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“African and African Caribbean Carers’ experience of caring for a family member with an enduring mental health problem in contemporary Britain”

by

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ABSTRACT

FACULTY OF HEALTH SCIENCES

Doctor of Philosophy

"AFRICAN AND AFRICAN CARIBBEAN CARERS' EXPERIENCE OF CARING FOR A FAMILY MEMBER WITH AN ENDURING MENTAL HEALTH PROBLEM IN CONTEMPORARY BRITAIN"

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Recent government reports indicate that there is a high incidence of enduring mental health problems in the African and African Caribbean communities living in the UK. Although research has explored the experience of service users from both of these communities, little is known about how family carers experience caring for a relative with an enduring mental health problem from the same communities. The aim of this investigation was to explore the lived caring experience of seven carers from the African and African Caribbean communities who cared for family members with an enduring mental health problem. A hermeneutical phenomenological approach, as described by Van Manen was used, which encompassed descriptions of carers' experience of caring and subsequent interpretation of their lived experience. Analysis of the findings revealed the caring experience to encompass: (i) being there and staying there; (ii) losing oneself and re-discovering self; (iii) keeping an on-going dialogue with others, (iv) a conscious awareness of cultural stereotypes and (v) sustaining hope during the caring experience. The study concluded that carers from both communities maintain a strong familial obligation in their caring experience. Carers also make use of local community care groups to assert their carer role with mental health and social care services. Recommendations for future research are discussed in relation to improvements in mental health and social care provision.

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DECLARATION OF AUTHORSHIP

I, Julia Ellena Pelle declare that the thesis entitled

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and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
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- I have acknowledged all main sources of help;
- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- none of this work has been published before submission.

Signed:...

Date:..

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Definitions and Abbreviations

ACCI	African Caribbean Community Initiative
AESOP	Aetiology and Ethnicity of Schizophrenia and Other Psychoses
APA	American Psychiatric Association
BAME	Black and Asian Minority Ethnic
BME	Black and Minority Ethnic
BPD	Bi-polar Disorder
CBT	Cognitive Behaviour Therapy
CPA	Care Programme Approach
CSIP	Care and Services Improvement Partnership
CTO	Community Treatment order
DHSSPS	Department of Social Services
DoH	Department of Health
DRE	Delivering Race Equality
ECI	Experience of Care-giving Inventory
EPIC Model	Enhancing Pathways into care
EPOC Model	Enhancing Pathways of care
GHS	General Household Survey
GP	General Practitioner
LGBT	Lesbians, Gays, Bisexual and Transsexual
MHG	Mental Health Guide
NBCCWN	National Black Carers and Care Support Workers Network
NCCSDO	National Co-ordinating Centre for NHS Service Delivery and Organisation
NIMHE	National Institute for Mental Health in England
NSF for MH	National Service Framework for Mental Health
ONS	Office of National Statistics
OPCS	Office of Population and Census Statistics
RMO	Regional Medical Officer
RMSAA	Resiliency Model of Stress, Adjustment and Adaptation
UCLAN	University of Central Lancashire
WHO	World Health Organisation

1. Chapter One: Introduction and Background

1.1 Introduction

This study explores the lived world of caring as experienced by African and African Caribbean carers, who care for a family member with an enduring mental health problem. The African and African Caribbean population are part of the wider Black Asian and Minority Ethnic (BAME) communities that make up the United Kingdom (Carers UK, 2011).

Currently in England there are half a million BAME carers who, it is suggested, save the state £7.9 billion a year, with the unpaid care they provide to their families (Carers UK, 2011).

BAME communities in the United Kingdom (UK) include people from Black African, African-Caribbean, South Asian and Chinese heritage, the Irish community, Eastern European communities (to include Lithuanian, Latvian, Russian, Polish and Slovakian communities) and the Gypsy Travelling community (DoH, 2005; DoH, 2007a; Grant et al, 2008).

The 1997 Labour government attempted to support two of the more vulnerable groups of the UK population, through different carer policy initiatives. The first group involves people who care for individuals with enduring mental health problems (EMHPs). These includes individuals who have been diagnosed with schizophrenia; bipolar disorder; clinical depression; personality disorder, dual diagnosis/co-morbidity; secondly, those members from the BAME communities, who experience a high incidence of enduring mental health problems in the UK (London Health Observatory (LHO), 2011; Fearon et al, 2006; Scottish National Health Service, 1997).

There is evidence from carer research that suggests that carers from the BAME communities have similar experiences as other carers of persons with an EMHP (Bhattacharyna et al, 2012; Carers UK and the Association of Directors of Adult Social Services, 2012).

The issues of caring which are common to all carers of people with mental health problems, fall under four categories: 1) carers' perceptions that their relative is not receiving the cared they need from mental health and social care services; 2) a feeling that mental health professionals tend not to listen to, involve or respect carers; 3) all carers consistently critique the poor dissemination of important information (including when the cared for person will be discharged from hospital back into the care of the family carer) to carers and 4) most carers found that their greater support came from local community social groups often not affiliated to a statutory service (Askey et al, 2009; Canning et al, 2009; Chambers and Connor, 2001).

However, BAME carers face additional problems, which include gaining equal access to support services, cultural and language difficulties, and access to appropriate support from statutory organisations (Carers UK and the Association of Directors of Adult Social Services, 2012; Carers UK, 1998; 2011). Some carer research has highlighted that different ethnic groups within the BAME community have their own unique experiences of caring (Dangsomyouth et al, 2008; Eley, 2003; Dakar-White et al, 2002).

Yeung et al (2012), in a phenomenological study of Chinese carers living in the UK, revealed that this group of carers do not necessarily feel the need to be involved in every stage of help-seeking and after first contact with statutory services their social networks became bigger and more diverse. Lloyd et al (2013) compared parental carers of people with EMHP from the North Indian

Punjabi Sikhs community and their White British counterparts. The North Indian Punjabi Sikh carers revealed low express emotion and larger family groups and kin support compared to the White British community of carers.

One of the reasons for focusing on the African and African Caribbean carers, who care for family members with an EMHP, centres on the incidence of EMHPs reported in both communities.

Several epidemiological studies report, upwards of six times more Black Caribbean and Black African people are diagnosed with EMHPs compared to the White population in the UK (Cooper et al, 2008; Fearon et al, 2006; Lloyd et al, 2005). The highest incidence of EMHPs includes individuals diagnosed with schizophrenia and bi-polar disorder. These are EMHPs that impact not just on the individual, but also on families and the wider society, leading to long term suffering and social exclusion and isolation (Ilic et al, 2012; Hunt, 2003; Harrison et al, 1989).

Further comparisons between the BAME communities indicate that Black Caribbean and Black African communities have a reported incidence of EMHPs, which is higher than in the South Asian and Chinese communities (Cooper et al, 2008; Fearon et al, 2006; Cooper, 2005). This is also consistent with similar incidence studies from the USA with African American communities in (Hines-Martin, 1998); in Canada with African and African Caribbean communities and in other parts of Europe (Menezes et al, 2011; Cantor-Graae and Selten, 2005).

In relation to carer burden, carer research literature has consistently reported the impact of caring on the mental and physical health of carers. The focus of care burden has indicated that an exacerbation of patient symptoms can increase carer distress. Onwumere et al (2010) indicates that carers and the cared for person are interconnected in their experience of social isolation, experiencing difficulties with coping with illness in the family and may themselves be diagnosed with a mental health problem. Therefore, it seems important to review some of the explanations for high incidence of EMHPs in the African and African Caribbean communities living in the UK; and to consider the future impact on carers who have a history of settling down in the UK.

Sharpley et al (2001) provides one of the most comprehensive reviews of all the explanations for high incidence of EMHP in African and African Caribbean communities living in the UK. These fall into four main categories with the first category referring to explanations, which challenge the diagnostic skills of White British psychiatrists and infer over diagnosis as based on ethnicity and cultural differences in perceptions of mental illness. However, following comparisons with Caribbean psychiatrists, the explanation of over diagnosis was unreliable (Wilson and Francis, 1997; Hickling and Rogers-Johnson, 1995).

In the case of cultural perceptions of mental illness, it is widely acknowledged that there is some divide between Western and Non- Western perceptions of mental illness. An example is that of 'hallucinations' which are often perceived in Modern western cultures as pathological (Aina, 2004). However, hallucinations can be construed as very real as opposed to 'as if real', in some non-western cultures.

A second category includes biological explanations, which suggest that individuals from both of these communities are predisposed to EMHPs through genetic disposition, the process of migration, complications during perinatal and prenatal periods, difficult childhoods which entail absent fathers and abuse of cannabis. However, there is no clear aetiological evidence to confirm any of the above hypotheses.

The third category refers to social explanations, which suggest that there may be some association between deprived run down inner city environments and higher rates of in-patient admissions within both these communities. The implications are that African and African Caribbean communities are at a social disadvantage due to racism, which exists in employment opportunities and subsequently has a domino effect of poor housing environments and limited educational opportunities.

Another issue is the excess of police involvement in psychiatric admissions from both communities. This can involve high intensive compulsory admission with a low level of General Practitioner (GP) input. This can be explained by the possible notion that patients may seek help from a GP, much later on during the experience of mental illness. Other factors which compound the patient experience includes perceptions by both relatives and patients that mental health and social care services are inherently racist (also referred to as *institutional racism*).

A final explanation ascribes to the psychological influences on incidence of psychosis, which include interpretation of life events and attribution style. Adverse life events can lead to the emergence of psychotic symptoms in vulnerable individuals; this suggests that patients from the African and African Caribbean community may be exposed to a number of events, which lead to the onset of psychosis. In this context, a person is perceptual or attribution style may predispose them to developing an EMHP.

However, mental health care service evaluation studies and service utilisation reviews tend to focus on patients' experiences of these services; the outcomes of these studies are largely negative. Askey et al, (2009) and Bhui et al (2003) suggest that there were higher rates of in-patient admission to mental health hospitals in black patients. Commander and Sashidharan (1999) found that black patients experienced more complex pathways of care and had higher levels of involvement with the police and compulsory detention compared to their white counterparts.

Cochrane and Sashidharan, (1996) in a review of mental health service provision, found that black patients complained of more coercive treatment and adverse experiences. Harrison et al (1989) explains the high incidence of EMHPs in the African Caribbean population in the UK, as a sign that patients sought GP help much later on in the presentation of signs and symptoms of mental illness. This then led to more dramatic and intrusive emergency interventions by mental health and social care services.

However, Rwegellera, (1980) found that African migrants to the United Kingdom were hesitant in contacting their GP because they did not understand the role of the physician or their potential to help. Despite overall satisfaction with mental health services, in terms of diagnosis and treatment plans. McGovern and Hemmings (1994) found that black patients and their relatives were more likely to perceive the services as racist, compared to their white counterparts.

The aforementioned studies assumed that carers from the African and African Caribbean community had similar experiences of the mental health and social care services as the relatives they cared for. Therefore, there was no distinction between carers' individual needs and that of the person they were caring for (DoH, 2005).

To date there has been very little research, which looked at the experience of carers from the African and African Caribbean community and the long-term care implications for future populations living in the UK.

To address some of the health and social care inequalities which have mainly occurred in mental health care amongst BAME communities, predominantly amongst African and African Caribbean communities, the previous Labour government launched a policy with an accompanying five year action plan entitled, '*Delivering Race Equality in Mental Health'* in 2005 (DoH, 2005). The focus of this policy was on enhancing the mental well-being and mental health service experience of individuals, for BAME communities in the UK, by reducing inequalities in access to, experience of and treatment outcomes in mental health and social care provision. The document was in part a response to the independent inquiry into the death of David Bennett, a Caribbean patient who died in 1998 in a medium secure unit after being restrained by staff. The policy was based on three areas of mental service provision, i) developing more appropriate and responsive services for BAME communities; ii) increasing community engagement by the introduction of 500 new community development workers (who were themselves representative of the diverse cultural groups in different parts of the UK) and iii) to further enhance the giving of information to both patients and carers. An additional provision under this policy was the setting up of a BAME board accountable to the Department of Health.

The outcome of this five-year action plan indicated that there was little evidence of direct discrimination by practitioners, but some reports cited differences in how people from BAME populations and White populations experienced interaction with mental health and social care professionals. There were some instances of mental health professionals working successfully with service users, who had a different ethnic background to their own. The community engagement projects proved to be successful and some new interventions were introduced which were tailored to address specific cultural needs. One specific approach included the development of a culturally sensitive form of cognitive behavioural therapy (DoH, 2009a). In addition, BAME service users and community members became more actively involved in training mental health professionals about issues around culture and ethnicity.

Furthermore, the report indicated a decrease in the rate of admission of patients from BAME communities, with a reduction in the number of compulsory detentions and fewer violent incidents (Boydell et al, 2012). This was paralleled with less use of seclusion. Service user surveys revealed an increase in feeling they were recovering from their illness. The report was equally positive about the capability of the health service workforce and its ability to deliver appropriate and responsive services. However, one of the report's recommendations was that different BAME groups should be engaged and considered separately according to their ethnicity, although the rationale for this was unclear.

Some of the experiences of African and African Caribbean carers have been published in relation to those who care for family members with advanced progressive illness (Koffman and Higginson, 2003); dementia (Lawrence et al, 2008; Adamson, 1999); stroke (Strudwick and Morris, 2010); learning disability (Hubert, 2006), and the impact of caring on young carers (Mills, 2003) from these communities. These studies have not so much revealed a high incidence of illness, but focussed on the inequalities in health and social care provision and highlighted the expectations and perceptions of the carers from these communities.

This invites a potential triple stigmatisation of carers from both these communities. Firstly, the carers may experience stigma related to caring for a person who has psychosis. Secondly, there is the possible stigma of being a carer and therefore, part of an invisible community. Thirdly, there is often a stigma attached to being a member of the African and African Caribbean community whose population profile in the UK contains a number of cultural stereotypes that can lead to both individual and institutional discrimination (Keynejad, 2008; Forbat, 2004).

Any discussion of African and African Caribbean carers' experiences in the UK, has to acknowledge the significant development of both i) carer policies in the UK over the last ten to fifteen years and the reform of the National Health Service (NHS) (DoH, 1999a; 2009a), the reform of the Disability Discrimination Act (1995; 2005), the reform of the Mental Health Act (1983; 2007) and the introduction of the Race Relations Act (2000) which all contribute to the major policy and legislative influences upon carers' experiences in the UK.

A number of the UK health and social care policies of both the previous and current governments have become more receptive to the needs of the diverse communities, which now make up the UK population. BAME communities have diverse cultural identities in their own right. Over the last forty years, consistent reporting of the high incidence of EMHPs in African and African Caribbean communities, suggests that research in this area not only needs to be imbued with 'sensitivity' to those who suffer with mental health problems, but also acknowledge the impact of mental illness on their families (Bhugra, 2003; Bhui et al, 2003).

The migration history of African and African Caribbean communities to the UK provides the contextual picture of adaptation, assimilation and acculturation for these two communities and its influence on their caring experiences (Bhugra and Jones, 2001). Therefore by studying the caring experiences of African and African Caribbean carers, it is anticipated that new information will emerge about access to required support services, the influence of inter-generational cultural values on caring and perceptions of mental health and well-being, experiences of living in the UK, as well as carers own identity within the wider UK community.

Terminology

It is apparent that carer policies have led to a number of different definitions of the 'family carer'. These include 'informal carer', 'non-professional carer', 'relative', 'carer' and 'spouse'. For clarity, this thesis will refer to family carers as 'carers' and the person they care for as the 'cared for person' or 'care recipient'.

Family Carers in Mental Health – widening the debate on terminology

The wider debate around the use of the term 'carer' and words used to describe the caring experience such as 'burden' remain contentious in carer research. Molyneaux et al (2011) contests that as opposed to being a burdensome task, 'caring' is considered by many families as a socially admirable role, which enhances the relationship between carer and the cared for person. Furthermore focussing on the burden of the carer would appear to exclude the experience of the service user or at least suggest their high level of dependency on the carer – a further stigma. Henderson (2001) supports this view in a qualitative study on partners of people with bi-polar disorder who rejected the carer and cared for identity in favour of one that describes the affection, intimacy and social nature of their relationships. In addition, there is a concern that carers own mental and physical health problems may be ignored due to the emphasis on their carer role in relation to the service user needs. Therefore, on occasions where appropriate in this study the cared for person will be referred to as the relative and the relative who cares for a family member, will be referred to as the carer, depending on the context of the discussion. Heaton (1999) suggests that in the discourse about informal caring in UK health and social care policy, carers are perceived either as 'providers' or as 'users'. Twigg and Atkin (1995) argue that health and social care practitioners vary in their perception of informal carers. Four models are proposed by Twigg and Atkin (1995), which include carers as 'resources' – they primarily provide free care whilst statutory services focus on the cared for person. Carers as 'co-workers', implies their partnership in the joint provision of care alongside professionals. Carers as 'co-clients', acknowledged carers are as having needs of their own. A final stage is referred to as the superseded model – where statutory services take over the care of the cared for person, removing the carer role. However, Henderson and Forbat (2002) found families did not necessarily identify with the terms 'carer' but placed emphasis on the interpersonal relationship with their relative and the emotional labour involved in caring. They propose government carer policies should take this stance.

Throughout this study, the terms African and African Caribbean will be used interchangeably with Black African, Black Caribbean, West African, Afro-

Caribbean, West Indian and black people; insofar that the context and period of research under review, indicates the need for a change of terminology.

1.1.1 Background to the study

All participants were from African and African Caribbean communities living in the UK. They provided care to one or more family members with an enduring mental health problem. The African and African Caribbean communities make up a very small ethnic minority within this region, compared to other ethnic groups (for example in comparison to South Asian communities which are a much larger ethnic minority group in this region) in terms of population size.

1.1.2 Epidemiology of BAME communities in the UK

In the recent UK Census in 2011, the population is estimated to be at just over 63 million (ONS, 2011). The BAME community makes up 7.9% (estimated at just over 5.9 million) of the UK population (ONS, 2011). Black Caribbean people make up 1.1% of the UK population and the Black Africans make up 1.8% of the UK population. Those defining themselves as Black Other make up 0.9% of the UK population. Black, Irish and other minority ethnic groups experience high levels of social and maternal deprivation when compared with the majority White population. The Black or Black British community, which comprises Black Caribbean, Black African and Black Other, are significantly smaller in number compared to the Asian or Asian British community and the White and Mixed Heritage populations. Currently, the Black or Black British community remains larger than the Chinese and other minority populations, living in the UK (ONS, 2011).

In the main, the African and African Caribbean community tend to live within the inner-city areas and over half are British born. They tend to experience poorer health, have reduced life expectancy and have greater problems accessing appropriate health and social services (Nazroo, 1997). In terms of mental health, there are major concerns around the disparities and inequalities in terms of rates of enduring mental health problems, experience of service provision and recovery outcomes. Enduring mental health problems are also referred to as severe/serious mental illness (Moller et al, 2008; Jeon et al, 2005); major mental health disorders; chronic mental disorders; psychosis and psychoses and neuropsychiatric disorder (Jenkins et al, 2003; Falloon, 1993). These mental health problems are to be distinguished from common mental health problems, which include anxiety, depression, phobias, obsessive-compulsive disorder and panic disorders.

Typically, enduring mental health problems are diagnosed using one of two classification systems, that is, the World Health Organization (WHO) International Classification of Disease (ICD-10) and Diagnostic Statistical Manual Version IV devised by the American Psychiatric Association (APA – 2000). Whilst such classifications have their uses in terms of determining treatment plans, the causation of enduring mental health problems is a much more complex interplay of biological, psychological and social factors.

Cantor-Graae and Selten (2005) suggested that migration might also be a psychosocial risk factor for developing schizophrenia in certain individuals. A study by Cantor- Graae et al (2003) found there was an increased risk for developing schizophrenia for all migrants in Denmark, particularly amongst migrants from Australia, Africa and Greenland. Therefore, it seems important to review the potential impact of migration history, on the incidence of EMHPs in African and African Caribbean communities in the UK.

Bhugra and Jones (2001) described a stage approach to understanding migration, indicating that migrants experience misdiagnosis of schizophrenia. This involves three stages of migration. In Stage 1: pre-migration occurs when the individual makes a decision to migrate and subsequently prepares for this process. Stage 2: is the actual physical relocation of the individual from their home country to another. At Stage 3: the individual is in post-migration and is considered to be integrated into the social and cultural framework of the new country, social and cultural rules and new roles can be learnt at this stage Other terminology used to further define this stage is adaptation, assimilation and acculturation. Their presenting symptoms may be more of a reaction to being out of their home country, the culture shock of a new country and the experience of loss and ultimately feeling socially excluded. Other factors may stem from whether migrants were invited to the host country or forced to migrate due to lack of employment; poor quality of life in their own country or to seek refuge in the host country away from religious and/or political persecution. Simultaneously, the African and African Caribbean carers' approach to caring for their family member could be influenced by these complex factors.

1.1.3 The impact of migration history on the incidence of EMHPs in African and African Caribbean communities

Within the stress vulnerability model of risk for psychosis, immigration is considered an important life event and prolonged difficulties in assimilation could lead to the onset of psychosis (Coid et al, 2008). However, the high rates of psychoses indicated in African and African Caribbean populations in the UK (as opposed to those living in Africa and the Caribbean) has been strongly associated with discrimination or increased levels of social adversity experienced by both communities in the UK. The increasing incidence of psychoses in second-generation descendants from both communities, migration of first generation migrants from Africa and the Caribbean still continues today. This may have inferences for the development of psychoses and emergence of multiple family carer roles in both communities. Bhugra (2004) described migration as a family or a group of families seeking a better way of life (increasing opportunities) or joining other members of their families who may have already moved to establish themselves. Migration may concern a group of individuals moving together to avoid religious persecution or to seek religious freedom. Bhugra and Becker (2005) proposed that during the third stage of a migration process, referred to as *post-migration* an individual can experience culture shock, discrepancy between expectations and achievement of goals, as well as acceptance by the host nation. A further two definitions refer to how individuals adjust post-migration; these are referred to as *acculturation* and *assimilation*. Acculturation is the process of cultural, social and psychological exchange that occurs when two cultures interact (Bhugra, 2001). Assimilation is the process of complete transfer to another culture at the loss of one’s won cultural traditions (Bhugra and Becker, 2005). Several authors (Morris, 2013; Eltis, 2000; Richardson, 1992 and McGowan, 1990) have attempted to describe the unique experience of the African and African Caribbean migration to the UK which initially started with a forced migration from the West coast of Africa to the Caribbean and USA. During the late 1940s through to the 1960s, individuals living in the Caribbean were invited to live and work in the UK. Thus began a mass migration of people from the different Caribbean islands with the promise of employment, better wages and a better way of life. Many believed that they would be experiencing equal rights as British citizens and had a high expectation of assimilation and acculturation (Mead, 2009).

1.1.4 The influence of the Tri-Continental Slave Trade

Dabydeen et al (2008), in the Oxford Companion to Black History, refer to the Tri-Continental Slave Trade as the Transatlantic Slave Trade or Atlantic Slave trade. The trading of slaves took place across the Atlantic Ocean and between three continents. These included Africa, Europe and the Americas. The Tri-Continental Slave Trade occurred during the sixteenth to nineteenth century and involved the forced transportation of African slaves, orchestrated by the political and commercial endeavours of Europe and then in America. At first, it was a simple trading process of slaves, goods and other trade from the central and western parts of the African continent. However, it became, increasingly more complex and large scale.

The economic focus of the British trade was London, but the centre of the slave trading shifted from London to Bristol and to Liverpool. Glasgow also came to dominate the slave trade in the production of slave-grown tobacco from the Chesapeake. Slaves were considered cargo of ship owners, sold to labour coffee, tobacco, cocoa, cotton and sugar plantations, gold and silver mines, rice fields, construction industry, cutting timber for ships, and as house servants. The Atlantic slave traders included the Portuguese, the British, the French, the Spanish, the Dutch and the Americans. They had established outposts on the African coast, where they purchased slaves from local African tribal leaders.

Current estimates are that about 12 million people were shipped across the Atlantic. Although slavery was practiced in some parts of Africa, Europe and the Americas before the onset of the Tri-Continental Slave Trade, the Atlantic Slave Trade was the largest volume of slave trade and with the greatest intensity. The consequences of the Tri-Continental Slave Trade were enormous, at their most extreme helping to bring down the indigenous African states and encourage violence and warfare in search of prisoner -slaves for onward sale to traders on the coast.

Early records show that black people have lived in Great Britain in small numbers since at least the 12th century, but it was the growth of the British Empire that signalled their increasing numbers during the 17th and 18th centuries (Banton, 1955; Shyllon, 1992; Sadhu, 2010). Britain was involved with the tri-continental slave trade between Europe, Africa and the Americas (John and Muirhead, 2010). Black people predominantly from Africa, were enslaved and ferried across the seas to work on plantations in the Caribbean or the Americas where they were involved in hard labour (Sadhu, 2010; John and Muirhead, 2010).

Other black people, in much smaller numbers, were ferried into the ports of London, Liverpool and Bristol. Black slaves were attendants to sea captains and ex-colonial officials as well as traders, plantation owners and military personnel. They transported to Britain on the same ships that brought imperial products such as tea, sugar, cotton, coffee, rum, fruit, wine, tobacco and oil to enrich the national economy (Sadhu, 2010; John and Muirhead, 2010).

Slaves were seen as reassuring companions, who might allay some of the loneliness felt by white expatriates on their long voyages back to the country they had not seen for years. Many of these black people were forced into begging due to the lack of jobs and racial discrimination they experienced. Although many black communities grew up in the port cities of London, Liverpool and Bristol; slave ships were also known to have used the South coast ports of England, namely Portsmouth, Cowes, Poole and Weymouth. The city of Southampton also traded with the West Indies in sugar and timber. Subsequently a number of West Indians settled on the south coast of England, including the coastline of Dorset and in towns like Winchester. This information gives some background to the socio-cultural integration of African and African Caribbean people in different regions of the UK, which were not always inner city areas, but south coast towns.

Slavery remained legal in Britain until 1772, and many Africans found themselves working as butlers or other household attendants in aristocratic families. Their duties were not necessarily onerous; their chief function often seems to have been to look decorative; thereby serving as an equivalence of the porcelain, textiles, wallpapers and lacquered pieces that English nobility was increasingly buying from the East (Banton, 1955; Shyllon, 1992; Sadhu, 2010).

Around the 1750s, London became the home of many Black, Jewish, Irish, German and Huguenots. Black people comprised somewhere between one and three per cent of the London population (Sadhu, 2010). Evidence of the number of black residents in London was found through registered burials.

Slavery was abolished in Great Britain in the 1830s; following this period, the First and Second World War brought in a steady migration of what were mainly seamen, army, navy and air force members from the Caribbean and Africa. The two very significant migrations of Caribbean people were when the *'Empire*

Windrush' ship arrived at Southampton from Jamaica in 1948. Again, in the 1950s, 1960s and early eighties, there was an influx of immigrants from both Africa and the Caribbean prior to the introduction of immigration laws which then saw a reduction in migration from these areas.

The current situation is that there are now first, second, third, fourth and fifth generations who consider themselves 'Black British' living in mainly inner city areas of the UK. Today, although the African and African Caribbean share very strong historical ties and a number of cultural traditions and beliefs, they are two distinct communities within the BAME groups. Nazroo (1997) found that African Caribbean people, born in the UK or immigrated below age 11 years were more likely to suffer from mental health problems and this has become an increasing concern, not only for the mental health services who serve these communities but also the family carers who invariably take on the burden of care.

Bhugra (2004) suggested that migrating from a rural location to a crowded urban city environment could increase stress, but not necessarily increase the rates of schizophrenia. He supports this with incidence data from countries in the Caribbean, like Jamaica (Hickling and Rodgers-Johnson, 1995); in Trinidad (Bhugra et al, 2000) and Barbados (Mahy et al, 1999) where the incidence of psychosis is lower than reported in the African Caribbean community in the UK. This does not explain the high incidence rate of EMHP in the second generation of African-Caribbean communities when compared to the first generation.

The onset of an enduring mental health problem like schizophrenia may 'cause' people to migrate in the sense that illness may have contributed to a restless desire to seek migration and/or that some vulnerable people choose to migrate and the possible stress of migration may lead to them developing schizophrenia. A number of research studies reveal evidence of migration causing stress and relate this to the stress diathesis model (Bhugra, 2003 & 2004, Cantor-Graee and Selten, 2005). The stress diathesis model infers that individuals can be predisposed (vulnerable) to certain stressors (life event or series of life events, which disrupt the psychological well-being of a person) that occur in their lives (Belsky and Pluess, 2009). When a combination of the predisposition and stressor exceeds a certain threshold, this increases the chances of a person developing a mental health problem. However, Bhugra (2004) suggest that this is difficult to conclude because elevated rates of schizophrenia occur 10 – 12 years after migration, which makes it less likely that stress due to migration, could be a causative factor.

Migration of individuals between the UK and Africa and the Caribbean has taken place for centuries and usually involves first generation descendants, who then decide to settle in the UK. Therefore, it is important to consider what influence migration may have on how family carers cope with caring for their unwell relative. Given the important role of carers in supporting those with EMHPs, it is important to consider the impact on family life of living with a relative who has an EMHP, for carers from both of these communities.

Some of the issues, for carers from the African and African Caribbean community living in the UK, relate to: i) the consistent high rate of incidence of enduring mental health problems in both populations which is now indicated in second, third and fourth generation descendants; ii) fears of discrimination and racism which stem as far back as the Tri-Continental Slave trade, that may have a psychosocial bearing on issues of mental illness and well-being; and iii) issues of forced migration and acculturation to living in the

UK iv) perceptions of black people by UK society and the wider British community.

1.1.5 Post-colonialism and mental health

In the post-colonial period following Tri-Continental Slavery, psychiatrists and medical practitioners questioned whether black people experienced mental health problems, suggesting their brains lacked the sophistication to develop a mental illness (Halliday, 1824).

Hickling and Hutchinson (1999, 2000) proposed that the incidence of psychosis experienced in Caribbean and African populations living in the UK maybe a symptom of forced migration and enslavement that has resulted in years of actual and perceived lack of acceptance in UK society. Much of these experiences were born out of the subsequent migration to England from the Caribbean, starting in 1948. Many of the Caribbean population who travelled to the UK, considered themselves members of British society, but met with a very harsh racist environment when they arrived in the UK. Indeed, this population from the Caribbean may have perceived themselves as 'White' because many were colonised within a British and/or European culture. Hickling and Hutchinson (1999; 2000) refer to this phenomenon as the '*roasted breadfruit syndrome'* which refers to people who although from the African and Caribbean community and black-skinned, tend to identify with a White/European way of life. This dichotomy between being acculturated into a predominantly British/European way of life through slavery and then remaining very close to and practising indigenous African and Caribbean traditions remains with the current generations from both communities living in Britain today. Hickling and Hutchinson (1999; 2000) suggest that the high incidence of enduring mental health problems in African and Caribbean communities in the UK could stem from a ‘double jeopardy situation.’ This is characterised by individuals who struggle with racial identity and a racist environment that still places significance on the impact of skin colour and its association with social acceptance into British society. This in itself presents an additional stressor for both the carer and the cared for person from both the African and African – Caribbean communities living in the UK.

1.1.6 Rationale for the study

It is evident from an examination of the background literature that there have been important influences on how carers assume and perceive their role but the picture remains fragmented. Therefore, the key rationale was to add to the limited literature on informal carers and in particular the experiences, needs, challenges and burdens of the African and African Caribbean communities.

In addition, as the voice of carers from BAME communities is largely silent, and, there is an ethical need to advocate for a group who experienced discrimination. This is, not just, because they are carers, but also because of the ‘stigma by association’ of caring for a person with an enduring mental health problem. Research studies on carers acknowledge that mental health carers experience high levels of subjective burden generally (Vella and Pai, 2013; Rowe, 2012; Saunders, 2003).

Previous mental health research which has included carers from both communities is often dominated by the cared for person’s experiences of mental health care, and more specific information about the carers’ experience of caring is absent (McLean et al, 2003; Keating et al, 2003; Wilson and Francis, 1997). Instead, carers are considered an extension of the health care experience of service users, rather than individuals in their own right. Incidence of schizophrenia in the African and African Caribbean community has been reported since 1960s and there remains a high incidence of schizophrenia since that time (McGovern and Cope, 1987; Dean et al, 1981; Hemsi, 1967).

Why focus on family carers and not service users?

Lawlor et al (2012) reported some ethnic variations in how service users (men and women) from the African and African Caribbean community accessed mental health services. Results showed that service users were less likely to access mental health services during a crisis and tended to make contact via use of the police services, compared to their White British counterparts. The admission rates to mental health in-patient services remains higher than average among individuals from the Black and White/Black Mixed heritage communities (Care Quality Commission (CQC) and National Mental Health Development Unit (NMHDU), 2011; Coid et al, 2008). However, this also presents an on-going challenge for family carers. In addition, there are pressures that come with being 'African' and 'African Caribbean' in the UK, where communities have experienced a number of social disadvantages in the form of, racism, unemployment and poor housing. Furthermore, differential perceptions of cultural identity, inter-generational differences, impact of migration through adaptation, assimilation and acculturation, can lead to more distress. Family carers are acknowledged as providing most of the community mental health care. A focus on the caring experience could highlight how service users experience their social world when they return home and live in the community. This may have inferences for their motivation to engage with statutory services and their approach to self-management of their mental health problems. Understanding different family approaches to managing mental health could also be shared or reveal maladaptive coping strategies which require more support. Weich et al (2012) in a study, which explored the illness and treatment experiences of service users and the experience of their carers, found that service users had negative experiences of in-patient mental health and community mental health care. In the case of community mental health care, service users experienced limited contact through one-off appointments or receiving home visits. However, home treatment teams were described as most effective due to more frequent contact times and more inclusion of the family in planning care with service users and professionals. In order to understand the experiences of carers from both communities there is a need to appreciate the complex sociocultural, psychological and practical challenges they face.

In order to ‘hear’ the voices of this group of carers, it was important to use a research method that best served this purpose and to develop the necessary skills in eliciting the phenomenon of ‘caring’, which not only describes the experiences of carers, but also interprets the wider meaning of their caring experiences through the language they use. As such, a phenomenological method was chosen to explore the complex caring experiences of African and African Caribbean informal carers of relatives with an EMHP, living in the Southern England.

1.2 Personal Motivation for the study

My interest in this topic stemmed from my role as an informal carer (which started in the 2nd year of my nurse training, over 20 years ago) and my experiences as a mental health nurse. I also share the same ethnicity as the participants in the study and a bi-cultural heritage, born in England to parents who refer to themselves as British Caribbean.

Working in an acute in-patient unit in a London mental health trust, I became all too aware of the importance of family carers not only in their role of helping a family member through the recovery process, but also seeing them as 'partners' in care and how more effective I became in my delivery of care. Equally, there were many opportunities to share in their cultural background and traditions, which shaped their values and subsequent attitudes to caring for their family member and this in itself was invaluable.

Being an informal carer for my mother who was diagnosed with rheumatoid arthritis (and polyarthritis), half way through my general nurse training, presented a challenge of adapting the home environment. I also encouraged other family members to learn new skills, which allowed them to share in the care of my mother. There was the additional challenge of becoming a qualified health professional with knowledge of the NHS, and the competing demands of continuing as an informal carer and my commitment to my role as a general medical nurse. Eventually I was able to balance both of those roles with relative ease, as my mother regained more independence with tailored medical treatment and I was then able to train and qualify in a second nursing registration as a mental health nurse.

However, when I then took on an interim caring role for a family member with mental health problem, the most stress-inducing period was the unpredictable nature of mood, behaviour, thought and general communication which at first was very bizarre and rendered me feeling 'powerless' to help even as a mental health nurse.

Another very important experience for me took the form of supporting a friend who was a primary carer for her daughter, recently diagnosed with an enduring mental health problem. The mental health staff failed to recognise signs of distress and displayed by the carer and despite her attempts to get more information about mental illness, she eventually left her daughter and went home in frustration. There were also cultural issues that arose about the kind of food her daughter liked to eat and the importance of her faith in coping with her illness. Staff did not consider these cultural issues in their care delivery, which meant increasing distress for both patient and carer.

However, although my informal carer role enabled me to empathise with other carers and influenced my motivation to carry out this study, I am very much aware that the context of caring was not the same as those of the carers in this study. In that regard, I hope to provide a spotlight, which illuminates their perspectives of caring for their family members. This was in order to answer, the research question, *"What is it like to care for a relative with an enduring mental health problem, in contemporary Britain?"*

1.3 Research aim and objectives

As indicated the overriding aim of the study was to explore the caring experiences of African and African Caribbean carers of and the objectives were to:

- Describe the caring experiences of African and African Caribbean carers caring for family members with different enduring mental health problems. These experiences were inclusive of the point at which carers' relatives started to experience signs and symptoms of mental illness and the subsequent contact with mental health and social care services.
- Explore how the caring experiences differed to other ethnic groups who care for relatives with an EMHP
- Examine the relationship between African and African Caribbean carers and their family members; the wider community; mental health, social care services and other public services.

