The Experience of The Role of Being A Caregiver for Carers Who Identify As ‘Black’: An IPA Study

by

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Declaration

I hereby declare that the work submitted in this dissertation is fully the result of my own investigation, except where otherwise stated.

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Acknowledgments

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Abstract

Background: Carers who identify as 'Black' are a group that is thought to experience exclusion and marginalisation within existing services (JCPMH, 2014). Whilst, there is some research that explores caregiving attitudes, experiences and needs of BME family carers, it is documented that little is known about knowledge or awareness and uptake of counselling services. Further it has been empirically noted that individuals from BME groups are less likely to access counselling services than White British people. This would suggest that this is an underrepresented area of research, particularly within the UK. Thus, the present study is concerned with the experience of Black carers with a focus on wellbeing and how they 'cope' in relation to their caring role.

Method: Semi-structured interviews were conducted with a purposive sample of six carers who identified as Black. Participants accounts of their lived experiences were recorded, verbatim transcribed and analysed using Interpretive Phenomenological Analysis (IPA).

Results: Three themes were identified: 'Being a carer', 'Being Black' and 'Being a Black Carer'. Although, separate from each other each theme is all part of the repertoire highlighting that although they are different from each other, they are also related to each other. These master themes are not opposites, but different yet integrated parts of Carers who identify as 'Black'.

Conclusion: The findings indicated that the experience of wellbeing for Black carers is predominantly influenced by cultural identity and perceptions. This research supports existing literature on carers who identify as Black. The findings of this research offer some useful implications for practice and service provision. Seeking to understand what constitutes and contributes to the experiences of carers who identify as Black

1 Introduction

The purpose of this study is to explore the experiences of Black carers, a group that is thought to experience exclusion and marginalisation within existing services. This chapter will briefly introduce the study and provide an overview of the organisation of the research ending with a reflexive statement.

1.1 Experiences of Carers who identify as Black

It has been widely acknowledged within literature (Carers Trust, 2016; Healthtalk.org, 2014; Mind, 2014) that the experience of caring for a family member with a variety of needs ranging from chronic illness, mild/severe disabilities or mental health can be a demanding task. Within the United Kingdom (UK) it is estimated that there are “half a million carers from Black and Asian ethnic minorities” (Carers UK, 2011). Whilst, several studies (Townsend & Godfrey, 2001; Parveen, Morrison & Robinson, 2011, 2013) have explored care-giving patterns and relationships, focusing on gender role stereotypes, family responsibility and willingness to care. An understanding of the support needs of carers who identify as Black appears to be limited, including from a Counselling Psychology perspective. As a consequence, there is a dearth of knowledge to support practitioners working within this field.

1.2 Organisation of the research study

Firstly, a review of the existing research in the area of wellbeing and Black carers experiences, where the theoretical framework and empirical data will be presented and critically evaluated. Additionally, the current study’s contribution and relevance in the field of Counselling Psychology will be presented before outlining the research question. This is followed by the methodology of the study, describing the procedures of the research in relation to sampling, recruitment, data collection and analytic process. The findings and themes that emerged from analysis of the data are introduced followed by an overall discussion of the research findings. These findings are provided by contextualising them within the context of existing literature, whilst considering the limitations of the study and suggestions for future research. In addition, the relevance of the findings to Counselling Psychology and to professional practice in the area of ethnic and cultural diversity will be considered.

Reflexive Statement

My interest in this research stems from my subjective experiences of the role of 'carer' which I will outline in the following passage. I was born to older parents from the Caribbean island of St Vincent, who settled in the UK in the 1960's. To me, my parents were not that old at all, they both worked full-time and led healthy active lives. I had a positive experience with my parents and had a close unique bond, especially with my father. I remember my father would carry me on his shoulders when my legs were too tired to walk, always had time for a chat and came to support me whenever I felt wounded. This was all similar yet different to the relationship I had with my mother who always had tolerance, patience, tea and sympathy for me when things got tough in my 'lived' experience.

On reflection, I had plenty of conversations with my father about his experience of being raised by his grandmother and how due to her lack of mobility through age changes he would take her out on the veranda to 'take sun'. What I was aware of was continuance of obligation to care even from a distance. My mother would frequently send items and money back to my grandparents and other elderly relatives she had formed special bonds with, in her youth. As I reflect on my subjective experience, it would seem my internalised cultural messages and identity (McKenzie-Mavinga, 2009, p.143) around the role of caring begun taking form here.

As I reflect on this, I am aware how subtly my parent's experience of taking care of grandparents and other elderly relatives informed my sense of 'norm' and 'value' within 'our culture' that because of love the younger would take care of the older.

Just over ten years ago I unexpectedly found myself allocated the role of carer for my elderly father who had come to stay with us for a 'short' visit. Even after all this time, I still find the circumstances of my enlistment to the role of carer both amusing and sad. Amusing because short means 'Pa' (as I referred to my father) had retired to St Vincent and the Grenadines more than twenty years prior to visiting us (the family) for a month. It became clear to us that when my father could not find his way home to us from the park, at the top of our road that something was not quite right with him. Something had changed, my fiercely independent father seemed less so, he was confused, fragile and different. In retrospect, I am aware I did not want to believe that, putting it down to Pa just being exhausted. Pa going missing for another few hours and turning up in some random kind person's car was the wakeup call for me. A few weeks later following scans and psychometric tests my father was given a diagnosis of Alzheimer's coupled with vascular dementia. He needed to be taken care of.

It had never occurred to me that I might one day find myself in a caring role. It was not a role I had planned for or indeed felt I had the capacity for. His diagnosis had a big impact on both of our lives limiting in a sense both of our freedoms. My independent father was restricted through his progressing limited mental capacity and I was restricted through the responsibility of having to be more available. However, for me there was no question at this time of finding a nursing home for my father. I was aware this was due to my personal experience of him and the quality of our relationship, that had a positive impact on me. As I reflect on my subjective experience of our relationship, I am aware that my decision to care for him was less to do with duty and more to do with love and gratitude for the support I had experienced from him over the years.

At around the same time another diagnosis was made within my family. Our youngest son was three at the time and whilst we had always been aware of the subtle differences about him, we did not expect him to get a diagnosis of Autistic Spectrum Disorder (ASD).

This ‘boy’ was happy-go-lucky, cheeky, affectionate and very communicative making friends wherever he went. So, there was a doppelganger situation, two close family members with two very different needs. Even with all the rationalising there were many times I did not feel I was ‘coping’ at all. On reflection, it felt like a balancing act I was constantly juggling my time and finding I was left with very little headspace for myself.

In my situation, advice and opinions came from all quarters ranging from extended family members to health professionals. In hindsight, I feel there was an expectation from the services that I ‘should’ take care of my father. Just as well I wanted to. To better support my father and son I joined the relevant national and local groups. Not only was I daughter and mum, I was the person who negotiated entitlements and services. There were times when I felt I was battling for these services and I was going mad from not being listened to and not being heard. In contrast, the actual caring role for me was less frustrating but nevertheless emotionally taxing. People would frequently state “you’re doing so well…” but this was not at all how I was experiencing things. As my father’s cognition was declining, my young son’s energy for life was increasing. My own mental wellbeing was suffering, and I would often feel powerless and mentally exhausted. No-one asked how ‘I’ was coping. What I wanted was a safe environment where I could explore my feelings and reflect on the impact of the changes that had occurred in my life. In retrospect, on taking on the journey to become a person-centred therapist and through personal counselling, I was able through reflection to explore my subjective experiencing and gain a deeper understanding of my personal beliefs and values.

In my experience whilst there was an element of stress and isolation involved in my caring role there were also many positive psychological benefits too. I value and appreciate the fact I was able to take care of my father. Writing this reflexive statement assisted me in increasing my own self-awareness by putting into context my personal previous (and still lived) experience and how such knowledge of the phenomenon that is being explored informed my study. Thus, potential biases can be recognised by the reader. Etherington (2004, p.36) suggests that in all stages of research, reflexivity requires more than self-awareness and includes a dynamic process of interactions within and between the researcher, participants and the data that informs decisions, actions and interpretation. Further, Epstein (1999) argues that reflection provides an explicit attitude to the incorporation of development and professional identity and understanding of personal beliefs and values for practitioners.

Further, as a practicing person-centred therapist and trainee counselling psychologist working with clients within a community-based branch of a national organisation that provides counselling services to carers, I am aware I hold a fairly established viewpoint which I will endeavour to make transparent and acknowledge. Additionally, 'bracket off' (Smith, 2004) through supervision and keeping a reflective journal consequently aiming to reduce the influence of my subjective experiences during interpretation.

This research has allowed me to explore a topic I feel personally connected to. Conducting the analysis expanded my awareness of multifaceted complexity of emotional needs of Black Minority Ethnic (BME) carers and more over further identify that there is an ethical need to give voice to BME carers in a growing diverse society.

2 Literature Review

2.1 Introduction

This section will present an exploration into the relevant clinical, theoretical and empirical literature on the lived caring experiences BME carers, and how they ‘cope’ in relation to their caring role. A broad description of what constitutes being a Black carer in terms of definition and prevalence will be provided, followed by a discussion of a theoretical framework and by drawing on relevant areas of theoretical literature. The existing literature on BME carers will then be explored including the research studies focusing on the impact of caregiving. Next, the relevant clinical and empirical literature on the mental wellbeing of individuals who identify as Black will be presented. In addition, race, ethnicity, religion and culture within psychological therapies will also be looked at. Finally, this review will lead to the identification of an underrepresented area in existing literature, particularly within the UK, in the existing knowledge base of the lived caring experiences of Black and Minority Ethnic carers, and how they ‘cope’ in relation to their caring role. Hence, within the literature review, studies carried out in the United States have been included to complement those found in the UK.

2.2 Current Position

It is well documented that individuals from Black Minority Ethnic (BME) groups (BACP, BPS, Mind, Rethink et al., 2013; Moffat, Sass, McKenzie & Bhui, 2009; Pacitti, Hughes, Statter, Alvarado-Rivero & Chaddha, 2011) are less likely to access counselling services than White British people. Although, it is recognised that counselling can be beneficial to carers (Lipinska, 2016), it is felt that the lived experience of how a carer copes may differ for specific groups such as BME groups. Whilst, there is some research that explores caregiving attitudes, experiences and needs of BME family carers, it is documented that little is known about knowledge or awareness and uptake of counselling services (National Black Carers and Carers Workers Network, 2008). This appears to suggest that there is a dearth of research within this area and that little is known about the lived experience of how BME carers cope and why they are less likely to access available counselling services.

A study conducted by Williams, Turpin and Hardy (2006) suggested that BME groups were marginalised and excluded from psychological services within the United Kingdom. These authors argue the chief reason for this is the lack of ability to adequately address, offer and provide a suitable range of clinical and psychological services that are sensitive to/respectful to the ethnic, cultural, spiritual and religious needs of a multicultural society.

The Department of Health (2011) draws from the proposition of the Equality Act 2010 to support their argument that 'race' is included in 'protected characteristics' which means that public bodies need to be mindful of how they meet their equality objectives. Within their document 'Analysis of the Impact on Equality of Talking Therapies…' (2011) the Department of Health suggested a 'four-year plan' that aimed to meet the needs of different communities.

2.3 Carer Role definition

Stalker (2003) argues that although the term 'carer' historically barely existed in the English language people have been doing the 'caring' for centuries. This author reported that historically the Association of Carers formed in 1981 established and developed the definition of a carer as 'Anyone who is leading a restricted life because of the need to look after a person who is mentally, or physically handicapped, or ill, or impaired by old age' (p.17). Further, this author reports that the Association aimed to encourage carers to see their own needs as being as important as those of the person cared for. This fits broadly with current definitions that a carer is anyone who provides or arranges care for someone else who due to illness, disability, a mental health problem or an addiction cannot cope without their support (Carers Trust, 2015; Mind, 2013). The kind of help provided ranges from giving emotional support, helping someone cope with a mental health problem, personal care, interpreting for someone who is deaf or has English as an additional language. Within the UK it is reported that the state saves £7.9 billion annually with the unpaid care half a million BME carers provide to their family members (Carers UK, 2011).

Studies investigating caregiving patterns in ethnic minority communities have reported that caregiving is significantly influenced by gender role stereotypes (Cloutterbuck & Mahoney, 2003; Townsend & Godfrey, 2001) with daughters or daughter-in-law's providing care. However, caregiving within ethnic minority families is frequently shared with the family network, including spouses and sons (Milne & Chryssanthopoulou, 2005).

2.4 Impact of Caregiving

Existing research studies (Milne, Hatzidimitriadou, Chryssanthopoulou, & Owen, 2001; Papastavrou, Kalokerinou, Papacostas, Tsangari & Sourtzi, 2007) have reported on negative psychological (stress, depression and burden of care) and physical outcomes (musculoskeletal injury tiredness, cardiovascular problems). However, there have been some studies that have reported on the positive benefits of caregiving. Hogstel, Curry and Walker (2005) conducted a thematic analysis study to explore the benefits of informal caregiving and reported on four benefit categories that emerged: Celebrating the small things, resolving past hurts and conflicts, developing strength and aging readiness and experiencing the older persons' full life. Whilst these researchers were investigating caring for older adults it is feasible that their findings could be applied to other caregiver situations. Another study carried out by Nolan, Ryan, Enderby and Reid (2002) reported that 55-90% of carers could identify satisfying aspects in their caring role.

