 'YES' to all of the above questions and would be interested in sharing your experiences, we would like to hear from you!

What is this research about?

We want to hear Black carers' views about what it was like when their loved one was involuntarily admitted to hospital (sectioned under the Mental Health Act).



What will be involved?

A confidential interview over the phone or online video platform where you will be asked questions about how you experienced the compulsory detention of your loved one. You will also be asked to complete 2 short questionnaires. In total, this should last no longer than 1 hour and 30 minutes.

Who can take part in this research?

We are inviting all English-speaking Black carers who have experienced the person they care for being detained under the Mental Health Act to take part in this study. You must be over the age of 18.

If you are interested in taking part in this study or would like to know more information, please contact the researcher, Nifemi Ajala at nifemi.ajala.18@ucl.ac.uk

Appendix C: Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Principal Researcher: Dr Miriam Fornells-Ambrojo, Miriam.fornells-ambrojo@ucl.ac.uk, University College London Department of Clinical, Educational, and Health Psychology, 1-19 Torrington Place, London, WC1E 7HB.

My name is Nifemi Ajala and I am studying for a Doctorate in Clinical Psychology at University College London. You have been invited to take part in a research study I am running with my supervisor Dr Miriam Fornells-Ambrojo. Please read this information sheet and ask us any questions you might have. Then you can decide if you would like to take part or not.

Study Title: An exploration of Black carers' experiences of their relative/loved one's detention under the Mental Health Act

We would like to invite you to take part in this postgraduate research project. You should only participate if you want to; choosing not to take part will not disadvantage you or your family member in any way. Before you decide whether you want to take part, please read this information sheet carefully and discuss it with others if you wish, so you understand why the research is being done and what your participation would involve. Please ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

This study aims to explore Black carers experiences when their family member/loved one was involuntarily admitted to hospital (sometimes referred to as "detained/sectioned under the Mental Health Act"). A carer may be a parent, spouse, partner, sibling, relative or friend who is in close and regular contact with the service user. We know that carers play a crucial part in the recovery and support of the service user, but there is a lack of research understanding the perspectives of Black carers.

We hope that by listening to the views and experiences of Black carers, this will help us to better understand their needs to result in improved partnerships between Black carers and mental health services.

Why have I been invited to take part?

We have invited all carers who are of Black African or Caribbean heritage who have direct experience of their loved one being detained in hospital against their will to take part in this study.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. During the study, you are still free to withdraw at any time and without giving a reason and any data collected will be securely destroyed. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you or the service user receive in any way.

What will happen if I decide to take part?

If after reading this information sheet you are interested in taking part in the study, you will speak with the researcher (Nifemi Ajala, Trainee Clinical Psychologist) to arrange a date and time for the session. The session will take place via an online video platform or over the telephone. You will also be able to ask any questions about the study before deciding whether you would like to take part.

The session will be a confidential interview with the researcher, lasting approximately 1 – 1½ hours. This session will be audio-recorded; this is a mandatory part of the study, and if you would prefer not to be recorded unfortunately you will not be able to take part. The

researcher will ask questions such as “What happened on the day your loved one was detained?” and “How has the detention of your loved one impacted your view of mental health services and professionals?” After this conversation, you will be asked to complete up to two short questionnaires. There are no right or wrong answers to these questions, we are genuinely interested in hearing your experiences. It is likely that answering some of the questions may involve recalling difficult and upsetting experiences. If you feel distressed at any time during the interview, please do let the researcher know. You can choose to move on to a different topic or stop completing the questionnaires.

The interview session will be audio recorded so that the researcher can transcribe the conversation after you have finished talking. The audio recording will be stored on an encrypted device and will be deleted as soon as the interview is transcribed. Transcriptions will be written by the researcher that conducted your interview and the researcher will remove any personal identifiable information so that the conversation will be completely anonymised. The researcher will identify key themes that arise during the interview and will choose some direct quotations to show examples of these themes in the final report. Following analysis of the data you will be given the opportunity to give feedback on the themes identified (you are not required to give feedback for inclusion in the study).

Will I be compensated?

Yes. You will receive a £20 gift voucher in compensation for your time in taking part of the main study. Additionally, if you wish to attend a second meeting to contribute to ensuring the analysis is a fair reflection of your views, you will receive an additional £10 voucher.

What are the possible risks or downsides of participating in this study?

You will be asked questions about the time when your loved one was sectioned under the Mental Health Act and about their hospital stay. For some people, this may be upsetting. Please be assured that any information you provide will be handled in the strictest confidence, and that you will be able to answer questions at your own pace.

If you feel upset at any time during the interview, please do let the researcher know. You can ask the interviewer to move on to another subject or terminate the interview altogether. You do not need to discuss anything that you do not want to, and you should discuss only the things which you feel comfortable sharing. The researcher will also have information on local resources and support services that you might find helpful.

What are the possible benefits of taking part?