The research sought to make a significant contribution to the literature describing the experiences of African and African Caribbean carers. It is anticipated that the study will provide a) further information for mental health and social care professionals, regarding the health and social care needs of African and African Caribbean carers and b) have a positive influence and impact on service users' journey from illness to wellness and recovery.

1.4 An overview of the thesis chapters

Chapter 1: Introduction: In this chapter, the reader is introduced to the epidemiology of BAME population in the UK, to indicate population density across ethnic groups. The current incidence of EMHP in African and African Caribbean communities living in the UK has consistently risen over the past 10 years. This is significant in reviewing the actual and potential concerns for family carers, as well as the cared for person. It further considers the implications this has for mental health and social care services.

Chapter 2: Literature Review: This details the search strategy in relation to caregiving research with African and African Caribbean carers from both national and international sources. Further background is provided on the impact of caring for carers from the Black, Asian and Minority ethnic communities in the UK. The development of carer policies alongside health and social policy reflects government involvement in shaping informal carer definitions. UK Carer policy has introduced a number of systems designed to support mental health carers from ethnic minority communities, some of which includes updated legislation on race and discrimination. The connections between families and perceptions of mental illness and well-being are equally considered in the context of caring for relatives with EMHP. Local community group approaches to social engagement of families from both communities in services designed to support both carer and cared for person, finalise this chapter.

Chapter 3: Methodology and Research Design: This describes the study methodology, design and ethical considerations. The content draws on the principles of hermeneutic phenomenology using Max Van Manen’s approach to guide a research design that would reveal the life world of the carer participants in this study. The rationale for choosing this research methodology is discussed. Issues of rigour and ethical considerations are also discussed in relation to the research process. The process of analysis is presented and the strategies used to enhance the trustworthiness of the findings.

Chapter 4: **Findings**: This presents the carer profiles and the findings, under the essential themes, which emerged from carer narratives.

Chapter 5: **Discussion**: This chapter reviews the findings of this study and discusses these in relation to current carer research literature, conceptual frameworks on care giving and the wider context of African and African Caribbean family carers in mental health.

Chapter 6: **Conclusion and Recommendations**: The final chapter draws on the main conclusions of this study before reviewing the strengths and limitations of the research undertaken. The relevance of the findings is considered with regard to implications for practice and recommendations for future nursing research.

2. Chapter Two: Literature Review

2.1 Introduction

The experience of caring for a family member with enduring mental health problems has been widely documented in the literature. Research studies can be categorised into two study groups: those, which explored the objective burden[1] of caring and those, which focussed on the subjective burden[2] experienced by family carers (Ahlstrom et al, 2009; Tranvag and Kristoffersen, 2008; Kartalova-O'Doherty and Doherty, 2008). These research studies were underpinned by the conceptual framework of *family caregiving w*hich suggests that caring for a person with an EMHP has a negative impact on the family life and is increases the burden experienced by family (Awad and Voruganti, 2008; Corrigan and Miller, 2004; Saunders, 2003).

Other research studies have focussed more on the emotional environment of families who care for a relative with an EMHP and subsequently developed an *expressed emotion framework* (Brown, Birley and Wing, 1972). This framework places emphasis on how high expressed emotion of families is indicative of patient relapse of mental illness (Kuipers et al, 2007). There is substantial evidence in the research literature to support the high levels of distress experienced by family carers of a relative with an EMHP, and the strategies used by families to manage their stress. This area of carer research is

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[1] **Objective burden** is defined as the presence of disruptive patient behaviours; which can be observed by others and consists of measurable effects (costs) on the household such as helping, supervising or financial aid

[2] **Subjective burden** is defined as the distress family members feel as a result of the patient behaviours; a relative's own perception of the impact of caring such as the experiences and emotional responses of a carer.

influenced by the *family stress and coping framework* which proposes a process of carer stress, which leads to use of coping strategy and ultimately leads to adaptation to the carer role (Mackay and Pakenham, 2011). None of these frameworks had an initial focus on different ethnic groups and family care giving.

Another conceptual framework focussed on the degree of resiliency in families during stressful life events. Furthermore, the emphasis was on how families responded to stress through the process of adjustment and adaptation. This led to a model of caring entitled, 'The *Resilience Model of Stress, Adjustment and Adaptation*' developed by McCubbin and McCubbin in 1996. In the model, the *'adjustment phase'* is where the family of carers only make minor changes in how they operate from day to day, in response to the 'stressor' which in this case refers to the onset of mental illness in the cared for person. McCubbin and McCubbin (1996) cited in Rungreangkulkij and Gilliss (2000) proposed that if the family is successful in response to the stressor, they produce a positive outcome, known as '*bonadjustment*'. Although this framework does allude to the influence of ethnicity in how families manage stressful events – to date, there has been limited research on the how this occurs in mental health carers from the African and African Caribbean communities in the UK.

Some carer research studies have explored the experience of family carers from different ethnic groups, for example, the Chinese community (Chang and Horocks, 2006); the South Asian community (Hepworth, 2004) and the Egyptian community (Endrawes et al, 2007). However, considering the high incidence of EMHPs in this ethnic group, very few studies have explored the experience of caring among the African and African Caribbean communities.

2.2 Search Strategy

A search strategy was used to identify all published research in relation to the experiences of carers from the African and African Caribbean communities who cared for a family member or spouse with an enduring mental health problem *(Appendix 2)*. This revealed a number of gaps in the carer literature on African and African Caribbean communities.

Published literature was identified using a combination of search methods, which included a) electronic database searching, b) hand searching and c) cross referencing (where reference sources in on journal article were accessed for information relevant to my research topic). The electronic database search centred on the period 1990 to 2008 and adapted to run in other databases and websites *(Appendix 3).*

During the 1990s there was a move towards more research on the experience of family carers in mental health care and some emphasis was placed on exploring the reasons for high incidence of enduring mental health problems in individuals from the African and African Caribbean community. It was important to include within the search strategy any UK Census information on African and African Caribbean carers. In the UK Census for 2001 a postal survey was administered to all UK households in 2001, and from this subsequent data were collected on the number of carers in the UK which was also included as part of this literature review. As part of the review, any literature that captured perceptions of mental illness and mental well-being, from the African and African Caribbean communities was also included. This latter exploration of the literature provided the context in which carer roles within families were established.

2.2.1 Defining the focus of the review

Grey literature was obtained by direct communication with other carer researchers. The focus of the review was on African and African Caribbean carers’ experiences of caring for a relative with enduring mental health problems. Enduring mental health problems included schizophrenia, dual diagnosis, clinical depression, bipolar disorder and personality disorder.

The literature review process commenced with reading current UK carer policies, which identified BAME Carers as one of the vulnerable carer groups in the UK. To appreciate the significance of the carer experiences it was necessary to make use of both the 2001 UK Census and the 2011 UK Census information (ONS, 2011, OPCS, 2001) and the literature on models of family caring. Equally, it was necessary to review the past carer research on the caring experiences of carers of persons with EMHP, regardless of their ethnicity, in order to compare the current study findings. Websites associated with BAME Carer groups were searched for information e.g. NBCCWN; Afiya Trust and Carer UK. A number of community engagement projects could be accessed via the Google search engine linked to BAME initiatives for patients and carers in mental health.

In terms of specific searches on African and African Caribbean carers of people with EMHPs, it was very important to review studies from the literature on incidence of EMHPs within each of these respective communities, which gave some insight into the experiences of service users with mental health and social care services, and how this affects their carers.

A number of different search terms were used in order to gain access to the literature on African and African Caribbean carers who cared for a relative with enduring mental health problems and a full list if these terms are presented in Appendix 3. However, the search terms which gleaned information relevant to this research topic were; ‘African Caribbean carers and psychosis’; ‘Black, Asian Minority Ethnic Carers’; ‘Community Engagement Projects for BAME Communities in the UK’; ‘Ethnicity and Mental Health in the UK’.

The review literature included community engagement projects, published research studies, health care reports and policy papers. To be considered relevant to this study they needed to meet the following inclusion criteria:

2.2.2 Inclusion Criteria

- Reporting on the experience of African and African Caribbean adult carers who care for a relative or spouse with enduring mental health problems.
- Focused on carers who were caring for adults with enduring mental health problems which include schizophrenia, borderline personality disorder, dual diagnosis, bipolar disorder and severe depression, but not organic disorder.
- Written in English.
- Reflecting on both mental health and social care service perspectives.
- Must be informal carers who are either close family relatives or spousal partners, but not professional, paid carers.

- Must be published in recognised peer-reviewed journals or other credible sources such as government reports, or third sector population based studies.

2.2.3 Exclusion Criteria

Where literature that only included child carers or young carers (who are under 18 years of age) of adults with mental health problems; carers of persons with physical health conditions only, this information was excluded from consideration.

2.3 Selection of literature for review

Full text articles and community project reports were read and reviewed independently against the inclusion criteria for relevancy. Twenty articles and reports were identified for this literature review. Six of the articles and reports were however excluded either because they were a) a repeat study of the articles included in this review, b) solely discussed carers from other BAME groups i.e. South Asian point of view or c) focused on carers from the same community who were caring for a relative with a physical health problem (e.g. stroke, advanced progressive diseases which included cancers, dementia, motor neurone disease), or a learning disability d) Department of Health reports which reviewed carers in mental health in the UK, but focused on BAME carers as a whole, rather than as a specific ethnic group.

By the above process, 14 papers were identified as relevant for inclusion in the review and the main findings recorded on a data-extraction sheet. Papers not meeting the inclusion criteria were excluded from the review. However, these -

papers provided useful background information to the health and social care experiences of BAME communities in the UK.

Of the fourteen articles and reports remaining, five of these were research studies published in peer-reviewed journal articles. Two of these, were regional based research studies. One larger scale study was conducted by a national voluntary organisation that represented carers from BAME communities. The remaining six were community engagement project reports funded by the National Institute for Mental Health in England (NIMHE – now known as the National Mental Health Unit (NMHU) and set up as part of the "*Delivering Race Equality in Mental Health Services Action Plan*" (DoH, 2005). A list of carer related experiences were then grouped into five overarching themes that make up this literature review.

2.3.1 Overview of Black, Asian and Minority Ethnic (BAME) Carers' experiences who care for a family member with enduring mental health problems

Black Asian Minority Ethnic carers in the UK are estimated to save the government approximately £7.9 billion a year, which is 41% of local authority total spending on social care (Carer UK, 2011). There are (according to Carer UK, 2011) estimated to be 503, 224 people from Black, Asian and Minority Ethnic communities in the UK, who look after a relative or a child, a partner or a friend, who needs help because they are ill, frail or have a disability. Research published by Carers UK during Carers Week in 2001 revealed that BAME carers were considered the most 'unseen and unrecognised of the large population of hidden carers in the UK'.

According to 1991 and 2001 UK Census data, the highest proportions of Black Asian Minority Ethnic communities lived in London. Currently, Black Caribbean carers represent 0.9%, of all carers or 44,402 carers. Unemployment is highest amongst carers from Black Caribbean communities (21%) (Carer UK, 2011).

Atkins and Rollings (1992) provided one of the earliest comprehensive UK reviews of Afro-Caribbean and South Asian experiences of care-giving roles. These care-giving experiences were influenced by a) migration patterns; b) generational and gender differences in the care of family members; c) the invisibility of black carers and d) language barriers within the Afro Caribbean community, which involved the use of dialectical language, usually in the form of 'broken English'. This review highlighted some of issues for carers from the African Caribbean community, which were unique from both White and Asian communities living in the UK.

2.3.2 Carer Policies, Mental Health Policies and Race Relations Legislation in the UK

Since the 1990s, there have been a number of government policies and legislation, which recognise the need for more carer information, separate carer assessments and more carer support. These include the *Carers (Recognition and Services) Act 1995,* which focused on the carers need for information advice and practical support (DoH, 1995). The *Carers and Disabled Children Act 2000* gave carers new rights to assessment and services independently of the cared for person (DoH, 2000). As part of the *National Service Framework for Mental Health* (DoH, 1999b), carers of people with an EMHP were to have annual needs assessments and personal care plans. These policies stress the importance of strengthening carers’ rights to assessment and support through application for direct payments and opportunities for respite from their carer roles. However, there has been very little reference, if any, to the needs of carers from BAME communities.

It was not until the NSF for MH (DoH, 1999b) was brought in, that there was a specific focus on carers of people with mental health issues and those from vulnerable communities, such as Black, Asian and Minority Ethnic communities.

That same year, the government launched the National Strategy for Carers (DoH, 1999a) document. This document emphasised the importance of local authorities involving carers more, in decision making and planning of care for the person they support. It laid out the mechanisms for supporting carers in employment; encouraging the business community to employ carers. Support for carers also included additional training on aspects of mental health, and increased support for young carers. The introduction of a second pension for unemployed carers or those on low income meant local authorities had a Carers' Grant to provide respite care for carers.

In the workplace, the *Employment Act (2002)* gave parental carers of children rights to request flexible working hours. The *Work and Families Act (2006)* extended rights to employees who care for an adult.

The Labour government built on the NSF for MH, (DoH, 1999b) and the NHS Plan (DoH, 2002b) by introducing reforms to improve mental health service provision for people from Black, Asian Minority Ethnic communities, through two key documents and census information on in-patient mental health admissions.

The first of these was published by the Department of Health (DoH, 2003), entitled "*Inside Outside: Improving mental health services for Black, Asian and Minority Ethnic communities in England"* report which aimed to reduce ethnic inequalities in service users experience of mental health services. The report recommended the building of an NHS workforce that had more cultural capabilities to care for a diverse population.

In March 2005, the Healthcare Commission published the first national *'Count Me In'* census which provided information on all mental health patients including admissions, demographic characteristics, ethnicity, language and religion; this was to be carried out on an annual census until 2010 (Care Quality Commission, 2011; Commission for Health Care Audit and Inspection, 2008; 2007b; 2007a; 2005).

The Labour government has persisted with tackling issues of institutional racism and poor access to services, which saw the introduction of the *Delivering Race Equality (DRE) in Mental Health Services (2005)* policy. This included a five year action plan aimed at developing more appropriate and responsive services; increased community engagement through employing 500 community development workers (CDWs) and provision of better information for BAME communities. Both documents signalled a requirement for all mental health and social care practitioners to deliver care in accordance with the *Race Relations (Amendment) Act (2000)* and the *Disability Discrimination Act 1995* and 2005 (DoH, 2005; Bhui et al, 2003; DoH, 2003).

When the government introduced the *Carers (Equal Opportunities) Act* (2004), there was a focus on looking at the socio-environmental issues that impact on caring and a desire to ensure that carers were given more choice and opportunity to have fulfilling lives.

This meant that carer assessments involved discussion of carer's leisure, training and education, work and housing situation in relation to their caring responsibilities.

In 2006, in the White Paper '*Our Health our care, our say'* (DoH, 2006), the government introduced a *'New Deal for Carers'* which established the Standing Commission on Carers in 2007; set-up a training programme for carers called '*Caring with Confidence*' in 2008 and launched an information helpline and website in 2009 (DoH, 2008).

Before change of government in 2010, the Labour Party carried out a major review of the National Carer Strategy of 1999 and brought in a new carer strategy '*Carers at the heart of 21st century families and communities'* (DoH, 2008).

This new carer strategy promised more financial investment (this was in addition to the Carers Grant) into statutory and voluntary organisations. More emphasis on additional awareness training for staff in statutory services; developing increased carer premium on income-related benefits; a carer-specific programme was introduced at Jobcentre Plus, Skills Health Check in careers service and adult advancement sites. Carers also had access to annual health checks from their primary health care services. Health promotion campaigns sought to raise awareness of caring in schools and conducting surveys of carers' experiences to date in 2011 Census. This was to form part of the Labour government's 10-year action plan for 2018 (DoH, 2008).

2.3.2.1 Carer Policy in the United Kingdom

In 2010, under the new coalition government, a new carer strategy was launched entitled, '*Recognised, valued and supported next steps for the carers' strategy'* (DoH, 2010). This document emphasised the need for health and social care services to focus on carers' health needs, through carer assessments, supporting carers to be more involved in the decision making around care. The strategy also repeated the need for carers to access respite care and to have more opportunities for paid work. However, it did not outline the degree of 'involvement' that carers can have in service planning and in the design of the care packages. It was also remiss in indicating to staff how this sort of partnership approach can work, which may be what is required. The strategy also hoped to encourage carers to fulfil their educational and employment potential. It was unclear what specific guidance would be in place for educational institutions and employers. A working group was set up to advise carers and employers was set up with a view to helping carers maintain individualised, personalised support enabling them to have a family and a community life. Again, the decision to reduce or cut local community services that carers found helpful to living an independent life did little to support that form of self-management.

Finally, the strategy contended that it would support carers to remain physically and mentally well. However, there was limited guidance on how GPs were to identify carers or help carers identify themselves and their needs? Along with this strategy, the government published an outcome report on carers and personalisation. The report gives several examples of how personalisation was introduced and worked for carers and has a very person-centred approach, which is interspersed with 'whole family *approaches'* to supporting the carer. The report endorses the carer as an 'expert' in his or her own right with a clear rationale for developing partnerships with statutory services. This report also acknowledges the different types of carers including black and minority ethnic carers. Examples of whole family approaches include '*family group conferencing'.*

The current austerity measure initiated by the coalition government and the subsequent reduction in the number of formal health and social care services may already negate a number of the strategy's key objectives for supporting carers in the UK. Equally, BAME carers in the UK, already experiencing social disadvantage, this was now an added burden.

Carers UK (2011) carried out a review of informal care in the UK and found that BAME carers faced a number of problems in terms of accessing support. They were less likely to be consulted about any impending hospital discharge or receive additional support from their GP, abut their carer role. Carers were also more likely to miss financial support or receive practical support. Therefore, despite the acknowledgement of BAME carers' in UK health and social care policies, both research studies and health and social care service provision reveal a low uptake of services from these communities (Carers UK, 1998; 2011).

However, BAME carers of individuals diagnosed with mental health problems also experience additional barriers to caring, which include i) gaining equal access to mental health and social care; ii) language, literacy and comprehension, iii) psychological and socio-economic impact of migration history to the UK, iv) perceptions of care, caring and mental health and mental illness; v) increased poor health, vi) low visibility in the communities they reside due to low population density and vi) institutional racism, which presents as lack of culturally sensitive services, (through lack of awareness and misconceptions of family cultural traditions, like faith and religion). Despite recognition of the importance of family carers in the recovery of their relative, mental health and social care services have ignored this carer role (Carers UK, 2012a; 2012b; 2012c).

Previous studies have found that BAME carers do not readily identify themselves as carers; they tend to see caring as part of the customary or familial role. In 1998, the Social Services Inspectorate suggested that there exists a common assumption that BAME communities like to '*look after their own*' (DHSSI, 1998). The notion that they should be identified or considered separately from the person they care for can be perceived as 'alien' and more likely to damage familial relationships. There may be other reasons why BAME communities are perceived as '*looking after their own'*. Yeandle and Buckner (2007) found that when affected by poor health and financial difficulty BAME communities sometimes face particular difficulties which include i) concealing ill health; ii) experiencing lower levels of employability; iii) being held back by reduced opportunities for social participation; iv) lacking the type of support they need as individuals and v) being hampered by limited coping skill. However, inter-generational differences may foster a perception of care and caring and being a carer that is very similar to their white counterparts for third and fourth generations of BAME communities.

BAME carers tend to access mainstream services as a last resort and are concerned about the lack of 'culturally sensitive' services (that is services that acknowledge the cultural identity of carers and what bearing this may have on their approach to caring). BAME carers are more likely to use these local BAME community organisations for support preferring the accessibility and appropriateness of the services provided. Because many of these organisations are dealing with a variety of issues, however, advice on caring may not be a priority (Carers UK, 1998; 2011; Haynes, 1996 and 1997). When BAME carers have contact with statutory services, they have also been concerned that there is not enough information on services provided in a range of languages. Some examples of differences between carers' approach and level of involvement of caring from different ethnic groups is useful in highlighting the reason for conducting research on individual ethnic groups of carers.

2.3.3 African and African Caribbean who care for family members with an enduring mental health problem

Research on carers from the African and African Caribbean communities who care for a person with an enduring mental health problem is sparse, but this review highlights a number of themes, which are indicative of the focus of research of carers from both of these communities. This section of the chapter will focus on African and African Caribbean perceptions of mental health and well-being. In addition, the psychological impact on African and African Caribbean carers who experience negative contact with mental health and social services is explored. The emergence of several inner city mental health initiatives for African and African Caribbean people places further emphasis on the unique ways of engaging with both communities. Consideration will be given to the problem of different terminologies used to describe ethnicity in the UK. Following the '*Delivering Race Equality in Mental Health Services' (2005 - 2009),* (DoH, 2009a) policy, the reader is informed of the current approaches to setting up culturally sensitive mental health and social care services for African and African Caribbean communities.

2.3.3.1 African and African Caribbean communities' perceptions of mental illness outside the UK

Any discussion about perceptions of mental illness and mental health services by both African and African Caribbean communities living in the UK needs to explore further the wider cultural perceptions of mental health from the continent and countries of origin in Africa and Caribbean. This may go some way to explaining the community barriers to accessing mental health services in the UK for both these communities.

Gureje and Alem (2000) stated that the majority of countries in Africa have populations sustained on low incomes, high levels of communicable diseases and malnutrition, with low life expectancy and poorly staffed health services. Attitudes to mental illness are influenced to a considerable extent by traditional beliefs in supernatural causes and the use of various remedies. This can further stigmatise those individuals who have been diagnosed with mental health problems and their families. At the same time, policy makers may perceive mental health as 'incurable' and consider this as a low priority for appropriate health care provision.

Gordon (2011) supports this view and reports a lack of mental health policy to date across Africa, which leaves mental illness a largely hidden health care issue. This reflects the perceptions of mental illness in the First World countries like the UK in the Victoria era through to First and Second World War period. Barke et al (2011), in a study, which explored the stigma of mental illness, in Southern Ghana, found that patients reported a high degree of experienced stigma, with secrecy used as a predominant coping strategy.

Outdated legislation on mental health can also compound the delivery of mental health care in both Africa and Caribbean countries. An important aspect of the community care in Africa strongly acknowledges the role of families in caring for sick family members. However, the onset of urbanisation and the daily challenges of surviving the social disadvantages that prevail may mean that not every family will want to care for their relative who has a diagnosis of mental illness. Perceptions of mental illness can be strongly influenced by its very interpretation in the different colloquial languages that exist in both Africa and the Caribbean. Gordon (2011) cites a study in Uganda where the term depression was culturally inappropriate; the terms *'Yo'kwekyawa* meaning '*hates oneself'* and '*Okwekubagiza'* meaning '*pitying oneself.'*

Deribew and Tamirat (2005) carried out a community based cross sectional study, which showed that community members of a town in Agaro, Ethiopia, perceived '*talking to oneself, sleep disturbances, strange behaviour* and *aggression* as the most common symptoms of mental illness. The well-educated tended to prefer modern medicine as an approach to treatment with the hope of a fulfilling life, whereas the less well educated were more negative in their perceptions indicating reduced marital prospects and work opportunities as representing a hopeless situation. Kabir et al (2004) presented a similar outcome in cross sectional study in Northern Nigeria, which found that 46% of respondents preferred orthodox medicine and 34% preferred spiritual healing.

Kohn et al (2000) carried out a survey on attitudes to mental illness with two communities living on the Caribbean island of Dominica. Respondents included community members and community leaders, who included nurses, teachers and police officers. All were given case vignettes of individuals with different mental health problems. Findings indicate that most of the respondents were able to recognise severe mental illness correctly; however, in the other three vignettes only 30% of respondents felt there was a mental health problem. More concerning was the fact that the community leaders did worse than community members.

Neckles et al (2011) reviewed the literature on mental health stigma in the Caribbean. This review acknowledged the diversity of Caribbean cultural values and beliefs, which emerged from the different colonial influences of France, Spain and Britain. They found that most Caribbean individuals attribute the onset of mental illness to punishment by God and demonic possession or curse.

These research studies imply that there are certain perceptions of mental health within countries like Africa and the Caribbean, which may influence any perceptions of individuals, who have been diagnosed with an enduring mental health problem.

2.3.3.2 Family carers' perceptions of mental health services in the UK

Initial research studies in the UK in the 1990s focused on the attitudes of relatives to the mental health services and the impact this had on the treatment of the cared-for person (Morley et al, 1991; McGovern and Hemmings, 1994). The view taken was that high rates of Afro-Caribbean patients compulsorily admitted to hospital were due to the attitude of relatives. Many expressed negative attitudes to mental health services and who perceived non-medical explanations to be the reasons for the onset of the cared-for person's mental illness.

Haynes (1996, 1997) argued that one of the strengths of the African and African Caribbean community has always been its tendency towards self-reliance and self-help. He suggests that different health and social care agencies have not been quick enough to exploit this strength; instead, they have been more anxious to condemn the failings of the family, than to endorse its relative merits.

Morley (1991) found that that none of the relatives (of black patients admitted informally and compulsorily) presented the negative attitudes hypothesised, and were in fact very similar to their relatives from the white community in their views. The study recommended that future services evaluate the interaction between family members and statutory mental health provision (Birchwood et al 1992).

McGovern and Hemmings (1994) found that 80% of black relatives judged patients as having no responsibility for their psychiatric symptoms compared to 94 % of white relatives. Seventy eight per cent of black relatives said they would seek initial help from a medical or psychiatric source if symptoms recurred (again, it is unclear what relatives knew about symptom recognition of EMHPs). More black than white relatives attributed mental health problems to substance abuse, particularly abuse of cannabis. Black relatives felt that day centres for black people were beneficial; however, it is unclear exactly how day centres were beneficial to families. They also found that black relatives had a conception of mental illness that was the same as white relatives. Nevertheless, this study was not specific about what these conceptions of mental illness were. For family carers of people with mental health, the relationship with professional health and social care services is crucial to their carer role.

2.3.3.3 The psychological impact of African and African Caribbean carers who experience negative contact with mental health services

Two studies looked at the psychological impact on service users and carers/relatives when making any contact with mental health service, this time with comparisons being made between the experiences of mental health professionals, police services and local black communities/voluntary groups (Keating and Robertson, 2004; McLean et al, 2003).

Keating and Robertson (2004) interviewed families and carers who expressed their fears about the unpredictability of their relatives' symptoms; researchers highlight that this may be due to lack of understanding about how different mental health problems present. Carers were also anxious about the lack of immediate response from local mental health services to their cries for help. Other fears centred on carers' perceptions of the power dynamic between themselves and mental health professionals.

Carers felt the need to 'tailor' their communication and attitudes to mental health professionals, for example, feeling the need to be silent in meetings, so that their relatives would not experience 'negative' responses to care. Their perception that psychiatrists had the power to incarcerate their relatives in high secure establishments with limited access was a very real fear. This study focussed on service users and carers from the African or Caribbean community. However, mental health professionals could have been from any ethnicity. They were also only required to work with service users from the African and Caribbean community. As this was a study about circles of fear between service users/carers and mental health professionals, knowing the ethnicity of mental health professionals would have been useful in either ruling out ethnicity as an issue of fear or acknowledging ethnicity as being part of the circle of fear.

The study by McLean et al (2003) revealed African-Caribbean modes of self-expression. This was in reference to the different turns of phrase, customs, and particular to African Caribbean community members, which were repeatedly misinterpreted by health practitioners as signs of pathology. They refer to vernacular use of language and a loud mode of social interaction as examples where normal behaviour was interpreted by (white) mental health staff. The fact that many African Caribbean communities primarily speak English tends to mask any specific cultural difference in language. Therefore, any African Caribbean language vernacular (as indicated in broken English or ‘Creole’) is not necessarily perceived as requiring special interpretation.

McLean et al (2003) suggest that the lack of acknowledgment of a dialectical language can diminish the confidence of the African Caribbean community and is likely to reduce engagement with mental health services. Both carers and service users perceived 'social exclusion' as an everyday experience, expressed through racism (which may also be a reflection of wider societal experiences). Many felt it was important to develop a more positive cultural identity, which moves away from the historical cultural identity experienced through slavery – because this was affecting their relationships with mental health services.

The use of their 'ethnicity' in a positive way through increasing knowledge of cultural traditions e.g. types of food, ways of expressing themselves, verbally and non-verbally, the wearing of their hair – are all significant in African and African Caribbean culture. Some carers and service users felt there were culturally appropriate services emerging, but not at the pace, they would like, and they worried about local council's commitment and local NHS trust commitment to maintaining this type of provision. Although McLean et al's (2003) study involved interviewing mental health practitioners, service users and carers from the African and African-Caribbean community; the outcome seemed to categorise carers and service users experiences as "one in the same". In addition, there was no clear definition of the terms African and African-Caribbean.

Finding out what the cultural traditions of the African and African Caribbean community are in comparison to other ethnic minority groups, does not need to be an arduous task (Gerrish et al, 1996). However, recognising that these are actually two distinct communities who share some traditions can present quite a further challenge to practitioners.

Hickling and Hutchinson (1999; 2000) proposed a cultural specific psychotherapy for service users which acknowledges that the African Caribbean community (which has the highest incidence of psychosis compared to the African community) has a cultural history where they were transported not only from Africa, but forced to adopt a British/European culture – experiencing further disruption to their cultural identity. The experience of family carers may be influenced by these post-colonial issues that affect the mental health of their relative.

2.3.3.4 Cultural traditions and language in African and African Caribbean communities

Despite the fact that African and African Caribbean communities have acculturated the English language and culture, there is an assumption that all African Caribbean people will for example eat English foods, whereas Asian people will eat Asian food provided (Gerrish et al (1996). African and African Caribbean communities use slightly different skin and hair care products compared to all other ethnic groups and take particular pride in their skin and hair products, which enhance well-being. This requires special black hair products, which are added items for family carers to get and pay for.

The usual language of African and African Caribbean communities living in the UK is English, but this may have its own cultural dialect, which could be Creole or Patois, both of these are unique to each of the Caribbean islands and to each country within the continent of Africa. Whilst most African and Caribbean people have a good command of verbal/written English – their language is expressed colloquially and in the UK, this may not be widely accessible to the wider the community, they live in (Gerrish et al, 1996; Atkins and Rollings, 1992). Putting cultural traditions aside, the context of inner city living in the UK, also heralded a number of social influences on carers experiences.

2.3.3.5 Inner city mental health initiatives for African and African Caribbean communities

Later studies indicated a response to incidence data on EMHPs in African and African Caribbean communities. These studies looked at ways the number of compulsory admissions to acute in-patient hospital could be reduced by developing more community-based services for these communities. Inner city mental health initiatives were introduced, in the form of community projects became involved in partnership working with primary and secondary mental health services as well as service users and carers from the respective communities (Watters, 1996; Jennings, 1996; Rai-Atkins and Joseph Rowntree Foundation (JRF), 2002).

Watters (1996) reported on an initiative designed to meet the needs of Afro-Caribbean and Asian service users in London, which also included relatives and carers. A relative's support group was set up for Afro-Caribbean carers, which gave members an opportunity to share experiences, receive mental health education on medication and legal aspects of mental health provision. Family carers shared the difficulties they faced with their relatives and the difficulties relating to different statutory agencies. However, exactly what specific carer needs and experiences were not evident. It was also not clear whether relatives had a primary or secondary carer role, if any carer role at all, in the relationship with service users. There was reference to relatives and carers and no clear differentiation was made between the two. Depending on the perceptions at that time, it is not clear whether the term 'Afro-Caribbean' also included individuals of African descent. The study highlighted the need to restore a sense of identity and personal pride for both service users and carers, through reviewing cultural history and traditions. This seemed to become a source of building self-esteem and eliciting hope for service users and carers.

The project employed a multi-racial professional team whose goal was to work in partnership with primary and secondary mental health services. However, this proved problematic as each of these services had a different philosophy and focus on mental health care. This posed inter professional conflicts between professionals, but also between professionals, carers and advocates.

Another problem with the initiative was the limited funding available, which means that they either become absorbed into the statutory services thereby risking a low referral from the target groups and therefore an unequal service provision. However, issues of inequalities in mental health service provision remained and the incidence of EMHPs in these two communities was still very high.

Watters (1996) discussed the influence of having a) an Afro-Caribbean Development Worker and b) a relatives' support group. Both proved to be most empowering to Afro- Caribbean carers and relatives; the Development Worker proved effective in responding immediately to the needs of carers, and served as an advocate for both service users and relatives. This role facilitated the emergence and reflection on, more positive use of language, around mental health, and perceptions of black people with mental health problems. However, with initiatives like this, it is difficult to gauge how much involvement carers had in developing these roles.

Jennings (1996) highlighted a lack of clarity about how involved Black carers could be involved with service set ups like this and how much involvement they actually wanted to have. Black carers as well as users also could not understand the 'slow pace' of mental health services in getting their needs addressed – which suggests educating the community about what is feasible within certain timescales and what isn't practical, to increase awareness and reduce the ensuing anxiety. This could be a possible way forward for mental health practitioners with to revise their perceptions of the African and African Caribbean community, and to review the ways they prefer to interact with any voluntary or statutory mental health service provision.

A regional research study by Rai-Atkins and The Joseph Rowntree Foundation (2002) supports this perspective. Their study highlighted the need for more effective advocacy services in mental health for BAME communities. However, whilst it acknowledges the importance of addressing service users and carers needs from these communities, little was said about how much carers knew about mental illness, little emphasis was placed on education about mental health and more emphasis was placed on i) education about mental health services available ii) cultural needs and iii) mental health service processes – which does not help people to learn about what mental illness is or its prevalence. Interestingly this would be an empowering aspect as an advocate. However, this study included participants from three ethnic communities, namely South Asian, African and Caribbean communities. The study also had participants who were both service users and carers – study outcomes suggested that the carer experience of advocacy from statutory and informal support groups was the same as the service user.

The diversity of the African and African Caribbean community, as well as the changing perceptions of these communities have led to different terminologies being used to describe their ethnicity in research studies. This poses a problem of representation across both communities.

2.3.4 The challenge of different terminologies used to describe ethnicity

Further problems arise when researchers use different terminology to describe both race and ethnicity in African and African Caribbean communities that highlights a number of ethnic variations.

In the research carried out by CSIP (2007) and NHS west Midlands Development Centre (2009) reference was made to service users and carers as 'Black African and Black Caribbean'. These terms have been more commonly used in the UK and refer to individuals and their offspring from Africa or the Caribbean. However, there are challenges to the meaning behind this term, which indicates location. Different groups may perceive themselves very differently and have no strong affiliations with either Africa or Caribbean. An example would be people born in Britain to Caribbean parents.

Keating and Robertson (2004), Rai-Atkins et al (2002) and Jennings (1996) refer to the participants in their studies as 'Black People'. Here the term ‘Black’ is generally assumed to refer to a person of African ancestry. However, within the area of politics, the term is also used to differentiate individuals who are of non-White minority from the White population and this can carry a number of stereotypical meanings of ethnic groups that has the potential to be offensive.

The term 'Afro-Caribbean' was used by Watters (1996), McGovern and Hemmings (1994) Atkins and Rollings (1992) and Morley, (1991). Also the terms 'African’, ‘African-Caribbean’, and ‘Caribbean' has been used in the work of NBCCWN, (2008); Keating and Robertson, (2004); McLean et al, 2003; and Rai-Atkins, 2002).

These terms have mainly been used in Europe and North America. Again, they refer to individuals with African ancestry who migrated via the Caribbean and as noted in the above studies, this term has been used inconsistently in the UK. Some people use it to refer to people who are Black and Caribbean, others to refer to people of either West African or Caribbean descent.

Notably there are differences between the African and Caribbean culture, which relate on a macro level to location and on a micro level relate to language and diet. Agyemang et al (2005) suggested that these variations are enough to acknowledge that putting both Caribbean and African populations in the same homogenous ethnic group can mask the differences between them.

The current term used in the UK to demark all ethnic groups has also been used with different emphasis in research studies with 'Black and Minority Ethnic Communities' (for example NBCCWN, 2008; Downes, 2006; DHSSPS, 2004; NCSSDO, 2002).

Agyemang et al (2005) explained part of the confusion has to do with the fact that race and ethnicity are used interchangeably as synonyms; both words have also changed in terms of definition over times and can be contextually defined. At any point in time, any of the terminologies above can be considered offensive and discriminatory; as such, a move towards the self-definition of race and ethnicity is favourable. In this study whilst African and African Caribbean have been used as 'overarching terms to reflect two ethnic groups', I have been careful and respectful of how each carer describes their own ethnicity and race. However, it is important to note that terms are developing and evolving all the time and what may be an acceptable choice of term in one time period may be unacceptable in another period.