2.5 Black and Minority Ethnic (BME) definition

Within the UK Black and Minority Ethnic or Black, Asian and Minority Ethnic is the terminology normally used in the UK to describe people of non-white descent (Institute of Race Relations, 2020). Bhavnani et al., (2005) argue that cultures exist in socioeconomic and power vacuums and we must constantly be alert to the ways in which we use the terms ‘race’ and ethnic minority’. These authors further point out that ‘race’ is a social construct and postulate that its varying manifestations reflect conceptual attempts to legitimise and dominate in different social and historical contexts. Additionally, they argue that the term ‘ethnic minority’ has been used discursively as part of the culturalisation of racism and highlight that ethnicity is also used to describe people who perceive a shared identity based on culture, descent and territory.

Lago (1996) draws from the research done by Nardirshaw and Goddard (1999) for his definition of the ‘minority ethnic group/communities’ and suggests that this is taken to include the collective term ‘black’. These authors argue that individuals of African, Caribbean and Asian origin commonly refer to themselves as ‘black’ a term underlying a common shared experience. Further, Evandrou (2000) suggests that in the UK ‘black’ refers to individuals with at least one parent who originally came from the Caribbean or Africa.

Minority can be defined as a numerically small group of people who differ from the majority in a given society (Perry & Perry, 2016). Hughes (2014) suggested that based on ethnicity, culture, shared language and/or skin colour BME/BAME describes minority groups living in the United Kingdom. BME communities within the UK consist of people from Black African, African-Caribbean, the Irish community, Eastern European communities (including Latvian, Russian, Polish, Lithuanian and Slovakian communities), South Asian and Chinese heritage (DOH, 2007; Pelle, 2013). However, Paniagua (2005) highlighted that practitioners should be aware that some people object to being referred to as minorities or members of a minority group as these terms imply superiority on part of the majority.

It would appear then that the term ethnicity is essentially a process of group identification (Bhavani et al., 2005) and can be described as the collective group an individual "belongs to and either identifies with or is identified with by others, as a result of a mix of cultural and other factors including one or more of language, diet, religion, ancestry and physical features traditionally associated with race" (Bhopal, 2007 p.311).

Through embracing language and historical backgrounds, ethnicity considers cultural and racial ideas and is thus defined as a collection of culture, language, religion, skin colour and family backgrounds (Fernando, 2002). Botsford, Clarke and Gibb (2011) conducted a review on the impact of ethnic background on caregiving for partners of people with dementia through the method of qualitative grounded theory. These authors found that ethnic background appears to account for differences in experiences of caregiving and argue that there is a need for socio-economic factors and education to also be taken into consideration. For example, they reported that whilst Greek Cypriot participants tended to emphasise family relationships; African-Caribbean participants tended to view themselves mostly as individuals or as part of a couple. However, although arguably relevant, these findings are limited to only two separate London BME communities (Greek Cypriot and African-Caribbean) and might have benefited from broader BME community participant inclusion. Fernando (2005) suggests for the purpose of categorization the concepts of ‘race’ and ‘culture’ have been replaced by the term ‘ethnicity’ to incorporate the two.

2.6 Migration and Acculturation definition

Whilst considering the term BME, it felt necessary to look at migration and acculturation, since minority communities have migrated from their countries of origin. Paniagua (2005) postulates that there are two processes of acculturation; one process being the external process of acculturation where an individual migrates from their country of origin to a new country. This author argues the ‘external process’ can be defined in terms of the degree to which an individual integrates or adapts new cultural patterns into their original cultural patterns. According to this author, the other process the ‘internal process’ of acculturation occurs when individual moves from one part of the country to another. For example, from a rural village setting to a big city.

Several studies (Gazard, Frissa, Nellums et al., 2015; Silveira & Ebrahim, 1998) have highlighted the socio-economic difficulties migrants experience. Bhugra (2003) reported that rates of depression vary according to migrant status and that migrants in some groups are less likely to report symptoms of depression. This researcher reported acculturated individuals are more likely to be depressed. However, others (Altschuler, 2013) have demonstrated that experiences of migration vary considerably. This researcher suggests that whilst for some migrants, migration represents years of isolation, economic uncertainty and exposure to prejudice. For a portion of other migrants, Altschuler (2013) postulates that migration offers increased physical, economic and political security and an opportunity for increased independence from family members than felt possible in their country of origin.

2.7 Mental Wellbeing definition

Broadly, it is acknowledged that the word ‘mental’ relates to the process of thinking. Carl Jung argued that there are two kinds of mental processes that are used in daily life and suggested that ‘the process of perception’ where individuals become ‘aware of’ was one of these processes. He postulated that ‘the process of judgment’ where individuals ‘organised or decided’ was the other kind of mental process that is used in everyday life (Berens, 2000).

Keyes (2013) suggests that the study of subjective wellbeing has been divided into two streams of research. One which equates wellbeing with happiness as feeling good and the other with happiness as a human potential. These two ideologies grew from historical perspectives on happiness and have a lot in common to the characteristics described by Aristotle (and Socratic) and Eastern traditions view. The hedonic tradition embraces human concerns whilst increasing the duration/amount of positive, pleasant feelings and reducing the duration/amount of unpleasant negative feelings. The second tradition Eudaimonia postulates individuals becoming ‘more fully functional’. The subjective characteristics that are associated with wellbeing are presented as ‘psychological’ wellbeing and include self-acceptance, environmental mastery or agency, autonomy, purpose in life, personal growth, positive relations with others and engagement with existential challenges in life (Slade, Oades & Jarden, 2017).

2.8 Influences of Collectivism/Individualism on Cultural Values and Caregiving Behaviour

The dyad of ‘collectivism-individualism’ applies to the dichotomy between Eastern and Western cultures. Collectivistic cultures focus on the community as a whole, whilst individualistic cultures focus on individual autonomy. Willis (2012) points out that the collectivist/individualist dichotomy has been used to classify individuals providing care to family members per their system of care. From the collectivistic perspective, the extended family is the central concept and the needs of the individual are not viewed on the same priority level as the sense of family responsibility. Demonstrated within collectivist families is closeness and interdependence whilst the individualistic family typically promotes the needs of the nuclear family over the extended family. Willis (2012) argues that from this point of view collectivists co-operatively provide informal care out of love for their family members. In contrast, individualists are not as willing to provide informal care doing so out of necessity.

It can be argued that dimensions of individualism and collectivism vary across countries (Schreier, Heinrichs, Alden et al., 2010) and that migration means there can be great ethnic and cultural diversity within a single country. For example, when it comes to family care within the USA, African-Americans, Hispanics or Latinos are usually reported as being associated with collectivist cultural norms while the white population is associated with individualistic cultural norms (Gallagher-Thompson, 2006). Willis (2012) suggests that another factor that may affect compliance to cultural values among migrants is acculturation: the process through which the host culture is adopted. This researcher suggests that this may include a shift from collectivism to individualism.

Cultural group differences in caregiving have been reported in a UK study carried out by Adamson and Donavon (2005). These researchers interviewed 36 carers from South Asian and African/Caribbean communities who were caring for an older family member with dementia across various locations in the UK. Using in-depth semi structured interviews, the researchers aimed to explore the meaning of being a carer for a family member through the method of qualitative grounded theory. It was reported that some of the participants within the study did not start ‘being a carer’ when their relative became in need of greater support but rather that caring was in some sense an already integral to their sense of self. Further, these authors reported that some participants did not appear to regard themselves as carers. For example, African/Caribbean spouses refereed directly to the marriage vows ‘in sickness and in health’, whereas South Asian spouses were more likely to attribute their role as carer to perceived cultural norms. These findings support those of (Parveen, Morrison & Robinson, 2011; Lawrence, Murray, Samsi & Banerjee, 2008; Adamson & Donavon, 2005) who reported that the carer participants stated that the motivation behind their role adoption was their caring nature and because of their marriage vows.

Parveen, et al., (2011) carried out a qualitative analysis of the experiences of caregivers from four ethnic groups (British Bangladeshi, British Indian, British Pakistani and White British). These researchers were interested in the difference and similarities between motivations and role adoption willingness to care, experience of role, adaptation to role, coping, use of and satisfaction with support. Parveen et al., (2011) found that the British Bangladeshi, British Indian, British Pakistani carers felt that they had no choice but to adopt the role as caregiver.

Lawrence et al., (2008) found that second or third generation African-Caribbean carers (those born in the UK) held less traditional outlooks on caring for family elders than first generation African-Caribbean carers. From these findings, it could be implied that within BME communities there are generational difference in the ideologies held on caregiving. Although, these findings have implications for how caregiving might be viewed depending on the generation of the carer, they may not necessarily be representative of BME communities in other UK areas. Milne and Chryssanthopoulou (2005) point out that culture and ethnicity need to be viewed as concepts that vary vastly between countries, places, communities, families and even individuals. These authors postulate the possibility that the concepts of culture and ethnicity are situational, contested, diverse and subject to temporal change. Further arguing that presumed stable ethnic identity through acculturation could be a cohort effect, confined to one or two generations.

2.9 Research Addressing Diversity

In their review of literature on barriers to access and minority ethnic carers; satisfaction with social care services in the community Greenwood, Habibi and Smith et al., (2015) point out that the numbers of carers from minority ethnic groups is rising and that carers from minority groups often failed to access care services. These researchers reported that 13 studies were included within their review and that most investigated either barriers to access or satisfaction levels. Greenwood et al (2014) found only four of the studies investigated minority ethnic carers satisfaction with social care and that few studies compared minority ethnic carers' perceptions with majority ethnic groups. These authors suggested that this made it difficult to identify issues specific to minority groups since most barriers described were potentially relevant to all carers, irrespective of ethnic group. Greenwood et al (2014) found that issues specific to minority ethnic groups included language barriers and concerns about services' cultural or religious appropriateness. These researchers reported that barriers common to all groups should not be underestimated and argued that a better understanding of the relationship between perceived barriers to accessing services and dissatisfaction with services is needed before the experiences of all carers can be improved. However, although the review explored possible barriers to minority ethnic group it focused on access to social care services and sheds little light on how BME carers experience their role.

2.10 Revisiting the Impact of Caring with a BME Focus

It is evident from existing research (Parveen, Morrison, & Robinson, 2011) that there are significant variations amongst BME communities in regard to their motivation to adopt the carer role, their willingness to care, the experience of being a carer, and the use of external support. Several of the available studies emphasised the theoretical framework of family caregiving that proposes that caring for a family member with a variety of needs has a negative impact on the carers family life (Devapriam, Thorp, Tyrer, Gangadharan, Raju and Bhaumik, 2008; McCann, Bamberg & McCann, 2015; Riley & Fenton, 2007).

Pelle (2013) suggests that research studies focusing on the experience of caring for a family member can be clustered into two main study groups: 'objective burden' of caring by family carers that reflects the actual physical dependency of the person cared for (Brodaty & Donkin, 2009; Pelle, 2013). The other main study group is 'subjective burden' of caring by family carers and is defined as the distress the carer feels as a result of the behaviour of the person cared; the carers own perception of the impact of caring such as physical and emotional impact, their psychological state and resources (Brodaty & Donkin, 2009; Pelle, 2013). These authors argue that the burden of caring involves a process that relates to the emotional, physical and psychological effects on the carer through the process of caring. The findings from previous studies on carer burden are mixed. Some studies (Pinquart & Sorensen, 2005) reported that minority carers such as African Americans and Latinos report equal or lower levels of burden and depression when compared to white carers. Whilst others reported increased levels of burden for Latino carers (Pinquart & Sorensen, 2005).

Broadly, it is acknowledged that strategies for coping are important correlates of subjective burden. Montoro-Rodriguez & Gallagher-Thompson (2009) suggest that coping strategies also mediate the effect of ethnicity and other external factors on the level of distress of carers. From a carer perspective, it appears that strategies of coping incorporate ways to adjust the stressful caring situation. This can be through seeking social support (active approach) and/or avoidance (emotional response).

The stress process model proposed by Pearlin et al., (1990) describes the dynamics between three major components: sources of stress, mediators of stress, and manifestations of stress. This model suggests that several sources of stress interact with each other to produce higher levels of stress. Within this model social support and coping responses are observed as significant factors of an individual’s adjustment to the care-giving role (Milne & Chryssanthopoulou, 2005). Zarit, Pearlin and Schaie (1993) suggest that stress occurs out of two general conditions: when discrete life events occur and the presence of relatively continuous difficulties or burdens. However, much of the stress-process theoretical frameworks, have been developed in work with white caregivers and information around whether racial differences in caregiver wellbeing are mediated by stress process variables is not clear.