Many people find the opportunity to share their story to be positive. We hope that the findings of this study will give mental health services valuable insight into what it is like for black carers when their loved one is detained under the Mental Health Act. We aim to share important and relevant factors with key stakeholders, including medical professionals and government departments.

What will happen to the results of the research study?

The results of this research will be published as part of a doctoral thesis. The results may also be published in a scientific research journal. There will be no identifiable information included in any publication, confidentiality and anonymity will be maintained. You will also be offered the opportunity to receive a summary of the main findings of the study.

What if there is a problem?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, UCL complaints mechanisms are available to you. Please ask the researcher if you would like more information on this.

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions, contact details are at the top of the document. If you remain unhappy and wish to complain formally, you can email ethics@ucl.ac.uk.

What if I no longer want to take part in the study?

If you no longer want to take part in this study, please let the researcher know. Your participation in the study is entirely voluntary and you are free to withdraw from the study at any stage. If you withdraw from the study, we will keep the information about you that we have already obtained only if you agree to this. If you change your mind and no longer want to take part in the study, you can contact us and you will be able to withdraw your data from the study up until May 2021. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Will my participation be confidential?

We follow ethical and legal practice and all information about you will be handled in confidence. The only exception is if you tell us something that leads us to believe that you may be at risk of harming yourself or somebody else, or that you are at risk of harm from somebody. In this case we will need to inform the relevant clinical team to make them aware of any risk. We will keep you informed about this.

All of your data will be stored and analysed in anonymised form (meaning all identifiable information will be removed). Only the lead researchers on the project will have access to your personal information and this will be kept separate from the data collected. Only researchers involved in this study and regulatory authorities will have access to the data. Data will be stored in locked offices and on password-protected databases at University College London. All information that is collected during the course of the research will be kept strictly confidential according to the General Data Protection Regulation (GDPR) and Data Protection Act 2018.

We will only use your personal information to contact you if you have agreed to be contacted for participation in analysis or this study or in follow-up and future studies. The information collected will only be used for research purposes as part of this study and will be destroyed after 3 years.

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, click [here](#)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and 'Research purposes' for special category data.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk

Who is the Sponsor for this study?

University College London (UCL) is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and UCL will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UCL will keep anonymised information from the study for 10 years after the study has finished. This is stored in a safe and secure off site location and access is strictly controlled.

Who has reviewed this study?

All research in UCL is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests.

Who is organising and funding this study?

This study is being organised and funded by University College London (UCL).

How have patients and the public been involved in this study?

Service user involvement was an important part of the study preparation, particularly in developing the interview schedule. A carer consultant provided feedback on the interview schedule to ensure that the wording of questions were clear, felt relevant, and addressed difficult topics in a sensitive manner.

Thank you for your interest in this study and for taking the time to read this information.

If you agree to part in the study, you will be given a copy of this information sheet and a copy of the signed consent form to keep.

Researcher Contact Details

Nifemi Ajala
Trainee Clinical Psychologist
Email: nifemi.ajala.18@ucl.ac.uk

Dr. Mirim Fornells-Ambrojo
Chief Investigator
Email: miriam.fornells-ambrojo@ucl.ac.uk
Tel: 020 7679 1897

Appendix D: Informed consent from

Study Title: An exploration of Black carers' experiences of their relative/loved one's detention under the Mental Health Act.

PARTICIPANT CONSENT FORM

Thank you for considering taking part in this research. The researcher must explain the project to you before you agree to take part. If you have any questions arising from the information sheet or explanation given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this consent form to keep and refer to at any time.

Participant Identification number:

Name of Researcher: Nifemi Ajala

Please
initial box

1. I confirm that I have read the information sheet dated May 2020 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.
3. I understand that I do not have to take part in the study at any point and I do not have to explain why to anybody.
4. I understand that my information will be kept confidential unless the researcher is worried about my safety or someone else's safety.
5. I agree that the researcher can record our conversation and keep it for up to 2 years. This will be stored safely at University College London. I agree that the written version of our conversation will be stored for 10 years.
6. I have been given the name and telephone number of who I can call if I want to ask any more information about the study.
7. I understand I will be given a £20 gift voucher as compensation for taking part in the study.
8. I understand that there is support available to me, if I become distressed during or after the interview and have been given relevant information by the researcher.
9. I understand that my participation will be audio recorded and I consent to the use of this material as part of the project.

10. I consent to the use of anonymised quotes or information in any resulting reports or publications. I understand that confidentiality will be maintained, and it will not be possible for others to identify me.