2.3.4.1 Terminology of culture, ethnicity and race

In order to appreciate the nature and meaning of the caring experience for carers from the African and African Caribbean communities in this study, reference will be made to their ‘culture’, ‘ethnicity’ and ‘migration’ pathways. Nadirshaw (2009) described ‘culture’ as a way of life symbolised by family patterns of behaviour; values, beliefs, traditions and language. Culture is dynamic and is as much about the immediate environment in which the individual resides as well as the wider community.

Ethnicity, or ethnic identity, was defined by Botsford et al (2011) as based on the notion that people identify with particular social groups in respect of cultural factors. These cultural factors derive from a tradition of common descent or intermarriage and a shared culture or history. A further definition affirms ethnicity as a sense of belonging, a perception of common heritage shared by a particular group or community, where heritage involves attention to social history, use of language, rituals, and preferences for music and foods (Spector, 2004).

As the carers in this study make reference to feeling like the mental health care environment is discriminatory towards them and their unwell relative, it is pertinent to give a definition of ‘race’, which is often used interchangeably with ‘culture’ and ‘ethnicity’ in research on Black and minority ethnic carers. Cooper and David (1986), in epidemiological research studies, refer to race as the grouping of people based on biological and physical similarities. This definition remains contentious; recent definitions of race refer to it as a more socially constructed definition. The term race is often used in an uncritical manner to define socio-political factors pertaining to different ethnic minority communities (Vickers et al, 2012).

Despite the emergence of various anti-racist policies in the UK (Race Relations (Amendment) Act 2000) the term ‘race’; is still used as an indicator of difference between ethnic groups in the UK. Informal carers in mental health invariably have contact with mental health and social care services, in their caring role. Ekman and Emani (2007) relay that health care and social care services in the UK have failed to deliver satisfactory and effective health care to both patients and their carers.

Research further demonstrates the fact the patients and carers from ethnic minority groups feel exposed when meeting with health care and social care professionals. Furthermore, they report experiencing insufficient communication and social interaction during these meetings. Keating and Robertson (2004) acknowledged that not only are African and African Caribbean communities over-represented within mental health services, it is also the social group to which the greatest level of fear seems to be directed within society as a whole. Establishing a dialogue with mental health and social care services presented one of the foremost challenges for carers in this study, but all were able to find that dialogue and some form of partnership with mental health and social care services after several abrupt and distressing interactions.

The NBCCWN (2008) debated the importance of recognising that 'ethnic' and 'racial' origin is not the only way to define a minority population and throughout their report *"Beyond We Care"*, they define 'Black people' as belonging to the Asian, African, African-Caribbean, Chinese and Vietnamese descent. The report acknowledges that all of these groups are culturally diverse, but indicates that they all share the common experience of racism and discrimination. However, the frequency and intensity of experience in these two areas is variable across cultural groups (Rai-Atkins, 2002).

The other issue with any of these terminologies is the specific 'racial identity' of individuals from these communities. It is quite possible to have a White African person and White Caribbean person in both of these groups. None of the research reviewed seem to clearly address this factor in their sampling, indeed the research reviewed seem to suggest that 'racism' only occurs with individuals who are considered to be the 'black' people in these respective communities.

In order to address issues of institutional racism experienced within mental health services in the UK, the Labour government, brought in a policy with a specific set of action plans to foster more community engagement with communities that felt excluded and lacked adequate mental health provision (DoH, 2003; 2005).

Following the introduction of the government, paper *Delivering Race Equality in Mental Health Services* (DoH, 2005) several community based engagement projects were set up across England to address the specific mental health and social care needs of vulnerable individuals and their families from the BAME communities. A few studies included both relatives and carers from the African and African Caribbean communities (Spinks et al, 2008; CSIP and UCLAN, 2007; Atkinson et al, 2007; Downes, 2006). These will be discussed in more detail in the sections that follow.

2.3.5 Setting up of culturally sensitive mental health services for African and African Caribbean communities – Post DRE policy

Following the introduction of the Delivering Race Equality in mental health Services Action Plan (DoH, 2005) a number of already established the community engagement services were given financial support to develop advocacy services for carers and service users from the different black and minority ethnic communities. As such, some studies emerged which focused on reviewing carers' experiences of these projects.

The National Black Carers and Carer Support Workers Network (NBCCWN) (2008) conducted the largest scale study of BAME carers in England to date. This included African and African Caribbean carers. The NBCCWN (2008) found that carers wanted more personal, face to face contact with statutory mental health services and valued the 'outreach' experiences of community engagement projects, befriending demonstrated by voluntary/charity organisations who addressed their specific cultural needs.

However, local voluntary services did not always possess the skills of caring or the knowledge and information about referral and signposting to statutory services, which carers of relatives with enduring mental health problems needed. Haynes (1996, 1997) discussed the main barriers to using self-help as an intervention within the 1980s were that i) statutory services passed the 'buck' to local community groups, some of whom were not equipped to provide all mental health information and support to family carers, and were really providing services on the cheap; ii) the use of potential or actual failed role models (he gives no specific examples, of what these would constitutes) can only reinforce feelings of inferiority and feed the consequences of racial prejudice within the African and African Caribbean communities.

NBCCWN (2008) showed no indication of carers' understanding of what EMHPs were and how symptoms present, the research seem to focus on carers of people with a range of health problems. .

The CSIP and UCLAN Community Engagement project (2007) introduced a befriending service for BME communities which carers found effective in reducing loneliness and isolation in BME service users. Carers also felt there was a lack of support from staff when visiting their relatives in hospital, in terms of updates on the recovery of the care recipient and orientation to the in-patient mental health services. Carers wanted more mental health awareness and education, which they believed would help in reduce the stigma of mental illness, which occurs at the same time for service users and carers, particularly where both live together. Again, this situation is not unlike how services were in the 1980s for carers from these communities.

Haynes (1996, 1997) discussed the effectiveness of self-help groups (these were developed out of necessity and the need to address a range of issues for the different BAME communities) as an intervention for in the 1980s inner city area of the UK. He proposed that self-help should be supported by statutory services for two reasons a) existing services are perpetually stretched and plagued by meeting the demands of either unrealistic government targets or cutbacks (a situation which has recurred several times and remains in the 21st century mental health services and b) each BAME community does have specific needs and there is a need for identity role models from their own ethnic group.

CSIP and UCLAN (2007) did not specifically focus on carer experiences, despite participant profiles including ex-service users, carers, and service providers. In addition, it was unclear as to whether the carers in this study were from statutory or non-statutory organisations. Carer numbers were small and their ethnicity unclear.

Downes (2006) found that one of the BAME carers needs included advice and information on health - no further information on carers' knowledge of mental health signs and symptoms indicated. This study indicated a very small sample of participants from the Caribbean (4 in total out of 11 participants) and no African carers were interviewed in this study. The study was focussed on Black and Minority Ethnic carers in general from different ethnic groups. This made it difficult to decipher the specific needs of the Caribbean participants in this study. It was also unclear as to whether carers were family carers or community carers working with statutory services.

Spinks et al (2008) in their study to explored the experiences, perceptions and knowledge of carers and service users engaged with mental health services. They found carers gave a balanced view of mental health service provision, but also indicated that the needs of their family members were not met through a) lack of cultural and religious needs b) staff changeover through different types of leave and c) not enough practical day to day support with their caring role. Fears about racism within the service were also discussed in this study and voluntary groups served as a kind of respite for carers. However, this research study covered carers of adolescents and young adults with mental health problems only. In addition, the study did not have a fair distribution of participants. There were 3 service users, 6 carers and 36 non-service users, a distribution which does not indicate fair representation of African and African Caribbean carers. In addition, the participants comprised both African Caribbean and South Asian people. The study does not clarify the definition of African Caribbean, but notably both African and Caribbean carers' narratives were included in the findings.

Atkinson et al (2007) found that African Caribbean community members (a mixture of carers and service users) joined the Mental Health Guide (MHG) programme because many wanted to get a better understanding of mental health issues were, particularly the causes and the solutions. In terms of the actual training experience, those who joined the MHG programme valued the learning they gained about mental health issues. It is unclear, exactly what these issues were and how their learning and understanding was evaluated, particularly from the other trainees who were service users and small project groups.

At the start of the course, a few people had little understanding of mental health issues and their discriminatory comments made others feel uncomfortable. This emphasised the need for more learning on mental health, with a greater focus on recovery, and key information about procedures during a section of the Mental Health Act, medication and the care programme approach (CPA). The service users and carers on the MHG programme felt that more experiential learning from other service users, carers as part of the training team. Two additional training sessions about mental health were given qualified status in response to feedback. One of the recommendations suggested that MHG training sessions should take place within all mental health services e.g. sports and recreation, which promote mental health and recovery from mental illness.

More recently, some research has evaluated local community engagement models used to support African and African Caribbean communities who have relatives with mental health problems (NHS Midlands, 2009). The work by NHS Midlands Research Development Centre (2009) presents four community based models of mental health care, which have successfully used with African and African Caribbean Communities. However, only two of these models start to look at the actual experience of caring for a loved one who has been diagnosed with any of the EMHPs. Furthermore, none of the models indicate what the actual carer experiences were and what impact this had on carers, who are already part of communities which endure a significant amount of discrimination, and social exclusion within the UK. The models and approaches to care will be discussed in the section below.

2.3.6 Models and Approaches to Care for African and African Caribbean Communities in the UK

Rai-Atkins (2002) highlighted the benefits of black advocacy service provision as gateways to contact with mainstream services. However, researchers expressed concern that the study had problems with accessing carers directly through mainstream or black voluntary organisations in the East Midlands and Yorkshire areas. The rationale given was that there were no black advocates that could assist with this access; mainstream white advocacy groups did not report any black service users and carers taking up their support, and the few black-led advocacy services found, were poorly resources in terms of both funding and human resources.

The NHS West Midlands Regional Development Centre (2009) reviewed four models of care for African and Caribbean communities. Three of these models reviewed have been devised based on work carried out by Professor Kamaldeep and Professor Kwame McKenzie, i.e. The Enhancing Pathways into Care (EPIC) model.

Model One refers to use of a partnership encompassing Outreach approach (between Sheffield African and Caribbean Association and Sheffield Mental Health Trust) to reducing length of stay for inpatients already known to the service. There was a great improvement in modes of communication with patients and between mainstream and voluntary services to manage this process. Again carers are mentioned almost as an add-on. It is unclear how much partnership involvement they will have in the care process, for example, what about service users and carers not known to the service, and how this group could be accessed.

Model Two was based on developing an understanding of how Black African and African Caribbean men accessed the assertive outreach team, with a view to enhance effective pathways out of care, in Birmingham and Solihull Mental Health Foundation. This model indicated the importance of partnership with carers and family and devised different modes of information exchange. This meant that there was better access to those unknown to the mental health services. This model allowed for work on the specific barriers to access and used a solution-focused approach to address these barriers. Relationships with third sector agencies were vastly improved and there was a clear emphasis on the importance of patient narratives as an implicit part for therapeutic support for patients and carers.

Model Three involved use of an Antenna Outreach approach that offered a more holistic approach to supporting service users, by focusing on the socioeconomic issues, which affect mental health e.g. housing, employment, benefit, for African and Caribbean people aged between 16 and 25 years old. The model was based on the principle that high visibility and low impact that involves families and carers from the point of assessment and works well with service users know to the services. The outcome with this model was a reduction in the number of service users placed under section of the Mental Health Act (1983), low rates of carer depression, 50 % of service users engaged with education and found employment once they made contact with this service. The service worked by making direct visits to service users and their families.

Model Four was based on the African Caribbean Community Initiative (ACCI) Wolverhampton – African Caribbean Outreach Support and community service for mental health. The service goal here was to improve and prevent mental ill health among African, Caribbean and Dual Heritage adults, which included carers, and involved operationalising support process for families that were accessible. This model highlighted strong carer empowerment and involvement in setting up more culturally appropriate services and accessing funding support to maintain several initiatives.

For all four initiatives, based on different models, were unclear in their definition of African and African Caribbean the reader is left unsure about this was a provision for both ethnic groups or predominantly for on ethnic group. All four initiatives were located in inner city areas, with a high population density of people from African and African Caribbean backgrounds; – and does not focus on carers who live in areas (more commonly referred to as, semi-rural and rural areas, located outside of cities like London, Bristol, Liverpool, Birmingham, Nottingham).

Direct communication and establishing partnership relationships with African and Caribbean members of the community were important features of each model; however, it seems the essential component of each, which was most influential, was the presence of service providers from the same community as service users and carers.

2.4 Summary

There is a substantial body of literature that has considered the impact of caring, for the carer of people with enduring mental health problems. However, the fact that incidence of EMHPS are elevated in African and African Caribbean communities in the UK, poses on on-going challenge to carers (Claasen et al, 2005, Carta et al, 2005). This incidence appears to have increased with third and fourth generation descendants (from the most recent migration of African and African Caribbean people to the UK). With concerns about institutional racism, stereotyping and the current socioeconomic picture, there is a need to capture the experiences of carers from these respective communities. (Kirkbride et al, 2008; Karlsen et al, 2005 and Sharpley et al, 2001).

An extensive review of the literature into African and African Caribbean carer experiences reveals research, which combines service users and carers' experience of mental health illness and mental health provision. In addition, research has also compiled these experiences alongside carers from other

BAME communities, which implies that all BAME carers have the same experience of caring. Most of these studies are research based on regional community engagement projects, which focus on a) BAME carers who care for relatives/spouse with enduring mental health illness and b) the African and African Caribbean carers in the UK. However, some have been short-term projects with poor funding and limited opportunities for evaluating the impact on the community. Many of these studies highlight the negative impact of caring and have not indicated the positive aspects of caring –this may be influenced by the research teams, being made up of ex – service users and carers who have been at the receiving end of poor delivery of mental health care and support.

NBCCWN (2008) highlighted that there was a lack of recent baseline data regarding the numbers, role and experiences of carers from BAME communities. Regional and community based projects have conducted studies which draw out some distinctions and impressions unique to these communities. Few studies have specifically explored the wider experiences of the different ethnic groups, who have unique cultural traditions and conceptions mental health and caring. Considering the high incidence of psychosis in the African and African Caribbean community in the UK, very few studies have explored the caring experience of carers from these respective communities. Consequently, this study has the potential to make an important contribution to the understanding of mental health carers from the African and African Caribbean community living in the United Kingdom.

3. Chapter Three: Methodology and Research Design

3.1 Introduction

The purpose of this study was to gain an understanding of the caring experiences of African and African Caribbean carers caring for a family member with an enduring mental health problem. As previously indicated, phenomenology was the chosen method used to explore the day-to-day lived experience of adults who cared-for their family member who had enduring mental health problems which included paranoid schizophrenia, bipolar disorder or dual diagnosis (substance misuse and a mental health problem). The objective was to uncover the essences, describe, and interpret the meaning of caring for these communities of carers.

3.1.1 Choosing a methodology

A qualitative design was used to capture the personal experiences of family and spousal carers from the African and African Caribbean community. Based on a desire to gain an understanding of what carers of the African Caribbean community were experiencing, a phenomenological approach was identified as the appropriate method for conducting this type of study. Groenwald (2004) infers that where the intention of research is to gather data regarding the perspective of participants about a specific phenomenon, a phenomenological design becomes a rich source of data (Adams and Van Manen, 2008). To simply explain phenomenology, Cope (2005, p168) offers this definition:

> "The aim of phenomenological inquiry is to understand the subjective nature of the 'lived experience' from the perspective of those who experience it, by exploring the meanings and explanations that individual's attributed to their experiences."

3.2 Phenomenology as a philosophy

Phenomenology emerged as a philosophy in Germany during the late 18th century, with the work of Kant and later Hegel (1770-1831). Hegel, who published a significant work on the term, called *'Phenomenology of Spirit'* in 1807; perceived the mind, although a universal structure, to hold information that changed over time. The Greek word for phenomenon is '*phaenesthai'*, which means 'to flare up, to show itself, to appear' (Dowling, 2007, Moustakas, 1994). Phenomenology became a philosophical movement in the 19th century when Franz Bretano (1859 – 1938) referred to it as 'descriptive psychology'. Bretano's philosophy was based on intentional relationships, referring to 'intentionality' as perceiving, judging, loving, and caring. Edmund Husserl (1859 - 1938) adopted Bretano's intentionality to understanding of conscious acts and individual experiences.

3.3 Phenomenology as a research approach

As previously stated phenomenology has its roots in philosophical tradition, and arose as a philosophy in Germany, before World War One (Dowling, 2007). However, later, phenomenology emerged as one of the group of qualitative research methods (Norlyk and Harder, 2010; Dowling, 2007, Price, 2003; Polit and Tatano-Beck, 2006). As a philosophy, phenomenology questioned the traditional role of science.

More recently, phenomenology has developed into a human science and is used by a number of professional disciplines e.g. education, business and law, clinical psychology and health sciences.

Phenomenological research is the study of the lived experiential meaning and attempts to describe and interpret these meanings in the ways that they emerge and are shaped by consciousness, language, cognitive and non-cognitive sensibilities, and by pre-understandings and presuppositions (Adams and Van Manen, 2008).

Phenomenologists ask what is the essence of this phenomenon as experienced by these people and what does it mean? (Polit and Tatano-Beck, 2006). Moustakas (1994, p13) provided another description of phenomenology as:

> '…a return to experience in order to obtain comprehensive descriptions that provide the basis for a reflective structural analysis that portrays the 'essences' of the experience.'

Phenomenology can carry different meanings depending on theoretical and practical contexts. The many perspectives of phenomenology can be located in various forms in the positivist (Husserl); post-positivist (Merleau-Ponty); interpretivist (Heidegger) and constructivists paradigms (Gadamer) (Dowling, 2007). This chapter will focus on the positivist and interpretivist forms of phenomenology, which influenced the chosen phenomenological approach used in this study.

Husserl suggested that all these conscious acts and experiences were internal. Husserl's phenomenology involved the detailed examination of things, as they appear in order to understand and appreciate human experiences. To keep an objective stance on these experiences, Husserl devised a process of ‘phenomenological reduction’ or ‘bracketing’ which facilitated the ‘setting aside’ of subjective perceptions in order to capture the essence of the emerging phenomena.

Husserl had developed descriptive phenomenology as a philosophy and now a method of natural inquiry into the lived experience of things themselves, which Husserl considered was the centre point of all knowledge (Dowling, 2007; Smith et al, 2009). In terms of a philosophy, phenomenology is concerned with what things are, not whether they are. The purpose of phenomenological inquiry is to enter into the experience of another through the art of reflection and use of intuition.

Martin Heidegger (1889 – 1976), a student of Husserl, agreed with Husserl on the concept of understanding human beings within the context of their lifeworld. Lifeworld refers to the ‘…everyday life we are busily engaged in the world ….and often a taken for granted experience of the world’ (Smith et al, 2009, p 13). However, Heidegger differed from Husserl in how he perceived the exploration of the lived experience. Heidegger felt that it was not enough to describe the experience but that an interpretative process was also involved and necessary for gaining a fuller understanding of that human experience.

Heidegger brought in the use of hermeneutics (interpretative) phenomenology and was interested in the existence of ‘self ‘and the how the self exists from a worldly perspective. Inter subjectivity is a phenomenological concept used in phenomenological research which refers to the shared, overlapping and relational nature of ‘our’ (people) engagement in the world. In other words, it is how we account for our ability to communicate with, and make sense, of each other (Dowling, 2007; Smith et al, 2009).

In order to accommodate both perspectives, this study uses the work of Canadian phenomenologist Max Van Manen. This uses both descriptive and interpretative phenomenology.

For Van Manen, thematic aspects of experience can be uncovered through participant descriptions of the experience by three methods a) the holistic approach b) the selective approach and c) the detailed approach. In the holistic approach, researchers review the text as a whole and try to capture its meanings. In the selective approach, researchers highlight those statements or phrases that seem essential to the phenomenon under study, in this case, the phenomenon of caring. In the detailed approach, the researcher analyses every sentence. Through this process, essential themes are uncovered (Polit and Tatano-Beck, 2006) which expose the 'essence' of the phenomenon under study.

In this phenomenological study, I as the researcher, sought to reveal the meanings and essences of the experiences under study, with a view to gaining a richer, more in depth, descriptive and interpretative account that elicits a better understanding of the phenomenon of 'caring'. By listening to carers from the African and African Caribbean community who care for family members with enduring mental health problems, it is hoped that a new understanding will be uncovered.

3.4 The Phenomenology of Van Manen

In Van Manen's phenomenological approach there is no set rule regarding the research process. However, he does present six research activities, which give a hermeneutical structure to the study. These include: a) turning to the phenomenon which seriously interests 'you' and commits 'you' to the world; b) investigating experience as we live it rather than as we conceptualise it; c) reflecting on the essential themes which characterise the phenomenon; d) describing the phenomenon through the art of writing and re-writing; e) maintaining a strong and orientated relation to the phenomenon and f) balancing the research context by considering parts and wholes.

3.4.1 Turning to the nature of experience of caring

My own experience of caring and my observation of others experiences drew me to the phenomenon of caring. Heidegger refers to this as being ‘situated’ in the contextual nature of this human experience. The situated person experiences an ‘embodiment’, which allows experience of their lived world. The essence of carer experiences is hidden in the language they use and how they use it.

3.4.2 Investigating experience as we live it rather than as we conceptualise it

This activity takes the reader through the process of recruiting the purposive sample through to the hermeneutic interview and the experience of interviewing carers is combined with attending to the lived experience discussed by each carer.

3.4.3 Reflecting on the essential themes which characterise the phenomenon

There are four key life world themes which Van Manen (1990) described as important to the lived experience: lived space or spatiality; lived body or corporeality; lived time or temporality and lived human relation or relationality (and sometimes referred to as lived communality). The challenge in this activity is to be able to distinguish between general and essential aspects of a theme.

3.4.4 Describing the phenomenon through the art of writing and re-writing

Van Manen (1990) stated that through writing and re-writing, one is able to examine the ‘essence’ of a phenomenon. By examining the essence of caring for the carers in this study, I sought to contribute an objective and rigorous approach to understanding the caring experience.

3.4.5 Maintaining a strong and orientated relation to the phenomenon

It was important to follow Van Manen’s six activities and encompass the three-stage approach to eliciting essential themes, in order to develop my skills of interpreting the meaning of caring for the carers in this study. This was by no means an easy task, as I found myself regularly revisiting (through a reflexive approach) ways to capture the essence of caring. This was done through group exercises facilitated, at a two-day workshop, which was delivered by Adams and Van Manen (2008), prior to interviewing the carers.

3.4.6 Balancing the research context by considering parts and wholes

The commonalities between the essential themes of the interviews transcribed were identified, and these led to the uncovering of the essences of caring, discussed in the findings of Chapter 4.

Figure 1 illustrates the more detailed association between the research activities of this study and the researcher’s role in the research process.

Figure 2 shows the process involved in analysing the transcribed conversations of carers and uncovering the lived caring experience of the carers.

Figure 1: Phenomenological Research: Outlining the Framework

Adapted from Van Manen (1984): Doing Phenomenological Research and Writing: An Introduction (Adams and Van Manen, 2008).

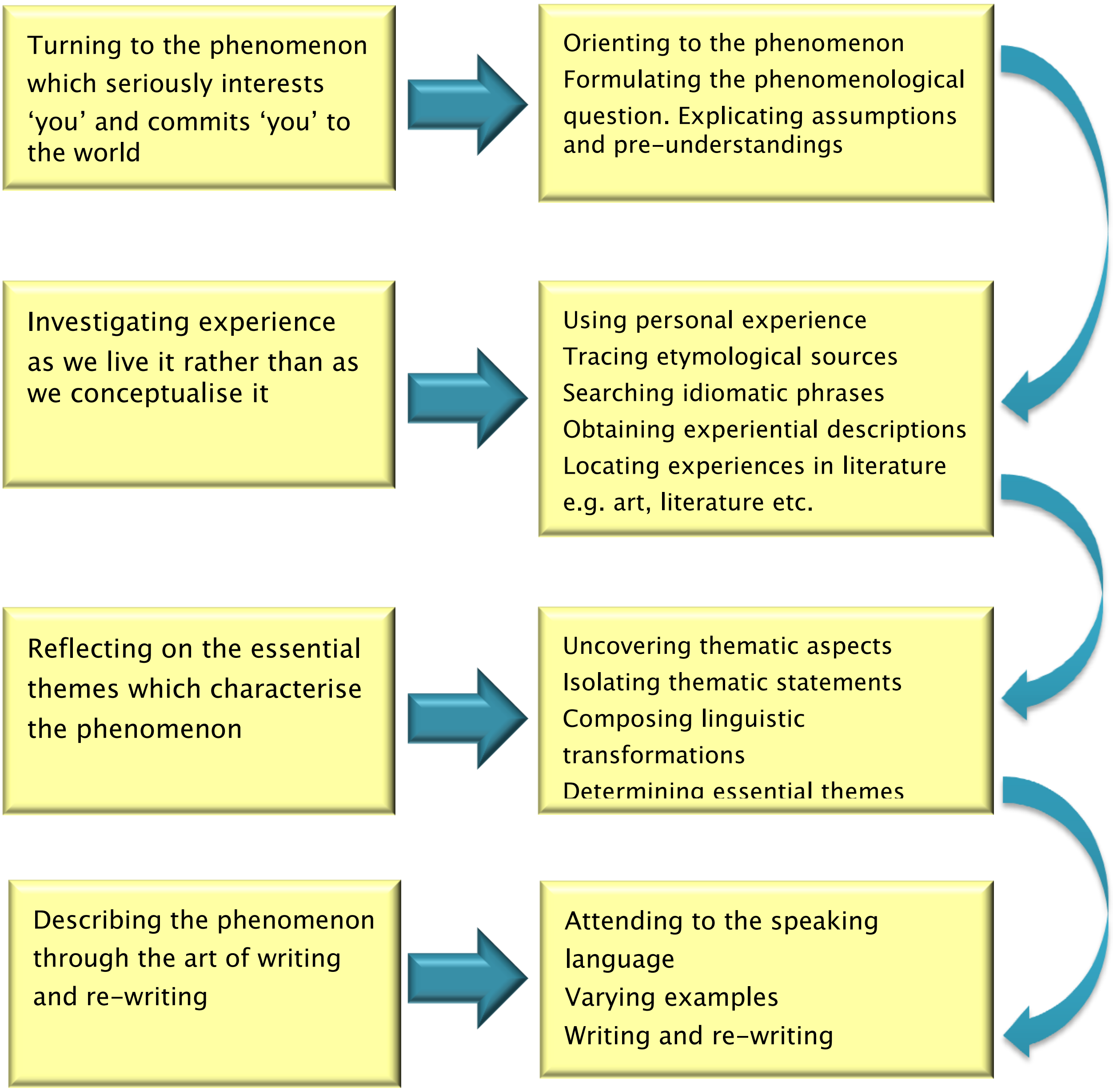
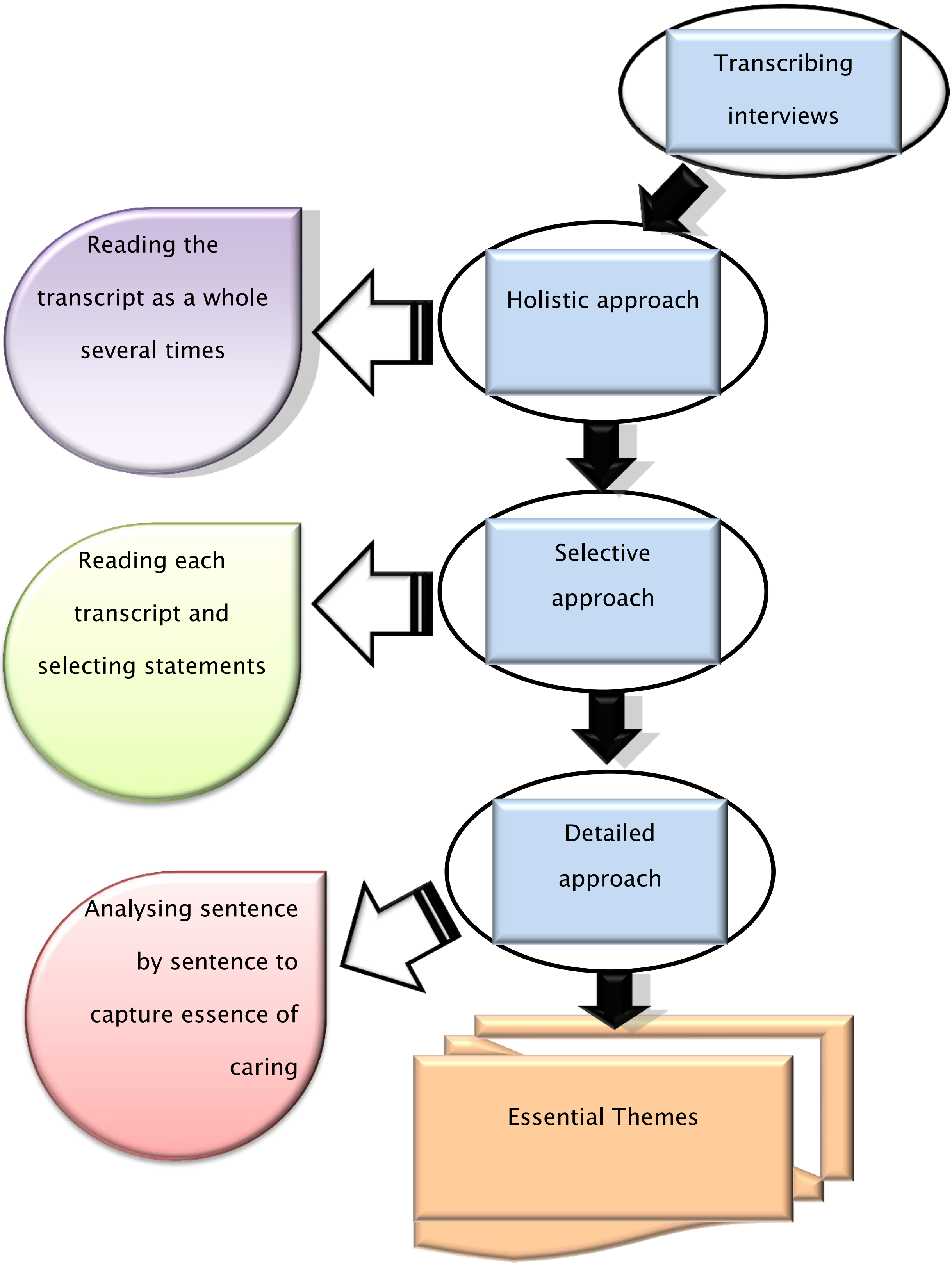


Figure 2: Phenomenological Thematic Analysis

Adapted from Van Manen (1984): Doing Phenomenological Research and Writing: An Introduction (Adams and Van Manen, 2008).



3.5 Research design

To understand the lived experience of African and African Caribbean carers the research design needed to ensure that there would be opportunities to capture their experiential data (Smith et al, 2009). The challenge was to capture the way in which understandings and meanings were derived in the life worlds of the carers. Therefore, methods were needed to enable appropriate interrogation of the data and to facilitate the recognition and further questioning of new insights and changing interpretations.

This section contains a detailed description and critique of the research design, illustrating how methods worked as they were implemented in the field. It covers the following areas: a) the sample selection which includes the inclusion, exclusion criteria and sample characteristics; b) the recruitment strategy and location for interviews; c) the process of data collection through in-depth interviews, prompt questions, narratives produced post-interview and the significance of reflexivity in the research process; d) the phenomenological framework used for data analysis and e) the ethical process that explains and justifies the ethical framework which underpinned the study.

3.5.1 Sample Selection

The study needed to engage with adult family carers who had experience of caring by using a purposeful sampling strategy, as the study sought to elicit meanings and interpretations of the phenomenon of caring (Smith et al, 2009). To ensure that carers with relevant experience were recruited, a sampling selection framework was chosen which incorporated specific inclusion and exclusion criteria. Norlyk and Harder (2010) suggest that it is important to explain what is '*purposeful sampling'* and what this means, in terms, of its use in phenomenology. Any variation in the sample group would be discussed in terms of the phenomenon under study. This was not based on demographic characteristics and size. Initial contact with local voluntary and carer group coordinators and community development workers who engaged with both patients and carers indicated that many in both these communities found it difficult to trust researchers. This mistrust occurred due to no dissemination of information about previous research conducted. As the carer research indicated, carers had a better trust for carer support groups unaffiliated to statutory services access to potential participants was sought through liaison with local voluntary and charity carer group organisations in Southern England.

3.5.1.1 Sample Inclusion and Exclusion Criteria

Carer participants in this study were informal carers of an adult (relative/spouse) with an enduring mental health problem (which includes schizophrenia. personality disorder, manic depression, clinical depression and self-harming behaviour and eating disorders). The reason for focussing on carers of adults with mental health problems was due to the epidemiological data on incidence of admissions to mental health hospitals. These data refers predominantly to adult patients with EMHPs from the African and African Caribbean communities (Care Quality Commission, 2011; Commission for Health Care Audit and Inspection, 2008; 2007b; 2007a; 2005).

Family carers needed to be caring for a relative with a specific mental health problem for six months or more. The initial stages of becoming a carer can have quite an impact on the available time to do anything more than support the cared for person, and therefore t was considered a more sensitive approach to allow for new carers to begin adjusting to the carer role and its implications before approaching them to engage with research.

It was important that carers had no previous contact with me in my role as a mental health nurse for receiving mental health care or support. This maximised the chances of them feeling free, to express themselves honestly and openly. However, carers having contact with local mental health services (community or in-patient services) over the last eighteen months was significant in previous carer research, as the time period in which carers identified themselves as doing a carer role.

The study sought to explore the experience of carers from African-Caribbean descent i.e. born in either Africa or the Caribbean, born to African and or Caribbean parents who were currently living in the UK. Non-English speaking participants were excluded from the study, as the use of an interpreter might constrain the collection of sufficiently nuanced and experiential data.

The sample needed to be of a sufficient size to enable the capture of information-rich data, whilst still being manageable within the resources of the study (Smith et al, 2009). Drawing on the experience of other hermeneutical phenomenological studies, it was evident that it is not the number of participants but the way in which the experiences were explored and shared which influenced the richness of the data and the subsequent findings (Groenwald, 2004; Van Manen, 1990).

3.5.1.2 Recruitment

Recruitment areas were selected for their potential to enable a variety of routes of access to carers from the African and African Caribbean community. Three voluntary sector organisations and two carer support groups were involved in the recruitment process. Before information could be disseminated contact had to be made with the ‘gatekeepers’ who were the coordinators for the voluntary agencies and carer support groups and people who would be willing to distribute recruitment material (Rugkasa and Canvin, 2010). Following a number of negotiations, which involved meeting with carers face to face to discuss the study, two voluntary organisations and two carer support groups agreed to disseminate recruitment material.

An outline of the study was presented to carers at support group meetings arranged with the coordinators of the local mental health carer charities/organisations. I was also available for further questions, should any attendees express an interest in participating in the study. Personal attendance and explanation at the voluntary organisations and carer support groups served to increase interest in the study (Ochieng, 2010). However, in order to reduce the possibility of coercion, carers were asked to contact me later, providing them with the opportunity to consider their commitment carefully.

Recruitment commenced in January 2009 and the coordinators of the carer charity/voluntary organisations were given study packs that contained the following information. The coordinators agreed to give these to those attendees who agreed to take part in the study. Each study pack included a letter of invitation to take part in the study *(Appendix 6)*;a participant information Sheet *(Appendix 7)*; a participant consent form *(Appendix 8)* and a paid stamped addressed envelope (for returning the consent form to the researcher). Six carers were recruited through this method; in addition one further carer approached me directly by email following contact with other carers who had informed her of this study.

In the *Participant Information Sheet* carers were informed that they had the right to choose not to participate. They could also terminate their participation at any point. Furthermore, carers were encouraged to ask for explanations at any time. In addition, all participants were assured that the interviews were entirely confidential apart from the researcher and the results would be published anonymously.

Carers who agreed to participate in the study were given two weeks to return the consent form to the researcher. A copy of the signed consent form was given to the participant upon meeting for interview. Consent and clarification of the research aim was checked at any agreed follow up interviews.

On receipt of the consent form, I made contact with each participant to arrange an agreed date, time and location to meet for interview. Prior to the interview, the informed consent was checked for confirmation that carers' were going to take part in the study. A further verbal explanation was given to participants at the initial interview. Once consent at interview was granted I proceeded with the interview.

A purposive sample of seven carers of relatives or spouse with EMHP participated. Five were family carers and two were carers of a spouse. Carers were aged between 40 and 68 years old. There were two male carers in this study, one caring for a mother and sister, and the other caring for a wife. The female carers included one caring for a son and daughter, one caring for a niece, one caring for two brothers, one caring for a stepson and one caring for a spouse. Of the seven carers, three carers were carers for two people in their family with enduring mental health problems.