The socio-cultural stress and coping model is a more recently formulated model that has been used to illuminate ethnic differences in carer stress, coping styles, appraisals and outcomes (Knight, Silverstein, McCallum, & Fox, 2000; McCallum, Longmire, & Knight, 2007). This model postulates that the effects of stressful conditions such as care recipient behavioural problems on the mental/physical health outcomes of carers, are mediated by the carers appraisal and ability to cope with those stressful conditions (Montoro-Rodriguez & Gallagher-Thompson, 2009).

Cox (1995) reported that depression, anxiety isolation, physical symptoms, strains in relationship and restricted activity levels are amongst the reported stressful effects of caregiving. This suggests that the task of caregiving can often be to the detriment of the carer's own health and wellbeing (Solihull Carers Centre, 2017; IRISS, 2012). Whilst this is broadly acknowledged within the general population in the UK, limited attention has been given to Black and Minority Ethnic experience and therefore less is known about the minority experience within the UK (Sashidharan, 2003). Parveen et al., (2011) argue that barriers to research within this population can include language difficulties made even more difficult by the lack of available standardized, validated assessment measures in languages other than English.

Adamson and Donovan (2005) emphasise on the co-operation between the state and the family for the provision of care. These authors suggest that this is particularly the case for carers of South Asian and African/Caribbean heritage due to the inclination to over-estimate the capacity of black families to provide informal care. Therefore, the need for support from other sectors for this group is underestimated. This supports the findings of other studies (Parveen et al., 2011; Pound & Greenwood, 2016; Strudwick & Morris, 2010) who point out the common misconception that BME carers have an extended support network and therefore do not have support needs beyond the family. For example, many family networks may have become fragmented due to migration with extended family members being left behind.

Devapriam, Thorp and Tyer et al., (2008) carried out a comparative study that aimed to compare the stress levels and unmet service needs in South Asian and white carers of adults (*N* =742) with learning disabilities. Within this study, the carer was defined as being 'stressed' if they reported feeling high levels of psychological, physical or social stress within their current situation. These researchers reported that substantial differences were observed between the two groups and that the South Asian carers reported significantly higher levels of care provision and unmet needs. Additionally, major psychological stress was reported in 22% (n=61) of South Asian carers compared to 16% (n=73) reported in white carers. The researchers suggested that it was possible that people who access services from South Asian communities are the ones with higher levels of problems. Although, the researchers stated the unmet needs of carers in terms of practicalities such as housing needs and needs for respite. It appears that the carers emotional mental well-being through the request for/offer of psychological therapies/counselling does not appear to have been explored.

2.11 Intersectionality and the experiences of Black women/carers

The term ‘intersectionality’ commonly denotes to the interdependence of multiple social identities (Crenshaw, 1991). The concept of intersectionality has its roots in Black feminist theory (Cole, 2009) and looks at the intersection of multiple social categories such as race, ethnicity, gender, sexual orientation, socioeconomic status and disability. Crenshaw (1991) sought to draw attention to the experiences of Black women arguing that they were unique and different not only to those of White women but also Black men. This approach argues that Black women have multiple sources of oppression such as being a woman and being Black (Mwangi& Constance-Huggins, 2019). From this standpoint it would appear that differences cannot be explained by a single social location or identity such as race or gender. More accurately, these identities interact affecting the lived experiences of Black women. Hankivsky et al., (2010) suggest that when applied to health, the approach of intersectionality offers the benefit of bringing greater clarity to the explanation of the priorities and issues facing Black women.

2.12 BME’s Relationship with Psychological Therapies

Previous reviews have mentioned the existence of variations in health outcomes and access to services and reported that there appears to be a tendency for poorer health outcomes for BME populations and lower than expected uptake of services (Atkinson, Clark & Clay,2001; Botsford, Clarke & Gibb, 2011; Szczepura,2005). Burman, Gowrisunkur and Sangha (1998) posited that the approach of psychology towards ethnicity and culture has been oversimplified and makes assumptions on the universal generalizability of early human experiences. In their report ‘Beyond We Care Too: Putting Black Carers in the Picture’ the NBCCWN (2008) argue that needs are universal and point out that solutions may be different. The report suggests that although carers from BME communities mostly have the same needs as others, culturally sensitive ways of enabling access to services was vital to enable BME communities to engage with available services. This view is also supported by Moodley (2000) who pointed out that research and practice have tended to universalize meanings of distress which has often led to neglect of the meaning to particular individuals in particular cultures.

Several studies have focused on the socio-cultural context of caregiving and highlighted the importance of differentiating universal elements of caregiving from those mediated by the representation and experience of specific cultural groups (Montoro-Rodriguez & Gallagher-Thompson, 2009). Cochrane and Sashidharan (1996) reported that there are significant and sustained differences between the white majority and black minority ethnic groups in their experience of mental health services and service intervention outcomes.

Eleftheriadou (2010) suggests clients from different cultural backgrounds have often been viewed as so ‘different’ they are ‘untreatable’. For BME carers this could mean they are overlooked for services such as psychological therapies because it is felt that more ‘specialist services’ are required. Rabiee and Smith (2014) carried out a study to examine understanding of mental health and the extent to which statutory and voluntary mental health services in Birmingham are meeting the needs of Black African and African Caribbean communities. These researchers reported that when asked to identify negative experiences participants within their study highlighted feeling not understood and respected, and lack of equity in accessing resources, particularly in relation to talk therapy. This also supports the outcomes of previous reviews (mentioned earlier) that suggest that individuals from BME groups are less likely to access counselling services. Moodley (2000) postulates that in terms of the small number of BME individuals who seek therapy a ‘not-knowing ‘mode seems to underlie much of the practice leaving BME clients ‘disenchanted with psychotherapy because of the failure to address fundamental issues. Issues such as illness presentation, therapist-client differences, client-therapist alliance and pigeonholing and stereotyping individuals.

Other studies (Lawrence et al, 2008; Rammohan, Rao & Subbakrishna, 2002; Strudwick & Morris, 2010) have identified religious values/beliefs as correlating with traditional caregiver ideologies. However, reported findings are mixed. Cloutterbuck and Mahoney (2003) found that religion did not form an important aspect of African American coping strengths. Whilst Lawrence et al., (2008) reported that they found that the majority of South Asian and Black Caribbean felt that providing care was consistent with being a ‘good’ Hindu or Christian and represented the normal and expected thing to do. Another study carried out by Drentea & Goldner (2006) found that for African American caregivers’ strength in religious belief had a stress-buffering effect.

Much research has reported on the negative outcomes from engagement with psychological services for BME communities. For example, in comparison to other ethnic groups BME individuals have experienced higher diagnosis of schizophrenia, compulsory detainment in hospital, being transferred to locked wards from open wards when they are patients in hospital, not being referred for psychotherapy when suffering from mental health problems (Fernando, 2005). How race and culture is addressed within the therapeutic environment is vital to the epistemological understanding of BME groups (Fernando, 2002; Lago, 1996). Whilst many approaches have something unique to offer, rather than speak of strengths and weakness of each paradigm given the limitation of space, I have chosen to focus on the Psychodynamic approach with its deep roots in European culture, contrasting the theoretical understandings with the experience of the BME individual who may deviates from this ‘Eurocentric norm’. Bassey and Melluish (2013) draw attention to the implicit and explicit Eurocentric bias influence of western psychotherapy. Additionally, these researchers argue that psychological approaches contain conflicting values and concepts to many minority ethnic groups.

2.13 Psychodynamic Approach to Race and Culture

Broadly, psychodynamic counselling focuses on the intrapsychic world and it has been suggested (Paniagua, 2005) that generally, the psychodynamic frame does not take into account environmental events thus placing heavy emphasis on the internal conflicts. Psychodynamic theory has its roots in Psychoanalytical theory (Capuzzi & Stauffer, 2015). Within the psychoanalytical approach there are four schools (Freudian, Ego Psychology, Object Relations, and Self Psychology) each of which have influenced psychodynamic theory (Richard & Huprich, 2009). These four schools offer distinct theories of psychopathology development, personality development and tools through which therapy is conducted.

It is reported (Tuckwell, 2006) that within existing literature that the applicability of the psychodynamic approach to racial and cultural phenomena in the present day has been widely overlooked. This author posits that race is a social construct that has no scientific basis and she argues that the concept of race is highly misleading. Academically many psychoanalysts, psychotherapist and psychologists have endeavoured to ‘unpick’ the issue of `race’, racism and ethnic diversity and difference. Tuckwell (2006) argues that the enduring nature of racial thinking despite contrary empirical evidences requires wider consideration.

Berzoff, Flanagan and Hertz (2008) suggests that there is an inescapable link between a person and their society and that this concept is fundamental to the understanding of race and racism. It is widely acknowledged (Jackson & Greene, 2000; Jones-Smith, 2014; Wheeler, 2006) that psychodynamic thinking comes from a Eurocentric assumption of normality that suggests that different ways of emotional expression or behaviour are pathological since they deviate from the Eurocentric ‘norm’.

The controversies of race and culture are beyond the scope of this critical literature review, but I feel it necessary to the epistemological understanding of BME groups to understand the construction of race and racism. It is argued (Berzoff, Flanagan & Hertz, 2008) that the construction of race and racism point to different fundamental epistemological and theoretical assumptions about the nature of humans and society. As previously mentioned, race is defined as two different processes (a category of persons who are related by a common heredity or ancestry) and ethnicity (a shared culture or lifestyle). Broadly, it is suggested (Solomos, 2003) that the concept of racism covers ideologies and social processes that discriminate against individuals based on different racial membership. Thus, it is suggested, the word ‘racism’ refers to two very different things. Namely, the matter of behaviour which is normally a ‘manifestation of hatred or contempt’ for individual characteristics which differ from our own; or belief concerning human races (Back & Solomos, 2000).

Widely, it would appear that in interpersonal relations, race and culture operate in a variety of multifaceted and subtle ways. Tuckwell (2006) proposes that as a social construct these are rooted in assumptions about white supremacy and black subservience. This author posits that race is a compelling force in ordering social hierarchy frequently implicit in the institutional practices and structures. From the perspective of psychodynamic theory, drawing on Klein’s ideas about unconscious schizoid mechanisms for meaning and displacing anxiety in the application of psychodynamic concepts to race and culture, some authors have discussed the paranoid nature of racism. In simple terms, Klein’s theory suggests that an infant is in a state of panic and terror when their needs are not being met and from this viewpoint sees this as an attack on its life. Frankland (2010) posits that within this concept, the paranoid-schizoid position suggests that the ‘paranoid’ element refers to the anxiety and terror regarding perceived persecution or attack from the outside world. This author suggests that the element of ‘schizoid’ refers to the split between all good and all bad. ‘All good’ denotes to the goodness within the person and ‘all bad’ denotes to the malevolence stemming from the outside world. This theory posits that as the infant develops, they are able to move to the depressive position and through pain, learn to combine experience and tolerate ambivalence and the loss of the idealised mother. Rustin (1991) investigates racism as a displaced manifestation of persecutory anxiety and hatred that is driven by splitting. From this positioning Rustin posits that through viewing the world in static categories of good/bad, white/black, in-group/outgroup that the undesirable part of the self is split off and projected onto the racial other, who may be degraded or attacked. This author highlights the interactive nature of this process, in terms of projective and introjective identification through which oppressors and victims of racial domination each play out their relative position in the racial hierarchy. Tuckwell (2006) argues that it is from this position that the Fanonist theory of white superiority and black inferiority may be seen in terms of projective identification where the white person evokes in the black person the symbolic self (aspects of self that are deeply denied). From this theoretical standpoint, it is argued that black individuals who have introjected beliefs of white supremacy, accept and identify with these projections. Whilst in synchrony, the black individual projects onto the white person the symbolic white self (the disowned parts of the self).

Further, as mentioned previously it has been highlighted that psychodynamic thinking is born from Eurocentric assumptions of normality. Tuckwell (2006) emphasizes that it is fundamentally important that the effects of racial and cultural dynamics on unconscious processes be considered and acknowledged. This author further argues that in therapeutic practice the application of Kleinian psychodynamic concepts to racial phenomena has a lot to offer in elucidating complex racial dynamics. It is possible, that the conceptual basis of the psychodynamic approach to therapeutic practice despite the limitations with regards to race and culture hold a unique and compelling point of view in understanding racism. Berzoff, Flanagan and Hertz (2016) posit that within a drive theory perspective, racist dynamics can be understood as expressions of psychosexual conflicts. For example, the black body is at a subconscious level associated with that which is unconscious and repressed. Taken together, whilst it can be argued (Berzoff et al., 2016) that no one theory can explain race or racism. The psychodynamic framework offers practitioners an approach for exploring the multifaceted dynamics of the clients' inner world, embracing racial and cultural beliefs about self and other.

2.14 Black/African Psychology

It is argued that Black/African psychology is a distinct disciplinary field of psychology that includes a community of academics and a history of academic inquiry (Cokley & Garba, 2018). Similar to other fields of psychology Black/African psychology incorporates a direction of inquiry that is consistent with the predominant methodology used in psychology.