11. I agree to take part in the above study.



Name of Participant Date Signature

Name of Researcher Date Signature

When completed: 1 for participant; 1 for researcher site file

<p>Data Protection privacy notice</p> <p>UCL’s Data Protection Officer is Alex Potts and he can be contacted at data-protection@ucl.ac.uk. You can read UCL’s privacy notice at: https://www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice and details of your rights at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/</p> <p>Your personal data (name, contact details, gender, ethnicity) will be processed as described in this information sheet. The legal basis for this is that you provide your consent (by completing and signing the study consent form) for you to “perform a task in the public interest”.</p>	<p>If I have any questions, who can I ask?</p> <p>Ask the researchers: <u>Dr Miriam Fornells-Ambrojo</u> (Principal Researcher) Miriam.fornells-ambrojo@ucl.ac.uk Nifemi Ajala Nifemi.ajala.18@ucl.ac.uk University College London Department of Clinical, Educational, and Health Psychology, 1-19 Torrington Place, London, WC1E 7HB.</p> <p><i>If you are unhappy about the study at any stage, please contact Miriam on the email address above. If you would like to complain further, you can email ethics@ucl.ac.uk.</i></p>

Appendix E: Interview schedule

Interview Schedule

Title: An exploration of African Caribbean carers' experiences of their relative/loved one's detention under the Mental Health Act.

Introduction

Thank you for meeting with me today and for taking part in this study.

Begin by giving brief reminder of information about the study, allowing opportunities for the participant to ask questions.

During this interview, I will be asking you questions about the process of _____ (name/ family member/partner/friend) being detained under the Mental Health Act and about their hospital stay.

There are no right or wrong things to say. I am genuinely interested to hear about your experience. Please feel free to take your time to answer the questions and let me know if you need a break.

As the interview goes on, if there is anything you feel you would like to add that may not have been covered, please feel free to let me know. At the end of me asking all the questions, I would like to spend a few minutes just asking for your feedback on how you found the process of meeting with me and going through the questions. Again, I just really appreciate you making the time to meet today, so I am keen just to see how you found it all.

Orientation

- How would you like me to refer to you as in relation to X?

I am now going to ask you about when [loved one's name] was detained/sectioned/forced into hospital/was brought into hospital by **(use carer's language)**

[If more than one detention as specified by demographic questionnaire: I understand that your loved one has been taken into hospital against their will more than once, so for this interview it may be helpful to focus on one specific time. So for example, you may prefer to talk about the most recent time, the first time, or a particular time that has stayed in your mind. Please tell me what your preference would be and when this was.]

Experience of Compulsory Detention

Interviewer to facilitate storytelling

- **In your view, what triggered the process to compulsorily admit [loved one's name]?**
- **Can you please tell me what happened on the day your loved one/relative was detained?**
 - Prompts: Who was around?
 - How was the decision made and how involved did you feel?
 - How do you feel you were perceived by health professionals?
- **How did you feel immediately after you found out that the outcome of the MHA assessment was to compulsorily admit [loved one's name]?**
 - Prompts: What were your immediate initial thoughts and emotions to the decision? Did you feel it was helpful?
 - Did your initial reactions change as time went by?

- If there was a change, what factors contributed to this?

Offer a break here

Thank you. For the next section, I am going to ask you questions about the period of time your loved one was in hospital.

The Hospital Admission

- **Can you please tell me where you were on the day [loved one's name] was admitted into hospital?**
 - Prompts: What happened on the day they were taken into hospital?
 - How did you feel?
 - Impact of Covid-19?
- **How would you describe your experiences with staff on the ward?**
 - Prompts: What was it like for you to attend joint meetings with health professionals e.g. CPA meetings and ward rounds?
 - What was your experience of [loved one's name] being given leave?
 - What were your interactions like with the different hospital staff? More and less helpful aspects.
 - How do you feel you were perceived by the hospital staff?
 - Please tell me about any support you were offered by health professionals while your loved one was in hospital.
- **Can you tell me about the decision for [loved one's name] to be discharged from hospital?**
 - Prompts: How did you feel knowing that your family member would no longer be in hospital?
 - How able did you feel to share your thoughts or considerations about the discharge with any of the health professionals?

Reflections

- **How has your experience of [loved one's name] detention under the MHA influenced your view of mental health services and health professionals?**
 - If the experience has influenced your view, can you please tell me more?
- **How has your experience impacted on how you view your position as a relative/caring role?**
- **Please describe what you feel could have been done differently throughout the process? What were you happy with?**

Thank you. I am now going to ask you some questions related to your individual characteristics and your views on whether you think any of these characteristics made a difference to how you were treated during the detention process and hospital stay. When I say individual characteristics, I mean factors such as your ethnicity, race, gender and religion.

Impact of demographic factors

In the beginning of the interview, I know that you described yourself as being xxxxxxx, so I just want to ask whether you feel your ethnicity/race or any other of your individual characteristics (such as gender, religion, class) made a difference to your overall experience.

- **Do you think being xxxxx was helpful in any way during your overall experience?**
- **Do you think being....had an impact on how you were treated through all the events you have told me about.**
 - If yes, I am really interested to hear what happened during the time [loved one unwell/sectioned/hospital admission] that makes you say this.
 - If yes, what impact did it have on you?