Four carers cared-for one person in their family with an enduring mental health problem. Four care recipients were diagnosed with bipolar disorder; four were diagnosed with paranoid schizophrenia and two had clinical depression. Most of the carers at the time of interview had been in a carer role for more than ten years and may have taken just as long to accept this role.

Rugkasa and Canvin (2010) examined the influences on recruitment of individuals from Black, Asian and Minority Ethnic (BAME) communities. They found three issues impacted on recruitment: i) gatekeepers' (e.g. voluntary organisation coordinators of community engagement projects for BAME communities) attitudes; ii) the (non) payment of participants who felt they may be subsidizing university research and felt labelled into a 'them' and 'us' relationship with researchers and iii) reciprocal relationships with local community groups who wanted to establish a relationship with researchers which had mutual benefits for service users and carers from BAME communities. Rugkasa and Canvin (2010) also found that recruitment was increased when they used face-to-face contact and a variety of communication mediums e.g. email, telephone and establishing a more long-term relationship through community group networks. All of these approaches were used in this study and proved the best way to access participants and at the very least, give information about the study. Strudwick and Morris (2010) supported this, in a study on the experiences of African-Caribbean stroke carers in the UK, and found that collaborating with individuals and community representatives face to face was significant in their engagement with health care research.

Throughout the stages of recruitment and data collection, I ensured that a protocol was adhered to regarding the vulnerability of participants at any point in the study and following data collection (*Appendix 10).*

This included ensuring participants' had information on which local mental health care support services to contact should they become in any way distressed at any stage of the interview.

Limitations in recruitment and retention of participants did not occur due to the size of the membership of the local charities/organisations (specifically set up for BAME communities) and the venues available for recruitment.

3.5.2 Hermeneutical Interview

Phenomenology uses lived experience descriptions as a source of revealing the thematic aspects of a particular phenomenon. This process involved embarking on a journey of discovery through partnership between the participant and the researcher. The taped interview method was used to a) explore and gather information, which gave a deeper understanding of carers' experiences, and b) as a mode of conversation with participants that captured the wider meaning of caring for African Caribbean carers.

Van Manen (1990) suggested that to know the essence of a phenomenon, it is important to reflect on the textual data that emerges from an interview. Furthermore, for the text to be accessible to others, it needs to be analysed through structures of meaning, or themes. Data were collected through face-to-face, unstructured in-depth interviews lasting between 1 and 2 hours. The initial question for the interview was, "*Tell me about your everyday caring activities?*"

Funk and Stajduhar, (2009) suggested that a more mixed method approach to interviewing carers would yield a more 'genuine' perspective of the caring experience; they proposed the use of interviews with participant observation. However, in this study, using the interview approach only was an essential part of establishing 'trust' before, during and after contact with participants. In a community which already had a number of 'trust' issues with mental health professionals, I felt the addition of more methods to data collection could be construed as ‘intrusive’ and potentially disengage participants with any future research (Stelter, 2010).

In this study, the ‘laddered question technique’ devised by Price (2003) was used to guide the interview process. This technique was originally used to obtain richer data surrounding the negotiation of student support for nurse distant learners. The laddered questions were devised using personal construct theory. Personal construct theory suggests that human beings develop constructs or explanations of their human experiences. These explanations help individuals to cope with their everyday lives. As such this technique fitted with the phenomenological method used in this study.

Laddering down refers to questions that allow the participant to feel more in control of telling their story. In this case, the interviewer may offer prompt questions, but allows the participant to be confident in the direction of discussion. Laddering up refers to the developing of questions from being less intrusive to more intrusive to elicit information which relates to the phenomenon under study. The technique also helps the interviewer to be aware of the sensitive nature of sharing human experiences; which for carers in this study did involve both negative and positive aspects of caring.

Examples of the different laddered question types are indicated in **Table 1** below.

Table 1: The laddered question technique

Description of question type	**When to use question type**	**Example of question type**	**Participants response during interview**
Description of events or actions **Less invasive questioning**	Useful at start and end of interview session	How do you begin your day? How do you plan your day?	Participant needs reassurance
Description of knowledge or description of meaning of events **More invasive questioning**	Useful halfway through the Interview, dependent on participants response	What sort of decisions do you make when……?	When the participant is more relaxed
Description of philosophy – associated with feelings, attitudes, values and beliefs **More invasive questioning**	Useful halfway through the Interview, dependent on participants response	You started off by saying that the choices you make are for the greater good. How do you feel about having to make those choices?	When the participant has developed trust in the researcher. This could take several contacts
Description of events or actions **Less invasive questioning**	Useful at start and end of interview session	How do you begin your day? How do you plan your day?	Participant needs reassurance

The laddered questions technique identified areas of discussion that participants found uncomfortable to talk about (Price, 2003). Such questions were kept back until later on during the interview. More importantly, this line of questioning needs to be used alongside observation of participants' body language and verbal expression to indicate how in-depth the interview process developed. As part of the interview process, each participant was telephoned before the interview; this became an initial icebreaker and a point to start building trust and an opportunity for participants to ask further questions about the study. Interviews were recorded and transcribed verbatim (Stelter, 2010; Norlyk and Harder, 2010 and Ochieng, 2010). Subsequent prompt questions were derived from the carers' responses and were guided by the ladder technique.

3.5.2.1 Prompt Questions

After the participant exhausted his/her response to this opening question, he/she was prompted to explore the following areas if he/she did not discuss them, or discussed them superficially, in the initial response. Some prompt questions were devised to help develop a deeper response to carers' experience of caring. Examples of prompt questions are presented in **Table 2** below:

Table 2: Prompt Questions for use with carer participants during the interview

No	Prompt Question
1	When did you discover that your relative/spouse had a mental health problem?
2	How did it feel the first time you started caring for your relative/spouse?
3	How has your experience of caring changed since then?
4	What sort of strategies do you use to manage caring for your relative/spouse?

3.5.2.2 Location of interviews

Carers were interviewed in the location of their choice. Four carers were interviewed individually in their homes. Herzog (2005) and Ashworth and Hagan (1993) indicated that homes are the more appropriate settings, so that the power dynamics between researcher and participant shifts towards the participant and the researcher maintaining the respectful role of a 'guest' in the home (Wilson, 2009). Two carers chose to be interviewed at a local voluntary organisation that works with people who have mental health problems. Again, participants indicated the environment in which they felt more at ease or used regularly as part of their supportive network.

Whilst all participants seemed relaxed and keen to talk about their caring experiences, two carers cried during the interview when recounting very painful events about their caring role. Although pre-arranged strategies and a plan were devised, in the event of an interviewees' distress, these were not required as I was able to manage their distress. All carers assured the interviewer that they had felt better for sharing their experiences.

Each carer was interviewed once only out of respect for their time and the level of intrusion caused. Interviews had taken considerable time and included significant arrangements and travel. The carers interviewed spent the majority, if not all of their time caring for their loved ones and the interview time was a pre-arranged event, which took them away from caring. In addition, going over the interview process could be construed, as exploitation and may render the carer more vulnerable bringing the study integrity into question. The technique of refocusing questions was also used when necessary to clarify descriptions of carer accounts.

The ensuing issue of establishing and maintaining 'trust' with carers from the African and African Caribbean communities, meant it was very important to achieve a balance of empathic listening and acknowledgment of these experiences as 'real'. A non-judgemental approach to interviewing is seen as essential in this form of research and as it creates a lasting impression on participants, especially where stigmatisation had occurred in the past (Carlsson et al, 2006).

3.6 Philosophical and ontological underpinning, rigour and ethics

3.6.1 Issues of rigour

In their seminal paper, De Witt and Ploeg (2006) proposed specific criteria for rigour that comprised an important quality component of this study. The five expressions of rigour were '*balanced integration*', '*openness*', '*concreteness*', '*resonance*' and '*actualization*'.

Balanced integration was achieved by articulating the presenting the philosophical theme and its fit with the researcher and the research topic; this involved keeping a balance between the voice of study participants (*description*) and the phenomenological explanation *(interpretation*).

Openness was expressed through giving a clear rationale for choice of research topic, methodology and research design. This process was described in the interpretive phenomenological nursing literature as opening up the study to scrutiny. The researcher gave careful attention to the interview techniques, transcription and analytical processes.

The issue of concreteness was addressed through the study findings being written in such a way that examples were given in order to situate the researcher concretely in the context of the phenomenon of ‘caring’ and also linked with specific experiences of each carer’s life world. Morse (2010) cautioned against collecting data as if it was a documentary description of a person’s life in phenomenological research, as this is more likely to lower any research rigour of the data collection process. Equally, Morse (2010) highlighted the need to avoid ‘cherry-picking’ data, without sound phenomenological scrutiny.

Resonance is expressed through the ‘felt effect’ of reading the study’s findings upon the reader. Finlay (2006) referred to resonance as findings that aim to ‘draw the reader in’, in other words the findings needed to resonate with the reader’s own understandings or experiences. An alternative view here would be whether the reader’s thinking was sufficiently challenged by the findings. Furthermore, Finlay (2006) suggested that resonance is equally communicated within discussions with academic supervisors and the wider academic community.

The term actualisation addresses the future realisation of the resonance of the study findings. There is an acknowledgement that phenomenological interpretation does not end when the study is finished. This implies that it will continue to be interpreted by readers in the future, which fits well with the research objectives.

3.6.2 Reflexivity

Newbury (2012) suggested that reflexivity is an important part of qualitative research, in that it is a changing process, which requires the researcher to maintain a strong sense of self-awareness (which includes values, identity, thoughts, beliefs and behaviour) throughout the research process. In particular, I became even more aware that I was of the same ethnicity (I refer to myself as 'Black British', a descendant of African Caribbean parents). I have been a carer of two people in my family, although my caring role has significantly changed due to both family members recovering from ill health and taking more responsibility for their own care. I was conscious of over empathising and over identification with participants.

Ochieng (2010) acknowledged this dichotomy in her article on the ethical and methodological dilemmas for Black researchers, who interview Black families, where participants felt more at ease and relaxed enough to discuss all aspects of their experiences, but also, observed that being of the same ethnicity could create a barrier to sharing of information. Whilst the overlap between my professional self and personal self in this study were inevitable, being aware of and recognising the difficulties this can present in terms of data collection and analysis was crucial. Supervision and writing a reflective journal were the main tools for 'bracketing' my presuppositions.

3.6.3 Using a research journal

In my research journal, I wrote down my own reflections on the motivation for doing this study, my thoughts about the phenomenon under study and my experience of interviewing each carer. I also drew diagrams of interview locations and the position of carer to me as interviewer to assist my memory of each event. Following two very long interviews, where the carers became upset during interview, I was able to end the interview and offer guidance on means of support. I then needed to reflect on the impact of this event on me as a researcher. The most accessible tool at my disposal during these times were the skill of writing rhyming poetry (a hobby which I do quite naturally), that captured my feelings of this experience. Van Manen (1990) also encourages researchers to use artistic resources as part of the data collection, exploring thematic descriptions of e.g. poems, art, music, literature etc. to increase reflection experiences. This allows a further interpretation of participants' experiences of the phenomena.

Part of my bracketing experience included the use of visual imagery relaxation prior to an interview and after each interview. This helped to suspend any beliefs, expectations, assumptions and interpretations from my professional and informal caring experiences.

3.6.4 Ethical considerations in data collection

The School of Health Sciences ethics research committee at the University of Southampton granted ethical approval. Participants were informed that all information they provided would be treated as strictly confidential and would be used only for the purposes of this study *(Appendix 7).* They were also informed that they had the right to withdraw from the study at any time. Participants signed consent forms before data collection began *(Appendix 8).*

Preparing the study for the ethics committee clarified how procedures would support informed, voluntary, sharing data, confidentiality and promoting the safety of both participant and researcher. Ethical strategies within the research design are discussed under the following headings of informed consent and confidentiality.

3.6.4.1 Informed consent

Informed consent was explained to each participant *(Appendix 7 & 8)*; demonstrating that participant's decision to participate was optional after having received accurate, clear and detailed information (Usher and Holmes, 1997).

It was important to be aware of the actual and potential risks to the participants in divulging, in most instances, very personal and intimate information. The researcher was sensitive to the stress-vulnerability issues for each participant and was prepared to stop the interview *(Appendix 7, 8 & 10)*.

3.6.4.2 Confidentiality

In order to maintain anonymity, the participants were not referred to by name within the data collection and recording process and data were only to be shared with my academic supervisors. Data were treated with the utmost care at all times and the following precautions were taken. The data were stored (with the permission of the participants) on a University desktop password-protected computer (used only for this PhD study). All recordings were listened to in private and transcripts were type written. The data were to be stored for 10 years in accordance with the Data Protection Policy of the University of Southampton *(Appendix 7)*

It was anticipated that the findings from this study would form a thesis and be published in journals and presented at conferences. The anonymity of the participants was guaranteed within any publications *(Appendix 7 & 8).*

Confidentiality was assured, and it was made clear to the participants that should they disclose information that the Lead Researcher considers puts their safety at risk, that there would be a professional responsibility to inform other key people *(Appendix 7, 8 & 10).*

Concerning freedom from exploitation, clear and concise information was given to the participants at all stages of the research process and all guidelines were adhered to.

3.7 Data Analysis

Data were analysed and interpreted using Van Manen's (1990) method of hermeneutic analysis. Data were hermeneutically analysed using the following stages:

Stage 1: Interviews were transcribed verbatim. During this process, all personal identifiers were removed by using pseudonyms through the transcription as an additional measure a participant interview code was assigned to protect confidentiality. The resultant transcription was used in analysis.

Stage 2: The transcribed material was read, with every effort being made, by the researcher to totally submerge 'self' in the text in order to identify the implicit basis of the experience, seeking the essential meaning of the experience – Van Manen's holistic approach.

Stage 3: The researcher isolated the thematic statements – using Van Manen's selective approach. The research was read as text several times. The researcher then asked the question,

> ***"What statements or phrase (s) seem particularly essential or revealing about the phenomenon being described?"***

Stage 4: Van Manen suggests that the final stage should involve following a more detailed reading approach, where the researcher looks at every single sentence or sentence cluster. The purpose of this approach was to explore whether this sentence or sentence cluster revealed anything about the phenomenon of caring. Once themes have been identified, they become the objects of reflection and interpretation. Through this process, essential themes were uncovered. Further details of these essential themes are discussed in Chapter 4: Findings.

3.8 Summary

Methods of data collection and data analysis needed to reflect the phenomenological methodology of this study. This was to promote engagement with the phenomenon under study, namely exploring carers' experiences in depth. The recruitment and purposive sampling focused selection to ensure that African and African Caribbean carers were recruited to the study. Reflection on the recruitment method of the study, suggests that personal attendance and explanation at the voluntary organisations and carer support groups was a useful method for recruiting carers to the study.

In depth, interviewing enabled carers to talk of experiences that were pertinent to them however, the use of prompt questions help to focus conversation on specific caring experiences of carers from both communities. This also prompted me to examine the ethical background to my study and consider the potential vulnerability of carers. One of the benefits of transcribing the interviews myself, was being aware of my performance in the interview, listening to my tone and pace, and using this information to improve my technique in future interviews. A hermeneutic data analysis framework enabled prolonged emersion in the data and a growing understanding of the phenomenon of caring. This framework also facilitated the movement from descriptive findings of the caring experiences to interpretative findings, which validated the meaning of the caring experiences. Recognising and reinforcing the concept of the researcher as an active participant in the research also brought a requirement to reflect on and make explicit how my own history of professional and informal caring, culture and language have been interwoven within the interpretations with the study.

4. Chapter Four: Findings

4.1 Introduction

As previously indicated the aim of this study was to explore and describe the lived experience of African Caribbean carers who care for their close relatives with an enduring mental health problem (mainly paranoid schizophrenia and/or bi-polar disorder). An analysis of the caring experience of seven carers, who were interviewed in 2009, is presented. Information about carers in the study, their individual carer (participant) profiles and the essential themes provide the necessary background to the descriptive and interpretative dimensions of each theme.

A number of essential themes emerged from the interview data, and can best be comprehended through participants' stories, presented in this chapter. Some stories are notably longer in description as some carers cared for more than one family member with an enduring mental health problem. What follows are specific lived descriptions of events that explored the meaning of caring for African Caribbean carers.

4.2 Participants

To protect identity, pseudonyms were assigned to each of the participants, their relatives and their locations. The choice of pseudonyms in most cases may or may not reflect the ethnicity of the carer participants as being either African or Caribbean. Notably, most carers have English Christian names; the literature on the historical origin of names for people from the Black African and Black Caribbean communities in the last four centuries, indicate ‘English names’ were given as part of a colonialist culture, and in particular first names.

4.2.1 Participant ‘vignettes’

4.2.1.1 Karen

Karen was a 44-year-old woman who lived with her partner and young son. After many years living in the Caribbean, she returned to the UK, to complete her further education and to develop her career. Karen arrived in the UK and found out from her brother Alan, that their older brother had been diagnosed with paranoid schizophrenia. At the start of her caregiving journey Karen witnessed her brother Bob becoming unwell, and assumed an advocacy role for him, when he was arrested and held by the police; who were unaware of his mental health problems. Karen experienced caring for Bob as overwhelming; she felt guilty about being complicit in her brother having to go into hospital. As a result, she experiences the caring role as an intrusion on her everyday working life. Karen also took on the role of primary carer for her brother Alan, who after many years of being an informal carer, was diagnosed with schizoaffective disorder. This comes as a real shock to Karen, but with Alan, she gets a deeper insight into how the ‘voices’ affect him on a daily basis, and this enhances their relationship. She also experiences the constant worry because (unlike her brother Bob), Alan does not readily tell her when he is unwell. Karen’s caregiving role for her brother Alan ends tragically when he is knocked over by a car, whilst experiencing auditory hallucinations. The experience highlights the life-threatening aspects of having a mental illness, but helps Karen reflect positively on the time spent with her brother before he died.

4.2.1.2 Juanita

Juanita was over 60 year's old, a married woman at the time the interview, and was a full time carer who was a retired general nurse. She had a carer role for two members of her family, namely her son (James who was 39 years old), who had been diagnosed with schizophrenia, and her daughter (Alison, who was 38 years old), who was diagnosed with bi-polar disorder; both had been diagnosed during their late teens and early twenties. Juanita experiences her carer role as a constant 'battle' with mental services and the police. She feels torn between her daughter and son. Although Juanita has worked as a general nurse in the NHS, she has little knowledge of mental health care. In her role as a carer, she finds engagement with mental health professionals disempowering. Juanita describes the further action (using Supervised Community Treatment Orders[3]) she has to take to get care, which meets the needs of her relatives, but acknowledges the help of health professionals who spend time getting to know the whole family. However, she was exasperated by the travel involved in her carer role. On a number of occasions, she has travelled some distance to advocate for her son in particular. She remains worried about how black people receive treatment within the mental health and police services.

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[3] **Supervised Community Treatment Orders**: This order is for a person detained under certain sections of the Mental Health Act (1983) who has permission to return to the community. A Responsible Clinician and an Approved Mental Health Worker coordinate the care of that person. Patients can be recalled into hospital at any time.

4.2.1.3 Angela

Angela was a 52-year-old woman, who was unemployed at the time of the interview. Previously she had worked as a dental nurse in her native home of South Africa. She had a care role for her husband, Harry who was 57 years old, who was diagnosed with paranoid schizophrenia, when he lived in South Africa. For Angela her caregiving role started from the moment she met her husband; this was offset by the challenges of being a black African woman marrying to a white African man. Although Angela knew about her husband's illness when they got married, she did not appreciate the stressful nature of the role, especially as she was later diagnosed herself with clinical depression. In the early days in South Africa, Angela would learn about mental illness by going to the local library. Her experience as a carer in South Africa meant she was not allowed into any consultation with her husband. This was challenging in that she had no direct information about his progress, other than what he told her afterwards. In the UK, Angela felt her carer role was better supported, particularly when she was able to meet with other carers, share their experiences, and get useful information to help her in the care of her husband. She is encouraged by the fact her husband (who also had a carer role for her) sees what it is like as a carer and what she has had to deal with in caring for him. However, Angela's experience as a patient is not a very good one, and she feels that this is because of the colour of her skin. As a patient, she feels disempowered but gets the mixed message from the mental health services. In one instance, she was considered good enough to be a carer for her husband, but she experiences barriers to accessing support for her own mental health needs.

4.2.1.4 Harry

Harry, is Angela's husband (see above). He was 57 at the time of the interview and was unemployed, previously having worked as a dentist. Both lived together in rented accommodation. Just as Angela had a caring role for him, he had a care role for his wife, who was diagnosed with clinical depression. In the early stages of the carer role, some seven years prior to the interview, he learnt to recognise the importance of effective communication to ensure his wife talks to him about how she is feeling. His attendance at the different carer support groups helps him to see the 'other side', almost stepping out of the patient role and into the carer role. He also highlights the need for mental health professionals to develop their communication skills more effectively, particularly in areas of giving information to carers. Harry became very disheartened when he tried to get support from the local GP Surgeries to put up a carer support group poster.

4.2.1.5 Dave

Dave was a 40-year old, single man at the time the interview, and was a full time carer who had previously worked as an Information Technology (IT) Consultant. He had a carer role for two members of his family, namely his mother (Milly) who was 67 years old), who was diagnosed with an EMHP in the past, but also had end-stage kidney failure at the time of the interview. Dave also had a care role for his older sister (Jessica, who was 43 years old), who was initially diagnosed with schizophrenia, and then four years later was re-diagnosed with bi-polar disorder. He had been a carer for the last twenty years and was not living with either of his family members. Dave's carer role started when he was six years old in the family home; his Mum had frequent visits to a local mental health hospital, which he found very disruptive.

Eventually his mother's mental state seemed to settle down as he approached his teenage years. Dave feels he was more ill prepared for the carer role of his sister; it was such a shock to him that his sister had become so unwell in the family home. He senses that as a family they were in denial and perhaps going through a post-traumatic experience due to the experience of caring for his mother. Dave finds his carer role for his sister emotionally exhausting and finds it has an impact on his personality, where he gets inpatient with her and frustrated. He finds solace in attending family therapy with his sister and learns more about his personal resilience. However, he expressed disappointment that other family members refuse to participate.

4.2.1.6 Jendayi

Jendayi was a 44 year old, married woman at the time the interview, and was working as a mental health nurse. She had a part time carer role for her stepson, Chionesu who was 19 years old, who had been diagnosed with paranoid schizophrenia two years earlier. However, the biggest challenge for Jendayi is how her son perceives her when he is unwell and the 'blurring of roles' when she is both a mental health professional and an informal carer. At times Jendayi worries mental health services do not listen to the carer and fears that this may have something to so with her colour. Jendayi also acknowledges that she appreciates the care her son receives in England, because in her native country of Zimbabwe, his mental health care would have been very different. Chionesu's illness has an impact on all family members, including his siblings. Jendayi explains this more profoundly, "…people forget the impact it has on the siblings. We talk about the carers, but those siblings are carers in their own right and they are part of the carer role as well. We have to work as a team". As parental carers, Jendayi and her husband start to blame themselves for their son’s illness, “…you know (laughs) …it caused a lot of friction within you know, within our relationship as well, between my husband and I.” Following the interview Jendayi, describes feeling of ‘peace’, at being able talk with another person, about her experience as a carer. .

4.2.1.7 Helen

Helen was a 50-year-old single woman at the time the interview, and was working as a general nurse. She had a part time carer role for her niece (Sarah) who was 24 years old), who had been diagnosed with bi-polar disorder. She has been a carer of her niece for the last seven years. Helen lived with her niece in private accommodation. Helen experiences the shock of her niece’s diagnosis and experiences guilt for encouraging her niece to come to the UK, from Sierra Leone. She also observes times when her niece is trapped in a bubble, where she does not recognise Helen as her aunt, which Helen finds very distressing. Helen is generally happy with the care her niece receives from mental health and social care services. However, there are areas of care delivery, which concern her. These include the lack of information about why and when her niece transferred to a different mental health hospital. She is also very worried that one day her niece will blame her for the fact she has a mental health problem (Helen invited her niece to migrate to the UK, for a better way of life). For Helen, she believes that most of her niece’s problems are to do with her commitment to her religion Helen would like her niece to have access to talking therapies and finds that this is not readily offered – she questions why that is.

4.3 Homogeneity and heterogeneity of the participants

Whilst all carers maintained a primary caring role for their relatives, they also shared the caring with other family members i.e. brothers, sisters, nieces, daughters, sons, husband and wives. For some carers' engagement with the wider community and the social network of family friends provided invaluable support to their carer role. Four were married and one was single and lived with her partner. Two were single without partners.

All carers presented themselves as advocates for their relatives (care recipients and/or cared for person). They indicated the onset of their relative's illness which commonly occurred during prolonged periods of stress/distress; either during the period of young adulthood or later life. Whilst three cared for more than one relative, all experienced a significant change in their relationships with each relative, when the care recipients were unwell.

Five carers owned their own homes and two (a husband and wife couple – lived in rented accommodation). All were unpaid carers and the average number of years of caring was twenty. None of the carers reported having any financial problems.

Carers mainly described the 'down' periods of caring and were also able to elicit periods when caring gave them a positive outlook towards the end of each interview. All experienced a period when they thought they were not receiving the right support from local mental health and social care services or the police because of their ethnicity and perceived cultural stereotypes.

In terms of engaging with local mental health and social care services; carers found there were individual health and social care professionals considered to be 'worth their weight in gold'. These professionals provided much needed reassurance and information; particularly where there had been long periods of feeling as though they were in a battle with not only the health and social care professionals, but also the processes and legal framework of the mental health care system. All expressed the importance of their culture and ethnicity in their daily lives generally as a source of self-identity, but was equally, a source of personal strength in their carer role.

4.4 Essential themes

The emerging essential themes from the combined interviews are detailed in **Table 3** (on next page) and enlarged upon in subsequent text.

Table 3: The essential themes and the thematic statements that make up each essential theme

Essential Themes	Thematic statements
Being there and staying there	Facing the unexpected
	Accepting the change in persona
	A conflict of roles
Losing oneself and re-discovering self	Feeling the loneliness of the caring experience
	Feeling trapped with the cared for person
	Needing your own personal space and time as a carer
	Drawing near, feeling uneasy, when experiencing the loss of a relative
Keeping an on-going dialogue with others	Sharing the care in the family
	Working with mental health and social services
A conscious awareness of cultural stereotypes	Migrating between two cultures
	Fear of the cultural stereotypes being used in the care of their relative
	A Tale of Two Countries: Comparing the differences in mental health services
Sustaining hope during the caring experience	Having their own 'personal' aspirations and desires as a carer
	Verbalising the aspirations and achievements of their relative to show the human being behind the illness

4.4.1 Being there and staying there

One way that Van Manen (1990) describes phenomenological themes, is to view them as 'structures of experience'. An example of this is revealed when carers describe a common problem of 'feeling shocked, anxious and ultimately powerless' when they first get the news that their relative has been diagnosed with an enduring mental health problem.

This feeling of shock is even more heightened in family carers who do not live with their relative or who have been away from the family home for a long period, and who eventually through no choice of their own, assume a primary carer role. How does the carer manage in this situation? What impact does this have on their everyday lives? So much depends on how they received the information about their relative.

Carers experience being there and staying there as building on the relationship with the cared for person. This is a relationship, which evolves from being a sister, mother, wife, husband, brother, stepmother and aunt to that of a substantial carer role, although most carers see this role as part of their familial duty. The 'revolving' aspect of this relationship is based on the events that led to the cared for person going into hospital and then returning home on different occasions. Despite all of the upheaval that the carer role brings, carers are still able to make a commitment to their relative to be there and stay there from illness to wellness. This means that carers experience can revolve between being close to their relatives and being very detached. .

Three thematic statements that comprise the essential theme 'being there and staying there,' these include 1) facing the unexpected, 2) coping with change and 3) a conflict of roles.

4.4.1.1 Facing the unexpected

Carers face the unexpected when they find out just how unwell their relative is. This creates shock, anxiety, and a series of emotions from sadness, anger, frustration and a fear of the unknown. Karen the youngest of five siblings in her family, experiences a gradual realisation of how unwell her older brother Bob is through listening to how her other brother Alan describe his experience of caring:

> "…Bob was one of the guys in town in the hay days, who people looked up to, he was a dresser and everything like, …he used to dress really nicely, but when I came over, it was quite a shock for me really, because being in the Caribbean for a while, I never experienced that, intensity of illness…but I couldn't come to terms with it…,"

While Karen adjusts to her carer role, for her brother Bob, Alan her other brother is diagnosed with bi-polar disorder (in his thirties) and this was very much unexpected as Alan was also one of the carers for her brother Bob,

> "…yeah and then all of a sudden, I dunno, it's just all of a sudden, he just started, acting strange, I don't know how it came about, honestly, you see what I mean, cos' that's right when Alan became ill, everybody was in total shock, because many people didn't know that this mental illness was there with Alan."

Juanita's experience of becoming a carer is different to Karen's in that despite her background as a general nurse, she had no knowledge of the Mental Health Act (1983) and what sectioning[4] involved. Experiencing this process came as another shock to her,

> "I was not aware of sectioning and all these things going on in the mental health you see. Anyway, they sectioned him and they took him, he was in the hospital. We got down to see him in the hospital, there,

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[4] ***'sectioning'*** refers to formal patients who are compulsorily detained under a section of the Mental Health Act 1983 and who lose some of the rights available to informal patients.

> the place was disgusting and horrendous and he was just lying there and on his back – I thought he was dead actually, because of being a nurse myself, I couldn't really, really envisage his situation."

The added impact of seeing her son cared-for in very squalid conditions demonstrated in the tone of her voice and the visual sadness displayed.

Angela recalls that her husband was diagnosed with an EMHP, in South Africa. She does not see her role as a carer but as a wife caring for the man she loves. However, Angela realises the burden of caring for her husband later on in their marital relationship; yet she feels that having this caring experience has brought them closer together in their marriage,

> "I never thought it would stress me out, but it did, things like that that he did then, I didn't look at that side of life, I just took him as a human being, cared for him and looked after him and that brought us even close together".

Harry was used to being the one who gave his views on how his mental health problems affected him. However, this changed when his wife was diagnosed with depression. Harry was able to see what it was like for his wife to care for him, when he was unwell.

> "...I learnt that it is not my views that are important, it's how I give support"

At the time of interview, in Dave's caring role for his mother, he focussed on supporting her through the physical aspects of care (due to her diagnosis of end -stage kidney failure). Dave sees this as a time of endearment with his mother, whom he reveres as an ardent storyteller and strong, hard-working woman. However, he is able to recall how unwell she was when he was younger,

> "…she was sectioned, it was horrible at the time, she would be in there for at the most, a long period would be three months and that would be a long period for Mum. Mum was, (pause) episodic in her problems, in as far they would come around every six, seven years, I suppose, and these would be quite acute, my earliest memory was about six..."

In contrast, Dave finds his care role for his sister is a completely different experience than the care he gave to his mother. His tone of voice is less upbeat and positive, "with my sister it was a revolving door you know and it's got worse and worse and worse." For Dave the onset of his sister's illness is littered with a number of unanswered questions about what led to her mental and physical deterioration,

> "I can remember that, it was just such a horrible period, it really was and she was like a blanket, she was going through her period (menstrual cycle) and stuff like that, she was just emaciated and caked in it. She wasn't washing, it was just really awful, and so that was what I alluded to about the guilt. How could my sister have got into that situation? How could you, Dad! You know Mum! What were you doing? "

Jendayi faces the unexpected in how she had to support individual family members. The family were overwhelmed by the sudden onset of illness experienced by her stepson,

> "…so it was not just only helping my son, I had my husband, my daughter, the eldest son as well, who was at university and who had to drop out of university, because he was really distressed..."

For Helen, concerns were raised by the pastor of her niece’s church; who rang Helen and informed her that her niece was behaving strangely. He indicated that she may have a psychological problem….

> “…she was admitted and then you know then…they later said she might have depression…I was shocked, I couldn’t take it all in ‘Why?’ I didn’t know really what to do…it took a long time to sort of accept.”

4.4.1.2 Accepting the change of persona

Carers are able to see how much their relatives change in persona over time, but just seeing that change is not enough in terms of managing carer stress levels. The carer journey is a long process of learning how to accept that, there relative may not be the person they knew before the illness was diagnosed.

Karen experienced the difference in presenting signs and symptoms between her two brothers. She focussed on the facial and behavioural changes in each brother to establish when they were unwell,

> “Bob's very expressive and his personality changes, the face and this and that, the only thing that I would say with Alan's thing is that his face changed a little bit when he would get sick, when it got, when it got later down into the illness… Bob was more aggressive with his illness, generally. Alan wasn't like that, he was quieter and he kept it in. It's only in the latter half of his life that he came out to talk about it…”

A source of distress for Juanita is the challenge of caring for more than one family member with an enduring mental health problem. She also observes the differences in how her son and daughter relate to her when they are unwell.

Both express different personas and this can affect the way in which Juanita is engaged in caring for both relatives,

> "Now, with her, Alison, when Alison is really unwell she becomes anti-me, she hates me they explained to me that in this illness, the person who is close to the patient and who they love the most, is the person they turn on, so I was able to accept that... "but with James, he doesn't want nobody round him; accept me when he's ill. Yeah, he just clings, and clings and clings to me."

Angela is so attuned to how her husband behaves on a daily basis; she describes his persona as,

> "I could tell that he's gonna get sick or that he's about to get sick, …the signs show he talks too much or he cries, or he tells people he loves them…"

Harry focuses on how he communicates and elicits what his wife is experiencing with her mental health. Harry finds that he has to negotiate between the woman who is his wife and the new persona of his wife when she is depressed,

> "…I try and think carefully before I talk and I ask a question that needs to be thought about, and provokes more than just superficial thought, but, deeper understanding of oneself and one's needs, especially to the one asking the question because it's the feelings that miss, because I can't really read somebody's mind"

Dave recalls being involved with his mother's care from an early age; he describes an accepted pattern to her mental health problem, which defines her time in hospital,

> “Mum was (pause) episodic in her problems, in as far they would come around every six, seven years, I suppose, and these would be quite acute. My earliest memory was about six, and by the time, I was in my late teens Mum was a lot more stable it would still happen. I would get a phone call…then I would go there [family home] and Mum would be there [in hospital] for a week, ten days, she became like hooked on the system,…and possibly I would say, ‘she just couldn’t cope anymore, she just needed to recharge her batteries.”

There are relational dynamics that influence Jendayi’s carer role for her stepson. She describes his change in persona as dependant on how much he trusted each parent.

> “...but at home he was quite aggressive towards his father never to me which was quite strange and when he was in hospital he didn't want to know me, he wanted to know his father so for three months I never saw him, because he just didn't want to know”

Helen observes her niece’s change of persona occurs in relation to her religious commitment and her need to keep busy on a day-to-day basis. Helen acknowledges this as the pattern or trigger to her niece’s illness recurring,

> “...she would go to church (four times a week), then she goes to the job centre, then she got some voluntary work, she wasn’t staying at home. Just going from one place to another, she wasn’t slowing down; in the end the main problem was the job”.

4.4.1.3 A conflict of roles

Jendayi speaks of the conflict between her role as a mother, wife, carer and professional carer. She described the way in which both her and her husband started to blame themselves for the onset of their son's illness,

> "...and my husband didn't understand and he was saying why, where have I gone wrong to be getting this he was talking about himself about his parenting, saying why has something gone wrong with the parenting that you he's doing this to me, and I was like it's not you, you know...you know there was a lot of blame of each other 'what did we do wrong',

The relationship between carers and their relatives evolves from an established identity as a family member, be that, a sister, mother or wife to a revolving role between a carer identity and their identity within the family. For carers they can move between being an insider (where they advocate for their relatives) to being an outsider (where they can be perceived as siding with the mental health and social care services against their relative). For some carers like Angela, other more significant life decisions actually influence her caring role, based on love and duty to her husband. Carers experience different periods of loneliness, as they journey with their relative. They find themselves between feeling lonely and then needing their own space (to be alone) in order to reflect on their journey.

4.4.2 Losing oneself and re-discovering self

All carers expressed different periods in their carer journey when they felt alone. This is particularly difficult when carers experience the loss of the persona they once knew. Carers develop a strong advocacy role for their relative and recognise times when they feel very isolated. On these occasions, carers infer a sense that they are invisible to the person they are caring for and overlooked by the statutory services. Losing oneself and re-discovering oneself, can mean carers can feel trapped in their relationship with their relative based on how they both experience the unpredictable nature of the mental illness. There is also a need for their own personal space to get back to their own sense of self. Losing a relative to physical death, after years of caring for that person, leaves 'emptiness' in one carers' life, and highlights another potential outcome of living with an enduring mental health problem.