In conceptualising African psychology in empirical literature Jamison and Carroll (2014) argue that this approach is grounded in the cultural reality of people of African descent These authors suggests that African psychology can be defined as a system of knowledge, philosophy definitions, concepts, models and practice. Whilst not every individual who identifies as Black will need or appreciated this model, 'Black' psychology is not a rejection of Eurocentric psychology (McInnis, 2018) but rather an advancing science of human functioning for Black individuals worldwide utilising the best of African thought, culture and rituals while focusing on wellness. Cokley and Garba (2018) posit that this approach values self-knowledge and intuition as equally important sources of knowledge. Further, this approach defines the nature of reality and understands human behaviour in distinctly different ways from those of traditional Eurocentric psychology.

African psychology and its application in therapeutic practice is suggested to be a strengths-based approach (Mapule-McInnis, 2018) taking into account the living conditions in which a Black individual exists (cultural context) whilst attempting to grasp an understanding of the individuals lifeworld. This theoretical framework assists contextualisation of the Black individual's reality by considering the heightened experiences of worldwide oppression of Black cultures; understandings of self-introduced from such experiences; the development of multidimensional understandings of self beyond a Westernised perspective as a tool for resistance.

2.14.1 The Tree of Life approach

The Tree of Life approach is argued to be a culturally sensitive counselling methodology that speak across cultures developed by narrative therapists Ncazelo Ncube and David Denborough (BAATN, 2020). This theory is informed by Narrative therapy ideas to ensue that individuals who have experienced significant trauma and emotional distress are emotionally safe when expressing their subjective experiences. The approach used in this theory puts forward the prospect for these individuals to take a break from the dominant sad/negative stories of their reality and reconnect with these stories in ways that give them hope, whilst acknowledging their subjective skills and values. Using their own drawings of a tree individuals are invited to use different parts of the tree to symbolically illustrate aspects of their lives. Parts of the tree comprise of the roots representing the individuals roots such as their place of birth, parents/sibling names. The ground represents their current reality such as regular things the individual chooses to do. The trunk is another part of the tree listing the skills and abilities of the individual. Whilst along the branches the individual writes their hopes and dreams. Within this therapeutic approach the leaves on the tree are represented by significant people/relationships in the individuals lives. Gifts or contributions others have made to the individual’s life are represented by colourful fruit.

From this standpoint this therapeutic model is a potentially effective way of engaging with an ethically diverse community and reported to meet the needs of individuals of African and Caribbean heritage more than other techniques (Mental Health Today, 2018).

2.15 Relevance to Counselling Psychology

In linking the relevance to Counselling Psychology to the need to understand what constitutes and contributes to racism I draw upon the argument of Solomos (2003) who postulates that racism is not a fixed phenomenon and in countries such as Britain, is produced and reproduced through mediums such as education system, political discourse and media. This author points out that racism in a wider social context has become an ‘integral element of diverse social issues’.

In agreement with Moodley (2000) I would argue that the issue of BME groups remain outside, both foreign and immigrant in theory, practice and research. Gaugler, Roth, Haley and Mittelman (2008) carried out a study to explore whether counselling and support reduce the burden and depressive symptoms of spouse caregivers of individuals with Alzheimer’s disease during the transition to institutionalization. A volunteer sample of 406 spouse caregivers from individuals with Alzheimer’s disease were recruited from an outpatient research clinic in New York. Participants were offered enhanced counselling and support intervention consisting of six sessions of individual and family counselling, support group participation and continuous availability of ad hoc telephone counselling. It was reported that burden and depressive symptoms were significantly lower for caregivers in the treatment group than for controls receiving usual care at the time of and after institutionalization. Although, this study did not report on the ethnicity of the participants the findings support those of other research studies (Gallagher-Thompson & Coon; 2007; Elvish, Cawley & Keady, 2012; Lipinska, 2016) that found that counselling and psychological interventions for carers can give an all-important, safe and confidential environment where individuals can vent feelings of anger, depression, grievances, create and try out different coping strategies and advocacy roles.

Reviewing the literature on carers experiences in multiple ethnic and racial cultures revealed a deficiency of information on carers needs. However, Cox (1995) conducted a study that examined caregiving among black and non-minority white individuals caring for a relative with dementia. The findings of this study shed some light on the emotional needs of BME carers. This researcher found that although neither group felt others understood their concerns, lack of emotional support had a significant effect only among the black caregivers. Alleyne (2009) points out that race enters psychotherapy in ways that parallel its workings in society as a whole and argues that whether racism is experienced as a one-off encounter or an ongoing experience, it can be damaging to the wellbeing of an individual.

Moodley (2000) has suggested that subjective distress is one of the most difficult to measure and least understood variables in psychotherapy. He argues that there is a disparity in what is known about how BME individuals represent and present their subjective distress and that less is known about how practitioners interpret these communications. As Eleftheriadou (2015) points out, each of us has our own unique combination of psycho-cultural and racial context, and broadly within Counselling Psychology theoretical text this often escapes illumination. This author argues that if we relate to an individual without their idiosyncratic psychosocial context, we may see something different and/or miss something significant. The findings of Owen and Khalil (2007) whose study addressed diversity in mental health care provide support of this and I would also argue in agreement that working towards more equitable services is a vital part of the counselling psychologists' role.

Dryden and Reeves (2008) suggest that the increasing presence of cultural diversity within clients presenting for counselling necessitates that counselling psychologists must increase their awareness of how cultural difference affects their clinical work. The BME population contains multiple sub-populations with rich historical, sociocultural values and experiences. Paniagua (2005) argues that the differences in ethnic identities across clients of the same race may be explained in terms of the processes of internal and external acculturation which can have significant implications for the assessment and treatment of the members of diverse groups. Thus, an understanding of the two different processes of race (a category of persons who are related by a common heredity or ancestry) and ethnicity (a shared culture or lifestyle) is relevant to counselling psychologists.

Bunting and Jenkins (2016) carried out a study to investigate the effect of caring among different cultural groups and recommend culturally congruent carer support interventions. These authors argued that carer support is vital for both the wellbeing of the carer and that of the individual they are caring for. As mentioned previously, it has been widely documented that carers are at high risk of depression and that many become 'hidden patients' because of the mental and physical strain that providing care has on them (Brodaty & Donkin, 2009). In addition, in their article 'Clinical Psychology and Diversity: Progress and Continuing Challenge' Turpin and Coleman (2010) argued that for practitioners the skill of applying cultural knowledge to practice is an integral aspect within the process of becoming culturally competent.

Within the context of health services cultural competence pertains to the appropriate provision of care to a diverse population (Bassey & Melluish, 2013). These authors argue that applying cultural competence to psychotherapeutic interventions calls for a more multifaceted approach and that psychotherapy is itself a cultural phenomenon that plays a key role in the treatment process. Whilst, there are some criticisms around the application of cultural competency. For example, Satel (2000) argues that cultural competence is motivated by political correctness. Others (Weinrach & Thomas, 2002) posit that positioning cultural competence as a requirement for work with particular groups based on ethnicity, discriminates against other diverse group characteristics (such as gender, [dis]ability or sexual orientation). This fits with the proposition of Bassey and Melluish (2013) who highlight that an emphasis on the ethno-cultural dimension of cultural competence is necessitated because of the implicit and explicit Eurocentric bias influence of western psychotherapy.

As previous research has demonstrated, it would seem that ethnic background appears to account for differences in experiences of caregiving (Fernando, 2005) and that the psychosocial effect of caring in different cultures is under-explored (Bunting & Jenkins, 2016). Whilst some studies have explored and brought about discussion around the future care needs of the growing BME community there has been considerable dearth of research into the impact of caring on the carer.

Farooq and Abbas (2013) reported that giving 'voice' and choice to clients who access psychological services is fundamental to the work of psychologists. These authors postulate that conducting research is one way to unmute the voices of those groups that are not heard. Further, they argue that as a result develop culturally appropriate psychological interventions. Inclusively, some approaches have applied tailored interventions to particular cultural groups. For example, Horrell (2008) reported on adaptations of Cognitive Behaviour Therapy for different minority groups in the United States. Whilst within the UK researchers (Rathod, Kingdon, Phiri & Gobbi, 2010) developed a Cognitive Behavioural Therapy manual for certain minority groups.

In their findings Riley and Fenton (2007) reported that one carer who accessed therapeutic counselling on the advice of her GP reported coming to the realization following her first counselling session of how much emotion she had been suppressing. Although, from the study it is not clear as to the ethnic variety of the participants taken together, it would seem that access to psychological therapies could be beneficial to BME carers. Additionally, it would appear that findings from existing academic research suggest that it is important and therefore relevant for counselling psychologists to understand carer experience from the carers subjective frame of reference and design client-led interventions that appreciate and combine social and cultural factors. Thus, cultural competency is an important aspect of clinical practice.

2.16 Summary and Research Questions

Much of the literature pertaining to the caring experience of BME carers is theoretical in nature. Burden of care models emphasize the physical dependency of the person cared for and the distress the carer feels because of the behaviour of person cared for, as well as the carers own perception of the impact (physical, emotional, psychological and resource). However, the papers are theoretical and draw on Eurocentric concepts to explain ethnically diverse cultural experiences.

This is also true of many other empirical papers that highlight the lack of culturally sensitive services but do not capture the potential internal conflict of BME carers coping with their caring role. Studies suggested BME groups are less likely to access counselling services than White British people and that the lived experience of how a carer copes may differ for specific groups such as BME groups. Additionally, current available literature indicates that there are significant variations amongst BME communities regarding strategies to coping with the carer role. Whilst searching the literature it became apparent that there seemed to be a lack of comprehensive phenomenological research on the ‘lived experience’ of BME carers and how they ‘cope’ in relation to their caring role. This concern is highlighted through findings references in empirical studies that limited attention has been given to Black and Minority Ethnic experience and therefore less is known about the minority experience within the UK. The aim of this Critical Literature Review is to develop and extend current knowledge and understanding of the lived caring experiences of Black and Minority Ethnic (BME) carers, and how they ‘cope’ in relation to their caring role.

The World Health Organization (2014) suggest that mental health is a state of well-being in which an individual realizes their own potential and can cope with the normal stresses of everyday life, working productively and fruitfully, able to contribute to their community. Slade et al., (2017) argue that it is hard for individuals to look after their own wellbeing if they live in an environment where they face discrimination and inequality. These authors postulate that the theory of effective mental health promotion needs action at individual, community and structural levels. They argue that without a structure and policy framework that supports mental health and wellbeing it is difficult to create an environment conducive to wellbeing.

The critical literature review identified a gap in the current knowledge about the experiences of carers who identify as ‘Black’. ‘Being black’ is a subjective experience a topic that has been inadequately examined (Stevens, Bell, Sonn et al., 2017) in psychology literature. It can be argued that human beings are relational beings and our understanding of reality is a social construction, not an objective truth since multiple realities associated to different groups and perspectives exist (Eatough & Smith, 2008; Lyons & Coyle, 2007). Consoli, Beutler and Bongar (2017) suggest that knowledge is not passively communicated or absorbed but constructed internally by the individual themselves. It has been widely acknowledged that knowledge is created in social interaction between investigator and respondents (Rodwell, 1998; Borzillo, 2007). My epistemological stance coming from a constructivist viewpoint calls me to enter the subjective lived experience of this group of carers. It is believed that through obtaining the subjective views of carers who identify as ‘Black’ who are caring for a family member with a variety of needs (chronic illness, mild/severe disabilities or mental health), through in-depth semi-structured interview, an enriched appreciation of the multifaceted intricacy of their subjective experience may help illuminate the lived phenomenological experience of this minority group of carers. Thus, the present study is concerned with the experience of Black carers, a group that is thought to experience exclusion and marginalisation within existing services.

The main questions that the study will address are:

- How do Black carers support themselves?
- How do they understand/perceive their own mental wellbeing?
- What is the effect of their role on their mental wellbeing?

3 Methodology

3.1 Research Design

3.1.1 Ontological and epistemological position.

Counselling psychology adopts a pluralistic stance which suggests that there is a great deal of diversity across human beings. It is acknowledged that humans are relational beings and our understanding of reality is a social construction, not an objective truth since multiple realities associated to different groups and perspectives exist (Eatough & Smith, 2008; Lyons & Coyle, 2007). Further, it is proposed (Consoli, Beutler and Bongar, 2017) that knowledge is not passively communicated or absorbed but constructed internally by the individual themselves. From such a standpoint, it is argued that individuals should not be reduced to a single set of characteristics, laws or mechanisms (Murphy, 2017).

My interest in the experience of carers who identify as Black came from my subjective experience as a carer who identified as 'Black'. In my years as a carer I was faced with many challenges over different issues and cultural values whilst navigating available services as I cared for my father. I attributed these to the fact that I came from a Caribbean background and whilst I had been born in the UK, I had been raised in a completely different culture with a different value system.

Coming from a Black Caribbean family and background has influenced the researchers' epistemological position, which tends to lean towards a constructivist viewpoint due to its contemplation of culture and context on experience. I believe that whilst as individuals we are always in relation to others, it is not possible for us to get out of ourselves and observe the world/others objectively. As such, subjectivity and intersubjectivity can be viewed as an opportunity to gain access into the lived experience of individuals (Finlay, 2002).