This is now the end of the interview. I really appreciate you sharing your thoughts and views with me, so thank you very much. I am also genuinely interested to hear how it has felt for you to be asked these questions. How have you found the experience of talking to me today?

Would you like to add anything else that you feel has not been discussed already?

Are there any things you would like to be taken out of the interview?

Do you have any further thoughts about today's interview? Any questions?

Remind participants of support available to them if they feel distressed.

End of interview.

Appendix F: Demographic questionnaire

Demographic characteristics

- **What is your age?**
- **What is your gender identity?**
- **How would you describe your ethnicity?**
- **Do you follow a faith/belief system?**
 - If yes, what faith/belief system do you identify with?
- **What is your relationship to X?**
 - Parent?
 - Grandparent?
 - Aunt/uncle?
 - Cousin?
 - Sibling?
 - Partner?
 - Friend?
 - Other?

Questions about the service-user

- **What is their age?**
- **What is their gender identity?**
- **What is their ethnicity?**
- **What is their diagnosis?**
- **Do you live with [loved one's name]?**
- **How long have they been in contact with mental health services?**
 - Less than 6 months?
 - Less than 1 year?
 - Less than 2 years?
 - More than 2 years?
- **When has your loved one/relative been detained under the MHA?**
 - Has this happened more than once?
 - Are they currently detained under section in hospital?
 - When was the last time they were detained under the MHA?

Appendix G: Brief Experience of Caregiving Inventory (BECI)

BRIEF EXPERIENCE OF CAREGIVING INVENTORY

The following statements commonly apply to persons who care for relative or friends with a serious mental illness. We would like you to read each statement and decide how often it has applied to you over the **PAST ONE MONTH**.

If it has **never** happened or **rarely** happened you would CIRCLE the number 0 or 1. If it has happened **sometimes**, then you would CIRCLE the number 2. If it has happened **often** or seems to have happened **nearly always**, then you would CIRCLE the number 3 or 4.

It is important to note that there are no right or wrong answers. Also it is best not to spend too long on any one statement. Often your first reaction will usually provide the best answer. While there seem to be a lot of statements, you will find that it won't take more than a moment or so to answer each one.

During the past month how often have you thought about:

	NEVER	RARELY	SOME- TIMES	OFTEN	NEARLY ALWAYS
1. Feeling unable to tell anyone of the illness.....	0	1	2	3	4
2. How health professionals do not take you seriously.....	0	1	2	3	4
3. Dealing with psychiatrists.....	0	1	2	3	4
4. I have become more confident in dealing with others.....	0	1	2	3	4
5. I have become more understanding of others with problems...	0	1	2	3	4
6. How to deal with mental health professionals.....	0	1	2	3	4
7. That he/she is good company	0	1	2	3	4
8. How health professionals do not understand your situation...	0	1	2	3	4
9. How to explain his/her illness to others.....	0	1	2	3	4
10. Others leaving home because of the effect of their illness.....	0	1	2	3	4
11. How to make complaints about their care.....	0	1	2	3	4
12. I have discovered strengths in myself.....	0	1	2	3	4
13. The illness causing a family breakup.....	0	1	2	3	4

During the past month how often have you thought about him being:

14. Unpredictable.....	0	1	2	3	4
15. Uncommunicative.....	0	1	2	3	4
16. Not interested.....	0	1	2	3	4
17. Irritable.....	0	1	2	3	4
18. Inconsiderate.....	0	1	2	3	4
19. Behaving in a reckless way.....	0	1	2	3	4

Appendix H: Example of Transcript analysis

Speaker 2 [00:00:00]: So for this interview it might be helpful just for us to focus on one specific time. So, for instance, you might want to talk about the most recent time. The first time...or any particular time that has stayed in your mind. So could you please tell me which time you'd like us to kind of focus the interview around?

Speaker 1 [00:01:43]: I'm waiting for the interview schedule to load...because that would form my choice. Okay, I would like this interview, you know, be as productive as...possible rather than just a tick box exercise.

Speaker 2 [00:02:01]: Yeah, of course, of course. And of course, I understand we're talking about really, really kind of personal things there, so I do want to make sure that you feel as comfortable as possible.

Speaker 1 [00:02:55]: It's really hard...because we've had some very positive, um, admissions. And then we've had some very, extremely inhumane... admissions as well. And I think...to be fair I'm gonna have to pick from the middle. Okay? Rather than dwelling on the best and the worst. Yeah. Okay, I've made up my mind. I think I know what...

Speaker 2 [00:03:31]: Yeah. Um, And I understand. And actually, you might find, even during the conversation, you might notice yourself going between different times. And that's absolutely fine. It's just in terms of it. Might just be helpful to think about that one time. So for the middle. So we'll be thinking about that time that, [carer] In your view, what would you say...kind of triggered that process for your loved one to be kept?