4.4.2.1 Feeling the loneliness of the caring experience: 'Drowning not waving'

Dave describes the loneliness of being a carer especially when his sister is feeling unwell. He refers to the way, in which he makes use of his own time and what he reflects on,

> "…it's only in the last couple of years, particularly, being a carer, cos' you have, there is a lot of solitude, particularly when somebody is actually going through their traumas and their quite withdrawn at times and even though you are with someone, you're the only one who is in the room at times."

Initially Jendayi implies the loneliness she feels in not being able to confide in her husband whilst balancing her role as a mother and an informal carer.

> "…it is very, very difficult as a carer to get anybody to sort of like offload to really yeah. I mean many a time I found it so difficult to talk to my husband, to deal with my son, my daughter, work…"

Jendayi describes her relationships with friends who she found gave her some practical support but also recognised when this is simply not enough.

> "…my friends are not in the medical field or they're in the medical field, but they are not mental health it is not enough, it's like it's going to ceiling level I want it to go to roof level…really want to get everything off your chest and somehow get help…they don't really understand you know, what you're going through, they've never gone through that journey"

4.4.2.2 Feeling trapped with the cared for person

Carers move their conversations between being involved in decision-making, being excluded from decision making, either by the cared for person themselves or mental health services. This can leave them with a sense of being trapped in their caring of their relative.

For Karen, encouraging her brother to take his medication when he is not very well poses a big challenge, particularly 'out of hours'. At these times, Karen feels a need for help from the mental health services. She does not want to be the one making the decision, and finds help and support is not always forthcoming,

> " Oh yes, he said he's gotta keep taking the tablets,' …that's easy for you (refers to mental health services) to say, easier said than done', … and I said, 'supposing he does not take these tablets…I had to put up with this during the weekend, so what happens out of hours and that?' and he goes (the doctor), 'that's the tricky thing we don't have anything like that, …if you need their help out of hours what are you meant to

> do and that? And he (the doctor) said, 'we're still looking into it at this point in time'…"

Juanita describes the loss of her own personal space through the journey of caring as analogous to being imprisoned.

> "I find that when people are admitted into hospital, they see everybody as a patient and not a person, you see instead of seeing the person, you become a patient straight away and, and that is something that really, really makes me feel sad, because of the simple reason that I find that the mental health illness, or disease or whatever they want to call it, is the only disease or illness that patients are entrapped, they entrap the patients and they entraps the relatives"

For Helen, space is demarked as a journey with many paths and not knowing which way to turn or to go. This is expressed when she realises that her niece is better off living with her than on her own,

> "…and then, you realised by then, this is gonna, it's a long term thing, and where do we go from here, so, (coughs)…"

4.4.2.3 Needing your own personal space and time as a carer

Karen recognises how her Brother Bob's illness affects her own working life. The tone of her conversation at this point, comes across as almost hysterical and dismayed by what becomes an intrusion on her everyday life. Karen describes that on this occasion her brother takes a trip to London, where he becomes unwell. For Karen there is an immediate sense of concern and worry as to how she is best able to support her brother. She liaises with an out of area mental health unit (where he resided) as to how to get him back home safely,

> “…This hospital calls, somebody in the hospital… we have a Bob Swain here, he says that your his sister, he was picked up last night by the police and that, we were wondering if you could come for him. I said, 'I am in the middle of my job, I can't come for him!' I said, 'Not being funny, is there any way that you could get somebody to put him on a train to Southampton and I can meet him by the train station, I can arrange that with my manager, but I can't physically , just leave my job here…”

This experience finds Karen calling out for help from the services and very quickly having to think on her feet and negotiate a safe passage home for her brother. The implication that she is so very available to care for her brother when she is working, leaves her shocked and perturbed.

Angela describes the need for space away from her husband, when they are both unwell,

> “….as he cares for me and I care for him and we are sometimes are at each other’s throats, but not very seriously, we just blow our tops and go out and get space and then come back and then everything is OK…”

Dave recognises that taking on his carer role was not a choice and this implies a duty of care. However, he also expresses a sense of frustration that there is no way out,

> “…I’ve gone on this journey of discovery…through the journey I have had to travel, not through choice, but through circumstance.”

Jendayi finds the biggest conflict in her carer role is not being unable to shut off, as she is caring for her son at home. The she has to go to work and do more or less the same type of work.

> “I was working on an acute ward, coming home to an acute ward as well. So it was twenty-four seven, right around the clock, you know, it was like going home, what am I going to need, plate? What can I work with?” You know I just take long walks and come back and you know, reflect, “What have I done? Where can I go? What have I got on my plate?”

Carers express the need to have a space of their own as carers to reflect on how they are doing, this becomes ever more important as a way to establish what support they will need in the future. Angela really needs her space as a carer away from her husband, mainly because both have mental health problems that they have to deal with as well as caring for each other. Karen identifies the unexpected nature of her brother’s illness, which can lead to him being in contact with mental health services out of his hometown. This presents a challenge to her, which is stressful in its sudden intrusion on her working life.

4.4.2.4 Drawing near, feeling uneasy, when experiencing the loss of a relative

For some carers watching their relative change in persona can be a loss in its own right, a loss of the person they once knew before the illness took hold. For one carer this can be coupled with actual physical loss through death.

Helen perceives that because she is so close to her niece that she could lose her, particularly when her niece recounts some of the decisions she has made about her care,

> “…well my greatest fear was that …because I have witnessed, the closer you are to them, they think you are the one causing the

> problem, or you are the, their enemy. That’s always in me, thinking whenever she’s ill, she might decide, ‘I don’t want to have nothing to do with you’ or something like that, and that would be (pauses), ahh, I don’t know how I would feel (sighs) it would be too much for me..”

Karen recounts the events that led up to Alan’s death, which are compelling in that neither Bob or Karen were fully aware that the emergency situation occurring around them, was about their brother; who had walked in front of a car whilst hearing voices. Again, there is an airy undertone in Karen’s voice,

> “…and I heard all these sirens , and saying 'but where are these, oh somebody's oh there is a terrible accident , something must be going on, but funnily enough, when he left me he saw my brother (Bob) as well, and he told my brother , 'take care, you awright Bob and that and make sure you thing, and he (Bob) said; 'yeah' and so my brother (Bob) phoned up and said, 'Alan was a bit strange!', so I said, 'why because he was nice to you', he said, 'No (laughing and that) he said, 'No, he said, I dunno, I can't put my finger on it’

This moment invites a picture of three children playing and one going missing. Suddenly the other two children realise the third child is not there and then the news that ‘he’ is gone, triggers an overwhelming sense of loss,

> “…Rob (Karen’s partner) rang me and said, 'the coppers are here!' and …'death' didn't even enter my mind! I just thought maybe he's got into an accident or he's done something or something like that, but 'death' never entered my mind! Then I saw them (the police officers) walking up the pathway by his girlfriend’s house, and I just broke down, I just knew, I just knew that was it…he was gone.”

4.4.3 Keeping an on-going dialogue with others

Keeping an on-going dialogue with others refers to three different partnership relationships that carers describe as important in their caring role. These include i) the partnership with other family members also involved in the care of their relative and ii) the partnership relationship with the statutory health and social care services their relatives come into contact with. However, family differences of opinion around decisions about care can make the carer role more distressing. Carers want to actively search for ways to develop partnerships with the mental health and social care services. However, any negative experiences that they have with statutory services, makes them very cautious of any future engagements.

4.4.3.1 Sharing the care in the family

As Karen recalls how her brother Alan experienced caring for their brother Bob. Alan shares with his sense of loneliness; isolation and distance from the immediate family. Karen noted that Alan struggled to keep his aspirations going whilst caring for their older brother Bob.

This sharing of information between two adult siblings about their relative who has an enduring mental health problem, illustrates inquisitiveness and a desire to get to the reason for their brother's illness. It is really a piecing together of how, when and where problems for their relative started. Their stories echo an early assessment and monitoring of their brother Bob's behaviour. However, the sharing of information also provides useful insight into the carer role, which serves as preparation for Karen, who eventually ends up caring for both brothers.

Dave, who has cared for his sister for the last twenty years, describes the frustration and pressure of decision-making in relation to his sister's care, which he shares with his father,

> “I was becoming inpatient, tired and quite, I wouldn’t say aggressive, but oppressive… there was an imbalance between the family my father was, as my sister’s other main carer, was quite passive and everything was down to myself, …as far as problems, situations, whatever, it was down to myself, that’s what I felt, and I said, well no, … you can still make choices and...”

He also experiences the ambivalence of being his sister's primary carer and starts to question whether he is the right person to be involved in the decision-making and ultimately the caring.

> “the way I see it, it’s a bit like trying to sort of (pauses) it’s known that there is or there was a beautiful garden there and it’s just overgrown at the moment in time but my problem that we have in so far this is where we have a conflict, am I the right person to be doing the weeding and the digging up and the re-planting…is that down to me, or is that down to the homeowner.”

Jendayi reflects on how her younger daughter was involved in the carer role, of Chionesu, her stepson. Jendayi gave her daughter information about what was happening, but also wanted to keep her daughter safe.

> “Having a younger child in the home setting made it that much more difficult as we had to protect her as well, she is now twelve, so she was ten years old and they had been very close, all of a sudden he didn't want to know her and so, you know she couldn't understand that”

Helen finds that although she has no family close by that she can still share the carer role with others. She is able to share updates on her niece via telephone calls to her niece's mother and father who live in another country.

> "… I was shocked I couldn't take it all in 'why?' I didn't know really what to do (laughs), at the time. But then, I've got very close relatives, you know so I communicated with them you know,... they were shocked as well it took a long time to sort of accept that she, … had a mental problem and then, you know, after a long conclusion…",

All carers see their role of caring as their duty as a family member or close relative to care for the people they love. For at least four carers they find the church a support in their caring role, identify individual health, and social care practitioners who helped to make the carer journey easier.

One of the areas of concern for carers is being involved in decisions about care for their relative. Carers become quite self-critical of their abilities, indeed their competency to be making certain decisions around caring on their own. There is a strong undercurrent feeling of 'powerlessness' which is demonstrated by their own cries for help and emotional support within their caring role.

4.4.3.2 Working with mental health and social care services

Juanita experiences mental health professional' distrust of her as a carer. This is a source of great frustration for her in the caring experience.

> " the consultant said to me she thinks that if she sends him home, he might not be medicated the way he should right, and she doesn't know if he would get the, get the care that he needs to have,."

Angela chose to be a carer to her husband, even before they got married and she was made aware of his mental health problems, this was a big life decision,

> "…my family was against it, that I should get married to him, because of his mental state and I just didn't care what they said and we just carried on and I've been married for the last twenty-three years…"

Dave describes his caring experience sometimes as if he is the patient, where both feel 'disempowered' by the mental health services, this shows how intertwined the experience of both carer and the cared for person really is,

> "I think sometimes that's what the system has done to us, it 'dis-empowers you', because what it says is, you know, 'you come in and we'll give you this depot, we'll give you that and you know, everything is going to be better…and you know, six months… two years on, ten years on, fifteen years on you're still in the same situation, you get pretty fed up and you get a pretty 'narked' at and you get pretty aggressive…"to tell me, you know, you must do this and you must do that, I've been here for like the last ten years, I'm still here and the water's getting deeper you know, in fact, I'm almost drowning, so you know please!"

Unlike Juanita and Dave, Jendayi started her carer role with a professional knowledge of the mental health care system, which puts her in a good position to advocate for her son, but 'knowing' is not everything,

> "…although they wanted to discharge him off a section we had to go to a CPA the first time, but at the first presentation of the CPA we were not invited as carers. Now I had qualms about exactly, what is the purpose of the CPA? I thought it was meant for carers to be able to

> say, 'look this person is coming back into my care, I need to have my say, what sort of support am I going to be having from you?' and yet we were not invited!"

Helen really wanted the mental health services and the GP to be better at letting both her and her niece know where she would be admitted to for care. The constant changes in information and subsequent transfers to the units where her niece was admitted caused more distress,

> "…then because, I was on my own like, here as her aunty, I had to explain, you know, I had to talk to my brother and his wife and the rest of the family to tell them what had a happened it was very difficult and very distressful…"

Being involved in the decision making of their relative's care has to occur at the right time for each carer. Their frustrations are very much centred on the poor communication and being excluded from the decision making process of care of their relatives. This can in turn, limits their opportunities to fulfil their caring roles. It also begs two obvious questions, who is responsible for the cared for person? Is partnership in care, an unrealistic option for carers?

4.4.4 A conscious awareness of cultural stereotypes

Throughout carers' conversations, they express a fear related to certain cultural stereotypes, which they believe to be inherent in mental health and social care services. Some of this stems from their experiences in education, employment and cultural traditions. However, this level of awareness is heightened when they feel their relatives are not getting their health care needs met; also when they do not receive any support in their carer role.

4.4.4.1 Living between two cultures

Dave describes the security he feels as a carer when there are mental health professionals who are of the same culture and ethnicity as him in the services.

> "…sometimes when you go in and you see a black person in a place, in a position of authority that can be decision makers on what you're gonna do sometimes it reinforces your belief in that particular environment will be productive for you…"

Juanita hints at a possible link between the onset of her daughter's mental illness and the way in which she, as a black mother brought up her children. She stops short of indicating that cultural traditions are involved,

> "I think it's related to her not you know, in the black community….well I don't know if it happens in every black family but in certain black person, but in my opinion, there are certain things that are allowed in families, and certain things you don't do …and to me it's a culture handed down to me from my great-grandmother to my mother and come down to me."

Jendayi explains what living within two cultures means to her as a person. She expresses her frustration at how mental health services seem to use this as a way of stereotyping, not only her son, but also stereotyping her in the role of carer,

> "…Well I'm, I'm Black African, although I am Black African, I'm quite mixed within, within that Black African-ness, I was brought up more Western, then I have my values, but people see you as black, I don't see myself as black at all, I don't see colour at all, until some people _______to bring it along, when they come in to section, you know, it's a

> young black man and already alarm bells, so do we need police escort, that's what I heard on the radio, you know, my, my, mind just (smiles) (facial expression).

Karen indicates that when she first saw how unwell her brother Bob was, she was shocked by the change in his physical appearance; but she also acknowledges that she had not been exposed to mental illness of this nature when she lived in the Caribbean,

> "…Bob was one of the guys in the old days, who they looked up to, he was a dresser and everything like, he still considered himself a sort of Michael Jackson, sort of a thing with the afro and everything, like in the nineties and everything and he used to dress really nicely, but when I came over, it was quite a shock for me really, because being in Caribbean for a while, I never experienced that, intensity of illness…"

4.4.4.2 Fear of the cultural stereotypes being used in the care of their relative

Dave acknowledges being brought up in a predominantly white populated area and experiencing a poor secondary education, had an impact on him personally. This also affected his relationship with his family. Through the process of being a carer, Dave describes the impact of his upbringing on his perceptions of mental health services,

> "...it's aspirational sometimes when go in and you see a black person in a place (health care environment), in a position of authority that can be decision makers on what you're gonna do, it reinforces your belief in that particular environment will be productive for you…if they can

> appoint black people, you realise that we can offer things other than cleaning (laughs)."

Some of Jendayi's worries relate to her concerns about how her son is treated as a young black man and how she and her family are treated because they are black. She issues a strong request for mental health professionals to see the person and not to stereotype her son because he is black.

> "...and I think the biggest problem that came along is that a lot of people, the nurses that came along to interview him were 'White' and he just could not relate to that…and women as well.. "it was a big challenge for him, until we, he became involved with Early Intervention Team for Psychosis (EIP) and got hooked on with a black worker we just started seeing a difference"

Jendayi is able to point out the part of the mental health services that met her son's needs and met her needs. Jendayi feels the EIP services were helpful in putting her mind at rest about the care her son was receiving. She emphasises the importance of having a mental health worker not only from the same community, and of the same gender; but who was of the same ethnicity as her son. However, at times Jendayi wonders whether the mental health services are intentionally ignoring her cries for more support, because she is a black person,

> "…he just became really, really paranoid again and we started telling people 'hello can you increase the visits, nobody will listen'; hello, hello and then eventually I said is it because of my colour that I am not getting help I said is it because of my colour that, because I am shouting here and no one is hearing me"

Fear that certain stereotypes are projected onto their relatives is evident for some carers. However, some carers experienced mental health services in other countries and are able to recognise that their relatives receive better overall care in England, despite some of their negative experiences.

4.4.4.3 A Tale of Two Countries: Comparing the differences in mental health services

Angela gives some insight into the experience of mental health services in the part of Africa where she and her husband lived,

> "…when he used to see the psychiatrist in Africa, I was not allowed to come into the room." …in this country (England), I am allowed to come in and listen and hear and see…if you're mentally ill, you just see the nurse or you see the psychiatrist and that is it, but your relatives can't come in, I don't know…"

Harry recounts the impact of his cultural upbringing on his philosophy of life, which also influenced his carer role in terms of advocacy. He describes the moment when his father found out he was dating a 'coloured woman' (Angela)

> "…when I was particularly ill, and he thought my choice of Angela as a wife because she was coloured, was wrong. We didn't discuss this, since the time he realised that I was involved with her, and then later when I married, we got married without telling them, and that evening, once the ceremony was done, I let them know, because I knew what their reaction would be, …but I knew anyway that they wouldn't agree, so I didn't bother telling them…"

However, Jendayi is able to acknowledge that if she her son was living in her hometown in Africa, mental health provision would have been worse,

> “I do appreciate, what, the help we've had, back home in Africa, you know he would have been in a ...somewhere because of the way they treat people there and the stigma you know, and people are just put up in a hospital and they are just kept, locked away... you know, you hardly see them”

Throughout the interviews with each carer, there is a strong desire to express the times when they become suspicious that their skin colour and/or their ethnicity has been used as the reason they receive poor support and their relatives receive poor care. This at times comes across as an inherent fear or worry. At other times, it is a source of expressed anger. For some, carers, they are reminded of their cultural identity as a comfort, in so far, they are able to ‘lean on’ cultural traditions for example, their faith and the wider support of their church community. Equally, the consistent support from immediate family members is evident throughout their conversations. There is also a need to be recognised in a more positive light as members of the African and African Caribbean community. For carers this means moving away from the stereotypical perceptions of black people as ‘big, black and scary.’ Reflecting on the overall care their relatives receive in the UK, carers find this is better than in other countries where they have lived. The way in which, they reveal their aspirations for the future, appears to be closely tied to their cultural identity and ethnicity, as well as their carer role.

4.4.5 Sustaining hope during the caring experience

All carers expressed their hope for the future in terms of their own aspirations (quite often tied to the aspirations of the cared for person). They also found encouragement in their carer role from their relative, this is evident in accounts which share the achievements of their relatives (in coping with a challenging mental health problem and a complex mental health system of care).

4.4.5.1 Having their own ‘personal’ aspirations and desires as a carer

Karen expresses her initial aspirations were to understand how the mental illness affected her brothers. In this next quote, she gives a distinct picture of ‘the voices’ as her Brother Alan relays them to her. At the same time, she is amazed at what her brother is experiencing,

> “…he said you don't know Karen, you don't understand Karen. ‘I (Alan)… put on the TV on full blast and their just coming at me’- and I (Karen) said what do you mean? What do you mean? and he said, well some days you could get good voices saying, 'Oh Alan you know, you done well on things today! Sometimes you could get voices putting you down and it is really threatening’ and it was so fascinating…I (Karen) found this really fascinating! …I was glad that he trusted me to tell me it, I was glad and I wanted a better understanding of it because I didn't understand…”

Carers do want to understand what is happening to their relatives; having their own personal lens into the world of mental health experiences can bring a peace of mind and renew the relationship with the cared for person. Providing carers with experiential education on mental health is an important aspect of the patient’s recovery and the carers’ journey in caring.

Juanita associates her personal aspirations very closely with her desires to be heard by mental health services. For Juanita, being able to project the person behind the illness, or how her relatives live their lives when they are well seems to be more an essential part of the carer role,

> "I think that they should listen, they should listen more to the carers especially when the patients are unwell because of course when they aren't well, I mean some patients are still not well enough to maintain their own... but then they have got patients who have their own, who are well enough to look, take my son cos' when he's well, he's working and there are others out there like him, some perhaps teachers, nurses in responsible jobs and so therefore, when those patients are unwell they should let the carers more into the situation"

Dave expresses the missed opportunities in his life because of his caring role,

> "...there are certain things I have had to put on hold and, pro (stops) as I alluded to you before, there are certain things which I realised I didn't need, they were superficial anyway something I didn't need…well, one thing is the relationships (laughs) well, prior to actually coming down, I had just come out of a relationship, which had broken down, I really do want children I really do want a family..."

Jendayi has a desire to just be able to talk about the journey of caring she is encouraged by how the family pulls together and having her faith to lean on during difficult times in her caring role,

> "I can open up to and I find a lot of solace in my religion. Our religion is Catholic, yeah so I find a lot of solace in that and that has helped me and I think had, being able to talk to my husband, that has been of great help to me as well, you know, able to just talk between the two of us"

Angela finds it hard to have any aspirations as she herself suffers with clinical depression (which she does not see as related to her role as a carer) Angela identifies needs that she has which have not been met, when she is a patient, these continue to affect her,

> "...when I got sick mentally, I was in Africa in 2002, I just flew to Africa. It's very difficult, I lost my baby, you know I was pregnant and I had a stillborn child and Harry's parents had nothing, wanted nothing to do with the child and they wished it sort of dead and said that I should give the child up for adoption if it's born…"

Angela has asked for counselling, but was informed by her psychiatrist that this would not be a good idea,

> "…she (Angela's psychiatrist) said, what is talk therapy gonna do for me? It's not gonna be better, the more I open up the more, it's gonna be in the back of my mind – that is her words..."

Angela's experience suggests that not only do mental health and social care services need to acknowledge the role of carers, but they also need to assess their mental and physical health needs in order to gauge what support they need to continue their carer role. Harry talks about the work he does with the medical school, where (with an audience of third year students) he talks about his experience as a service users and carer,

> "…that's why I am so passionate about helping to train the third year medical students so that, when they reach that milestone, they'll think back of me, that they might have learnt from me of their training that might help them to overcome the stigma that I'm sure for everybody feels against mental health…"

An opportunity to share their carer experiences with future health professionals, can offer hope that mental health does not remain a mystery.

This can also go some way to addressing the stigma that not only tarnishes the patient experiencing mental illness, but also affects the carer.

For Helen, her aspirations are closely linked to future treatment for her niece,

> "…you know, well the main thing, I would like her, because she hasn't done this before, I would like her to have a therapy of a sort, like then with medication, you know because I was watching like 'Trisha' (Channel Five – chat show host and someone who has had depression in her life) she too had some problems she had a kind of therapy it wasn't just the medication…"…I am still asking, because I find that you know, she's got some issues with herself, especially with religious issues, …"

Carers indicate having to put their aspirations on hold (due to their carer role), feeling that their aspirations for their relative's recovery being thwarted by poor mental health provision and all carers express a positive voice when verbalising the aspirations and achievements of their relatives.

4.4.5.2 Verbalising the aspirations and achievements of their relative to show the human being behind the illness

Carers emphasised the aspirations and achievements of their relatives as a way of keeping a positive outlook on the person behind the mental illness. This highlights their importance within society; but also seemed important to enhancing the personal self-esteem of the carers.

Juanita verbalises her son's achievements. She also explains how he uses this to assert himself with mental health professionals,

> “…now my son has a first class degree when my son is unwell, that is the only time he exhibits his educational... and the reason why he does it is because they come at him as a patient and want to treat him, and he is not having it, you see!”

For Juanita, her relative’s achievements are a source of empowerment. Dave highlights his sister’s intellectual abilities at different points in conversation to present her achievements. He states this is as much a part of who she is as the mental illness she has been diagnosed with,

> “.....my sister is very articulate and very intelligent and (pause) very ambitious and similar....”

Jendayi describes her son as an intelligent young man with aspirations to be a lawyer, how much he likes to read, she smiles, feeling proud. Again, she feels empowered as a carer and as a parent is keen for her son to be back on track with his education,

> “…he's a highly intelligent young man, …and you know he's got all these aspirations all this, if he gets the right support and at the moment he's getting the right support he gets his depot at home the EIP service every fortnight, come in to administer the depot injection at home he's happy”…he's doing very well, he's got a job, and he's got friends you know, he's got a social live you know, he pushes a few boundaries here and there just like any other teenager (laughs) would we can sit down now and we can talk, something that we could not do before,”

Helen acknowledged that her niece is an intelligent person, who likes to be independent, but she gets stressed when trying to hold down a job,

> "…because she did the accounting course she went through the exams as well, you know, she was quite good really, and she found that she couldn't work …she likes to be independent as well…"

Most carers espouse their sense of pride in the aspirations and achievements of their relative. It also becomes apparent that this is a source of hope for the carers, who feel compounded by different racial and cultural stereotypes both in their roles as carers and as part of the wider community. Carers from these communities do want their relatives to have autonomy, they encourage them to be assertive and involved in their own mental health care. They are also open to opportunities to access mental health and social care that supports that development. Carers born in African countries recognise that the mental health provision in the UK is substantially better that what they would receive in Africa, and therefore would not necessarily block access to mental health services. However, this is contrary to previous research, which indicates that African and African Caribbean families try to do things within their communities, and only access help when they are relative is in the chronic stages of illness.

5. Chapter Five: Discussion

5.1 Introduction

The current study used a hermeneutic phenomenological approach to explore the meaning of caring for African and African Caribbean carers who cared for a relative or spouse with an enduring mental health problem. The literature review highlighted some early work on carers from both communities in the 1990s, then a number of community engagement projects, which had been conducted during 2007, following the introduction of the *Delivering Race Equality in Mental Health* strategy (DoH, 2005).

These projects focussed primarily on service users in mental health, with little exploration of carers' experiences. In addition, some studies focussed on carers' experiences under the overarching term 'Black, Asian and Minority Ethnic carers' thereby revealing the commonalities between different ethnic groups.

However, very little research had focussed on how African and African Caribbean carers conceptualised their caring experience and the association with their cultural identity. The literature review also yielded four conceptual frameworks, which were used to explain the caring experience: family and caregiving burden, expressed emotion, family stress and coping models and family resiliency models. These conceptual frameworks are used here to ground the discussion within a phenomenological paradigm.

The essential themes presented in Chapter Four are now discussed in relation to the wider carer research literature. The five headings include *being there and staying there, losing oneself and re-discovering self, keeping an on-going* *dialogue with others, a conscious awareness of cultural stereotypes* and *sustaining hope during the caring experience.*

Symbolic within the carer role is the experience of caring as a journey which begins with an illness crisis and progresses through adverse circumstances that lead to the hope of recovery for both carer and the cared for person.

In the first instance, family and spousal members were propelled into their respective carer roles, by the trigger of severe mental distress as experienced by the cared for person. At the start of their caring role, they felt compelled to fulfil their familial duty of supporting the cared for person, without being fully aware of the impact on their everyday lives as carers.

The first theme of *'being there and staying there'* suggest carers' actively decide to be there in terms of support for the cared for person, due to their familial obligation, but at times question their need to stay there for the cared for person.

Theme two, *'losing oneself and re-discovering self'* is depicted by carers' desire for their own time and space to re-evaluate the effectiveness of their role and their relationship with the cared for person. The focus is on how carers' address their own emotional, social and leisure needs. Equally, whom they engage in the caring experience and whom they exclude from the caring experience, was another important factor. The status of the individual carers' within their family becomes another mediator of their adjustment to the carer role. Filial relationships provide a typology of individual family carers who have different experiences of caring for the cared for person.

Theme three, *'keeping an on-going dialogue with others'* is another clear mediator of the caring experience for carers in this study and signifies the importance of both professional and non-professional support for carers. The complex mental health and social care systems, with established professional networks, can take time for carers to decipher and can make it difficult to adjust to the carer role. Professional support is discussed in relation to general practitioners (GPs); carer support workers; statutory carer support groups and mental health practitioners (who include, mental health nurses, social workers, psychiatrists, psychologists and psychotherapists). Non-professional support relates to other family carers, community based voluntary, charity organisations, and non-statutory carer support groups.

Theme four, *'a conscious awareness of cultural stereotypes'* makes reference to the additional burden of the caring experienced by carers' in this study. Life experiences of carers, some of whom migrated to the UK from either a Caribbean Island or an African country, may include experiences of racism within education and employment institutions that are repeated in their caring experience.

Theme five, *'sustaining hope during the caring experience'* relays the caring experience as a worthy role because carers' are able to observe over time the achievements of the cared for person through the trials and tribulations of the illness experience. This builds on the reciprocal nature of the relationship between the carer and their relative.

The investment in 'being there and staying there'; 'losing oneself and re-discovering self'; living with 'a conscious awareness of cultural stereotypes', and 'sustaining hope during the caring experience', highlights the carer journey for African and African Caribbean carers in this study. Ultimately, carers from both communities present a strong commitment, acceptance and advocacy in their carer roles. This is underpinned by a desire to help enhance the independence and personhood of their relatives.

A critical review of the current mental health and social care policies in the UK, and their influence on the lived world of mental health carers will form part of this chapter.

5.2 Being there and staying there for another

'Being there and staying there' suggests carers' actively decide to be there for the cared for person. This is experienced as anxiety about how to best to be effective in their care role for the cared for person. A lack of knowledge about the mental illness of the cared for relative, further exacerbates carers' worry, anxiety and fears.

Champlin (2009) described a similar situation in her phenomenological study, where carers' perspective on 'being there' for the mentally ill person involved 'willing' themselves to be there for the cared for person.

Carers' feelings of shock, anger, worry, anxiety and fear have been reported in other phenomenological studies. Chang and Horrocks (2006) discovered that carers' experienced an exponential rise in the intensity of stress, anger and dissatisfaction when their relatives were unstable, and they needed to take full control of their day-to-day activities.

Current study findings suggest that 'being there and staying there' was also experienced as 'powerlessness', particularly when carers found it hard to understand the presenting symptoms (which included delusions, hallucinations, periods of mania and depression, escalation of aggression and sleeplessness) of their relative. This is consistent with the hermeneutical study by Endrawes et al (2007) who found family carers experienced the shock of diagnosis of their relative and felt a need to protect their relative from themselves and others. In addition, Shah et al (2010) in a review of the psychological distress in carers of people with EMHP, suggests the frequency of behavioural disturbances manifested by the cared for person was identified as the strongest indicator of carer distress.

Family carers in the present study tended to keep on caring and maintaining contact with their relative, regardless of this sense of ‘powerlessness’, lack of support, isolation, embarrassment, isolation and stigma they experienced. Harvey et al (2001) examined the predictors of frequent patient-relative contact and concluded that despite the surmountable distress experienced by carers, there was no evidence they avoided frequent contact because of the caring relationships.

The current study findings revealed that carers also experienced, ’being there and staying there’, as grief (in relation to non-death) for the loss of the person they once knew prior to the onset of mental illness. They describe aspects of the persona that were lost and seem to subtract from the character of the cared for person. Loss was also described in terms of missing aspects of social and work life. Similar findings were discussed in the study by Rose et al (2006) where carers described loss of the person they was knew as a grief that was ever present. They also echoed the loss of a normal life in their narrative accounts.

An additional source of distress for carers in the present study was not getting the support they needed from the mental health and social services, when they tried to access this information. This may also explain why some carers from the African and African Caribbean community reduce contact or decide not to engage with statutory services. Keating and Robertson (2004) explored the impact of fear of mental illness and mental health services on service users, families and carers. They found families and carers reported fears about the unpredictable nature of emotional distress, which appeared to be based on a lack of knowledge and understanding of the illness and the unresponsiveness of mental health services to their pleas for help.

This is indicative of findings in the current study where carers' shock at the onset of mental illness and the subsequent change in persona of their relative, was in part due to lack of knowledge and understanding, but this was also heightened by mental health services and social care not listening to family carers concerns.

Part of '*being there and staying there'* also involved reconnecting with the cared for person, following a period of severe mental distress. This was expressed as conversations they would have with their relatives about how the mental illness affected them. Carers integrated this information with their own observations of their relative, which helped them to understand and appreciate the impact of the illness on their relative. Similar findings occurred in the study by Rose (1998) as carers demonstrated their ability to accept both the illness and the person varied among participants and seemed to influence how well they redefined their personal relationship with the cared for person to include the impact of the illness.

Treanor et al (2011) in an interpretative phenomenological study on relatives' responses to a family member with recent onset psychosis, found that although relatives described distressing experiences and feelings of frustration and anger they still felt able to show empathy and commitment to support the cared for person. Furthermore, Stern et al (2004) explored narrative insights into the experience of family members caring for a family member with an EMHP and found that in stories of restitution and reparation, carers experience of caring was transformed into meaning, they could see the significance of their carer role in their everyday lives. When their narratives were expressing chaotic or seemed to indicate they had become stuck, the caring experience became a series of random events.

Guilt appears as the most consistent feeling for all carers in this study and mediates their experience of distress and the potential for conflict in their relationship with the cared for person. However, the research by Leith and Baumeister (1998) proposed a very different perspective on the significance of 'guilt' in relationships, which may explain some of the carers' experiences in this study. They suggest that the guilt-prone person (in this instance, the carer) appears to be someone inclined to be able to understand the other person's (in this instance, the cared for person) perspective. Guilt may thus conceivably reduce conflict and strengthen relationships by helping individuals to step outside of their own views and concerns in order to appreciate the other person's point of view. Compare this to the shame prone person who becomes upset in response to another' s distress, but the shame prone person's own feelings predominate and seem less directly helpful than understanding another's perspective for the sake of resolving the conflict or solving the problem.

For carers of more than one relative with an EMHP, in the current study, there was evidence in their conversations that they experienced distress in different ways with each family member who was unwell. The distinction here is made between carers of people with an EMHP like schizophrenia and carers of people with bi-polar disorder. Rafiyah et al (2011) also found in their review of carers of people with schizophrenia that definitions of carer burden tended to focus on the negative outcomes of caring for the carer and included patient symptoms, demographic factors and time spent per day with the cared for person. .

Milligan (2003) examined the importance of place, and its conceptualization, in the care of frail older people. This concept could also be applied to the caregiving experiences of African and African Caribbean carers, particularly where the carers describe their experiences of lived space as not only feeling trapped but also espousing the feeling of loneliness in the caring experience. The lived body experience presents as a sense that although they are physically present, they still feel invisible and unheard. The notion of being there and staying there was both a negative experience and a positive experience for carers in this study.

Stern et al (2004) reporting findings of a study investigating carers' accounts about serious mental illness occurring in their family, describe *narrative form* as a primary means of ordering, structuring, and communicating illness experiences, reflecting some of the processes that carers intend to master and understand. Psychotic episodes entailed a frightening disruption that forces carers to face fundamental existential, moral, and psychological issues because they call into question the continuity of lives and life-projects. Two types of narrative structure were identified. In *stories of restitution or reparation,* the experience of the event is transformed into phenomena having meaning, occupying a place in carers' lives. In *chaotic and frozen narrative,* the illness remains a series of random events.

Consequently, some carers feel stigmatised in their carer role simply by association. Several studies infer the shame of the carer role when viewed as a form of social disgrace in caring for a person who has an enduring mental health problem, as opposed to a common mental health problem or indeed a physical health problem. The more severe the mental health problem, the more dangerous the individual is perceived to be and carers can feel blamed for this or feel guilty about being the cause of the severity of illness.

The stigma associated with being a family carer as opposed to a professional carer, as if being a family carer is less than being a professional carer is evident in the intonation of some carers in the current study, yet they demonstrate decision-making skills commensurate with a professional approach to mental health assessment and care planning. Furthermore, sharing of care in the family can be analogous to a 'multidisciplinary team approach' to mental health care.

5.2.1 Familial obligation and the caring experience

Familial obligation featured very strongly as a motivation to become a carer in the current study. Carers perceived their familial obligation to their relatives as a natural part of being a family and wanted to be involved in all aspects of care provision for their relative (Sabogal et al, 1987; Steidel and Contreras, 2003; Mucchi-Faina et al, 2010).

Lawrence et al (2008) in their study on family carers caring philosophies indicated that African Caribbean carers maintain a very traditional and family orientated approach to their care-giving roles for their relatives; they perceive the caring role as a familial duty. This is also evident in the way carers perceived their carer role. Most of the carers in this study preferred to be recognised as an aunt, wife, husband, sister, mother, brother or son who and perceived their caring role as both a duty and a reciprocal form of demonstrating their love for the cared for person.

Molyneaux et al (2011) suggests abandoning the term ‘carer’ and replacing this with descriptions more akin to the direct relationships indicated by carers in this study. There is an implication that the term ‘carer’ may imply blame on families and an onus of responsibility, which negatively influences their relationship with mental health and social care services.

Ethnic group differences in the association between culture, care giving and family were reported in US studies, for example between African American and White carers (Dilworth-Anderson et al. 2005). Dilworth-Anderson et al (2005) administered a scale measuring extent of agreement with ‘cultural justifications for care giving’ to carers from the two ethnic groups. These included scale items like “it is my duty to provide care to elderly dependent family members”, and “it is what my people have always done” (Dilworth-Anderson et al. 2005, p. S258). African American carers scored more strongly than the White carers did on the cultural justifications for caregiving scale.