Through this study I was hoping to find out what it was like for other carers who identified as Black. I acknowledged that it was a different experience for those who had migrated from the African continent, those who had migrated from the Caribbean and those who had been born here. Indeed, there was a complexity there in itself about those who identified as Black and were first, second or third generation.

During the interview process I was aware of a need to be ‘therapist’ to challenge some of the things shared by the participants. Kavle (2007) mentioned the metaphor of the ‘traveller researcher’ and drawing on this proposition was able to ‘wander with’ the participants on their journey. For me, this journey has been emotional and inspiring, discovering the different experiences of the participants. As I reflect on this, I am moved to thanking the participants for sharing their personal experiences with me and their contribution to this research.

Critical realism provides a framework that suggests that phenomena exist independently of our knowledge of them and that human knowledge is socially produced, historically transient and fallible. This standpoint further suggests that there are rational grounds for preferring some theories and explanations over others (Sorrell, 2018).

Taken together, these ontological and epistemological stances have influenced the choice of research method being IPA which calls the researcher to enter the subjective lived experience of the participants and the meaning they place on their experience.

3.1.2 Methodology.

The aim of this research is to explore the lived experience of a group of carers who 'identify as Black' and how they 'cope' in relation to their caring role. It is felt that a qualitative phenomenological approach would be best approach. Qualitative research methods (Brodaty & Donkin, 2009; Kartakiva-O'Doherty & Tedstone Doherty, 2008; McCann, Bamberg & McCann, 2015) have been used to investigate carers experience of their caring role. It was felt that this approach would allow the researcher to gain a deeper understanding thus elucidating the lived phenomenological experience of this group of carers.

3.1.3 Rationale for phenomenology.

Phenomenology is a philosophical approach to conscious experience that takes into account an individual first-person viewpoint and refers to the study of human experience and consciousness (Murphy, 2017). Further, it is concerned with the experiential reality of life, the meaning of things and others (Eatough & Smith, 2008). Husserl advocated engagement with experiences through reflection and encouraged bracketing off what is taken for granted (Willig, 2001). Owen (2006) proposes that with phenomenology, it would appear an explicit interpretive positioning is required in order for the researcher to be clear to themselves, participants and the public about how they make sense of prior to action of any psychological situation. Husserl's student, Heidegger, proposed humans are being-in-the-world, challenging Cartesian dualism (Eatough & Smith, 2008). From this perspective, the whole world is already present to understanding and action so understanding parts makes sense because of the whole world (Owen, 2006).

3.1.4 Interpretative Phenomenological Analysis (IPA).

Influenced by the philosopher Edmund Husserl, the approach of IPA proposes that individuals should ‘go back to the things themselves’. Consequently, this means focusing experientially on the content of consciousness and each particular thing (Smith, Flowers & Larkin, 2009). This approach is concerned with the subjective lived experience of the social world of individuals and the sense the individual makes of that experience (Frost, 2011, Smith & Osborn, 2003). Thus, IPA is concerned with ‘detailed examination of individual lived experience and how individuals make sense of that experience’ (Eatough & Smith, 2008, p.179). It focuses on perceptions rather than objective statements (Smith & Osborn, 2008) by examining ‘life-worlds’ asking ‘what is it like to be experiencing this or that for this particular person?’ (Eatough & Smith, 2008, p. 181). It describes and documents rather than providing explanations (Willig, 2013). Within IPA research, a dual interpretation process known as double hermeneutic evolves with participants trying to make sense of their own world and the ‘researcher trying to make sense of the participant making sense of what is happening to them’ (Smith et al, 2009, p.30).

Counselling Psychology is interested in ‘phenomenological models of practice and enquiry’ and seeks to ‘engage with subjectivity and intersubjectivity’ (BPS, 2005, p.1), therefore there is a natural fit of paradigms.

3.1.5 Alternatives Methods Discounted and Rationale for IPA.

In considering methodology and method several forms of qualitative approaches were considered. For example, the approach of Discourse Analysis (DA) that observes how language is used and the assumptions that configure ways of talking and thinking about topics of interest and social functions that the discourse serves (Slade & Priebe, 2006). However, because this approach is driven by research questions about the content and characteristics of language as opposed to questions about individuals and their experiences (Willig, 2012), it was felt in order to answer the research question that DA was unsuitable. Additionally, the approach Grounded Theory (GT) that aims to ‘generate’ or ‘discover’ theory from participants’ process data thus allowing the researcher to generate theory from the substantive explanation that emerges was also considered. Moreover, it was felt that since the aim of this research was not to test a theory or look to identify factors that influenced outcomes this approach was unsuitable. In considering methodology, quantitative methods were also considered.

The Interpretative Phenomenological Analysis (IPA) method will be chosen as method of analysis. The approach of IPA recognises the interaction between the researcher and participant and the researcher’s view of the world. In addition, this method recognises the central role for the researcher in making sense of how participants perceive objects or events (Willig, 2013). This approach was considered the best approach for the research question since the interest within this research is exploratory and the emphasis is on understanding the carers subjective experience. Thus, the aim is to get as close as possible to the individual’s personal experience. Whilst I the researcher am not professing that this research will say something about all BME cultures, what I hope this research will provide is detailed descriptions and commentary about one particular community BME carer group, ‘carers who identify as Black’. A strength of the IPA study is that it can be evaluated in terms of the insights it provides concerning the topic under investigation. Smith and Eatough (2006) suggest that in adopting this approach over time later studies can investigate other groups and generalization becomes possible through a steady accumulation of similar cases.

Through the vehicle of phenomenological analysis (Smith, 2004), IPA is an idiographic approach that aims to study individuals through giving voice to their subjective experiencing. Fade (2004) argued that the basic IPA method was suitable for smaller samples of up to ten participants. This method is an ‘idiographic case study approach’. Since ‘the basic method’ is particularly suited to exploratory research it was felt to be the ‘best fit’ for this study.

3.2 Participants

Previous research has focused on burden of care models that emphasize the dependency of the person cared for and the distress the carers feels because of the behaviour of the person cared for, as well as the carers own perception of the impact (physical, emotional, psychological and resource). However, these papers are theoretical and draw on Eurocentric concepts to explain ethnically diverse cultural experience. Many other empirical papers highlight the lack of culturally sensitive services and suggest that BME groups are less likely to access counselling services than White British people. Thus, indicating that limited attention has been given to Black and Minority Ethnic experience and therefore less is known about the minority experience within the UK. This suggests that the lived experience of how a carer copes may differ for specific groups such as BME groups.

The study sought to recruit participants using purposive homogeneous sampling. Six participants were recruited as fewer participants can be examined at a greater depth (Hefferon & Gil-Rodriguez, 2011). As previously mentioned, ‘the basic method’ of IPA is suggested to be suitable for smaller samples of up to ten participants. For the recruitment strategy to be effective it is important that participants are recruited from a closely defined group for whom the research question will have relevance and subjective significance (Breakwell, Hammond, Fife-Schaw & Smith, 2006). It can be argued that the ‘belonging’ to an ethnic group holds subjective meaning to the individual concerned.

Due to its salience in race relations researchers, Bar- Haimô, Saidelô and Yovel (2009) identified skin colour as an important criterion. These authors propose that "the tendency to use skin colour to categorize faces into different races seems almost automatic and unavoidable" (p,145). Thus, individuals who self-identified as belonging to a White ethnic minority group were not included in this research study. It was felt that the 'lived experience' of BME carers who identify as 'Black' was specific enough to define the boundaries of the sample.

Since the aim of the study is to explore the experiences of carers who identify as 'Black', the inclusion criterion set for this study are: -

i) Participants belong to a Black and Minority Group and identify as 'Black'.
ii) Primary carer for someone who is dependent on them.
iii) Aged over 18.

The exclusion criterion: if the carer is currently experiencing psychological distress at time of selection.

Participants were recruited from regional Carer Support Groups which provides help and advice to carers. Invitations to participate were placed in the monthly newsletters of regional Carer Support Groups.

3.2.1 Participant Profiles

The participants were six women who identified themselves as being 'Black, aged over 18 and the primary carer of someone who was dependent on them. Additional information on each of the participants is provided below:

Table 1:
Summary of participant' details

Participant (pseudonym)	Age	Ethnicity	Generation	They care for	Length of time as Carer
Chantelle	18-25	BC	2nd Gen	Mother	5
Tanya	18-25	BC	2nd Gen	Mother & Uncle	3.5
Yvonne	26-40	BC	1.5 Gen	Mother	10
Marsha	26-40	BC	2nd Gen	Mother	15
Precious	41-60	BA	1st Gen	Son	31
Fola	41-60	BA	1st Gen	Son	35

BC, Black Caribbean, BA, Black African

3.3 Materials

An information sheet (see Appendix D) was given to the participant to inform them about the study and a consent form (see Appendix E) was used to obtain consent. To assess whether a carer was eligible to participate they were asked to complete the GAD-7 (see Appendix A). Although, existing research (Parkerson, Thibodeau, Brandt, Zvolensky & Asmundson, 2015) has highlighted the need for culturally sensitive GAD screening tools in the absence of availability the standardized GAD-7 will be used. The GAD-7 is a practical self-report anxiety questionnaire that is suggested to be a reliable and valid measure of anxiety in the general population (Lowe, Decker, Muller, Schellberg, Herzog & Herzberg, 2008).

Participants were also asked to complete the PHQ-9 (see Appendix B) which is suggested to be a valuable and reliable tool to screen depression in the general population (Kocalevent, Hinz & Brahler, 2013). This tool was used to exempt more vulnerable individuals from the study. Participants who have mild to moderate mental health problems on both the GAD-7 and PHQ-9 scales would most likely meet criteria.

Informed by relevant literature, discussion within supervision a semi-structured interview schedule (Appendix G) relevant to the study aims was developed and used for data collection. Smith and Osborn (2008) and Smith (et al., 2009) suggest that semi-structured interview schedules work well with IPA as the aim is to guide rather than dictate the flow of the interview. Thus, fostering a facilitative environment where individuals can provide detailed and open accounts of their subjective experiences.

Further material included a distress protocol (see Appendix H) and following the interview a debrief sheet (see Appendix F) was provided listing the researcher's and the university's details and information regarding a range of support such as counselling organisations if a participant felt this was required following the research. A reflective diary was kept following each interview to record the researcher's reflections on the interview.

At the end of the interview participants were asked to complete a brief demographic questionnaire (see Appendix C) from the Adult Carer Quality of Life Questionnaire (AC-QoL) devised by Elwick, Joseph, Becker and Becker (2010) to obtain background information. Questions include age, gender, ethnicity, hours spent caring, the length of time in the carer role. The full AC-QoL was devised as an instrument to measure quality of life in eight domains for carer satisfaction before and after an intervention to evaluate the effect of the intervention. However, as the aim of this research is to explore the subjective experience of the participants through Interpretative Phenomenological Analysis, only the demographic questions were used. Additional materials included an audio recorder and transcription software.

3.4 Procedure

3.4.1 Interviews

Participants were interviewed within a safe, quiet and confidential space at their convenience e.g., a counselling room within the Carers support organisation. Semi-structured, open ended questions were used to assist the researcher to gain insight into the participant's unique phenomenological world. From the researcher perspective, this approach to collect data has the advantage of allowing the researcher to explore unanticipated or interesting avenues of questioning. All interviews were audio recorded with permission from the participant and later transcribed. At the end of the interview participants were thanked for their participation in the research and given a verbal and written debrief.

3.5 Ethical Considerations

Ethical approval for this project was granted by London Metropolitan's University's Research Ethics Review Panel in December 2017 (Appendix I). The ethical considerations for this project were produced in agreement with the British Psychological Societies Code of Human Research Ethics Guidelines (2014).

3.5.1 Informed Consent

All of the participants were over eighteen years old. Each of the participants received a participant information sheet (see Appendix D) that explained the research and the requirements. The participants had the opportunity to ask question before the research so that they are fully informed. In addition, participants were verbally informed that they are free to withdraw from the research at any time without consequence/or having to give a reason up to the time of data analysis. Participants were required to sign an informed consent form (see Appendix E) which will highlight how confidentiality will be protected, right to withdraw and that was countersigned by the researcher. Participants were asked to complete a demographic questionnaire (see Appendix C) to obtain basic background information.

3.5.2 Confidentiality

How confidentiality will be protected and the limits to this were outlined to participants verbally and in the participant information sheet. To keep their personal data anonymous participants were assigned a pseudonym name to conceal their identity throughout the research. All data related to the research was handled with respect and discretion. Within the transcripts any identifying information was altered or omitted. Data was kept securely in a lockable cabinet and a password-protected computer. It was made explicit to participants that if sensitive information in the nature of intended harm to self or others was disclosed that confidentially may need to be broken.

3.5.3 Protection of Participants

It is felt that this topic will be personal and confidential in nature to participants and was anticipated that the researcher required an increased level of sensitivity. To protect the participants from discomfort and distress, every measure was taken to reduce the risk of upset. It was made clear to participants that they could end the interview at any time or take a break. Additionally, interviewees were also informed they did not need to answer questions they did not want to/or felt uncomfortable with. Participants were given an opportunity to ask questions and discuss feelings that might arise in the interview. Further, a debriefing sheet (see Appendix F) that lists the researcher's and the university's details and information regarding a range of support i.e. counselling organisations if a participant felt this was required following the research was provided.