Speaker 1 [00:03:56]: Yeah. Um...sometimes it's gonna take me a while to answer the questions because i have to think.

Speaker 2 [00:04:05]: No please take your time.

Speaker 1 [00:04:08]: I don't want to just be emotional about it. rapid eye. I want to try and be as factual as possible...(20 second pause). Yeah, I suppose what

triggered it, was concern over the loved one's irrational behaviour.

Speaker 2 [00:04:53]: Um, would you feel comfortable elaborating a little bit more upon that [carer]?

Speaker 1 [00:05:03]: Well it was building up, it had been building up for a while. Obviously we'd already had contact with um..the service. And um, he was put back into the community. But like I said, we...it came as a shock. We all had difficulty identifying exactly what was going on and accept it. He had problems accepting. I had problems accepting that. Um... he had a long-term diagnosis and it wasn't explained to us. It was...initially that could also be a part of the assessment process...that it was like a watch and wait and see if it was just a blip. Or something that was gonna happen. Or...so I think there was a problem with complying with the medication, because it made him feel very unwell, so he asked...or we all asked...for the medication to be reduced. Because he was complaining alot. And...Um...so do you want the exact..? I think in this instance...he was beginning to...become a bit more aggressive. And um...I think he actually did warn me and say I think... I'm not feeling comfortable. He did express concern about his thoughts process. That he was unable to sleep. And because we had had similar breakdown before...I began to suspect that, um...he was becoming psychotic again. And he was um, referring to demons you know, supernatural things and supernatural strength. And um, I knew, he was becoming rapidly unwell and...we called for help. Yeah.

Speaker 2 [00:07:36]: And so can you tell me from that stage before, from when you called for help? What that looked like for you all?

Speaker 1 [00:07:45]: It was scary because I had younger ones in the house and his dad doesn't live here. So...he's a big lad. Very big. Uh, tends to...like...stay awake and just watch him. And the help wasn't forthcoming. It was like...maybe towards the end of the week. We couldn't get the doctor to come in on time, and we needed a doctor. So eventually, I had to call the police. i had to call the police...just to protect him and protect the people in the house.

Speaker 2 [00:08:31]: And what was that like for you, [carer]? When you contacted the police.

Hurdles just to access help and services, escalation of loved one's behaviour and early warning signs, unusual behaviour from loved one. Carer key to noticing loved one becoming unwell

Fear, impact on family environment, police involvement to safeguard loved one and others. Police as last resort due to no help from other services

Carer initiating help for loved one

Fear

Trauma, carer all alone

Must have been so frustrating for carer - who is actually there to support them to get into services?

So traumatic for carer and family

Speaker 1 [00:08:35]: Very traumatic. Was very traumatic. I felt lost. Abandoned, You know? It was frightening. It was scary for me...the younger children. It was scary for him too.

Speaker 2 [00:08:53]: And...So from when the police got involved, did that tend to...Did that speed things up for you?

Speaker 1 [00:09:00]: Police would call, and I think I have to call them several times because they would come and say we're not doctors, can you call your GP? But you call the GP and the GP said well...well, book an appointment for him to go into hospital. It was just a no win situation, we were just banging head and going around and around in circles.

Speaker 2 [00:09:21]: And was this you, [carer]? You were the only one doing all the contacting here as well with all the different agencies?

Speaker 1 [00:09:26]: Yes. Yes it was me. Because I didn't want him going out in the streets and getting into trouble.

Speaker 2 [00:09:36]: Yeah...and so can you tell me then, [carer] how it came to be on the actual day that you loved one was kept?

Speaker 1 [00:09:44]: Sorry? Say that again.

Speaker 2 [00:09:46]: Sorry, let me speak into the mic. Can you tell me, please, [carer], for how it came to be on the actual day that you loved one was kept?

Speaker 1 [00:09:56]: Okay, I think...this particular one I was referring to....Um, yeah, I think like I said, I had to call the police a few times. And it escalated and they would come and leave. I think on the fourth attempt...I really had to make a case and...and he was degenerating quite rapidly and getting more agitated and screaming and shouting. And then the police came and there was a confrontation with the police. And, um, they tried to calm him down and he got a bit more agitated. And I think they wanted...um, a doctor or somebody to come and, you know, assess him...before taking him away or deciding what to do with him. But there was no doctor or psychiatrists who was willing to come there? Was on a Friday or something or on a Saturday. So...the actual process was very traumatic. I think what happened is my other children told me to leave the room, leave the living room and I had to wait in the car. And um...I just know there was a huge racous he got tasered.

Trauma, Abandonment, lost in the system

Hurdles of accessing help

Trauma, hurdles of accessing help

Absolute failure of services to listen to the needs of this family. Could this whole escalation have been prevented?

Disregarded by services

completely separated from services

Speaker 1 [00:11:46]: Oh gosh I'm so sorry.