In the long term, when their relative’s mental health improved, the cared for person would become less dependent and the carers in the current study assumed a supportive, advisory role. This contradicts some areas of the research literature, which suggests that relatives from both of these communities like to care for their own relatives exclusive to the statutory services and tend to want to control the way in which care is provided.

Rowe (2012) reviewed literature about the relationships and engagement between family carers of a relative with an EMHP found that the role of family arose out of familial obligation, but that this was either voluntary or involuntary.

Although familial obligation was admirable in both these community of carers, they were nonetheless affected, by the burden of care (Chamberlain, 2003). Sayegh and Knight (2011) found that familial obligation and cultural justification had an indirect effect on carers' poor mental health and subjective physical health through avoidant coping strategies.

The current study findings showed that familial obligation was different for individual family carers. Parental carers felt a strong obligation to continue or extend their parenting role for the cared for person from adolescence in to adulthood; sibling carers felt a familial obligation to care for their relatives, particularly when parental carers were absent. Marital obligation was important for the spousal carers in the current study who felt an obligation to be there for their spouse as part of their marital vows.

Although the findings of the current study cannot be generalised to other spousal carers, a literature review on mental health carers by Robinson et al (2008) concludes that mental illness amongst married couples co-occurs at a level far greater than expected by chance i.e. that mental illness in one spouse is associated with mental illness in their partner. As such mental health problems of carers may go unidentified and unaddressed, which can have long-term ramifications for their own wellbeing and the well-being of the recipient.

Idstad et al (2010) found that spouses of persons with mental disorder scored significantly lower on subjective wellbeing and significantly higher on symptoms of anxiety and depression compared to spouses of index persons without mental disorder.

However, there are a number of challenges to the ‘familial obligation’ to care which was expressed by all carers in the current study. The context of family life and being a primary and/or secondary carer of a relative with an enduring mental health problem presents the problem of trying to balance both informal caring and paid employment introduces a further challenge to carers from both these communities.

Caqueo-Urizar et al (2009) reviewed the main factors associated with the quality of life (QOL) of carers of people with schizophrenia. This research also found that carers had to leave jobs, modify their working hours or change to another job, moreover, for some carers; stress seemed to be associated with a triple shift; job, household duties and caring for the cared for person.

Furthermore Robinson et al (2008) in their review of the literature on carer research found that as the duration of care increased, carer income and earnings decreased. However, some combination of caring with an external work role can be beneficial to carers possibly as a means of social contact, social support and a buffer from the stresses of the caring role; it may also act as a protective factor for carer mental health and physical health problems.

Gray et al (2009) indicate that mental health carers are often unemployed and face severe difficulties in combining their carer role with paid and voluntary employment. Some carers experienced inflexibility within the workplace because employers were not up to date on carers’ rights in the workplace. Equally, despite, government policies on carer benefits, many carers were unaware of what allowances they were entitled to.

The findings in the current study suggest that carers were content to support the use of western approaches to mental health alongside family involvement and obligation to care. Challenges to their familial obligation included trying to balance their work and paid employment commitments and the carer role and caring for more than one relative with an enduring mental health problem.

In a phenomenological study on family carers by Jeon and Madjar (1998), *two themes were revealed a) temporality, and the need to "live each day as it comes" without being able to make long-term plans; and b) relationality, the need to "look at the world through the other's window," always aware of how the world responds, not only to oneself but also to the person with mental illness.*

The familial obligation to care becomes a reciprocal relationship where family and spousal carers experience a psychological benefit of being a carer for their relative. Sayegh and Knight (2011, p.7) refer to this as 'familism' which they define as the,

> "…strong identification and solidarity of individuals with their family, as well as strong normative feelings of allegiance, dedication, reciprocity, and attachment to their family members, both nuclear and extended."

They have the opportunity to learn more about human resilience and strength, and feel more motivated to be advocates of care for their relatives. Veltman et al (2002) found that carers reported common negative impacts but also beneficial effects, such as feelings of gratification, love and pride. The main themes that emerged from Veltman's study included stigma, service systems issues, life lessons learned, and love and caring for their relative.

However, for some carers, the caring experience has been a sacrifice and a journey on which they did not want to travel but felt forced to, due to their status in the family. This is revealed when carers express a need to have access to either counselling or psychotherapy services so that they can discuss how affected they have been by their carer role.

Furthermore, Knight and Sayegh (2009) highlight that familism is a multidimensional construct, which includes the value of filial piety, felt responsibility and filial obligation and differences between the effects of each dimension on distress, may exist. This suggests that despite the strong familial connection that exists within the African and African Caribbean communities, carers would value professional emotional support to cope the experience of caring.

5.2.2 Expressed emotion and the carer role

There is an established research literature which shows trends in the stressful family environment and the life course of mental illness in the cared for person. This was studied using the concept of expressed emotion (EE) (Leff and Vaughn, 1985). It was found that service users living with relatives who displayed high levels of criticism, being overwhelmed, who displayed hostility or over-involvement relapsed more than service users whose families were less expressive of their emotions. These behaviours were named ‘High Expressed Emotion’ (High EE) (Kavanagh, 1992). Expressed emotion does not tell us much about the causes of schizophrenia, but it can be a predictor of its course when someone with the illness lives with relatives. Low Expressed Emotion (Low EE) relatives tend to display higher levels of warmth and a higher level of positive coping strategies.

Moller-Leimkuhler (2006) found that predictors of stress in family carers were associated with relatives' expressed emotion and neuroticism, their generalized negative stress response and life stressors – all of which were considered to have significant direct and indirect effects on relatives' stress outcome. Stress reduction was caused by an interaction of relative's generalized positive stress response and patients' residual symptoms.

Using the 'Expressed Emotion' (EE) concept of caring, the current study revealed that carers' expressed high emotions during the beginning of their carer role and during periods when the cared for person had several in-patient admissions within the same year. Carers did indicate there were periods where the caring experience was perceived as overwhelming, and they felt that the cared for person may have made wrong decisions and choices about how they wanted to receive care. Equally where carer and cared for person had disagreements about the direction of care delivery, was also a source of high expressed emotion by the family carer. Ohaeri (2003) in a literature review of family and informal carer burden; also found that care-giving burden was associated with the problematical behaviour, disability and the severity of symptoms of the cared for person. High expressed emotion indicated the family's attempts to help the patient; and was mediated by controlling behaviour, stigma, burden, and carer perceptions of the patient's control over their own behaviour.

Similarly, Kuipers et al's (2007) investigation of how illness perceptions affected expressed emotion (EE) in carer-patient dyads, suggest that carers were more pessimistic than patients about illness persistence were and consequences were. Those carers with low mood were particularly pessimistic about persistence and controllability. Discrepant views about illness consequences were related to greater anxiety, depression, and lower self-esteem in patients, while discrepant views on controllability were associated with greater distress, depression, and lower self-esteem in carers.

The presentation of high expressed emotion was not consistent across carers in the current study. In most cases, carers' agreed with their relative's approach to how care should be delivered by statutory services. Ultimately carers were able to reach a point of low expressed emotion, when they had more information about how mental health and social services could support the family in terms of education about mental illness and when the cared for person had established better coping strategies to cope with the impact of their illness.

However, research by Rungreanggkulkij and Gilliss (2000) suggested that the concept of expressed emotion theory does not fully acknowledge research, which has found a very strong association between high expressed emotion and patient relapse of mental state. This model could be interpreted as blaming family carers for the cared for person is mental distress, which is not helpful in developing partnership relationships, with formal care services. This theory also seems to place family carers into two distinct categories of emotional experience. As indicated by the carers in the present study, their experience can move between high expressed emotion and low expressed emotion over the time of their carer role, this suggest that responses to caring for a relative with an EMHP are dynamic and therefore, prone to changing during the caring experience.

Laing and Esterton (1964) in a study of family life and mental health analysed family members' perceptions of each other that included how they communicated with each other. They discovered that families readily engaged in perpetuating lies, which sustained a degree of social order. However, this proved to be difficult for the more vulnerable family members (Laing and Esterton, 1964) to express themselves and ultimately to appreciate what was the truth about any given situation. Laing and Esterton (1971) did not blame families for this conflict, as he concluded that many were oblivious and perplexed by how they got into this ‘family nexus’ or consensus view within a family.

Another area of conflict in the carer experience includes the different roles of responsibility that carers possess which stand outside of the carer role. This includes the role of the carer in the family as a mother; father, brother, sister or aunt. Other roles following this is the responsibility for other children (older and younger), other sick members of the family (who may have physical health problems). Equally, those roles associated with paid employment. All can present a number of additional challenges for carers in their carer role.

5.2.3 Conflict of roles and the caring experience

Carers can experience a conflict of roles, the carer role is often perceived to be a full time job in itself and carers invariably have other responsibilities, which may include paid employment, caring for other sick relatives and young children. When thinking about care-giving one often thinks about care-giving to only one individual, or perhaps to care recipients from the same generation (as with parents or offspring). However, increasingly care giving may be to multiple persons across multiple generations. Adults in middle age are now termed the ‘sandwich generation’. Current study finding highlights that some carers (two carers were working as nurses at the time of the study; three had retired early from their health professional role) have a dual carer role of being a health professional and an informal carer.

The carers who were both health professional and informal carer role found it hard to see where their professional carer role ended and where their informal carer role started and vice versa. There was also the unexpected nature of feeling like '*they are constantly on duty or on a shift*'. For the mental health professional in this study, this dual role involved giving additional support to other family members in the form of mental health education and not knowing how to separate work like from family social life.

This is indicative of research by Ward-Griffin (2004; 2005) whose study on nurses as carers of their elderly relatives, gave credence to the name '*double-duty carers*'; her study revealed that nurses who held an informal carer role were caught between public and private domains of care-giving, where they were constantly negotiating between professional and personal care-giving.

An important consideration proposed by Mills and Aubeeluck (2006) is that those nurses providing care for their own family members have specific needs with regard to their dual role as a health practitioner and family carer. They suggest it is important to provide a more equal and effective level of support to these carers because as Scott et al (2006) states, fatigue and stress levels were significantly higher among nurses caring for both children and elders. As a result, nurses were more likely to make errors at work.

Studies looking at double-duty caregivers also looked at the significance of ethnicity and dual role in caring. Lawrence et al (2008) highlighted that a high proportion of the African Caribbean carers of family with dementia were also professional nurses, who felt that working in a caring capacity formed an intrinsic part of their identity and equipped them to deal with the informal caring role. Chevannes (1997) noted that nurses from different ethnic minority groups may care for more than one family member with chronic health problems due to both their professional carer role and traditional care-giving ideology, based on their familial obligation to care for their family members.

Being a professional and informal carer is more likely to happen with persons from the African and African Caribbean communities in the UK due to the high number of professionals from these communities represented in the National Health Service – indicate the period when the migration of African and African Caribbean also increased numbers in the NHS (Kingma, 2007).

Carers UK (2012a) in the 2001 Census found 3 million people combine work with caring responsibilities for a disabled, ill or frail relative or friend; 400,000 people in the UK with caring for 20 hours a week or more, of these 200,000 are caring for 50 hours per week or more. Many carers work part-time, the prevalence of working part-time is higher in the carer population, than the non-carer population.

Thomas (2005) described the impact of various forms of non-employment and vice versa and psychological distress on men and women. Staying at home to look after family was associated with psychological distress for women. However, transition from these roles to formal employment led to an improvement in mental health. According to the survey, *'Employers for Carers'* working carers caring at a distance were under particular stress (Carer UK, 2011).

Additional pressures include long hours outside the workplace, giving up their work, poor local services support, and potential financial hardship up to retirement. Working carers were more likely to be unqualified, and less likely to hold university degrees, than people who did not have a carer role.

In this study, the three carers gave up their paid work to become full time carers. They cited the stress of long distance caring (LDC) and having to travel from one part of the country to another to care for their relative, due to out of area transfer of care for their relative or because they themselves were located in another region in the country. The fact that some carers had caring responsibilities for two relatives with enduring mental health needs added to the degree of burden.

The experience of caring for all mental health carers is inextricably linked to their engagement with mental health and social care. This represents one of the influences on the subjective burden in both communities. The cycle of feeling trapped in the caring experience and then searching for that space and time to reflect leads to periods where carers feel very alone and seek partnership with mental health practitioners who they perceive as being able to understand and appreciate their caring experience. Being there and staying there also meant making a conscience decision to seek out other life experiences that gave them the motivation and hope that ‘things will get better’.

5.2.4 The impact of migration on the caring experience

Another important finding in this study relates to carers experience of migration. At least three carers had migrated from either Africa or the Caribbean to the UK when their carer role started. Migrating from Africa and Caribbean to the UK, means that carers and their relatives are no longer the majority population but the minority population – Low population density of

African and Caribbean communities can make carers and their relatives feel isolated and encourage greater reliance on any family networks. This can increase carer subjective burden. Generational differences between carer and relative can also influence carer experiences.

There is an acknowledgement that 'lived space' is perceived very differently for African and African Caribbean communities who have an expectation that they will need to travel abroad to seek a better way of life within their families, if they still reside in Africa or Caribbean.

For carers born in the UK, or who reside in the UK, there is some expectation they will need to maintain links with their families abroad in Africa and the Caribbean. Moving from the felt space of the country they were born in to another country where they migrate to is already stressful, but they expect this. The lived space of cohabiting with cared for person, increases subjective burden of caring. The lived space being in one's own home and the cared for person having separate accommodation of their own, is considered least stressful by carers in this study.

The social science literature eludes to notions of home as a 'haven' or refuge, often drawing on the dichotomy between public and private space (Rose, 1993; Sibley, 1995; Mallet, 2004). These meanings include a space of belonging, place of origin, the embodiment of identity, place of independence, control and resistance from oppression, as well as a place of alienation, fear, isolation, violence, and insecurity (Bowlby et al, 1997; Blunt and Varley, 2004; Imrie, 2004; Mallett, 2004. Geographers have highlighted the significance of place for caring relationships, arguing that while care extends across public and private space, the interconnections between them vary over time and space to produce 'specific geographies of care' (Milligan, 2003).

In particular, ‘home space’ has been recognised as an important social space that is constantly changing in response to caring practices and relations (Twigg, 2000; Milligan, 2003; Conradson and McKay, 2007). However, few studies have explored the spatial dimensions of caregiving or the effects on different ethnic carers’ migration and experiences of home space.

Rashid (2000) reported that black families are able to maintain strong links with family members, both in Britain and abroad even following migration. Hill (1999) family traits of ‘strength’ and ‘endurance through adversity’ were transferred through African ancestry. However, Hildreth (2000) states that when black families experience discrimination in other areas of their social lives such as education (Christian, 2005), employment, criminal justice system, political racism (apartheid), difficulties in maintaining oversees or family links occur and a climate of ‘suspicion’ of public service involvement in their lives and that of their relatives ensues.

Willis (2012) argues that ethnic identity becomes salient after migration and becoming a part of an ethnic minority group in the new country. Study findings suggest that carers appear to infer a caring identity through their relationships with the cared for person, family members and their cultural heritage. At the same time they expressed their concerns about the caring experience by describing the impact of others stereotypical perceptions of their culture and ethnicity.

5.3 Losing oneself and re-discovering the 'self' again

There was evidence that carers sometimes felt trapped with the cared for person, expressing feelings of powerlessness and hopelessness. Carers experienced lived space as filled with all of the cared for person's needs, but their needs were did not exist. Many described a feeling that they were invisible in the experience of caring and needed their own space to be cared for and supported. This increased their feelings of loneliness and isolation in their carer role. Findings in the current study found that carers spoke of different occasions during the caring experience when they just needed to 'deal with themselves', their own thoughts, their own emotions, their own life and some of what they struggled with was getting back to who they were, the person, and not the carer. On other occasions carers' described the loneliness they experienced in their carer role and the need to talk about their feelings with someone other than the cared for person or other family carers. The way in which carers sought their social support to combat 'feeling trapped' and the 'loneliness' of caring, suggests that early engagement by mental health and social carer services to counsel and advise carers is needed.

5.3.1 Needing space in the carer role

An important aspect of the caring experience for carers in this study was being unable to identify personal space and time when the cared for person was experiencing severity of symptoms and lacked any insight into their illness experience. This led to the cared for person being more dependent on the carer, which subsequently restricted their personal and social life. McGilloway and Donnelly (1997) reported on a number of carers categorised as 'cases' (individuals who experienced mental distress) who showed a high level of burden was indicated by personal and social restrictions on their daily lives.

A number of other issues arose for carers’ in the current study. Carers’ experienced lived time (temporality) as going very fast when addressing care provision with their relatives. This was uncomfortable and carers needed time for themselves, in order to reflect and review the experience of caring and having their own ‘place’ to where they focus on their needs. An opportunity to experience their own lived space within the carer role presented a problem for carers, who were often balancing work, care of other family members e.g. children, teenagers, more than one relative with an enduring mental health problem. *‘Losing oneself and re-discovering self’* also meant that carers in the present study gave up on their dreams and rethought their future goals. Some carers indicated that they sacrificed opportunities for promotion at work, settling down and getting married; going out socially and they reported feeling physically drained. Several studies report on the same caring experience with other carers of family members with EMHP. Some feelings of ‘losing oneself and re-discovering self’ were mediated by the carers’ experience of mental health and social care professionals.

Gavois et al (2006) in a grounded theory study to develop a model of mental health professional support found family members perceived more stress when excluded from care by mental health professionals and less stress when they were included. Gray et al’s (2009) study reflected on some of the experiences of carers in the present study. There was a perception that service users were given priority whilst the rights and needs of carers for information became a secondary concern. Almost all carers in the current study described needing personal time and personal space to give attention to other family members that may have included siblings, husbands, wives, and friends. Carers still wanted to maintain a close family tie to their relative and be involved in the decisions around their relative's care; they also wanted sometime just to be on their own and reflect on their role as carer and any particular needs they had. This alluded to needing respite. There remain some contradictory findings on the benefits of respite care for carers.

However, carers in this study welcomed regular breaks to maintain their own health and wellbeing. In some instances, carers felt able to organise respite amongst the family of carers, and take turns to provide respite.

Jeon and Brodarty (2006) in their review of respite care for carers of people with an EMHP found that the literature did not indicate respite care was beneficial for carers. However, there is significant unmet need in provision of services for the person with EMHP. Part of the problem, may be about the type of respite care and whether this is organised informally (through non-professional/non-statutory organisations or formalised professional networks).

'Losing oneself and re-discovering the self' could also be mediated by the stage of the carer process for the carer. Savage and Bailey (2004) in their review of the literature on the impact of caring on carer's mental health found evidence that where carers are at in their caring career influences the impact of caring on their mental health.

Nolan et al (1996) described various stages that the carer may go through in response to the caring situation, which include noticing, discounting/normalising, suspecting, searching for explanations, recounting, taking it on, going through it and turning it over. The length of time that carers have been in the caregiving role ad their stage could have an impact on their perception of self in the role. Much of the literature that relates to this theme comes from research studies, which have explored the 'self-esteem' of carers as they progress through the caring experience. Carers in the current study felt trapped in terms of how they were perceived by health professionals. The stigma attached to being a black person in 21st century UK; the stigma of caring for a person with EMHP and the stigma of being a carer.

Pejlert (2001) the majority of carers described how they felt 'stuck' in terms of how best to cope with the variation in illness patterns and recovery time of their relative. Biegel et al (1991) used a stress-coping framework to examine the predictors of carer burden with a sample of 103 lower social class family carers of persons with EMHP. A third of carers described feeling trapped.

The current study findings are also consistent with a review of research studies by Loukissa (2006) who found family carers felt embarrassed, overloaded, trapped and resentful when they cared for person went into hospital. Sales (2003) examined objective and subjective dimensions of family burden – carers spoke of feeling trapped in this carer role, and associated this with being confined to their homes, unable to socialise with others due to a need to monitor the family member.

Reinhard and Horwitz (1995) used the burden assessment scale for families of the person with an EMHP and found carers described worries for the future of the cared for person and also feeling trapped in the caring experience. Baronet (2003) investigated the impact of family relations on carers' positive and negative appraisal of their caregiving activities, carers expressed their worries about the future and making things worse in their caring role for the cared for person; but also felt trapped in the carer role.

Rowe (2012) conducted a systematic review of the literature in family carers of people with EMHP; carers felt they were hidden and invisible, trapped and isolated in the narrow confines of their carer role. Burton (2008) who explored different social constructions of the caring experience for family carers, found that if carers focussed on what they had lost because of caring, they found the carer role harder to cope with. When carers focussed on what they could learn from the cared for person, there was an increase in self-control and feeling less trapped and more positive in the caring experience.

Marini (2011) highlights the impact on carers of giving social support to their relative was that they felt they had no control to change the situation if they found caring difficult and as a result they felt trapped. Another study by Ali et al (2012) described the daily life and management strategies of young informal carers who lived in constant readiness for something to happen to the person they cared for, but they also described caregiving as feeling trapped in their daily lives with all the emotions that come with the caring experience.

Copeland and Heilemann (2011) explored mothers' experiences related to the housing options available to their adult children with mental illness and a history of violence. Carers described feeling trapped in their caring roles. The inferences from these studies were that carers wanted support that offered them a break from their relative. They wanted to have a break to do the leisure activities with the cared for person and a break to fulfil other life responsibilities. Koo (2012) in a qualitative study of 14 carers exploring illness representations of affective disorders in British Chinese communities found that carers expressed feelings of hopelessness or being trapped by their caregiving roles.

For carers in this study personal space occurred when they received support from a General Practitioner (GP), a mental health practitioner, assertive outreach teams who maintained contact with the carer and the cared for person, as a family. Carers felt regular and structured contact from mental health services actually gave them some respite from the caring experience, allowed them opportunities to receive advice, role model coping styles from the mental health professional, and decreased the distress of the caring experience.

However, some carers expressed concern about accessing mental health professionals when they had to communicate with a new professional of each occasion or they were asked the same questions during the assessment of their relative. This added to the feelings of loneliness and isolation, because carers felt no one was listening and they remained trapped with the cared for person. Local non-statutory and charity-based organisations set up to support mental health carers were considered a very good form of support by carers that accessed them. Carers found they had time to get some validation of their caring experience, had a chance to gain some control over their daily lives and to re-discover their own personhood.

Weimand et al (2013) in a qualitative study of carers' experience of caring for a relative with EMHP, found relatives wanted to be able to prioritise some private time. The unpredictable nature of EMHP in their relative made it difficult for them to establish balance in their lives.

For instance, Carers UK (2012a) in the 2001 Census found 3 million people combine work with caring responsibilities for a disabled, ill or frail relative or friend; 400,000 people in the UK with caring for 20 hours a week or more, of these 200,000 are caring for 50 hours per week or more. Many carers work part-time, the prevalence of working part-time is higher in the carer population, than the non-carer population. Thomas (2005) described the impact of various forms of non-employment and vice versa and psychological distress on men and women. Staying at home to look after family was associated with psychological distress for women. However, transition from these roles to formal employment led to an improvement in mental health.

According to the survey, *'Employers for Carers'* working carers caring at a distance were under particular stress (Carer UK, 2011). Additional pressures include long hours outside the workplace, giving up their work, poor local services support, and potential financial hardship up to retirement. Working carers were more likely to be unqualified, and less likely to hold university degrees, than people who did not have a carer role.

5.3.2 Experiencing the loneliness and isolation of the caring experience

A further illustration of *'losing oneself and re-discovering self'* was indicated in the theme *'travelling this journey alone'*. Carers described several times in their conversations where they not only felt trapped in the carer role with the cared for person, but they felt alone. Cognisant throughout carers' conversations was the sense of isolation they felt when they were not informed about any aspect of care regarding their relative.

Gray et al (2009) found similar outcomes on a study on 'confidentiality smokescreens where carers who were uninformed or kept out of the loop by professionals felt disempowered, angry, experienced feelings of loss and any carer identity, as well as isolation. Askey et al (2009) explored 'carers' experiences of caring and found that carers talked about the emotional impact of mental illness had on their own well-being and the sense of loss they felt, in terms of loss of social life; the powerlessness of not knowing how to cope when their relative was experiencing severity of symptoms. Champlin (2009) further supports these study findings where carers' described their caring experience as a lonely and isolating experience, particularly when friends and close family withdrew their support. This made the caring experience increasingly difficult.

Jonsson et al (2011) in a study to elucidate what it means for family members to live with an adult person who has Bi-polar disorder, showed that family members felt alone with their experiences and struggled to make sense of and maintain normality. Ewertzon et al (2012) also summarised the sibling experience of caring for a relative, as a lonely journey. .

5.3.3 Social support networks in the African and African Caribbean community

In the current study, carers were mostly positive about the support they received from their immediate family members and the communities they lived in. They also emphasised the positive support they received from attending local carer support groups. Aranda and Knight (1997) concluded that black carers were more likely to use constructive caregiving approaches and make use of not only family kin networks but also wider community networks such as friends and neighbours to support the caring role. Guarnaccia and Parra (1996) also found that African American families more likely to seek out the advice of other family members.

Some carers in the present study received support from a faith group or church organisations. This is similar to the study outcomes by Brown et al (2007) who found that African Caribbean patients with diabetes accessed their faith and churches more, as social support networks. Dilworth-Anderson et al (2002) also concluded that African American family carers were also more likely to be caring for a sibling, other relative or friend. These carers ranked God and religion as their first source of informal support, followed by family friends and neighbour.

However, this may be associated with their age and spiritual upbringing. Mak (2005) African American carers experienced a higher level of personal growth, as did those who were married and lived with their partner. Hines-Martin (1998) and Sterritt and Pokorny (1998) and McLean et al (2003) discuss the importance of religion as a strong community support for carers from both African and African Caribbean communities.   However, Rogers et al (2012) suggests that churches may not always provide the most effective support; there is evidence that the church community may be uncomfortable and dismissive of mental health issues, lack knowledge of mental health problems and may make matters worse for carers, through 'well-meaning' advice.

The strongest form of social support for most carers in the current study was either voluntary sector organisations or charities focussed on supporting African and African Caribbean carers and service users and or specific carer support groups for carers of people with mental health problems.

Das-Munshi et al (2012) suggest that the neighbourhood individuals live in may function as a reservoir of risk or resilience' in the cause of mental illness in ethnic minority groups. This can have a number of implications of carers from the African and African-Caribbean communities who are reliant on community support networks. Mir and Nocon (2002) report that carer's fear of being excluded from service decisions for a host of reasons, some of which included low population density of ethnic minorities in an area and having cultural values different to service philosophy of care. However, Das-Munshi et al (2012) were not able to make that strong association between low population density and incidence of psychosis in these communities because African people were not included in this study, and they were conscious that there may be a differences in how populations support and infer ‘density’ and ‘connectedness’ over geographical distance.

Dilworth-Anderson et al (2002) found informal social support was more diverse in African American family carers, more likely to report a friend or neighbour as important helper. Koffman et al (2012) explored social support networks and their meaning among Black Caribbean and White British patients living with advanced cancer. Koffman et al (2012) observed that one of the most notable influences of ethnicity and culture was on the size and composition of social support networks, frequently offering Black Caribbean more opportunities for assistance than White British participants.

Carers experienced higher levels of carer burden when friends and family do not understand the intensity of the carer role, like the sudden onset of distressing symptoms or the discharge of their relatives from in-patient care when carers were not ready to receive the cared for person home. An on-going concern for carers was that they felt excluded from access to psychotherapeutic interventions within mental health and social care services.

There is general agreement about the positive outcomes of community carer support groups, which has been evidenced by several studies and by carers in this study. Study findings suggest/imply that a family psychosocial intervention for family carers of people with EMHP is a positive means of support for carers that could be further developed by the mental health and social care services.

McLean et al (2003) supports this finding suggesting that access of non-drug therapies was seen to be denied to the majority of local African and African Caribbean people, due to the financial cost. Participants in Mclean’s study felt that there was a demand for non-drug therapies such as talking and music therapies, but in general, financial cost prevented African Caribbean people from being able to access such therapies privately.

Epiphaniou et al (2012) conducted a study, which aimed to identify existing coping and support mechanisms among informal cancer carers in order to inform intervention development. Carers' existing coping strategies included distraction, mental stimulation, and emotional release, looking for the positive aspects of caregiving, and disengaging from stressful thoughts. The majority of the participants described the importance of support and understanding from family and friends. This study concluded that feasible and acceptable interventions would be those that are targeted to carers to assist them in optimising existing coping strategies and support from family and friends.

Burnell et al (2012) describes peer support interventions that focus on delivering emotional, informational, and appraisal support rather than instrumental support. These different types of social support may be found in embedded or naturally occurring support networks, or in both. However, carers might not access them in times of stress. Peer support interventions aim to fill this potential gap in support, by providing access to a peer through health care and volunteer services.

Family Based Intervention groups are based on a broad psycho-educational and cognitive behavioural therapy (CBT) approach. It is acknowledged that educating families about the illness alone does not reduce levels of EE in families with High EE). However, working with them to tackle practical problems such as improving communication, effectively developing coping skills and helping families to attribute the symptoms to illness can decrease their critical or over-involved behaviours. These interventions can reduce relapses for this population. As awareness and knowledge increase, tension and stress throughout the family decrease, improving the quality of life for all concerned (Barrowclough et al, 1999). The reduction in families' ambient and chronic stress levels and a reduction of face-to-face contact to fewer than thirty-five hours per week can enable the service user to cope better with unavoidable stressors and reduces their risk of relapse (Falloon et al, 1993).

Garety et al (2008) tested the effectiveness of Cognitive Behavioural Therapy (CBT) and family intervention in reducing relapse, and in improving symptoms and functioning in patients who had recently relapsed with non-affective psychosis. In people with carers, CBT significantly improved delusional distress and social functioning. Therapy did not change key psychological processes, but the involvement of family members in the therapeutic intervention was significant in effective management of psychosis.

In 2010, Kuipers et al developed an empirically based model of the relationships of those caring for people with psychosis. Good evidence supports a number of hypotheses concerning the origin and maintenance of these relationship outcomes, which relate to specific differences in carer attributions, illness perceptions, coping behaviour, social support, distress, depression and low self-esteem predicted by our mode. Family work in psychosis, which improves relationships through problem solving, reduces service user relapse. Current and past literature from the USA indicates a strong resilience to social stressors in communities with an African and African Caribbean heritage. Shah et al (2010) suggests there is an essential role for mental health and social carer professionals to help carers to improve their coping skills, support existing skills and facilitate the development of new ones.

Currently carers tend to use strong informal relationships and the presence of informal support in their local communities. Some carers have also accessed spiritual and religious support. However, all indicated their personal need for more formal support, which could be provided by the mental health and social services. These include different psychotherapeutic approaches and/or combined with training and education interventions. Carers mediated their informal and formal support networks by ‘keeping an open dialogue’ with not only other family carers, friends and the local community, but also local mental health and social care services (Chen and Lukens, 2011).

5.3.4 Stress and Coping Theory

Mackay and Pakenham (2011) proposed that the application of the stress and coping theory to informal caring could identify modifiable risk and protective factors associated with adjustment to carer role. However, other research suggests that stress and coping in caring may be mediated by the degree of relative’s expressed emotion. Joyce et al (2003) carried out a study to test how distress or satisfaction in the caring experience was depicted in the framework of a ‘stress-coping’ model using data from a group of carers of people with psychosis. Carer distress was most strongly associated with coping. In turn, coping was associated with two sets of factors – one related to appraisal and care-giving difficulty, the other to social support. There was again a strong association between carer distress and current coping. Support from confidants assumed an important relationship to effective coping. The level of effective coping increased over time while care-giving difficulty decreased, but carer appraisal and distress did not change.

As such it can used as a framework for shaping thinking, decision making and prioritising of care delivered to both carers and the cared for person from the African and African Caribbean communities. The theory potentially offers a basis for building a partnership of caring between the relative with enduring mental health problem, their family carer(s) and the mental health and social care services. By developing this partnership of care, it is hoped that nurses, indeed, mental health practitioners, will make constructive use of culturally specific knowledge to support family carers, improve relative's mental health care and recovery and add to their professional development skills.

However, Rungreankulij and Gilliss (2000) suggest that the stress and coping framework is focussed on the individual family carer, rather than the family as a whole. This limits opportunity for acknowledging multiple family carers and may only consider the primary carer role.

5.4 Keeping an open dialogue with mental health and social care services

5.4.1 Engaging with mental health and social care services

Although all carers in this study agreed that the provision of mental health and social care is better than the mental health provision their relative might have received in countries like Africa or the Caribbean; they were very clear about the areas of service provision, which they found unhelpful and helpful in the UK. Carers experienced lived relations with statutory services as a 'barrier'/closed gate' to their caring experience or a 'gateway'/open gate' to deeper understanding of enduring mental illness and opportunities to develop better coping strategies. Relations can be facilitative/supportive or frustrating/destructive. However, much depended on the point at which carers engaged with services and the specific individual needs of different types of carers, as well as how much of the migrant cultural values they maintain in everyday family life.

Carers described a negative relationship with mental health and social care services, during their caring experience. This was particularly evident at the beginning of the carers' role; when the cared for person experienced an increase in severity of symptoms of their EMHP and when the cared for person was admitted to an in-patient hospital. Similar findings were found in the study by Cleary et al (2006) who concluded that carers of in-patients experienced more subjective burden than carers of outpatients. George and Howell (1996) presented a more mixed view on carers of in-patients. In their phenomenological study on the lived experience of patients with schizophrenia during re-hospitalisation, carers saw re-hospitalisation as an event that provided a safe place, stabilisation, effective medication management and a renewal of hope. However, carers in George and Howell's study also found re-hospitalisation to reinforce feelings of frustration with mental health services and reduced individual control.

Winefeld (1996) posits another view, and considers that some of the barriers to an effective therapeutic alliance may be system wide inadequacies in resources for an area of health and social care, which is still somewhat stigmatised. Other barriers would appear to be attitudinal in nature. Winefeld proposes that family carers and mental health professionals work constructively as co-therapists.

Gray et al (2009) found that carers interpreted ‘confidentiality’ as if it were a conflict of interest (in the case of carers) and gave this as a reason to withhold information from carers. The same study revealed carers were viewed as ‘trouble-makers’, ‘fusspots’ and as ‘part of the problem’ (perceived as over-involved and over-protective) and not ‘part of the solution’. These findings also reflect the experience of carers in the current study, who felt a sense of powerlessness, which increased their carer burden.

Nicholls and Pernice (2009) described mental health professionals and family carers’ perceptions of the informal carer role and found that family carers perceived professionals as lacking insight into the family carer’s role and also lacked empathy with his or her needs. As in the present study, carers in Nicholls and Pernice’s study also felt a growing distrust towards mental health professional because their caring expertise were often questioned, they did not feel they were believed and often blamed for making matters worse, they were not informed and ignored in the decisions around care for their relative.

However, Champlin (2009) reports that carers’ in her study viewed their knowledge of their relative as both an advantage and a disadvantage. The advantage was that this knowledge helped them seek early intervention when needed, but the disadvantage This was also found in the current study, where carers became so attuned to any changes in mood, thought or behaviour of their relative, they would make contact with the primary or secondary mental health services to instigate an intervention. Contrary to the findings in Champlin’s study none of the carers in the present study hesitated to intervene, when they thought their relative had become unwell. In the Nicholl and Pernice’s study, mental health professionals were unsure about how family carers could be involved in a partnership of care and had concerns about patient confidentiality. They also felt there were institutional demands, high workloads, and difficulties with over-protective families, which compounded the concept of partnership with family carers. Shah et al (2010) noted in their review on family carers, that increased distress and anger towards mental health services stemmed from carers' feeling that the cared for person's needs were not being met.

One area that came up throughout conversations with carers was related to confidentiality. Carers discussed issues of confidentiality in two areas of conflict. In the first area of conflict, they described being excluded from updated information about the cared for person, particularly when their relative was admitted to an in-patient hospital.

Another new finding was in the second area of conflict, where carers who held both a professional and informal carer role were worried about breaches of confidentiality, which occurred in their workplace, which was also the place where their relative was admitted to receive mental health care.

The two most psychologically distressing aspects of engagement with mental health and social care services was firstly, around the process of discharge of their relative from an in-patient hospital back to their care or into a community environment. The second most distressing experience was when the cared for person was transferred to another in-patient hospital out of area.

Engagement with mental health and social care services was perceived as positive, when the family carer was consulted and jointly involved in decisions around the care of their relative. Carers experienced good self-esteem and because they shared the responsibility for care with professionals, they felt more effective in their carer role. An identified mental health practitioner allocated to work with family carers and the cared for person proved to be the most positive support. These practitioners were mental health nurses, psychiatrists, assertive outreach teams, community mental health practitioners or general practitioners. Gavois et al (2006) noted similar outcomes from their study to develop a model of mental health professional support to carers. Carers felt able to leave any crisis in terms of the care of the cared for person behind when there was on-going contact with the mental health team of professionals. On-going contact increased carers sense of security and ability to cope with the cared for person.