3.5.4 Risk Management

It was anticipated that this topic would be personal in nature to participants and in anticipation an adapted version of the London Metropolitan's distress protocol (see Appendix H) was discussed before each interview. If the participant appeared to become upset during any of the interviews the distress protocol would be implemented if necessary. Action may have involved the termination of the interview or referring the individual to mental health/or emergency services depending on the level of distress. Confidentiality limits were outlined and explained to each of the participant before interviews. Potential risk to the researcher was also discussed and measures taken to ensure the researcher was safe (i.e. contacting a trusted individual) prior to and following interviews.

3.6 Analysis

Interpretative Phenomenological Analysis is the chosen method of analysis. This form of analysis involved each individual case being recorded, fully transcribed and analysed using IPA as outlined by Smith et al., (2009). This was followed by cross case analysis and the final themes translated into a narrative account.

3.6.1 Individual Case Analysis

Initially, each transcript was individually analysed. Transcripts were examined closely, line by line before making initial notes on significant or interesting features, identifying commonality and paradoxes within the text. This was often done in combination with listening to the original recording in order to contextualise the participants voice and for ‘I’ (the researcher) to fully immerse myself in the individual’s subjective world. This process consisted of going through the transcripts multiple times and making notes. Sections of transcript were considered to be richer than other sections and were commented on more and the different meanings reflected on.

The analysis moved to a higher level of interpretation as different meanings were reflected on involving a more critical engagement. The left-hand margin was used to note emerging themes and the stage involved moving away from the interpretation of the interviewee text and making connections between the exploratory comments.

For each individual case emergent themes that transpired were clustered into sub-ordinate themes according to similarities that captured the central meanings. Most of this work was completed by hand, involving cutting up themes and placing them on a large surface to arrange them. Smith and Osborn (2008) propose that at this stage imagining a magnet with some themes pulling others in, helping to make sense of them. These sub-ordinate themes were then formatted into a table with quotations from the participants transcribed verbatim (Appendix J).

3.6.2 Cross-case Analysis and Narrative Account

Following the analysis of each transcript, the sub-ordinate themes that transpired across all cases were clustered to produce a master theme table (Appendix K). Moving towards a more theoretical level (Smith et al., 2009), the participant transcript verbatims were revisited to identify any recurrent patterns across the data as well as any conjunctions or deviations. Through the use supervision tested and developed the consistency and plausibility of my interpretation. A final table illustrating the theme for each participant, showing how themes are nest together within the super-ordinate themes was used to outline the analysis write-up.

The final identified themes were written up into a narrative account showing the findings from this research. This narrative account is supported by the participants excerpts from their transcripts as well as sections showing the self-reflective process of the researcher. This narrative puts forward an account of the participants subjective sense-making of their experiences alongside the researcher’s interpretation of this sense-making. Smith et al., (2009) suggest that the analysis is a joint product of the participant and the researcher and that IPA encompasses a centre position between an interpretation of empathy and an interpretation of suspicion.

3.6.3 Validity

Yardley (2017) suggests that sensitivity to the data in qualitative analysis is crucial and researchers should employ a selection of credibility checks to enhance the study's validity. Further, commitment and rigour can be demonstrated by in-depth engagement with the topic. To identify verbatim evidence to support interpretations transcripts were read repeated and a range of annotated transcripts were peer reviewed to ensue clear links were evident between the original text and interpretations.

Smith et al., (2009) propose that the truth claims of an IPA analysis are always tentative and that analysis is subjective. As the researcher, I am aware that my own subjective experiences will interact with the research ideas and that I cannot eliminate explicit and tacit propositional constructs from of my experience (Reason, 1988). A reflective journal and personal counselling were used throughout to "bracketing off" and identify my own assumptions and attempt to put them aside (Braun & Clarke, 2013).

Methodological reflexivity

In order to further facilitate the rigor of the study I will attempt to outline the possible impact I had as a researcher on this section of the research (Willig, 2012). Researchers within studies involving participant action research are often situated as insider and outsider, as they conduct research within their own community, workplace or social groups whilst occupying an outside position of the researcher (Crean, 2018). In response to a greater consciousness of situational identities and to the perception of relative power (Angrosino, 2005) a critique of researchers roles has developed illuminating the importance of understanding the researchers context (e.g. ethnicity, gender, class) as part of narrative interpretation. Dwyer and Buckle (2009) highlight that within research, researchers are increasingly making known their membership identity in the communities they study.

Initially, one of my assumptions was that carers who identify as Black struggled to access adequate support not only for those, they cared for but for their subjective wellbeing. I realise how existing literature and my subjective experience as a carer who identified as Black led me to hold this assumption. Drawing on the suggestion from Kasket (2012) who posited that in order to explore more completely, counselling psychologists need to remain open to different perspectives. As such, I needed to have an open mind that carers who identified as Black might not feel unsupported by existing services in their caring role.

A further assumption I held was that due to their subjective experiences individuals who identify as Black find it difficult to express their thoughts and feelings to those outside of their ethnic identity. My assumption of Black ethnic identity led me to fill in explicit discourse about ‘being Black’ without the vocalisation. Through reflexivity I realised that the experience of ‘being Black’ seemed to be an unspoken part of the interaction with the participants. They were expressing ‘being Black’ but not always including it within the dialogue assuming perhaps that since I the researcher was ‘Black’ I could grasp what they were expressing. This could be viewed as coming from an Insider research perspective where the researcher shares an identity and experiential base with the study participants allowing the researcher more rapid and complete acceptance by their participant (Adler & Adler, 1987; Asselin, 2003)

My interview questions were structured in an attempt to ensure that carers would express themselves and focus on their experience of the carer role. There was no mention of ‘being Black’, my presupposition was that this would emerge since blackness is a salient feature. Reflecting on the interview schedule with my research group, I was able to identify and monitor my assumptions in order to circumvent blocking the voice of the participant (Finlay, 2002). This facilitated the interview schedule being constructed to priorities participants’ experience over the researcher’s assumptions. During the interview process, as part of my reflexivity I monitored this issue noting in my journal the way ‘Blackness’ as an identity was expressed.

Individuals from the Black and ethnic minority communities are often considered ‘hard to reach’ but this is not necessarily true (NBCCWN, 2008). These researchers suggest that it is not much so a case of ‘hard to reach’ and has been described as more like ‘easy to ignore’. In line with their comment, recruiting for the study went smoothly with all participants recruited within 6 months. Managing my perplexity as to why so few studies have explored the experiences of carers who identify as Black enriched the ‘process of becoming a reflexive researcher’ (Etherington, 2004).

During the interview process, reflexivity led me to new understandings. In preparation for the interview, before I started, I would read my reflexive journal in an attempt to improve my ability to 'bracket off' my assumptions. In upholding the values of my profession as Orlans & van Scoyoc, (2009) indicate, I have attempted to carry out each interview as a naïve researcher respecting each participant's unique experiences. When the interview ended, participants expressed gratitude towards the researcher for the opportunity to take part in the research. All of the participants commented they felt motivated to take part in the interview process due to their subjective experiences and what they had noticed around them. Further, they described how expressing themselves within the interview had highlighted their journey to them giving them a greater understanding and appreciation of how the carers role impacted on them. Taken together, it can be argued that through demonstrating the values of the Counselling Psychology profession that participants experienced the interview process as not only empowering but facilitative of understanding and growth (Kasket, 2012).

4 Analysis

4.1 Analysis overview

In this section I am presenting and discussing the results of an Interpretive Phenomenological Analysis (IPA) of the experiences of carers who identify as 'Black' in the United Kingdom. This IPA analysis resulted in the emergence of three master themes that encapsulate the lived experience of the participants. I explore each master theme and subordinate themes within subheadings. A master themes and subordinate themes table with selected quotes is represented in Appendix K. These master themes and their related themes are summarised within the table below, Table 2. The master themes table separates themes highlighting that although they are different from each other, they are also related to each other. For instance, the theme 'Being a carer' is all part of the repertoire of ‘Being Black’ and ‘Being a Black Carer’. These master themes are not opposites, but different yet integrated parts of Carers who identify as ‘Black’.

MASTER THEMES	SUBORDINATE THEMES	CORRESPONDING QUOTE
1. **BEING A CARER**	1.1 The penny drops – awareness of ‘being’ a carer.	*‘I was in college full time, but my mum got really sick with seizures, so she was unable to look after my uncle, so it was just me…’* **(Tanya, l4-5).**
	1.2. Can I get my head around this?	*‘Because it just affect you sometimes you can’t change your life you look and everything is just green though you can’t see an end to the problems so it kind of affects you personally.’* **(Precious, l95-97)**.
	1.3. Help seeking/Accessing Services	*‘Yeah, so, I’m really grateful to her to be quite honest. Because if not for her maybe I won’t be where I am today, I won’t be sitting here. I would be somewhere else.’* **(Fola, L21-22).**
2. **BEING BLACK – ‘he who feels it knows it’**	2.1. Suffering in silence	*‘I think like 2 years ago I was super depressed, I was like crying all the time and but like I am the type of person a bottle until it rises to a fizz so everything comes out, I would hold things in and then 6 - 8 months later everything will come out’* **(Tanya, L71-73).**
	2.2. Being a Black woman	*‘I had a really strong Caribbean upbringing where the women are strong and carry everything’* **(Marsha, L74-75).**
	2.3. From whence will my help come?	*‘I just think that I have not really had any support I've*

		just had to get on with it'. ***(Yvonne, L53-54).***
	2.4. Going against the grain	*'I have to work against the grain, if that makes sense erm like they shut down a lot of services and the type of epilepsy that my mum has erm they don't do it anymore and so like I have to go everywhere just to care, adequate care that she deserves so yeah…'* ***(Chantelle, L28-30).***
3. **BEING A BLACK CARER**	3.1. Internalised pressure and the boiling pot	'*Sometimes I think "Oh God, when is this going to end?" then I might make jokes at work like you know that kind of thing…'* ***(Yvonne, L36-39).***
	3.2. Walk of despair	*'It feels very lonely even with my sister there I've realised that like sometimes I'm not feeling her emotionally, she's not feeling. Cos someone can't be everything to a person.' (***Tanya, L82-85).**
	3.3. Cultural view – Do you see what I see?	*'Sometimes, I just want to say it as it is and know that person knows where I am coming from… as a Black person I don't always feel confident that my cultural differences are considered.'* **(*Marsha, L41-45).***

Table 2: Master themes and related subordinate themes

4.2 Master Theme: Being a Carer

How individuals adapt to becoming a carer is a phenomenon which lacks consensus in the wide variability of the experience of caregiving. Existing research (Greenwell, Gray & van Wersch, 2015) suggests that future research should build upon psychological theory to gain a better understanding of the mechanisms that explain how carers adapt to the caregiving role. Heidegger (1962/1927) posited that only through the lifeworld do individuals have access to experience of themselves. He suggests that individuals understand themselves and their existence by way of the activities they pursue and the things they take care of.

Intrapsychic factors are said to be the innate and enduring features of a person's character that either enhance or impair the individual's ability to adapt to change and problem solve (Lange, 2012). There is a thread running through this theme around adaptation, incorporation and the struggle of this. Core beliefs we hold about ourselves and the world encapsulate patterns of behaviour. This theme explores participants' discussions of the experience of being a carer alongside the emotional consequences on discovery of role assumption. Being a carer is not something people see themselves as straight away; they first identify as mothers, fathers, wives, husbands, partners, sisters, brothers, sons or daughters.

4.2.1 The penny drops – awareness of 'being' a carer.

Becoming a carer is often not a planned occurrence and can happen gradually or very suddenly, lasting for days or years (Marie Curie, 2018). When asked when they became a carer it seemed on conceptualising the question that there was an element of surprise in the participants' subjective experience in their acknowledgement of 'being' a carer. When Fola was asked when she became a carer and for how long she had been a carer for she explained:

> *'Right I have been a carer for about over 35 years specifically, but I did not even know I um about it, was a carer. Um, cos to me, my boy was damaged at birth and I'm taking care of my son and um, as a mother and um working…'* (Fola, L. 3-6).

For Fola, she had given birth to a son over thirty-five years ago and from her perspective she was doing what new mothers did – take care of their babies, nurturing them until they reach adulthood. Due to a difficult birth Fola's son was 'damaged at birth'. In the context of Fola's discussion (she is from Nigeria) the meaning she places on 'damaged' needs to be considered from a cultural viewpoint. Fola's son being 'damaged at birth' meant to her he was imperfect, the imperfection as she perceived it stigmatising her. Damaged possibly meant added responsibility. There is a sense of aloneness and abandonment of being left to care for her son, not only as his mother, but also as his carer.

It would seem that in being 'a mother' that the additional care needs of her son were part and parcel of that role. Whilst the awareness of 'being a carer' could be generalised amongst and across all ethnic groups it would appear for Fola that culture also factored strongly when she further expressed:

> Fola: '*Then at the same time being a Black woman caring for my son. …'* (L. 15).