Speaker 2 [00:11:46]: And taken into detention, the police station. Because we'd been asking and asking for him to be taken into hospital. The process was...unsurmountable you know? We more or less had to...um...trigger him for, you know....to, I don't know prompt him to react in such a way that he would be arrested. The officer actually told me because he'd taken my phone. And the officer said, well the only thing we can do is arrest him for taking my phone or for holding on to my phone. And take him into custody and it was true...Because it was from custody that they arranged for him to be taken into a unit. That was the only...that was the only way...we could get help, to get him arrested.

Speaker 2 [00:12:59]: And...and during that whole time of you contacting so many different agencies, how do you feel you were being perceived by health professionals?

Speaker 1 [00:13:07]: A complete nuisance. I was perceived and treated as a complete nuisance (laughs).

Speaker 2 [00:13:17]: And that just just adds to the whole stress of the whole process. I can imagine And so once your loved one had been arrested and held in the police cell...Were you involved in the next steps following that?

Speaker 1 [00:13:36]: Absolutely no involvement. I didn't even know where he was.

Speaker 2 [00:13:41]: So is that because your family members had kind of taken the reigns?

Speaker 1 [00:13:46]: Yeah, it was taken away. I didn't know it was...well they did say to me he would be in the custody suite. There was no further communication. His phones were taken off him. And um, I think it wasn't until the next day. Ah, I think the custody...his inspector or whatever called to say...they give me a bit of updates that you know he was okay. And they're arranging for him to be taking to a psychiatric unit. Because even then...it was...um...he needed an assessment to see whether he was going to be detained...as a criminal...or taken to the psychiatric ward for treatment.

Speaker 2 [00:14:36]: Okay. Yeah. And when they um contacted you to tell you that this was the process that was going to happen, what were your kind of initial thoughts and emotions?

feeling dismissed

Ignored by services

Trauma response.
Police detention the last
place for a vulnerable
place to be

Speaker 1 [00:14:48]: I was just, um, you know...by then you're dead! You just go into auto pilot. And just...because I've still got younger ones in the house. And...Mmm, so you just do the bare basics to stay alive. And hang on to the phone and try and called. Devastation...you know? I was just more worried about...I...them not...because he's a big boy and when he kicks off, he kicks off really badly. I didn't want them to choke or suffocate him. And so I kept going on about, Please try not to hurt him and the quicker they get him into a unit the better. Because, um obviously the police is not trained to handle...they don't have, you know...designated safe places for people who are unwell. They should be in hospital. Not in detention.

Trauma, fear

Speaker 2 [00:15:46]: Absolutely. Absolutely. Um and at that time when you heard it...was ever any part of you that felt like this was a helpful decision or an unhelpful decision for your loved one?

Speaker 1 [00:15:58]: What do you mean? What decision?

Speaker 2 [00:16:01]: Sorry...Knowing that he'd be kept.

Speaker 1 [00:16:02]: Kept where?

Speaker 2 [00:16:05]: In hospital.

Fearing the absolute
worst. Previous stories
maybe of Black deaths
in custody?

Speaker 1 [00:16:09]: That's why I said that I was anxious for him to get into the hospital. Being in detention even was making it worse. Because I knew that...could lead to death. So I was very worried. Exacerbated my anxiety...my anxiety was exacerbated by him being in police detention rather than in hospital. I wanted him to be in an hospital, but in a good hospital. Not just...any hospital.

Fear

Speaker 2 [00:16:41]: And prior to this experience did you have...kind of knowledge or...in terms of for you what felt like a better hospital that you wanted him to be placed in?

After a while knowing
the system and
different experiences.
Care of loved one like a
postcode lottery?

Speaker 1 [00:16:50]: Yeah. I was very specific. I wanted him to go to the [name of hospital]. But they didn't have a bed there. So they were gonna take him to [name of hospital] which was very inappropriate and a terrible experience. However, that is not the worst. Like I said, I'm trying to...erm...err on the middle ground now. Some very bad bad hospitals like the one in, um in [name of area]. I didn't want him to go there, that's terrible. It's not fit for him. Not fit for him and human beings. There's another one...um in [name of area] that is bottom off the pits.

Postcode lottery

Even animals should not be kept there. But, you know, like I said, I want this interview to be productive. It's not just a complaints procedure. I want good to come out of it. And I would hope that...those really terrible places...would not continue to be in existence. I hoped they would have been changed by now. Like I said, it's years ago, that's 2013. So it's nearly seven years ago. So I would hope those places would still not exist. You know I can't fight all battles. But with [name of hospital] I think it's kind of middle ground...from, you know, on the spectrum of really bad to acceptable. Eventually, he got taken to the [name of hospital] which is a kind of the middle ground.

Speaker 2 [00:18:39]: Okay. Thank you, [carer] and thank you so much so far. Um, would you like a break here? Would you like to carry on?

Speaker 1 [00:18:47]: Carry on...carry until about quarter past, which we said we would do up to 30 minutes of the interview. So that next time we start, we do another clear one hour.