Other influences on the positive relationship carers experienced with mental health and social care services included their liaison with local voluntary/charity based organisations set up to give information and support both carers and service users in mental health. Support given by these organisations included opportunities for family carers to meet wither carers who were in the same position as them and sharing their stories. These organisations also provided information and advice about financial support, carers' rights and the rights of the cared for person. As a result, carers felt they received more emotional and social support and were able to get some respite from their caring role. Grandon et al (2008) concluded that although carers and families were frequently excluded when key decisions were made around care of the cared for person with statutory service provision; by contrast, they found community based support groups provided a sense of inclusion and common purpose. Another new finding in this study was that carers tended to use the voluntary and charitable organisations as a 'conduit' to asserting themselves in their carer role with statutory mental health and social services.

The issues around confidentiality for carers were raised in a paper by Wallcraft et al (2011), which acknowledged some of the key barriers to partnership was a lack of clarity on the issue of accountability, a lack of support and training of all stakeholders and poor policies on partnership and how to implement it. Competing objectives between service users, family carers, health and social care professionals, managers and commissioners presented a longstanding problem.

These findings are also supported by Askey et al (2009) who sought a broader understanding of the needs of carers of people with psychosis in a UK study, reports that carers and service users did not believe that service users' basic needs were being met by mental health and social care provision. Carers asserted that the needs of service users and carers were interconnected and should not be seen as separate. Furthermore, carers felt strongly that professionals tended not to listen, involve or respect them in the care of their relatives, which in turn increased carers' sense of burden and distress.

Despite this, the current study findings suggest that whilst carers see they are very much interconnected to their relative, mostly through familial obligation, they also welcome opportunities to have a focus on their specific needs, which were different to their relative. An example of this would be education on the strategies for managing the variation in behaviour of their relative when they are experiencing severe mental distress.

Szmukler and Bloch (1997) suggest that sound ethical practice is needed within mental health service provision, which fosters a family approach to care delivery. The foundations for this begin with an open discussion with both the cared for person and initially the primary carer. The relative benefits of this approach should be sought and outlined by the health and social care *professional, the carer and the cared for person. The barriers to this approach include fears that any of the parties involved may have about sharing information, issues of confidentiality and competing interests.*

5.4.2 Multiple care giving in the family

Sharing the care in the family can be both involve helpful and unhelpful support to the carer. This data suggests that carers describe the benefits of sharing care in the family as having that group support and being able to take it in turns to carry out the carer role, share different parts of the caring experience, carrying out joint decisions. More group advocacy for cared for person and carer. Lived relations were experienced as a burden shared was a burden halved.

However, the challenges begin when family carers have differing perspectives on how the carer role should be carried out and not all family carers want to be proactive in caring for their relative.

Parental carers find they have to consider not only the needs of the cared for person, but they also have other children/offspring in the family to attend to. Spousal carers' experienced a commitment to caring embedded within their marital vows and duty. Sibling carers note a change in the level of trust in their relationship with the cared for person. An increase in subjective burden is apparent when carers' care for more than one family member with an EMHP each of whom have different diagnoses of EMHP. Those that try to maintain both a professional carer and an informal carer role can see any appreciation of how carers' 'time and space' is experienced.

Hatfield and Lefley (2005) carried out a survey with the siblings of relatives with an EMHP. They found siblings mentioned caring was difficult with the demands of their own personal families and work life, their relative's hostility and lack of cooperation would be barriers to providing the support their relative needed. Some of the challenges for siblings were just how much of their relative's presentation was due to behavioural problems related to their illness or manipulation; they also highlighted fears of genetic vulnerability. Other problems were more about the long-standing context of the relationship with the care recipient, lack of understanding of mental illness, poor family social dynamics.

Hatfield and Lefley (2005) found that if sibling carers lack knowledge of mental illness and the skills in coping with challenging behaviour, they may inadvertently aggravate conflict and anger, in the cared for person. However, even with the knowledge of mental illness, sibling relationships which can be very close within a family may still aggravate more conflict and anger particularly around the issue of whether their relative is being manipulative, the generic feelings of jealousy and competition may still be present, but become more exacerbated.

Roick et al (2007) found that parents were more likely to experience carer burden, particularly when their relative was living at home and was diagnosed with an EMHP at an early age. They also highlighted there was increased burden in carers married to patients with an EMHP.

Savage and Bailey (2004) in their review of impact of caring on the mental health of carers found that parents reported more satisfaction with the caring role than spouses, and spouses reported more satisfaction than adult offspring. Living with the cared-for person was associated with greater negative effect on well-being, and less satisfaction than not living with the cared for person. How close the carer was to the cared for person was also significant in carer burden. Parents and spouses tended to be more positively involved in care giving than adult offspring. Intimacy and love between carer and cared for person were associated with lower levels and minor mental health problems.

Shared care between family carers then moved to a stage where there were a series of unwritten agreements or consensus on how each will be involved in the caring role. The shared care experience resembles that of a team of nursing staff where aspects of care are allocated to staff with certain skills. Carers in the same family decided between themselves who would manage certain aspects of the caring, who felt comfortable being an advocate, who felt happy to have the cared for person live in the same accommodation with them and how they would support each other. However, the decision around how the care could be shared can be difficult for carers in the same family.

The literature review on mental health carers by Robinson et al (2008) concludes that mental illness amongst married couples co-occurs at a level far greater than expected by chance i.e. that mental illness in one spouse is associated with mental illness in their partner. There are associations between partners in their reporting or recent psychological distress i.e. symptoms of anxiety and depression. For some the similarity in a couple's mental health was greater in accordance with the length of time they had been living together, up to about five years (Butterworth and Rodgers, 2006). For relationships of five years or longer, the similarity of psychological distress between couples was at it maximum.

In addition, carers (who were often the primary carer in the family) experienced periods where they were unable to express their needs, which added to their subjective burden. One of the difficulties in adjusting to the role of a carer is recognising when the filial/spousal relationship ends, and the carer role starts.

This can be further complicated when the filial/spousal relationship is blurred. It is at these times that using a collectivist family carers' approach to caring for a relative with an enduring mental health problem brought further loneliness, isolation and distress in the carers of this study. This could be explained by the findings in Harvey and Burns (2003) which examined family carers' characteristics, found that it was difficult in some cases to distinguish the primary carer in multiple carer families. They also found when primary carers were compared with non-primary carers psychological distress was the same in both groups.

However, Madigan et al (2012) in a randomised control trial of care focussed group psycho education for multiple family carers of persons with bi-polar disorder, found carers in the intervention and solution focussed group demonstrated greater knowledge and decreased burden than those in the treatment as usual group. Grandon et al (2008) found that lack of about depression, highlighted instances where families and friends were unwilling to provide on-going support.

The present study revealed that some carers had difficulties with engaging other family members in sharing the care in the family. Younger siblings who may have had a very good relationship with the cared for person, were observed by primary carers to be afraid of the cared for person and to experience a 'break' in their relationship with the cared for person that took time to rebuild. Older siblings over the age of eighteen were observed by carers in this study to adopt a strong advocacy role with parental carers or other sibling carers in the family.

Family carers try to avoid ‘stressors’ or triggers that could lead to mental health problems, developing more self-care approaches to mental health. The danger of this is that family members may blame themselves for the onset of cared for person’s illness.

5.5 A conscious awareness of cultural stereotypes

The findings in this study begin with carers feeling concerned that relative (s) will be treated uncaringly because of their cultural background and ethnicity. Racial undertones were symbolised by a further worry that their carer role was being hampered by the fact that they were ‘black’ people. These perceptions occurred when the care provision by mental health and social care services was deemed poor and when their relative experienced an increase in mental distress. This led to an increase in the subjective burden of care for family carers. The colonial historical relationship of both first generation African and African Caribbean migrants and successive generations within the United Kingdom adds yet another stigma to the carers’ experience, derived from being an ethnic minority and societal perceptions of people from such communities.

The stigma of caring for a person with mental health problems and being part of the ethnic minority community increases carer burden. Carers adjusts to carer role over time, time goes slower when they have little knowledge of mental illness, but they experienced lived time as fast when their relative becomes unwell and they have no control over how best to help them, until they make contact with statutory services.

Lived relations was experienced with the cared for person as a series of changes over time, influenced the amount of support from the community and other family members, the previous relationship with the relative before diagnosis and support of statutory services and carers prior knowledge of services as a result of their professional caring status.

Lived body (corporeality) was experienced when both the carer and their relative became unified in their perception of being stereotyped (*almost as if they are being treated as one person and the same, by mental health and social care services*). Lived Relations (relationality) occurred when both the carer and their relative reduced their level of interaction and contact with mental health and social care services or used legal aspects of mental health law to ensure discriminatory care was reduced.

Gregory (2010) also found that black carers spoke of the emotional strain of caring and racism from health care services added to their anxiety and depression. Most experienced what was referred to as culturally inappropriate provision and misunderstanding. Some of the problems carers incurred in the present study may be related to what Cheetham and Small (1986) described as stereotypical beliefs about minority families, held by health and social care professionals. She stated that these stereotypes are damaging as they may be applied to all or most of the members of any ethnic group, thereby influencing decisions and judgements that health and social care professionals make. One of the prevailing stereotypes about carers from BME communities is that *'they like to look after their own'.*

McNeil (2013) presents an alternative perspective in the influence of stereotypes in health and social care where family members were hesitant to identify discrimination as a primary obstacle to carer support. They concluded that complex processes may be at work that elicit the participation of family members in the reproduction of discrimination by interfering with their ability to recognize and resist its multiple and subtle forms.

In addition to carers' experience of mental health and social care provision in the UK, there are cultural perceptions of mental illness that carers may have from their own upbringing, which have been passed on from the cultures they have migrated from and through family generations. Understanding the cultural perceptions of mental illness and well-being by both the African and African Caribbean communities, may also give mental health and social care professionals some insight into fears of cultural stereotypes and perceived discrimination.

One of the areas of similarity that both these communities share is in their perceptions of wellness, illness and mental health. Equally, family caring practices are considered very similar in both communities. Schefer et al (2012) in a study about the cultural beliefs of BME communities identified that cultural beliefs influenced both relationships with family and, consequently, help seeking for individuals with mental illness.

However, Goulbourne and Solomos (2003) suggested that African Caribbean people have more in common with the White British UK community despite being racially different. This relationship stems from a colonial history, which meant that they shared the same language, religion, customs and traditions.

McCabe et al (2003) examined several hypotheses related to racial and ethnic variations in carer strain and perceived social support among parents caring for children with emotional/behavioural problems. African Americans reported significantly lower carer strain then did non-Hispanic Whites (NHWs), whereas Asian/Pacific Islanders (APIs) and Latinos did not differ significantly from NHWs.

Contrary to prediction, both African Americans and APIs reported significantly lower perceived social support than NHWs, whereas Latinos did not differ significantly from NHWs. When perceived social support was controlled, the tendency of African American and API parents to report lower carer strain than NHWs became more pronounced. Thus, differences in perceived social support did not explain African Americans' lower carer strain. Other cultural variables such as familism and tolerance should be examined to identify processes that result in reduced perception of carer strain among African American parents caring for children with emotional and behavioural problems.

McLean et al (2003) raised the important point that the fact that African Caribbean community uses the English language as a first language may mask their cultural differences and unique cultural traditions. The study which reviewed the experiences and expectations of exclusion in interactions with mental health services – highlighted the misinterpretation of the modes of expression of members of the African Caribbean community e.g. raised tones of voice were reported as threatening to those unfamiliar with African Caribbean culture. This misinterpretation was reported as reducing African Caribbean community members' confidence in mental health services, deterring them from seeking support and treatment.

The current study revealed that carers wanted mental health services to appreciate the unique cultural entity of both carer and their relative. This included acknowledging the original country of their birth and unique cultural traditions, be it a language unique to a subgroup of that culture, the foods and music they liked, traditional clothes they wear and modes of communicating within a close family network and why that was important for carers.

The inferences from carers in the current study were that there was need to see professionals from their culture and ethnic group as a way of building confidence in mental health services. In particular, this was considered important when the care recipient needed to have contact with the in-patient and community mental health services for any length of time.

Aranda and Knight (1997) review the literature on ethnic minority carers and suggest that ethnicity and culture play a significant role in the stress and coping process for Latino carers. Non-kin carers were more prominent in Black samples as compared to their Anglo counterparts, which may indicate a greater tendency toward inclusiveness in the caregiving role of individuals outside the primary kin network. Black families were less burdened caring for a family member with dementia than were Whites and were much less likely than Whites to institutionalize a cognitively impaired family member.

A study of South Asian and Black Caribbean carers in Britain concluded that both of these groups used cultural scripts to account for informal care, and that the purpose of this was to reinforce their ethnic identity (Adamson and Donovan 2005). As these migrant groups were in the ethnic minority in Britain, reinforcing their ethnic identity became an important biographical task for them. One way to achieve this was to use cultural justifications for caregiving behaviour. An interesting aspect of this cultural script was the demonstration of how their own cultural values were different from the ethnic majority - the White British. The minority carers believed that White British people do not provide care to their family members, and that doing so only comes from ‘traditional’ cultural values (Adamson and Donovan 2005). Indeed, the idea that White British people provide little informal care to family members while minority ethnic groups are paragons of filial responsibility is a common assumption in Britain, although it has been challenged in some literature referring to it as the *'look after their own'* assumption (Atkin and Rollings 1996) and refuted by recent quantitative work (Willis 2009).

There appears to be some bias in the research literature in the UK where much is written about African Caribbean people and their ability to care (under subject disciplines such as the social sciences, education, criminology, and psychology), but very few research studies make reference to African communities and their role as carers. However, this could be indicative of researchers categorising African and African Caribbean in the same ethnic and cultural background. This may in part be explained by what Agyemang et al (2005) argues is a failure by researchers to consider the several areas of diversity within African and African Caribbean communities, which include as many differences in perception of health and illness as well as similarities.

There is a danger of ignoring the individual nature of caring and mental illness that supersedes any cultural norms. Both the distinction and similarities within both groups need to be considered, coupled with the great diversity within each group, for research to truly capture caring experiences.

5.5.1 Perceived discrimination and stereotypes carers fear

The perceived discrimination and stereotypes carers in this study fear are common within everyday society. The Council of Psychological Associations for the Advancement of Ethnic Minority Interests CPNAAEM (2003) presented some of the common stereotypes attributed to African and African Caribbean communities in 21st century society. These include intellectually inferiority; more likely to be culturally disadvantaged; more prone towards violence and aggression; consumed with oppressed hostility; sexually promiscuous; in pursuit of a White ego ideal; weak superego and ego development; poor impulse control; lacking initiative and insight; displaying apathy and resignation, lacking abstract reasoning and deep thought and lazy and lacking motivation.

In terms of interactions between ethnic minority communities and the health services, Bhugra (2002) suggests there are issues of mistrust within African and African Caribbean communities in the UK, some of which relate to poor ethnic matching with practitioners and low population density of practitioners from the African and Caribbean communities. Language barriers, spirituality and religious barriers can reinforce also stereotypes and can influence poor access to psychotherapies for people from ethnic minority groups. All carers in the current study spoke English as their first language; however, some did report feeling more at ease and less likely to infer or perceive cultural stereotypes when there were professional carers from their ethnic background, who were involved in the formal care of their relatives.

On further analysis of the sociological literature on mental health, the difference in western perceptions of treating mental illness compared to the traditional approaches to mental illness in countries like Africa and the Caribbean suggest a divide which may influence community engagement with western mental health services.

5.5.1.1 The medicalisation of mental illness can be a problem for carers

The medicalisation of mental illness in western society presupposes that mental illness is a universal concept and discounts the variety of perceptions that exits through the process of upbringing, language, spirituality, community and experience of mental illness. Carers from the African and African

Caribbean community may be in a struggle with the traditional perceptions of their cultural upbringing and the wider concept of mental illness in the UK.

CNPAAEM (2003) had fears about clinicians' stereotypes being reflective of society's assumptions, and stereotypes about the different ethnic groups. They propose that the use of universal diagnostic tools in mental health practice needs to be moderated with more culturally specific knowledge, which also incorporates the context of mental distress, values and beliefs about health and illness.

Rosenman (2012) critically examined the World Health Organisation World Mental Health Survey Initiative, which uses instrumentation that suggests mental illness is a universal psychopathology. He concluded that it is culturally insensitive by virtue of a lack of consideration of different interpretations of mental illness in countries of the world; the context and importance of different languages and the meanings of mental illness in countries of the world, and the dominance of medical models, driven by an Anglo-American perspective of mental illness.

Some of the fears experienced by carers from both these communities relate to past and current migration patterns in the UK. Hickling and Hutchinson (1999; 2000) suggests that the cultural control within an environment (country) could be what differentiates the experience of African and African Caribbean people living in Africa and the Caribbean from those living in the UK. People living in Africa and the Caribbean have been able to identify with their culture through the population density and sense of community belonging, as well as shared community activities like religion and music. These act as protective factors against the challenges of the slave trade history.

As a number of carers in this study work in the health and social care services, some of their fears could also be based on their experience of working as an ethnic minority in the UK health and social care services.

5.5.2 Perceptions of mental illness and help seeking behaviour in African and African Caribbean cultures

Perceived causes of mental illness within African and African Caribbean cultures and help seeking behaviour can help to raise awareness of cultural norms and values around mental health. In this study, carers used a combination of familial cultural traditions (such as seeking advice from each other; praying; meeting regularly as a family) and westernised approaches to managing mental health.

However, several studies on culture, ethnicity and mental illness describe community-based perceptions as suggesting that mental illness is brought on by a ‘spell or spirits’, it is a punishment for wrongful deeds, the person affected is crazy, dangerous, or weak in character, it is hereditary and the persons affected are pretending to have mental health problems (Waldron, 2003). Gopaul-McNichol (1998) suggests that although carers have a westernised upbringing, they still practice the cultural traditions from African and Caribbean ancestry in their homes.

This is illustrated by Brown et al (2007) in a study examining the health beliefs of African Caribbean people with Type 2 diabetes found that participants were strongly influenced by memories of growing up in the Caribbean, migration to the UK, and ‘friends and families’ accounts of diabetes, as well as their own experience of illness. Carers in Brown et al’s study described mistrust in the value of advice given by professionals and a preference for natural treatments.

Health professionals were generally praised, but some interviewees felt that the NHS did not cater properly for black people. They did not describe overt racism, but a lack of understanding the needs of Caribbean people. There was also a key preference for use of an approach similar to the *'Sickle Cell Model of care'*, which was perceived as a successful approach to care.

Barke et al (2011) also investigated attitudes of an urban population in Southern Ghana with regard to mental illness and mentally ill people and found a heterogeneous picture. More than 40% of the respondents, however, saw no problem with denying mentally ill persons their individual rights. A better education was accompanied by more positive attitudes towards mentally ill persons across all subscales. Researchers in this study also found that 57.9% of the Ghanaian respondents believed that mental illness in the family brings shame on the family name and 57.5% that it is wise to keep it a secret as much as possible.

Codjoe et al (2013) explored perceptions of wellness in Black African and African Caribbean individuals with at risk mental state (ARMS) for psychosis; six factors emerged that may explain cultural perceptions of wellness in both communities. These included 'a sense of social purpose explanation; the surviving God's plan test explanation; the internalisation of spirituality explanation; understanding attribution of symptoms and witchcraft explanation; avoidance and adversity explanation and seeking help to cope explanation. This may explain a hierarchy of explanations that individuals from both these communities work through before they consider accessing mental health and social care services.

In the current study, all carers had direct contact with the statutory services as soon as their relative showed signs and symptoms of any form of bizarre behaviour, change in persona or increasing aggressiveness. Here, there is some indication that they pathways to accessing statutory care may be due to the type of symptoms their relative's present with, the environment where the relative becomes unwell, and who outside the family was present when the relative became unwell. Strong family cultural traditions were described as important in the carer role in both the African and African Caribbean communities. Knight and Sayegh (2009) suggested that the effects of cultural values and other ethnic differences in stress and coping appear to involve social support and coping styles rather than burden appraisals.

One of the ways in which carers overcame the emotional distress of caring and their fears of cultural stereotypes in the cared of their relatives was to focus on the life achievements and aspirations of their relative, through the adversity of mental illness.

5.6 Sustaining hope during the caring experience

Lefley (2010) stated that due to the long illness trajectory of EMHPs like schizophrenia and bi-polar disorder, family carers can become demoralised, demotivated and lack hope for the future of the cared for person. The present study showed that carers have a number of aspirations for their relatives and for themselves during the caring experience. This is a way of maintaining their sense of hope, but also encourages them to perceive the recovery of their relatives. Hope was predominantly accessed within the relationship between the carer and the cared for person.

Most carers were able to achieve their own personal aspirations and still carry out their carer role. In families where caring was shared between different family members, most carers were able to hold onto hope because they had a social network to share their worries, fears, anxieties with. Multifamily caring also provided exchange of information about coping styles, understanding of mental illness, which reinforced hope, and mastery of the caring experience (Jonsson et al, 2011, Lefley, 2010).

However, at least one carer had delayed the opportunity for marriage in order to concentrate on the care of both of his relatives, This reciprocal relationship between carer and the cared for person was considered a' natural' if not expected part of the carer role. Family carers, who felt they had sacrificed aspects of their personal lives for their relative, do so because their relative had sacrificed aspects of their personal life for the carer. Similar findings were found in a phenomenological study by Park (2012) who examined filial piety (duty and respect to care for one's family) and in family carers, found that reciprocating the sacrifice was a way of coping with a family member's mental illness.

Hope is experienced as a time to celebrate achievements of the cared for person; it also symbolised a break with what was a challenging, often stressful present and the opportunity to be part of a better future (Bland and Darlington, 2002). This is also a time when carers reflected on the challenges they faced during the caring experience. Muhlbauer (2002) examined the development and process of severe and persistent mental illness from a family carer's perspective; findings indicated that during crises in the illness course of the cared for person, the family carer experienced periods of hopelessness to start with which led to hope.

Duggleby et al (2010) suggest that a strong overall feeling of hope has outcomes of increased feelings of control, decreased feelings of loss and grief, improved physical and psychosocial well-being and feelings of coping with the situation. However, they infer that hope occurs within the context of uncertainty for family carers. Current study findings showed evidence of carers reviewing the value of time invested in caring for their relative. An added incentive for caring was being able to reflect on the adversity their relatives overcame with their enduring mental health problem. They may have already become so aware of the hopelessness they felt during the difficult aspects of caring, that they felt able to choose hope as a way of moving on from that adverse period.

These findings are consistent with a number of studies that focus on the purpose of hope in the caring experience. For instance, Bland and Darlington (2002) explored the importance and meaning of hope for family members of people with mental illness and they confirmed the argument that ‘hopefulness’ appears to be central to how a family copes with the impact of mental illness. In Bland and Darlington’s study, carers perceived hope for recovery from mental illness, moderated their hope that the cared for person would get to full recovery or abandoned their hope for their relative getting better.

In the present study, all carers’ sustained hope for their relative having a better quality of life in the future, but in some cases abandoned their own hopes and dreams. This could be explained by the formal and informal supports they accessed to sustain their hope. Family carers inferred hope when describing particular health and social care professionals that understood both carer and cared for person’s needs and worked in partnership with them.

Jonsson et al (2011) suggest that health professionals supporting families need to be respectful and aware of the importance of creating and sustaining hope for family carers. However, carers inferred a sense of hopelessness when addressing difficulties in the caring experience, which warrants further consideration by mental health and social care services. Pejlert (2001) in a study investigating parental caring of people with mental illness concluded that carers' expressions of hope for the future were interpreted as a way to cope with present challenges in their caring experience. Clarke (2003) concluded that hope is what sustains a person through psychological adjustment to any enduring mental health problem or threatening situation.

Evident within carers' stories was the hope they alluded to when describing contact with local community support groups or voluntary/charity based support groups. This initiated a further validation of the emotional burden of caring for relatives with an EMHP and gave them access to a wider network of carer support agencies and groups. Jonsson et al (2011) proposes that the outpatient mental health services as a way of maintain contact with professional services and options for carer support could design this provision.

However, Chen and Lukens (2011) suggests that the current climate within mental health services indicate resources are limited and mental health and social care professionals need to consider ways of incorporating support of carers into their everyday working practice. An opportunity to reflect on the current mental health and carer policy in the UK raises some further concerns.

5.7 Reflections on the UK carer policy in context

Gregory (2010) suggests the experience of black and minority ethnic carers tends to be affected by the marginalisation of 'race' equality within social policy, which results in the specific circumstances and needs of black and minority ethnic communities remaining invisible and excluded from mainstream service delivery (NBCCWN, 2008). The first National Carers Strategy, *'Caring about Carers'* (DoH, 1999a) contained little direct reference to black and minority ethnic carers, with correspondingly poor outcomes for these communities. Similarly, updated carer strategy, “Carers at the Heart of 21st Century Families and Communities: A caring system on your side, a life of your own” (DOH, 2008) did not provide the necessary guidance on how to meet th especific needs of carers from black and minority ethnic backgrounds (NBCCWN, 2008).

The lack of central direction places greater onus on involving black and minority ethnic organisations and carers in the implementation of the Carers Strategy at a local level. However, many Primary Care Trusts and local authorities have little knowledge of their community groups and no meaningful engagement with those living with disabilities. The assumption that black and minority ethnic carers are a homogeneous group overlooks the diversity between and within communities and the ways in which ethnicity and disability intersect with other aspects of carer and service user identity. The experience of black and minority ethnic carers tends to be compounded by obstacles to service access, such as language barriers, unrepresentative staff, complex service structures and lack of information about rights, entitlements and available support.

The coalition government’s new mental health strategy ‘*No health, without mental health*’ spoke generally about carers and gave very little focus on mental health carers and Black and minority ethnic groups. The acknowledgement of the impact of mental health issues on the UK population was welcomed and highlighted the wider public health aspects of mental health. However, there is potential here for a rhetorical approach to management of mental health and social care delivery, which may leave carers picking up the even more of the caring role in the future.

Perhaps the most concerning aspect of the coalition's 'Health and Social Care Bill' is the New GP Commissioning and service cuts/grant cuts to charities and voluntary organisations which mean that community service support in mental health in both statutory and voluntary sectors have been reduced or unable to deliver service. This is likely to lead to increased subjective burden on mental health carers from vulnerable communities.

The coalition government (2012) state that under the new Bill will introduce new local health and wellbeing Boards whose remit will be to improve the health and well-being of local people by bringing together commissioners across the NHS, public health, social care and children's services, along with local councillors and new scrutiny bodies like '*Health Watch'*. The Government argues that this approach will encourage better integration and joint working and will improve local accountability. However, Carers UK (2012a) expressed concern about how the BME carers' communities of the UK would be included in the health and well-being boards plans for improving health and well-being in UK populations. A further concern is if the health and well-being boards do not build BME issues in to planning early, this could lead to increased health inequalities. Furthermore, any poor engagement of BAME carers could lead to reduced access to local services. The poor understanding of the impact of caring on family carers (who are ultimately faced with different time pressures) can increase vulnerability of this population.

5.7.1 Black, Minority Ethnic carers in 21st century UK

Sewell and Waterhouse (2012) in a report on "*Making Progress in Mental Health*" participants indicated that the '*Delivering Race Equality in Mental Health*', was a very good initiative, but was unclear about how this work would be continued in this current NHS. Participants also cited the tight financial climate (cuts in Community Development Workers (CDWs); cuts in specialist staff and services that have supported BME groups previously) and the subsequent changes to the health and social care system (as a result of the coalition government's Health and Social Care Bill (2012). This could potentially influence future attention to race equality in mental health and social care services.

To address issues of inequality, the coalition government introduced the *Equality Diversity Services* (EDS) to ensure that any inequalities within the health and social care services would decline in time. However, there is no clear mental health focus indicated in its service remit, this may reduce its effectiveness in the mental health services and subsequently reduce the impact on the more vulnerable BME community groups.

Currently participants indicate there is a lack of national leadership and coordination of sharing positive practice. Whilst many of the participants' welcomed the focus on race equality and the need to improve outcomes for the Black and Minority ethnic communities, indicated in the *'No health without mental health',* many stated that without a supporting implementation plan, the issue of equality could not be properly addressed.

6. Chapter Six: Conclusions and Recommendations

6.1 Introduction

This study helps to deepen the understanding of the caring experiences of two relatively under-explored carer communities. It also provides an opportunity to inform the mental health and social care practice of professionals working with family carers to supporting their relatives with an EMHP.

The key findings from this study reveal that African and African Caribbean carers maintain a strong and reciprocal sense of family caring. This is based on acceptance of the change in their relative and an unwavering commitment to ‘being there and staying there’ with the cared for person.

One of the challenges to the carer role for carers in this study came in the form of double duty caregivers. Historically, African and African Caribbean communities work as employees of the NHS. With their strong sense of family connectedness and professional caring role, getting personal space and time can be difficult. In additions, carers of more than one family member with an EMHP experience a substantial carer burden, which means they will need some form of respite to maintain the carer role.

However, carers expressed their own need for personal space to carry on with the carer role. This works to combat the feelings of isolation and restriction as a family carer, but also provides respite from caring and an opportunity to re-discover ‘the self’.

An undercurrent thought that all carers intimated was the fear of perceived cultural stereotypes, which they suspect or have actually experienced in their contact with statutory services. Despite this concern, all carers strongly advocate for more partnership with mental health and social care services.

A new finding to carer research in mental health, is the process by which carers in this study used local community support groups, as a 'conduit' to assert their carer role with statutory services. The resiliency of the carers in this study, is evidenced by their on-going hope that life will get better for the cared for person.

This chapter will present the study conclusions. In the next section, the strengths and limitations of the study will be considered. The relevance of the study findings is considered with regard to implications for mental health practice and recommendations for future nursing research.

6.2 Conclusions of study

6.2.1 Being there and staying there

Personal carer stories reveal that the carer role did not just happen overnight but encompassed a journey towards caring and acceptance of the carer role. Familial obligation and connectedness strongly influenced the decision to become carers. The reciprocal nature of family caring in this community was equally important in maintaining 'hope' for carers and eventually fostered a closer relationship to the cared for person, than had previously been experienced.

6.2.2 Losing oneself and re-discovering self

However, carers expressed periods within their carer journey when the carer role was very challenging. At these times, they seem to move between wanting their own personal space and concurrently not wanting the isolation and loneliness that came with caring for their relative. The lack of information (about mental illness and what mental health and social care services could actually provide), unhelpful confidentiality policies and poor support from mental health and social services added to carer distress.

Acknowledging their own emotional needs was key concern for family carers. This could be interpreted as needing time to review the effectiveness of their carer role and its impact on the cared for person. Equally, carers imparted their sense of needing to find themselves again, rediscover their own self, through their own personal life goals.

This need for personal space could also be interpreted as needing 'respite' from focussing on their carer role and having the opportunity to engage in social and leisure activities away from their relative. For carers who had a professional and informal carer role, there is a desire to know how to 'switch off' from caring and to consider their individual need for respite.

6.2.3 Keeping an on-going dialogue with others

Concerns about engaging with mental health and social care were consistent with fears of service users and carers from other studies on engagement with mental health services (Keating and Robertson, 2004). Carer research of caring experiences in other ethnic minority groups living both within and outside of the UK, reveal very similar patterns. An understanding and awareness of the carers' experience of any form of discrimination both within and outside the health and social care services needs to be acknowledged and discussed more openly.

6.2.4 A conscious awareness of cultural stereotypes

Some carers and their relatives have experienced racism and discrimination in other institutions of social life whilst living in the United Kingdom and prior to taking on a carer role. They may already have certain presuppositions about how a largely white dominated workforce of individuals who also have access to aspects of mental health law, can be both supportive and helpful to them in their carer role.

An insight from this study, which was also contributing to carer distress, was their perception that cultural stereotypes were inherent within statutory services and posed a threat to not only their carer role but to the care provided to their relatives. This fear of cultural stereotypes may be born out of wider post-colonial perceptions of mental health and social carer services, (as discussed in Chapter One) passed on from one generation to the other within both communities living in the UK.

Family carers perceived their strongest support to come from local based charity and voluntary organisations set up by members of the African and African Caribbean community. They are also happy to receive and engage in support by health and social care services, but they want support based on helping them to remain connected to their family member in a positive way i.e. helping their family maintain their independence, sustaining hope in their family member achieving life goals around education, employment, social and leisure activities.

6.2.5 Sustaining hope in the caring experience

Finally, this research has shown that family carers elicited hope for the future recovery of their relative by being able to share in the achievements of their relatives. Hope meant seeing their relatives' maintain their independence regardless of their EMHP.

6.3 Strengths and limitations of the study

As indicated in Chapter One and Chapter Two, relatively few studies have explored African and African Caribbean carers' experience of caring for a relative with an enduring mental health problem. Therefore, an in-depth exploration of this phenomenon was appropriate.

A strength of the study all carers were primary carers of their relative and most either lived with the cared for person or were located very close to their relative. This meant they were able to give very vivid accounts of caring for their relative from the point of diagnosis to subsequent engagement with mental health and social care services.

Other strengths of this study, relate to the number of relatives the primary carer cared for in any one family. Three carers had primary caring roles for two members with an enduring mental health problem in their family. This presents a new area to consider in carer research which to date focuses on the carer role for one family member in the family with an enduring mental health problem. Furthermore, carers in this study had been caring for their relatives for two years or more and had a wealth of experience to draw on in their recounting of the caring experience.

With regard to sample size, the caring experiences of seven carers formed the study findings. This could be considered a limitation of the study, due to lack of generalisability. However, hermeneutical phenomenology is directed towards gaining an understanding of the experience of a phenomenon and, as such, does not aim to provide generalisable results.

A purposive sampling method was utilised, examined retrospective recall of information, which was necessary to capture carers’ experience of caring from the moment they perceived themselves as carers.

In my role as a researcher, I have had a long clinical experience of working within mental health care. It is therefore possible that despite keeping a reflective journal and addressing any potential biases with my supervisors, this pre-understanding could have influenced the analysis of subsequent findings in an unconscious manner. During the different stages of analysis, I had frequent discussions with my supervisors; in workshops and with other doctoral students who had experience in mental health care, or carer research or qualitative analysis. This assessment and evaluation was performed with a view to ensuring the credibility of the analysis and to counteract any possible research biases caused by undetected pre-understanding (De Witt and Ploeg, 2006).

The knowledge developed through this study is not represented here as an absolute truth, rather as an interpretation. Nonetheless, it is an interpretation developed through a framework of reflexivity, questionings and justifications. The next section of this chapter considers the study findings and their implications for mental health and social care practice.

6.4 Implications for clinical practice

This phenomenological description and interpretation of African and African Caribbean carers provides insight into how they frame and find meaning in their caring experience. It is evident from carer stories that they do want to keep an open dialogue with the mental health and social care services throughout their carer role. However, an important part of this involves mental health and social care professionals taking time to understand the importance of family relationships and the need for strong family connectedness in both of these communities. Furthermore carers want to be involved at every stage of care delivery to their relatives, but also want their observations of the patterns of change in mental health state of their relative to be acknowledged and taken into account in on-going care and treatment.

Perhaps family members who persist in their requests for involvement might be considered overbearing or difficult. Maybe those who resist professional expertise or recognise their relative's right to self-determination could be labelled dysfunctional or irresponsible. A more recent approach to family caring, known as *'trialogues'* is being introduced into recovery orientated approaches to mental health practice. Trialogues refer to an encounter between three key groups of individuals, namely the mental health service users, their family carers and mental health professionals. The encounter occurs outside of the usual service settings, family homes and therapeutic environment, with the aim of facilitating communication about the distress of mental illness, its impact on family, life, work and relationships (Amering et al, 2002). Trialogues encourage all participating groups to share their subjective experiences in order to start a common language that builds on more partnership and effective working in mental health. Sessions usually take place weekly, bi-weekly or monthly and can last between 90 and 120 minutes with 10 to 60 people. This can close the gap between professionals and service users and carers, and place each group on an equal footing. However, Amering et al (2012) indicate that conflicts can occur between the three groups depending on their perspective on what causes mental illness (be this social, biological or psychological or all three).

In addition, the power dynamics of professionals and service users and carers may stem from a very different perspective and influence the direction of discussion. The approach started in Vienna in 1994 and is emerging as a framework for working with families who care for a relative with psychosis; as such, this is not an approach that has been considered with families from African and African Caribbean communities in the UK.

Family members who express feeling overwhelmed or exhausted, in need of respite, may be perceived as weak or a burden to the system or may quite simply be perceived as contributing to the mental distress of their relative. Mental health and social care practitioners need to encourage family members and relatives to ask questions, challenge authority, and expect equality. This means acknowledging carer complaints, understanding their anger and facilitating their participation and partnerships at all levels, particularly at the level of programme planning, service planning, policy making, education and research.