When Fola is referring to herself as a Black woman she appears to refer to the stereotypes about being a Black woman where there are certain expectations in relation to gender and race. Fola appeared to have acknowledged her multiple role position of not only being a mother but working/being in employment as well.

Precious, (also from Nigeria) appeared to some extent to hold a similar view. When asked when she became a carer and for how long she had been carer she stated:

> *'I am a carer for my son and erm and I have been a carer to him and the struggles that it brings since he was only 17 and he is 48 now, you can imagine.'* (Precious, L. 3-4).

It seemed that Precious had anticipated nurturing her son to adulthood but the ‘struggles’ brought on by his additional needs had added to the planned ideal she had in mind. With the expression ‘you can imagine’ Precious seems to convey desperation and exhaustion for the fact that this has been ongoing for over 30 years.

Precious further expresses concern about the future:

> ‘*... I am seeing a kind of an enigma, in that you need somebody to encourage him to look after himself, to make the best of himself...’* (Precious, L. 20-21).

It would seem that Precious in fulfilling her role as ‘mother’, hoped that her son would eventually become independent of her. However, she appears to be concerned as to how this will progress and who will be looking after him after she is no longer around.

Central to most of the narratives was the element of awareness of ‘out of the blue’ change in behaviour of the cared for and the increased need for support. This seemed to coincide at some level with an awareness of the vacancy for the role of carer, for example, in Tanya’s comment:

> *‘I was in college full time, but my mum got really sick with seizures, so she was unable to look after my uncle, so it was just me...’* (Tanya, L. 4-5).

It seemed that Tanya had no choice but to stop her college course, sacrificing her education and change her life as conveyed by the ‘it was just me’.

Surprise was also apparent for Marsha, Yvonne and Precious who described:

> *‘I had noticed she was a bit more forgetful than usual, but I just didn’t think. I thought no not mum she’s just so strong. I just put it down to stress...’* (Marsha, L. 5-7).

> *'So, I just thought that on that day that I didn't think that she could manage on her own anymore…'* (Yvonne, L.5-6).

> *'It started with him stripping, turning the furniture upside down which was strange to me I had to call the doctor in…'* (Precious, L.4-5*).*

The participants are expressing noticing subtle changes over time or sudden changes, which made it for them impossible to ignore that there would be a new reality of being a carer. There seems to be a sense of bewilderment or finding it hard to believe, 'I just didn't think', that their loved ones had changed or were not the ones they used to be.

4.2.2 Can I get my head around this?

After the penny drops and the participants realise that there is a point of no return now, in that their loved one has extra/different needs, they are talking about getting their heads round the changes in their circumstances. They integrated the role of carer into their lives through acceptance, family and culture values some of which came at a cost. Fola explains:

> *'Then at the same time being a Black woman caring for my son. Yeah, and other children anyway, and um yeah, I became really ill and stress related illnesses. Yes…'* (Fola, L. 15-16).

As discussed earlier on, it would seem that 'being a Black woman' was a complexity in itself, possibly suggesting that this was no easy feat and the caring role added to this, requiring a rethink of her reality to incorporate this. There is a feeling of her being overwhelmed and pressured and at the same time a feeling that she cannot do otherwise, she just has to cope with it; she may not want how she feels to be put out there for everyone to see. The cost was that she became ill with what she felt were stress related illnesses.

The effect of the perplexing situation and acceptance was also put across by Precious who said:

> *'Because it just affect you sometimes you can't change your life you look and everything is just green though you can't see an end to the problems so it kind of affects you personally.'* (Precious, L. 95-97).

Interestingly she uses the word green to express her feelings. I wondered whether green denoted to unripe, waiting for a harvest that was yet to evolve. For Precious the awareness of the task of being a carer appeared to have a somewhat sobering effect. Her reality seemed to be one of no escape with little choice but to accept. Through this acceptance she was personally affected.

Religiosity was mentioned by five of the participants, as a way of getting their heads round their new situation. For example, Tanya described:

> *'Like, I'm like a Christian, so I pray a lot, I try to pray and like to have faith ... So that's how I maybe cope with my emotional needs. But sometimes it's like 'oh' but I realise that life is not maybe perfect, but I continue to try to have faith…'* (Tanya, L. 54-57).

For Tanya, it appears through prayer and belief in her faith she feels more equipped to cope with her emotional needs. The task of caring provokes an enormous emotional reaction and praying a lot to cope with her emotional needs seems to provide Tanya with a source of strength. It seems that at times it almost feels as though her emotional needs might break through that threshold. For example, when she says 'oh' there is a sense of desperation that at times it is more of a challenge and more difficult for her to cope and continue having faith.

Participants who were daughters of the cared for person experienced getting their heads around the caring role in almost as almost a role reversal Marsha stated:

> '*…Yeah, it's sort of like I've become my mums' mother, I have to get everything right, remember everything…'* (Marsha, L. 24-25).

Marsha's statement of '*I've become my mums' mother,'* is a powerful one because it feels as though a role reversal has transpired that she is attempting to get her head around that at some level feels quite pressured. The impact of pressure on carers has been considered in the literature as has the more implicit pressure of being a Black woman within society.

4.2.3 Help seeking/Accessing Services

In dealing with difficult times participants described various experiences of help seeking and accessing services. Fola described when her GP first intervened:

> **'***Yeah, so, I'm really grateful to her to be quite honest. Because if not for her maybe I won't be where I am today, I won't be sitting here. I would be somewhere else.'* (Fola, L. 21-22).

Fola expresses gratitude towards her GP for acknowledging the impact the caring role was having on her. It feels that had her GP not noticed and intervened the outcome might have been detrimental to her subjective mental wellbeing with 'somewhere else' possibly meaning not here in this capacity at all.

Whilst contemplating her subjective position as a carer Precious sought to engage with local services expressing:

> *'I found what I am going through is not unique all the carers have the same issue with the cared they are offering their family. The problem is with professionals they don't want to know that people have something to say'.* (Precious, L. 79-81).

Precious acknowledges that difficulties could be faced by all carers irrespective of their race. There is a feeling of resignation of not considering her problems that special and a sense of powerlessness that despite her struggle's professionals do not want to listen to what she had to say. The impression is of implicit anger and frustrations it is also possible that threads from 'Being Black' and 'Being a Black Carer' belong here.

Accessing the right services and seeking support appeared to have been quite a journey for Yvonne who described:

> *I got carers for my mum now and my mum has moved into her own home. I suppose the support that I get is the support of having the carers there, that is a support. But other than that, I've just had to figure it out.* (Yvonne, L. 44-46).

She does not seem clear about the support she 'gets' and it seems that whilst there is some support, she has had to adapt the support to suit her needs and it seems just left to work things out for herself. She seems also to convey a sense of having to be independent and the impression of isolation. Having to figure things out implies running a programme of trial and error, in other words learning from her own knowledge and experience.

On the other hand, Chantelle describes feeling supported by her local services expressing:

> *"I get a lot of support ... have helped us a lot…Last year was a total mess"* (*Chantelle, L.* 53-54).

Prior to seeking help and accessing local services it seems that Chantelle was struggling to cope expressing last year as a ‘total mess’ conveying a sense of chaos in grappling with her subjective needs whilst dealing with the complexities of the caring role.

4.3 Master Theme: Being Black – ‘he who feels it knows it’

An inescapable link between a person and their society is posited by Berzoff, Flanagan and Hertz (2008) and is a concept that is fundamental to the understanding of race and racism.

4.3.1 Suffering in silence

Recognising the signs and symptoms that her mental wellbeing was being impacted was expressed by Fola:

> *‘Um because ...I was ill, maybe ‘bout if I say like, cracked up, yeah because of the workload (pause) and I become very ill because I had been having been in a very um taking up a very challenging um work and there was so much responsibility…’* (Fola, L. 11-13).

Fola became ill, recognising that her mental state was overstretched. It seems she felt fragile and vulnerable with an overwhelming sense of fearfulness when she states that she ‘cracked up’. With the added pressure of her employment it seems and the responsibility of taking care of her son that everything was piling on top and Fola feared she would be engulfed by it. This could be seen as Fola carrying the image of ‘strong Black woman’ and suffering in silence under the weight of her load, reaching breaking point.

These overpowering feelings of recognising that you are overstretched and suffering in silence were also put across by Tanya:

> *'I think like 2 years ago I was super depressed, I was like crying all the time and but like I am the type of person a bottle until it rises to a fizz so everything comes out, I would hold things in and then 6 - 8 months later everything will come out' (Tanya*, L71-73).

Tanya acknowledged extreme feelings of low mood, expressing this as 'super depressed' and 'crying all the time'. She uses the powerful metaphor of being a like a bottle 'until it rises to a fizz, so everything comes out'. It seems that Tanya sees herself as a bottle, a container holding a profusion of experiences that impact on her emotionally. Possibly, this is a statement about strength, saying something of how strong she is and how much she can take. However, I got the sense of tolerance, of how much Tanya could swallow before everything (rage) came out.

The weight from suffering in silence impacted Precious in a way that was also significantly draining:

> *'I just felt I lost interest in life…I think that tipped me over the edge a bit…' (Precious*, L70-71).

The loss of interest in life feels debilitating, all-consuming and frightening. For a while, it appeared that Precious felt unable to control her situation and tipped over the edge. It appears she was hanging in the balance within a void, suffering in her own silence.

It seems that Fola felt that any exposure of vulnerability or request for help might impact on her negatively, so she continued to suffer in silence. She conveyed:

> *'I did not tell them I had a child with disability because they might tell me to be on a lower rank, you know or step down ... In a way they might kind of look down on me thinking that I won't be able to hold the responsibility…' (Fola*, L65-72).

It feels as though Fola perceives others will judge her as having too much on her plate to deal with since on the surface there appears to be more complexity involved in parenting and caring for a child with a disability. For Fola, this appears horrifying, almost like a punishment in some way for having a child with disability that someone could relegate her to a lower position. There is an element of stigmatisation and shame here as she expresses, she feels her employer's response might be to look down on her judging her to be incapable of holding the responsibility of her job role because she was defective in some way. Amidst the horror I feel a sense of anger, a sense of outrage in 'how dare they judge me?' and 'what do they know of what I am capable of or not?'. Additionally, it appears Fola felt her own adulthood was challenged here and she felt infantilized by how she perceived her employers would interpret her situation.

This thread of keeping one's difficulties to self through the belief she would not be heard and suffering in silence was apparent in Marsha's experience:

> *'... so, I just tend to shut up for peace sake. Sort of use to no-one listening'. (Marsha*, L.48-49).

There is also a sense of resignation, it feels as though efforts by Marsha in the past to express herself have been shut down. Possibly, this has left her feeling not important enough for people to care/or listen to. The impression is of just wanting to close up and try to cope alone.

The enormity of the emotional drain of suffering in silence was also apparent for Yvonne who conveyed:

> *'You don't realise how much strain it probably is putting on you cos you just get up, you just keep on going. You just do it because, you know you just do it but, it is*

> *a lot. It absolutely is a lot; it is a lot and you know you can't compensate for that.' (Yvonne*, L. 142-144)

There is a sense of pressure to carry on regardless when she expressed just getting up and keep on going. This tireless task feels exhausting. As she went about her caring responsibilities it seems that Yvonne paid little attention to the pressure the role brought her way. When acknowledging the volume of the journey she has been on there seems to be a sense of disbelief at her subjective accomplishment. In the midst of this seems a sense of regret for loss of time for other things perhaps, that she does not feel what she has been through can compensate for.

4.3.2 Being a Black woman

Being strong as a Black woman was a thread that ran across several of the participants experiences. For example, Fola expressed:

> *'Yes, so, I think that pressure actually 'cos working hard all I know, is that I want to be able to provide for him. And the only way I could do it, is to work hard, to have the resources but I was wrong, so that put pressure my, that put pressure on me'.* (Fola, L.35-37).

It appears the pressure of having to work was overbearingly difficult. Fola felt a responsibility to provide for her son and from a cultural perspective 'working hard' was the only way she knew. This feels like a desperate situation, feeling overwhelmed and drained by the pressure of responsibility but feeling there is no other choice but to go on. Fola recognises how much pressure this way of being/thinking put on her. When she acknowledges "I was wrong" there seems to be a strong sense of regret. The repetition of pressure in this short comment is rhetorical highlighting and emphasizing the impact of this overbearing experience. Within this experience there is also a sense of abandonment and being left alone this is expressed by Fola when she states:

> *'…they left the woman to deal with it…'* (Fola, L.138).

Earlier in the interview Fola had disclosed feeling abandoned by her husband and being left to deal with the added responsibility of caring for a disabled child. There is a feeling of angry frustrated resignation here to being left to get on as a strong Black woman and 'deal with it'.

The subjective theme of 'being a Black woman' and portraying strength whilst concealing trauma was apparent in the narrative of Precious who explained:

> *'I have never spoken about the other thing. That thing is draining to live with everyday what if after I am gone, they get to know - he is my only son. Is that what mummy has been keeping from us? But they must be upset you see "You have been keeping this since 1999" that's about 18 years ago… so all that is there that HIV thing…'* (Precious, L.155-158).