Speaker 2 [00:18:59]: Okay, Brilliant. So for the next section [carer], we're going...I'm going to be asking you questions about the period of time that your loved one was in hospital. So [name of hospital] it sounds like. Um, so can you please tell me where you were...Kind of on the day your loved one was taken in to hospital...if you can recall?

Speaker 1 [00:19:22]: I was in my house.

Speaker 2 [00:19:25]: You were in your house, yeah. And do you remember what happened on that particular day in terms of who contacted you?

Loved one being so far away from home. How can services be more empathetic when these are the only options? How can staff communicate this to carers in a way that feels supportive?

Speaker 1 [00:19:34]: It was the custody suite. The police said they are making arrangements for him to be transported. And the place they were taking him to was [name of hospital]. And I said it's so far from home and I would rather he went to [name of hospital]. And they said, No, they haven't got beds there. That's where they've taken him and that's it.

Being separated from immediate community

Speaker 2 [00:19:58]: And how did you feel? Just knowing that your loved one wasn't going to be...in terms of where you were hoping he would be? Um in a place that was a bit further away from home and not your first choice. How did that feel for you?

relief

Hospitals not being perceived as places adequate for loved one's recovery and healing

Need for carers to be involved in decision-making. Space for co-production?

Challenges of the ward environment

Speaker 1 [00:20:14]: Bad and worse and worrying. But I hadn't really known much about [name of hospital] back then, but I just felt, thank God at least he's not in custody...police custody. That could have...led to his death because of use of restraints. It's a small relief, that at least eventually he'd been taken into hospital.

Speaker 2 [00:20:40]: Okay, Yeah. Thank you. And so can you...Can you describe what your experiences were like with the staff on the hospital ward?

Speaker 1 [00:20:53]: Well...it depends. The staff wasn't very pleasant. They were not...Um, it was not very pleasant. The environment was not very pleasant...in terms of hygiene...as well. And um...it seemed very commercialised, like the care was very basic. And because he'd already been in [name of hospital] I could see the difference that...it was um...not very targeted. It was just more like...We'll just keep him and make money while he's here. It was the same theme that was being repeated by, you know, the core patients and families who had loved ones there. That...Not enough care was being given to them. It's just...it's to drug them up and keep them here for as long as they need to be.

Speaker 2 [00:22:19]: And what were your experiences of...kind of attending meetings. So whether it's like ward rounds, CPA Reviews...So any kind of joint meetings with health professionals?

Speaker 1 [00:22:31]: Most of the decision was taken while we were absent. Yeah, and you just come the following day and they say, we've increased the medication. Or... you know, there was something that happened overnight. And...They were more reactive rather than proactive. There was a lot...alot of violence going on there.

Speaker 2 [00:22:57]: On the ward with the other patients?

Speaker 1 [00:23:00]: The other patients and...you know from staff to patients and patient to staff, between patient to patient. Lots of fights and scuffles. Injuries wasn't well managed.

Speaker 2 [00:23:19]: And so, with...when you'd attend these meetings, would it just be for them to tell you, [carer], oh this is the new change that's happened rather than to kind of be involved in that process?

Relief

Hospital place of safety, lack of compassion and empathy

Top-down decision making

Speaker 1 [00:23:30]: Yeah. Usually sometimes...even there was very junior members of staff. It was not continuity...like the doctor you saw today would not necessarily be the one you see tomorrow. And um...not familiar with this case file. You know...very disjointed. And um...and most of the time...not properly qualified. Because if I'd have contact with...A more better established hospital. This was just like, you know, on office that was converted, not properly. And there's no outside space, no stimulation. It's just like a cell. And i was really fearful of his safety while he was there. Because he would kick off. And I knew if he kicked off, they would...you know, do anything to keep him. It was actually more dangerous than a police station because they were not properly trained. All they did was give him sedatives to keep them calm. You know, like i said, this was not even the worst case scenario. The one in [name of area] was more scary than that. The one in [name of area] and there's one they took him to. I never got to go there because it was so far away. I've heard about it on the news. Is it [name of hospital] or something? It's, um...[name of area]. I think he stayed there for about a week on, and um I had to call my MP because it was about 200 miles away and I couldn't get there. And he would phone to say, he's not sure he will ever see me again. So...we had to try and get him moved back to [name of area]. So, even this [name of hospital] too, on a scale of 1 to 10, maybe [name of hospital], was about a three. The others...were like euthanasia centres and people were dying there.

Fragmented systems, terrible experience of different hospitals, being bounced from one hospital to the next

Fragmented services, harm vs help

Hospitals appearing to be lifeless vessels

Speaker 2 [00:25:53]: Oh my gosh.

Speaker 1 [00:25:53]: They were like sloths. They would snuff the life out of them.

Speaker 2 [00:26:02]: And I mean...even just being there and here in what the environment felt like for you, you know, for your loved one and for you. How did it feel...kind of going into...coming into the hospital to, like, attend the meetings and to visit your loved one? What came up for you?