A potential intervention, which mental health professionals can access, for working with family carers, is family psycho education. Family psycho education (FPE) remains one of the most effective interventions for families caring for a relative with EMHP (Fadden, 2006; Smith & Velleman 2002). FPE requires a positive and non-blaming attitude from professionals towards families; partnership working with carers and including them in each stage of care planning with their relatives, sharing information, giving support, advice and education about mental illness and mental well-being (Harvey and O'Hanlon, 2013). However, there are a number of barriers to its use in mental health practice, which health and social care practitioners need to address. These include poor clinical management of staff and engagement with a FPE model to mental health care and a lack of training and on-going supervision to use an FPE approach to practice (Fadden, 2006; Smith and Velleman, 2002).

A further suggestion is that that providers engage in critical reflexivity (as part of their clinical supervision) to consider resistance to power sharing, their role in privileging professional knowledge. Furthermore, it is important to discuss why professionals feel threatened by their potential loss of power.

The study conclusions suggest that mental health practitioners could help family carers manage the care of their relatives at home or in the community. Family carers welcome more education and training around their carer role. Mental health professionals need to encourage and develop a working knowledge of community based support groups, and discuss different types of respite care with family carers. More conversations with carers that focus on family based interventions and where required, individual psychotherapy for those carers who wish to address their own mental health and well-being.

The inferences for mental health and social care professionals are that it is time to review the education and training of staff about cultural and the different ethnic groups who live in the UK. With an increasingly diverse population growing, in terms of new migration of people from other parts of the world into the UK and settled migrant communities, this seems an essential component of health and social care education and training.

An investigation into the types of contact by different mental health and social care professionals with African and African Caribbean carers, may give further insight and understanding of how interactions occur and where barriers to access exist and also where there are clear partnership interactions which aid the recovery of the cared for person. This would also provide an opportunity to talk directly to mental health and social care professionals about their perspectives on engagement with carers.

6.5 Recommendations for further research

Further research should investigate the context of subjective burden and the sociocultural factors, which give raise to this burden as a focus for intervention. In doing this, the aim would be to reduce family distress as well as improve outcomes for the cared for person. Future studies exploring the adaptive and maladaptive coping strategies used within both communities of carers should also be considered. The importance and use of family based interventions for carers from both these communities versus traditional community support groups is worthy of investigation. This would provide an opportunity to evaluate diverse approaches to supporting this group of carers.

Further research in this area should focus on gaining an understanding of what support carers need from mental health and social care services and developing more effective ways of meeting their needs. Supporting carers should be a core part of mental health service provision and sharing areas of good practice will be an important part of this endeavour.

Evident within carer stories was the support they received from other family members who shared the carer role, in some instances alternating between a primary, secondary and tertiary caregiver role. These included other children or teenagers in the family, spousal partners, some extended family members but also family friends. The following section will reflect on areas for further research and consider alternative research designs to the one undertaken in this study, before ending with a closing statement on the meaning of caring for African and African Caribbean carers.

6.5.1 A focus on carer typologies in the African and African Caribbean communities

The current study discovered that carers reported the impact of a family member with an EMHP on other carers in the family. Indeed, the findings indicate there were four typology of carers in this study, namely sibling carers, parental carers, spousal carers and filial carers (an aunt), who implied different perspectives in caring, which should be explored.

Future studies should also focus on the significance of the caring experience for child and adolescent carers, sibling carers, parental carers and spousal carers. An investigation into the relationships between carer and cared for person could be explore din more depth within family dyads. This would be a useful area of research, in establishing which aspects of the caring experience are most helpful to the cared for person with an EMHP and what impact carers have in the recovery of their relatives.

A closer exploration of the experience of individuals, who hold both a professional and informal caring role, would be useful in reviewing the impact of the caring experience in this group, who already face a number of unique challenges to their carer role as indicated in this study.

The role of carers who care for more than one family member with an enduring mental health problem is equally important to investigate further. Three carers in this study fulfilled such a role. The nature of distress as well as the skills acquired in managing/coping with different EMHPs could provide yet more insights into cultural experiences of caring and strategies for coping.

Study findings identified that family members who have en enduring mental health problem could also be diagnosed with a long-term physical health problem. One carer in the present study cared for a family member with a diagnosis of clinical depression and a diagnosis of cancer of the kidney. An outcome from this study suggests that service provision for patients diagnosed with cancer, concluded that service provision was better than care provided for patients with an EMHP. This is poses an area of concern, in light of the health and social care inequalities which already exist amongst ethnic groups. A review of how services are delivered to persons with long-term health conditions mental health and physical health is warranted. The implications of this for family carers should be an intrinsic part of any future study

A gap in the carer research on mental health family carers revealed by this study; was the experience of grief following the physical loss of a relative diagnosed with an EMHP. This is certainly an area worthy of further exploration.

6.5.2 Cross-cultural studies on the caring experience across ethnic communities

African and African Caribbean carers comprise/constitute an important group among those who are affected by the care of a family member with an enduring mental health problem. It would be desirable to develop knowledge about carers across the different ethnic and cultural groups living in the UK. This proposes a cross-cultural approach to investigating the caring experience, which may yield different perspectives on caring that, could be used to support all carers. Many of the research studies discussed in Chapter Two and Chapter Five of this study were predominantly carried out in the USA or Europe.

From the literature review in Chapter Two and current research discussed in Chapter Five, it has been indicated that there is great diversity in the African descent populations. As such one has to avoid implying that they all share unique characteristics in common.

The current study did not indicate explicit differences in caring experiences of carers from African and African Caribbean communities. In this study, carers shared common experiences in their fear of stereotypical or discriminatory mental health practice. However, sociocultural issues unique to the diverse populations within both communities and whether they are first, second, or third generation descendants may influence their perceptions of mental illness and the process by which they decided to engage in partnership with mental health and social care.

Furthermore, ethnicity allows epidemiologists and public health researchers to break free from the concept of race, which carries historical taints of slavery, eugenics, and undue emphasis on biological heritage. There remain important problems of increased incidence of psychosis in African and African Caribbean communities living in the UK. These also includes varying access and utilisation of health and social care services, which cannot be properly addressed unless they are studied; otherwise the populations are grouped together as one homogenous group.

6.5.3 Understanding the caring experience of African and African Caribbean Carers

In conclusion, this thesis began with an acknowledgement that caring for African and African Caribbean carers involved subjective burden. However, the stories shared by carers reveal new insights into how they perceive caring in the context of their family relationships, but also how they chose to engage with mental health and social care services.

Definitions of caring for African and African Caribbean carers were filled with multiple meanings. For many, caring was about monitoring for signs of illness and or relapse and ultimately how to prevent relapse. The process of supporting their relatives sometimes meant that carers' were like 'shadows' of their relatives, always present, connected to the cared for person, but sometimes invisible and often trapped with their relatives.

Advocacy for their relatives was clearly indicated as a passion for many carers who were keen to ensure the cared for person received effective mental health and social care. Equally caring meant knowing when and how to access help from mental and social carer services. Recognising when they needed help occurred more readily with carers who were supported by a number of family members who were caring for the cared for person. However, carers' conscious awareness and experience of stereotypes about their culture from statutory services increased their concerns about engaging with practitioners. This also further served to encourage stigma within the carer role and the feeling that they would be better supported if practitioners were from the same ethnic group as them. For carers who were the single carers recognising their own personal health and social needs proved more difficult, yet all carers found a mental health or social carer professional who they could positively engage with and develop a partnership in the care of their relative.

The meaning of caring was also influenced by other roles carers' had in their family and in the wider community. The experience of caring was not just about the cared for person, but also caring for other children in the family, being a professional carer in the health and social care service and responsibilities associated with employment.

Finally, undertaking this study using a hermeneutical phenomenological has displayed the ways in which caring is experienced not only as familial obligation, but is also about carers indicating the importance of familial relationships which are embedded in certain cultural traditions. The dilemma of needing personal space and also not wanting to be alone and isolated presents further challenges for carers. Keeping their cultural identity and working through the fears of cultural stereotypes in mental health practice is a barrier to partnerships in care, for this group of carers. However, carers recognise the importance of engaging with statutory services and make use of both informal networks of the immediate family, carer support groups to assert their carer role with local mental health and social services. As indicated by previous sociological research, both communities are known for their resiliency in the face of adversity and this is duly reflected in the caring experiences shared in this study. Hope is used as a way to adapt to the carer role and remain positive about the recovery of their relative.

Appendices

Appendix 1: African and African Caribbean Migration History in the England

Year Date Profile	Century	Social commentary
1200s	**12th century**	Black men and women lived in the UK in small numbers
1593; first record of an African in London: 'Cornelius'	**16th century**	Queen Elizabeth I declared Black Negroes and Black Moors were to be arrested and expelled from her kingdom
Many of these slaves forced into poverty, lived in North, South and East London. Endured racial discrimination.	**17th century**	Slave Trade: Britain part of Slave Trade between Europe and Africa and The Americas. Initially slave attendants, merchant ship assistants, resided in Liverpool and Bristol.
1722: Slaves entering country after this time deemed free men. 1772: Slavery was legal in Britain until this time	**18th century**	1750s London became the home of many Blacks, Jews, Irish, Germans and Huguenots. By the Middle of the 18 century Blacks comprised somewhere between 1- 3 % of London population.
1807: British Slave Trade was abolished 1834: Abolition of slavery across British Empire	**19th century**	Black soldiers, black seamen New shipping links with Caribbean and West Africa.
World War I (1914- 1918) Growth period for Black people in London – arrival of merchant seamen and soldiers. Continuous presence of small groups of	**20th century**	Largest black communities found in port cities of England e.g. London's East End; Liverpool; Bristol and Cardiff's Tiger Bay. 1916 the West-Indian regiment volunteered to fight for the British Army. Other black communities set up in Tyne &

Year Date Profile	**Century**	**Social commentary**
students from Africa and the Caribbean slowly migrating to London – oldest black community in London. World War II (1939–1945) Another growth period for black people in London, Liverpool and other towns in Britain. Many black people arrive from Caribbean and West Africa in small groups as Wartime workers Merchant Seamen Service men – Army, Navy and Air forces.		Wear and Glasgow. In 1919, South Shields Race Riots. Post war period: Largest influx of black people – mostly from the West Indies. Over ¼ million West Indians, overwhelming majority from Jamaica. Settled in Britain in less than a decade. Mid 1960s: Britain became the centre for the largest oversees population of West Indians –sometimes referred to as the '*Windrush.*' Most widely used terms 'West Indian' and *'Coloured.*' The term Black British did not come into widespread use until ……..

Appendix 2: Key research gaps and recommendations for carers from the African and African-Caribbean community

Gaps identified in this review
Cultural perceptions and definitions of enduring mental health problems in African and African Caribbean Communities
Cultural perceptions and definitions of mental well-being and recovery These carers are providing care to their family members.
Differences in caring experiences between African and African Caribbean carers in inner city areas compared with carers from the same communities living in rural and semi-rural areas.
Comparative study between African carers and African Caribbean carers who care for a relative with enduring mental health problems
Comparative study Between African and African Caribbean carers who live in a) UK b) USA c) Canada d) The Caribbean and e) Europe
Impact of media coverage of African and African Caribbean people in the UK on the same community
African and African Caribbean Mental Health Professionals experience of delivering mental health care in 21st century UK
Experiences of African and African Caribbean Carers (All types) in 21st century UK)
Up to date literature review, which collates and reports on the BME community engagement projects completed in the UK between 2007 and 2010.
African and African Caribbean Young Carers' experiences of caring for a parent

Gaps identified in this review
and or sibling with enduring mental health problems
Experiences of African Caribbean Carers living with a sibling with enduring mental health problems.

Appendix 3: Database Search for the Literature Review

Electronic Databases:

CINAHL

PsycInfo

PsychoLIT

Hand Searches:

- Scandinavian Journal of Caring Sciences (1990 – 2008)
- Health and Social Care in the Community(1990 – 2008)
- Social Science and Medicine (1990 – 2008)
- Journal of Mental Health (1990 – 2008)
- British Journal of Psychiatry(1990 – 2008)
- Psychiatric Bulletin (1990 – 2008)
- Qualitative Health Research (1990 – 2008)
- Social Psychiatry and Psychiatric Epidemiology (1995 – 2008)

Websites:

- Carer UK
  - National Institution for Mental Health in England (NIMHE)
- Department of Health
  - Sainsbury Centre for Mental Health
  - National Black Carers and Carer Support Workers Network
  - Afiya Trust
  - Joseph Rowntree Foundation
  - Delivering Race Equality website (2005 – 2010)
  - MIND
  - Mental Health Foundation

Search Terms Used:
Psychosis and West Indians
Psychosis and West Africans
Ethnicity and Mental Health in the UK
Psychiatric morbidity in inner cities
African carers and African Caribbean Carers
Black, Asian Minority Ethnic Carers
African carers and psychosis
African Caribbean carers and psychosis
Black carers and psychosis
Psychosis and carers and African groups
Psychosis and carers and African Caribbean groups
Psychosis and carers and Black communities
Psychosis and carers and African Caribbean groups
Psychosis and carer-givers and Black communities
Psychosis and carers and Black, Asian and Minority Ethnic groups
Psychosis and carers and African Caribbean groups
Psychosis and informal carers and Black communities
Psychosis and informal carers and African Caribbean groups
Psychosis and informal carers and Black, Asian and Minority Ethnic groups
Community Engagement Projects for BAME Carers in the UK

Search Terms Used:
Community Engagement Projects for BAME Communities in the UK
Community Engagement Projects for African and African Caribbean Carers in the UK

Appendix 4: Time line of development of the Carer Movement and Carer Policy in the UK

Year	Development in Carer Movement in UK
1942	The Beveridge Report
1963	Mary Webster
1965 – 1982	The National Council for the Single Woman and Her Dependents
1970	Council Report: Single Women Talking
1974	Council Report: The Wages of Caring
Undated	Council Report: Conflict in Caring
1981 – 1988	The Association of Carers
1984	Council Report: The Faces of Caring
1984	Council Report: Carers in Transition: A Relief and Respite Role for The National Council for Carers and their Elderly Dependents
1984	The Social Services Inspectorate: Fifty Styles of Caring
1985	DHSS: Helping the Community to Care
1985	King's Fund: Carers Unit
1986	The Audit Commission Report: Making A Reality of Community Care
1988	The Griffiths Report: Community Care Agenda for Action
1988	The Carers National Association
1989	King's Fund: Carers Unit: Carer's Needs – A 10 Point Plan for Carers
1990	The Social Services Inspectorate: The Role of Carers
1990	NHS and Community Care Act
1990	The National Black Carers Network

Year	Development in Carer Movement in UK
1995	The Carers (Recognition and Services) Act
1995	The Disability Discrimination Act *****
1998	The Social Services Inspectorate: Inspection of Community Care Services for Black and Ethnic Minority Older People ******
1999	The National Service Framework for Mental Health ******
1999	White Paper: Caring for Carers
2000	The Carers Act
2000	The Carers and Disabled Childcare's Act
2001	Census ******
2001	Carers UK
2004	The Carers (Equal Opportunities) Act
2005	The Mental Capacity Act *****
2005	The Disability Discrimination Act ******
2005	Delivering Race Equality in Mental Health Services *****
2006	The Work and Families Act
2006	White Paper: Our Heath, Our Care, Our Say *******
2007	Supporting Race Equality in Mental Health Care ******
2008	White Paper: Carers at the heart of the 21st century families and communities *
2010	Recognised, valued and supported: Next steps for the Carers Strategy

Appendix 5: Summary of research studies on the caring experience of African and African-Caribbean carers' who care for relatives and/or spouses with an enduring mental health problem

No	Year Date	Author (s)	Study design, sample, methods and instruments	Key findings
1	1991 (UK)	Morley et al	Pilot Study The attitudes and experiences of relatives of 15 patients admitted compulsorily and 10 admitted informally were compared	The relatives' attitudes did not differ between the two groups. There was also no difference in the severity of current symptoms or the relative's assessment of dangerousness. Neither group was characterised by the sorts of attitudes to illness that had been hypothesised.
2	1992 (UK)	Atkins and Rollings	Literature Review on articles, projects on Asian and Afro Caribbean communities	Changing demography across age, gender, degree of chronicity and type of illness. Lack of visibility of black carers. The myths and reality of family networks in African and African Caribbean community. Locus of care within families – gender differences. Increased socioeconomic costs of care.
3	1994 (UK)	McGovern and Hemmings	27 white and 32 black relatives were interviewed included all black and white patients with a first admission diagnosis of schizophrenia admitted to a Birmingham psychiatric hospital between 1980 and 1984. They were interviewed as part of a follow-up	Black relatives were more likely to attribute causation of illness to substance use and to view services as racist. Most black patients and relatives thought that black day centres would be beneficial. 60% of black relatives thought that black people would get better treatment with more black staff. As to comparisons between black and white, the black patients were significantly more likely to agree that black

No	Year Date	Author (s)	Study design, sample, methods and instruments	Key findings
			study in 1989. Contact was also made where possible with the relative/partner closest to each patient as identified by the patient.	people did not get treated as well as whites by psychiatric services compared to white patients.
4	1996 (UK)	Jennings	BAME Community Project Report based on partnership working between I) black voluntary sector; ii) service users; iii) black carers and iv) community members. Two London-based 'Sanctuary' community mental health project for black people from Hackney and Lambeth. Identified through a process involving selective tendering and networking. Author discusses both projects when they are in Year 3 of development. Projects were developed to enhance sensitive and effective mental health services for black people, more specifically to:	Problems establishing a shared vision between stakeholders. Power, trust and respect difficult to attain consensus when attributes in one person has a different value to others. Problems with establishing stakeholders' power attributes lead to mistrust and disrespect manifested in i)veiled and open conflicts ii)low attendance at committee meetings iii)decisions made at meetings being overturned outside meetings iv)low morale. The process and structures involved in developing a mental health service i.e. long winded meetings full of technical jargon; baffling procedures; enmeshed in piles of paper = disempowering of users and carers – who have more pressing needs. Lack of black mental health user led networks made it difficult to get black user views which became represented by white user organisations, professionals and black carers.
5	1996	Watters	Mental health service evaluation for	The Afro-Caribbean Development Worker stressed the role

No	Year Date	Author (s)	Study design, sample, methods and instruments	Key findings
	(UK)		Afro Caribbean and Asian community members.	racism played in causing mental illness among Black people and argued that it was ubiquitous in mental health services and in wider society. Black people developed a more positive sense of their identity. Empowerment was the key and explicit principle underpinning this work. Racism was considered to be a significant aetiological factor in Black people's mental health problems and a means of addressing racism, at both an individual and an institutional level, was through the development of strategies aimed at empowering Black service users and their relatives and carers.
6	2002 (UK)	Rai-Atkins and J RF	Case Study and Semi-structured interviews: Regional Based Project: Yorkshire and East Midlands Region Sample: Purposive	Lack of black led advocacy Problems of access – fuelled by poor engagement processes, lack of responsibility in helping black communities. Lack of bilingual advocates Lack of awareness Different perceived meanings of advocacy

No	Year Date	Author (s)	Study design, sample, methods and instruments	Key findings
				Lack of influence over culturally appropriate services.
7	2003 (UK)	McLean, Campbell and Cornish	Qualitative case study approach, interviews, and focus groups Sample: Purposive (N = 30) Carers were described as African-Caribbean carers of African-Caribbean clients of the mental health services Other groups interviewed: GPs, Police Officers, Mental Health Staff, Employment Officers, African-Caribbean Statutory organization members, African-Caribbean Voluntary agency members, African-Caribbean users of local health services and Lay African-Caribbean community workers.	We find that social exclusion comprises an explanatory framework which is repeatedly invoked by community members in describing their interaction with mental health services. Interviewees assert that experience and expectation of racist mis-treatment by mental health services are key factors discouraging early accessing of mental health services, and thereby perpetuating mental health inequalities. We conclude that participation and partnership are vital means by which to generate both the objective and subjective inclusion that are requirements for an accessible and appropriate health service.
8	2004 (UK)	Keating and Robertson	Qualitative- participatory approach Focus Groups	Families and carers are reluctant to become involved in services because they fear the outcome for the person they care for. This fear arises from stigma attached to mental illness. The sense of shame is more acute as a result of

No	Year Date	Author (s)	Study design, sample, methods and instruments	Key findings
			Sample: Purposive African Caribbean Carers (N=15 (79%); African Carers (N = 4 (21%) Demographic questionnaire Unstructured Interview	racism, and the pejorative ideas about black families and individuals. Views on mental illness informed by the perception that mental health services area acting as a form of social control, especially when they are marshalled by the police, social workers, psychiatrists and family members.
9	2006 (UK)	Downes	Qualitative approach and semi-structured interviews Carers – Barbadian Black (N = 1) Carers – Jamaican British (N = 3)	Black carers wanted to meet with other black carers but if this was not possible they wanted to meet other carers who had to care for family members with the same health problem regardless of their ethnic origin. Racism experienced by carers during the assessment process leading to distrust and reduce help seeking behaviour. Language barriers and form filling. 'Pridefulness' as a barrier to accessing the services

No	Year Date	Author (s)	Study design, sample, methods and instruments	Key findings
10	2007 (UK)	CSIP and UCLAN	Survey semi-structured Independent design questionnaire: Sample: Purposive African Caribbean Carers (N = 3) African Carers (N = 1) White and Black Caribbean (N = 1)	Carers wanted more support from mental health staff when in the ward environment. Importance of the church in reducing loneliness and isolation for service users
11	2007 (UK)	Atkinson et al	Qualitative, focus groups, Not clear exactly how many were carers and how many were service users The researchers gathered eleven personal stories from MHG trainees during the project.	In sites where all participants were Black (NACRO, Clapton Rangers and Nile Centre) the participants said that African and Caribbean MHGs had a good understanding of the issues that concerned them because of their shared experiences of being Black. It was said that some people from a BAME do not identify with a Black cause or struggle in the same way as many members of the team and MHG session participants. Class differences or the need to survive in a white dominated profession may make them feel and behave differently. Some of the data was used for this report but the main purpose of the story telling was to publish a story book and a journal article of their 'community narrative'. Funding for the story book has been acquired through Mellow and work on both publications will begin

No	Year Date	Author (s)	Study design, sample, methods and instruments	Key findings
				when the research comes to an end.
12	2008 (UK)	NBCCWN	Survey : Sample: Purposive BAME Study on carers in the UK Out of the 302 responses, 29% of these were from African - Caribbean (or Black British) No of carers from East Midlands N = 80 No of carers from West Midlands N = 54 No of carers from Yorkshire and Humberside N = 24 No of carers from East of England N = 4 No of carers from North East N = 13 No of carers from North West (N = 70)	Needs are universal but the solutions will be different - people and carers from BAME communities mostly have the same needs as others. However, culturally sensitive ways of enabling people to access services are needed. Services for BAME communities are often set up on a time-limited project basis, and are not always evaluated. As a result they are vulnerable when the project ends. Monitor, evaluate and collect data: it is important to know who is using the service and whether strategies to increase accessibility or reach out to BAME communities are effective. African and African Caribbean carers were more concerned with getting peer support and having the option of company and culturally sensitive activities with others in the community e.g. playing dominoes and sewing. This group was far more likely to access mainstream leisure and other facilities.

No	Year Date	Author (s)	Study design, sample, methods and instruments	Key findings
			No of carers from London (N = 25) No of carers from South East (N = 23) No of carers from South West (N= 9)	
13	2008 (UK)	Spinks et al	Pilot study. Aim to explore the needs and experiences, the perceptions, knowledge and accessibility of mental health support for young males (14 – 25) from African, Afro-Caribbean, South Asian and mixed heritage backgrounds within Preston. African, Caribbean, South Asian and Mixed Heritage participants No of carers = 6 Quantitative and Qualitative study Focus groups and semi structured interviews	The service mapping of 29 organisations found that 11 different organisations were providing services predominantly for young people, including eight that had activities exclusively for young men. Participants showed negative perceptions of services, both from personal experience and from images in the media. Some of these perceptions were voiced as a brutal and racist service that dis-empowered service users. Carers gave a more measured response, but the disappointment in the failure of services to meet the needs of the young person they were caring for remained. This included: Disruption to care, as staff leave or are on long-term sick leave. Carers described how distressing and frustrating this disruption can be. Lack of consideration for cultural and religious needs. The need for practical support to enable them to fulfil their role. These views of the service clearly

No	Year Date	Author (s)	Study design, sample, methods and instruments	Key findings
				created barriers to accessing mental health services. Carers wanted to see services that took into account the culture of a person and involved not only family, but also peers and school and college in a care package. There was an expectation that services would have some element of racism. Although the ethnicity of workers did not seem important, there was a clear leaning towards preferring to discuss problems with women from the young people. This may be because of the caring role women are boxed in to in some cultures and their experiences of this.
14	2009 (UK)	NHS West Midlands R D C	Aims to review the research evidence base for different models of care for Black African Caribbean communities	*Model of Care 1* – Partnership with Sheffield African Caribbean Mental Health Association Ltd, Community Outreach Service and Sheffield Care Trust Crisis/ Home Treatment Team *Model of Care 2* – Enhancing Pathways out of Care (EPOC) for Black African Caribbean men using Assertive Outreach services in Handsworth, BSMHFT *Model 3* – Enhancing pathways into care – A case for mainstreaming change – Antenna Outreach Services, Haringey

No	Year Date	Author (s)	Study design, sample, methods and instruments	Key findings
				Model 4 – The African Caribbean Community Initiative (ACCI). Wolverhampton – African Caribbean Outreach support and community service for mental health. The key theme that all these models highlight is the need to work in partnership across sectors to support improving the health and well-being of patients.

Appendix 6: Letter of invitation to Participants

Date

Dear________,

Re: **African-Caribbean carers' experience of caring for a relative with an enduring mental health problems**

My name is Julia Pelle; I am a lecturer and mental health nurse, employed by the School of Nursing & Midwifery, University of Southampton.

I would like to invite you to consider joining a research study which is concerned with exploring your experience, of caring for a relative/spouse with an enduring mental health problem.

Enclosed with this letter, you will find two forms:

- A participant information sheet. The participation information sheet provides more detail about the study and what will happen if you agree to take part.
- This is for you to keep. Please read this carefully.
- A consent form. This is for you to sign and return if you agree to participate in the study.

If you agree to participate in the study the enclosed consent form should be returned to me using the paid stamped addressed envelope provided. I will then contact you to arrange an interview date at a mutually agreed time and location.

A copy of the signed consent form will be given to you at interview.

Through your participation in this study, I hope to understand the essence of caring as it reveals itself through your experience and to find the answer to my question, "*How African-Caribbean carers experience caring for a relative with (state enduring mental health problem (s)?*"

You will be asked to describe specific episodes, situations, or events that you experienced whilst caring for your relative/spouse. I am seeking information of what these experiences were like for you i.e. your thoughts, feelings behaviours, as well as situations, events, places, and people connected with your experience. This will involve a roughly 1 - 1 1/2 hour interview starting with the statement *"Tell me about your everyday caring activities?"*

I value your participation and thank you for the commitment of time, energy, and effort. If you have any further questions before signing the consent form or if there is a problem with the date, time and location of our meeting, I can be contacted on telephone number 02380 597962.
With kind regards,
Julia Pelle

Appendix 7: Participant Information Sheet

Title of study: African-Caribbean carers' experience of caring for a relative with an enduring mental health problems

1. *An invitation to join the study*

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything not clear or if you would like more information.

2. *What is the purpose of the study?*

The purpose of this study is to understand African-Caribbean carers' experiences of caring for a relative/spouse with a mental health problem.

3. *Why have I been chosen?*

You have been chosen as you are a carer from the African-Caribbean community who cares for a relative with any one or more of the following enduring mental health problems e.g. s*chizophrenia, manic depression, personality disorder*, *clinical depression and self-harming behaviour, eating disorders).*

4. *Do I have to take part?*

It is up to you to decide whether or not to take part. Whilst the study provides the potential to influence the decision making processes that involve provision of mental health services to the African- Caribbean community, in Southampton and Portsmouth, you may derive no personal direct benefit from taking part. If you do decide to take part you will be given this information sheet to keep and asked to sign and return the enclosed consent form. Deciding not to participate in the study will have no effect on your health care or any other services you or your relative/spouse might receive from doctors, nurses, or social services.

5. What will happen to me if I take part?

The research study will commence in July 2008 and will proceed for five months. You will be invited to an interview for a period of 1 - 1 1/2 hours duration. The interviews will be aimed at exploring your carer experiences over the last six months. The outcome of the interviews will be recorded and will form the research data, which will be analysed as an on-going part of the research process.

There may be a risk that talking about the experience during the interview may bring up sad memories; make you feel tired, or anxious. If you would like to talk to someone about your feelings, you can call any of the following helpline telephone numbers:

- Rethink – a leading national mental health membership charity, that works to help everyone affected by severe mental illness recover a better quality of life Tel.*: 023 8022 5664 or after-hours number 023 80 453 297 (for carers from the Southampton area.*
- Carers Helpline *on Tel: 08457 221122* (*for carers from all other areas in the Hampshire) Monday – Friday 4.30pm – 11,30pm; Weekends and bank holidays 8.30am – 11.30pm. Voice and text phone calls at local rates*
- Carers Active Listening Line*: 08000 3 23456 offering telephone support for all carers.*
- Hampshire Carers Helpline *provides a listening ear, information, and practical help to all carers Tel: 0345 221122 Monday to Friday 5pm-8.30am Sat, Sun and bank holidays 24 hours.*

You can also access any of the local support groups and health and social care service numbers listed at the end of this form. Remember, you can stop the interview at any time you feel tired or for any other reason.

Following the interview, I will send you a type-written copy of the interview content for you to read through and check for any corrections you may wish to make. You will have two weeks to read through the information and return any additions and/or corrections in a stamped addressed envelope to me at the address indicated on this sheet. If I do not hear from you I will presume that you are happy with the content.

6. Will my taking part in this study be kept confidential?

No personal identifiable information will be revealed to anyone outside of the research team. All information collected from the interviews will be anonymous and kept strictly confidential.

7. What will happen to the results of the research study?

The results of the research study will be used to inform mental health providers, carers and service users of mental health services in the UK. It is also proposed that the findings of the study will be shared through publication and conference presentations in order to spread good practice.

Data collected will be held and stored (with permission of the participant) on a) a university desktop computer (used only for this PhD study) of the researcher in the School of Nursing and Midwifery, University of Southampton, the computers will be password protected.

During the course of the study only the Lead Researcher will have direct access to the data. Data stored on the University desktop computer will be placed in folders with special permissions for access by the Lead researcher only in order to protect from unauthorised usage.

The University desktop computer will be located at the Nightingale Building, School of Nursing & Midwifery, in Southampton. Any data in the form of paper records i.e. field notes, will be kept in a locked filing cabinet of the Lead Researchers desk, and (only the Lead Researcher will have key access to the filing cabinet) located at the Nightingale Building, School of Nursing & Midwifery, in Southampton.

Once the study is completed (approximately May 2010), control of the data will be passed on to the Research Office, School of Nursing and Midwifery, University of Southampton. The data will be stored for 15 years in accordance with the Data Protection Policy of the University of Southampton.

8. Where can I seek independent advice about being involved in this research study?

Professor Val Lattimer, Director for Research
University of Southampton, School of Nursing and Midwifery
Building 67, Highfield, Southampton, SO17 1BJ
Email address: V.A.Lattimer@soton.ac.uk Tel: 02380 597957

9. What do I do if I need to complain about the conduct of the research study?

If you have a concern or a complaint about this study you should contact Dr Abigail Burgess, Academic Adviser & Co-ordinator, in the Research Support Office at the School of Nursing and Midwifery (Address: University of Southampton, School of Nursing and Midwifery, Building 67, Highfield, Southampton, SO17 1BJ ; Tel: 023 8059 8205; Email:A.L.Burgess@soton.ac.uk).

If you remain unhappy and wish to complain formally Dr Abigail Burgess can provide you with details of the University of Southampton Complaints Procedure.

10. Who is organising and funding the research?

The research is being organised by Julia Pelle, a lecturer and mental health nurse at the School of Nursing & Midwifery. The research is part of a PhD study that is partially funded by the School of Nursing at the University of Southampton.

11. Who has reviewed the study?

The study will be subject to ethical review by the School of Nursing and Midwifery Ethics Committee, University of Southampton.

12. What do you have to do?

If you agree to participate in the study you will be invited to sign and return the enclosed consent form. If you would like to discuss any aspect of this study please contact the Lead Researcher on the details listed below:

Julia Pelle, Lead Researcher,
School of Nursing and Midwifery, University of Southampton, Building 67,
Highfield, Southampton, SO17 1BJ.
Email address: jep2@soton.ac.uk **Tel**: 02380 597962

Appendix 8: Participant Consent Form

Title of study: **African-Caribbean carers' experience of caring for a relative with an enduring mental health problems**

Name of Researcher: Julia Pelle

Please initial the boxes:

I confirm that I have read and understood the participant information sheet dated ……for the above study and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and that I am free to Withdraw at any time, without giving a reason and without detriment to myself. ☐

I understand the interview in which I am participating, may be recorded and used for transcribing purposes. ☐

I give permission for the recordings to be made and understand that my contributions will be anonymous. ☐

I agree to take part in the above study. I also understand that I can withdraw my consent to participate in the study at any time. ☐

I grant permission for the data to be used in the process of completing a Ph. D. degree, including a dissertation and any other future publication. ☐

I agree to give my contact details in order to arrange a mutually convenient ☐

time to be interviewed for a period of between 1 to 1 ½ hours.

Participant Contact Address:

____

____

____

____

Contact Telephone No: ___________________________

I have read and understand this form, and consent to the research it describes to me. I have received a copy of this consent form for my records. ☐

I understand that deciding not to participate in the study will have no effect on my health care or any other services that I or my relative/spouse might receive from doctors, nurses, or social services. ☐

I understand that there may be a risk that talking about my caring experience during the interview may bring up sad memories; make me feel tired, or anxious. ☐

Should I need to talk to someone about my feelings, I know that I can call the following helpline telephone numbers

a) 023 8022 5664 or after-hours number 023 80 453 297 (for carers from the Southampton area)

b) 08457 221122 (for carers from all other areas in the Hampshire)

c) The Carers Active Listening Line 08000 3 23456

d) Hampshire Carers Helpline Tel 0345 221122 Mon to Fri 5pm-8.30am; Sat, Sun and Bank *holidays 24 hours* and/or contact one of the local support contacts listed on the *Patient Information Sheet*.

I know that I can stop the interview at any time I feel tired or for any other reason. ☐

Name of participant in block capitals Signature Date

Name of person taking consent in block capitals Signature Date

Appendix 9: Thank you Letter to Participants – (to be sent one to two weeks after interview with participant)

Date

Dear_________,

Re: Title of study: African-Caribbean carers' experience of caring for a relative with an enduring mental health problems

Thank you for meeting with me in an interview and sharing your experience of caring. I appreciate your willingness to share your personal thoughts, feelings, events, and situations.

I have enclosed a written copy of your interview. Would you please read through the document? Be sure to ask yourself if this interview has fully captured your experience of caring for a relative with a mental health problem.

After reading through the information, you may realise that an important experience (s) was not mentioned or needs further detail and would further explain your experience (s), please feel free to make any additions or corrections to the document. The way you tell your story is what is important.

When you have read through the whole transcript and have had an opportunity to make changes and additions, please return the transcript in the stamped addressed envelope. You have been given two weeks from the date at the top of this letter to return the transcript to me with any additions or corrections.

I have greatly valued your participation in this research study and your willingness to share your experience. If you have any questions or concerns, do not hesitate to call me.

If I do not hear from you I will presume that you are happy with the content.

With kind regards,

Julia Pelle (**Lead Researcher**

Appendix 10: Protocols for participants experiencing stress during the interview

Vulnerable research participants

Participants may be vulnerable to distress through research inquiry where one or more of the following are associated:

- Their health status/progress becomes insecure. Recording their story could prove traumatic.
- They are unable to understand the demands of research (e.g. experiencing learning difficulties or are too confused to appreciate what is being sought)
- Research questions may engender a sense of guilt or self-blame or even provoke self-harm
- Research may confront them with issues or debates that they felt they had concluded in privacy with other staff and at other times.
- Research focus then to re-evaluate their relationships with others (become introspective)
- Participants are under the influence of the researcher or her associates (e.g. currently receiving care from the researcher). Patients should not fear that their treatment or care is dependent upon cooperation with the research.

If a participant is in any way distressed, the interviewer (an experienced mental health nurse) would:

- Stop the interview
- Offer to remain with the participant
- Offer basic emotional support, such as attending, listening and empathising
- Allow the participant to decide whether to continue with the interview
- If necessary, and with the participant's approval, refer him or her to the most appropriate health and/or social care service support *(See information on next page)*

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