Devastation and fear. Carer having no choice but to constantly confront traumatic environments

Speaker 1 [00:26:21]: Oh, scary, it was devastating, heartbreaking. But I just had to keep doing it because, um...I was the only one he had, you know who was looking out for him. And I knew if I didn't go in there, um...I tried to make friends. Even though I didn't like the staff, I forced myself to try and make alliances with

Surviving through the trauma, visibility of carer, having to appease professionals

them. Try make friends, buy sweets for them, which I know they didn't need. Buy foods each time for the ward and just make my presence felt. And joke and chat and just try and lighten up.

Speaker 2 [00:27:05]: And was that something [carer] for that you felt you had to do in order to...

Speaker 1 [00:27:12]: I was forced to do it. For the safety of my loved one.

Speaker 2 [00:27:16]: And did you notice a difference in doing kind of what you what you described?

Speaker 1 [00:27:22]: Yeah, definitely. Which is sad really, because they get paid for doing a job. I didn't have to go in there buying sweets and things and trying to...and sit down and befriend them. They should be trying to befriend me!

Speaker 2 [00:27:42]: Absolutely. Absolutely. Um and so I'm just wary of the time aswell. So we've just got a couple minutes before we'll pause for break. So yes, I keep checking the clock. I don't want to go over your time.

Speaker 1 [00:27:55]: You can finish this section of the interview so that we don't have to come back to this section. Um, so that you round it up nicely. So if you have to over shoot...you know the time, then that's fine.

Speaker 2 [00:28:10]: Oh okay, thank you [carer], I really appreciate that. What was your experience of kind of your loved one being given leave during his time?

Speaker 1 [00:28:21]: Yeah, leave was for me, like...you know, a reward for good behaviour. And it was like...um...the light at the end of the tunnel. By the time you get to that stage of being given leave, it was like a bargaining tool for him as well...and say it was like currency and say, if you cooperate, just try to calm down. Yeah, and then you can go out and do some shopping. It was, um it was like a victory of sorts.

Speaker 2 [00:29:02]: And, um, even when you're thinking about your interactions with different health professionals in the hospital, how do you think you were actually perceived by them? What impression do you think they had of you?

Failure of services.
Carer having to do all
the hard work

Appeasing

Leave signalling hope.

Hope

Hostile environments,
lack of cultural
understanding

Speaker 1 [00:29:18]: They were actually very hostile towards me...they were hostile towards me. And I could see where they were going...where they were coming from. Um they wanted to have absolute control and do it their way. Whereas their way wasn't necessarily the best way for my loved one. Um...his ethnicity and cultural and religious beliefs were not being...were not taking into consideration. It was just like um...one size fits all...for them. You know, we're very religious people...and when we have difficulties...the natural thing for us, to do would be to pray. But they perceived prayer as an indication of unwellness and...like I said... we're of African origin and we're very tall and six foot 1. My son is about 6 foot 6...so that was kind of alarm bells for them. And they were already stereotyped and perceived...this is going to be trouble and we're ready for you, and just get more people in. It was like a money making venture for them to say, oh You know, we need more staff and I need more hours, even when he hasn't done anything wrong.

Fight for control, cultural
humility

Speaker 2 [00:30:46]: And were there...sorry, [carer] did I cut you off?

Speaker 1 [00:30:47]: No that's alright. Were there..?

Speaker 2 [00:30:53]: Were there any kind of...in your mind when you think about the interactions you had the staff, were there any aspects that were actually helpful aspects or less helpful aspects in terms...When you think about how they interacted with you?

Carer having to
strategise just to get
answers or to feel heard
and involved. Hospitals
feel more like
businesses rather than
places of care. Sounds
like prison

Speaker 1 [00:31:11]: I think um...both both. Less helpful and some helpful. I think...I'll start with more helpful aspects were that I...just had to use an educated approach to tackle the situation, to try and turn it around. I targeted people that I thought...I could some penetrate. There were people that were my own age, my ethnicity, about my orientation. And I just...you know, got to know their names and joked with them and...try and have a relationship with them. Um, and tell them like, my concerns and what I want them to look out for for me. And, you know, going there and..oh, can I have a drink or something? And just try and start conversations and like I said, you know, buy gifts for them and just little things. Not that they...you know, I wasn't trying to bribe them or anything. Just trying to worm myself in...into their hearts. And then they were just...On the negative side, there were some that were you know,

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openly hostile. Because I could see the conflict that...we need to...Make it a profitable...You know, venture. Us against...can we get him out on time. They were not happy to get him out on time. Which they could have done. That that conflict was there. So I just had to...And I knew...you, you know....he was there for nearly a year! And this was like a converted office block with no open space. Closed in, blocked windows. So...thank God he was younger then...so he was fitter (laughs). So Oh, yeah.