That' thing' never spoken about was isolating and exhausting to live with on a daily basis. The worry was not something that could be brushed aside it felt intense, so much so it crept in to her every thought. He was her only son and she feels strongly protective towards him. Whilst caring for son's additional needs, she is also 'mummy' to her other children. Holding back has been a struggle for Precious, she has not been able to share her concerns fully and openly about care plans for her son. There is an impression of guilt around not being able to be transparent with her other children. Precious also seems surprised that she had managed to keep this information to herself for 18 years. The impact of how draining her silence in this area has been is conveyed by her awareness of exactly how long the timespan has been.

Cultural perspectives were shared by Yvonne who mentioned:

> *'I suppose there are just times when you've got things to do so you've just got to have to get on with it. That's what I've been taught growing up. Definitely as a Black woman'*. (Yvonne, L. 74-75).

Similar to Fola, Yvonne seems to be expressing that at times there are tasks that felt beyond her scope, but she had no choice but to 'get on with it'. She further draws on values taught by her caregivers in her childhood and internalised by her. Yvonne defines this racially in her statement 'definitely as a Black woman'. There is a sense of what one ought to do/should do and what is expected of one. With this expectation, there seems to be a sense of pressure with no outlet to express or explore the impact.

Marsha makes reference to her Caribbean background:

> *'I had a really strong Caribbean upbringing where the women are strong and carry everything…'* (Marsha, L74-75).

Marsha acknowledges how her strong Caribbean background influenced her perspective. The women being strong and carrying everything conjures images of tall, strong woman, going about their everyday business, bearing not only their load but that of others. 'Carrying everything' with no room for vulnerability. Whilst there is an element of pride it also seems to feel isolating.

Tanya voices feeling pushed to adjust her expression through fear of judgment:

> *'When I am talking to health professionals or whatever I have to make sure I am super polite because I don't want to intimidate them, and they be like 'oh she came off really aggressive' stuff like that. So, I have to make sure that I be on my p's and q's always. I always try to be polite but I always try to like go the extra mile, so they don't hinder my mum…'* (Tanya, L. 28-31).

When talking to professionals Tanya feels compelled to be 'super polite' regardless of how she is feeling subjectively, fearing any expression of objection may be seen as aggressive and intimidating on her part. It is possible that Tanya feels intimidated by not feeling able to voice her subjective concerns or feelings through fear of reprisal in terms of the care needed for her mother. This feels not only frightening but suffocating and demoralising as well. Tanya is having to be hypervigilant through fear of being viewed as the angry Black woman, minding her 'p's and q's', stifling her natural way of being. There are many cultural connotations here in terms of the impact from slavery, feminism and colonialism. There is a feeling of not feeling part of a system and not feeling accepted.

4.3.3 From whence will my help come.

Many of the participants described how important they felt their role was and needing more help specific to their needs and the needs of those they were caring for:

> *'But I live for my son, so that is what I mean by we need more, and we need more help. Cos looking back into my own situation I just believe black women need more help. We need more help…'* (Fola, L.111-112).

As previously mentioned, the role of motherhood and caring for her sons' additional needs were of great importance to Fola. From her subjective cultural perspective Fola seems to feel isolated which is exacerbated by feeling misunderstood. For example, Fola had mentioned disclosing domestic abuse she had suffered to her GP. The GP's solution was to have the husband arrested however, whilst needing help Fola felt misunderstood. There is a sense of abandonment, isolation and being left to cope. Fola seems to be expressing that her experience as a Black woman calls for help or support tailored to her racial experience in general and in relation to being a carer. There also appears to be a feeling of desperation of whether as such any help might emerge.

Marsha's acknowledgment of needing help at times also called for services that were more tailored towards her cultural needs:

> *'I know I need help sometimes ... I come to the centre but it's very generic'.* (Marsha, L.95-96).

The experience of not feeling supported is touched upon again by Yvonne and Precious:

> *'I just think that I have not really had any support I've just had to get on with it…. I don't know if it was really offered to be honest with you. Erm, nobody's ever offered me counselling in this particular situation in my life…'* (Yvonne, L.53-96)

> *'Anxious, anxious you know in that, what will eventually happen because I have said before nobody will support (name of cared for person), he hasn't got a personal friend that I'm going to sort out to see. So, I am the friend, I am everything. So anxious, about that, what if anything happened. Who will look out for him and when you think which is me all the time it causes me to be depressed'* (Precious, L.141-144).

Within her carer role Yvonne was left to get on with experience, unaware of any support for her mental wellbeing. Precious expresses feeling 'anxious'. There is a feeling of great responsibility, overwhelming anxiety and sadness around this as she is left to cope with everything. It seems that her experience of no help/support created worry and stress through increased unease about her situation. Acknowledging, her isolation impacted on her mood evoking a sense of hopelessness.

The rewards of being a carer was mentioned by Chantelle who stated:

> *'Being a carer kind of has its rewards as I like doing it but I just don't want to be overstretched, you have to put boundaries up sometimes and say maybe I can't do it and someone else might be involved, so that's what I'm learning'.* (Chantelle, L.13-15).

Whilst enjoying the role, Chantelle is mindful about overstretching herself. It feels like there is something about self-care here and the right to look after oneself. In order to maintain an equilibrium, she recognises that she will need to ask for help. She appears hopeful about the level and type of support she might receive. There is a sense of fresh openness here, it appears that previous difficulties encountered in her caring role have provided a learning curve for Chantelle.

4.3.4 Going against the grain

For some of the participants seeking information or accessing adequate care was likened to going against the grain. Meaning that this was an uphill struggle. Tanya disclosed that she had experienced difficulty communicating with her uncles housing officer expressing that he had refused to talk with her until a support worker intervened:

> *'...she rang him up and explained the situation further and that's how he actually talked to me cos before he was not talking to me at all. Even though I wanted to become my uncles advocate like he would not talk to me, he wouldn't engage with*

> *me but until (support worker) was like okay let me ring him. (support worker) rang him up and then that's how it got sorted out. (Support worker) has been a massive help before we were like stabbing in the dark.'* (Tanya, L. 47-51).

It seemed that Tanya one of the youngest participants felt angry and frustrated by the housing officer's refusal to engage with her to the point of desperation before the support worker intervened. As a young carer, I wonder whether she also felt disempowered by this dismissal.

Chantelle shared a similar experience of going against the grain on her quest to find services for her mother expressing:

> *'I have to work against the grain, if that makes sense erm like they shut down a lot of services and the type of epilepsy that my mum has erm they don't do it anymore and so like I have to go everywhere just to care, adequate care that she deserves so yeah…'* (Chantelle, L.28-30).

This feels like a battle, having to fight for adequate care for her mother. There is a sense of despair, hopelessness and disbelief that something so necessary is so difficult. Further, there is a sense of solitary frustration that her plight is unrecognised, and this feels isolating.

4.4 Master Theme: Being a Black carer

Whilst previous research has demonstrated that the invisibility of care giving affects carers from all ethnic backgrounds it has also found that Black carers face additional barriers to accessing services.

4.4.1 Internalised pressure and the boiling pot

A number of participants identified they felt their mental wellbeing had suffered as a consequence of their caring role. Fola claimed her mental state was overstretched when she became ill from taking on more responsibility than she could cope with at that present time. Her subjective cultural expectation of her as a Black woman kept her going on regardless of the internalised pressure.

> *'I become very ill because I had been having been in a very um taking up a very challenging um work and there was so much responsibility. Then at the same time being a Black woman caring for my son. Yeah, and other children anyway, and um yeah, I became really ill and stress related illnesses.'* (Fola, L.1-16).

Culturally, it feels that Fola subscribes to an image of an all-encompassing matriarch. Fola's expectation of herself as a Black woman appears to allude to the 'Superwoman' stereotype referred to by some researchers. For example, she seemed to relentlessly apply herself to multitasking, taking care of her son with additional needs, cater to the needs of her other children and work in a challenging job that expected much of her. There is an impression of frustration and disappointment that feels difficult to face on acknowledging that she can no longer take on what she did before. The result of this internalised pressure was a boiling pot of stress related illnesses.

In carrying out their caring role other participants also expressed ignoring their own wellbeing.

> '**…***all my things and I don't mind it have gone to a back burner… sometimes like I'm ill and I have to like to put my health at risk…*' **(**Tanya, L.79-81).

Tanya hopes and dreams appear to be parked to one side, neglected in a sense in her facilitation of focusing on her carer role. So much so, that even when she feels unwell and in need of a break, she has no choice but to put her health at risk.

Marsha conveyed:

> *'... I mean, I just try and blend in, but I don't think people sometimes understand my dilemmas.'* (Marsha, L.63-64).

Whilst recognising her experiences as a Black carer were different from her white counterparts Marsha's way of coping was to try to blend in. This left her feeling misunderstood and isolated in her dilemmas.

Different to the rest of the participants Yvonne put forward a strategy for coping with the internalised pressure she experienced in her caring role:

> *'I have quite a nice active social life which I have just had to make sure I do that in order to maintain my happy cross. But there were times when it was quite stressful when the only thing I could do which meant that I had time for myself was to actually just pick up and travel. Just get away…'* (Yvonne, L.36-39).

Yvonne's circumstances enabled her to keep an active social life. She acknowledges the role of carer is burdensome and without maintaining some balance between the role and her personal life that the scale could tip negatively. Her balance is the 'happy cross' one she can bear, carry and cope with. There is a sense here of expectation versus choice. The internalised pressure from her caring role has been such that it has reached boiling point and getting away has been the only choice she felt she had in order to cope. Yvonne further expresses:

> *'Sometimes I think "Oh God, when is this going to end?" then I might make jokes at work like you know that kind of thing… I'm talking to you and I'm feeling a little bit choked up because and again it's like "Oh my God, you do all of this…'* (Yvonne, L.125-141).

The intricacies of the caring role feel overwhelming, in wanting an ending it is possible Yvonne is also asking herself how much longer she will be able to cope. Using humour through making jokes at work is one of her ways of coping with the internalised pressure. I wonder whether this might also be her way of expressing she is struggling to cope. Whilst going about her caring role Yvonne has not time to take stock and reflect on her experience as a carer the magnitude of what she does. There is a sense of disbelief and the questioning of self, asking herself how. This feels like an enormous achievement a role that Yvonne might have felt uncertain she could maintain.

4.4.2 Walk of despair

Feelings of despair, loneliness, isolation and hopelessness were themes that ran across many of the participants experiences. Fola voiced:

> *'I used to walk, I just walk and sometimes, but when I am really, really down I just cry like 'ouwh' there is no one there for me to help. I wish you know, like when you wish things could be better, yeah that was how I use to feel'.* (Fola, L.53-56).

There is a sense of gloom and desperation, as she walks in despair. The walking does not seem aimed at any particular location but seems to be a search for solace. At times it is as though the feeling of despair is too painful and she cannot help but let her anguish out. It feels bewildering for her that there is no-one to help. I wonder whether she feels invisible to others in her distress, abandoned and that she does not matter. Still, she has hope, demonstrating her internal strength in her wish that things could be better.

The sense of feeling isolated and lonely was expressed by Tanya who conveyed:

> *'…it feels very lonely even with my sister there I've realised that like sometimes I'm not feeling her emotionally, she's not feeling. Cos someone can't be everything to a person'.* (Tanya, L.82-85).

Although, Tanya had the physical presence of her sister she felt mentally isolated recognising that there were times that she struggled to connect with her emotionally. Whilst in the struggle to connect it seemed that Tanya was aware of her sister not being able to connect with her. There is a sense of not feeling understood and an element of feeling unknown by someone who is familiar to her. When she states 'cos someone can't be everything to a person' it is possible Tanya is expressing several things here. Firstly, that in spite of their close relationship they each need an outlet since they cannot expect to be so dependent on each other. Also, her statement here could be a reflection of her carer burden and how she experienced the role. Being everything to a person feels burdensome and consuming. I wonder whether Tanya felt it would be beneficial to have the space to express herself emotionally.

Difficult relationships with her siblings seem to have left Marsha feeling abandoned and alone in her caring role. She expressed feelings of isolation, loneliness and lack of support:

> *'I don't have a good relationship with my siblings … I don't really get that support'.* (Marsha, L.64-66).

Another participant mentioned how her caring responsibility impacted on her:

> *'…me and *** want to be going on holiday but I can't find anyone to look after mum or uncle F* so I have to put that on the back burner and like for instance erm*

> *just like events like going out for parties and stuff like someone always has to be home or both of us…'* (Chantelle, L.56-58).

Wanting to get away on holiday suggests that Chantelle needs some time out from her caring role. The inability to source someone able to look after her mother and uncle feels frustrating. There is a sense of resignation, placing her subjective needs on the back burner. There is no time for parties, life feels serious as though there is little room for her subjective wellbeing.

The theme of despair was also expressed by Yvonne who stated:

> **'…***this is getting on my nerves so I'm fed up of this" or you know there have been lots of times where I have felt like frustrated with the whole thing and when you are frustrated with the whole thing sometimes I have just learnt to just walk away'.* (Yvonne, L.113-117).

There seems to be times when she feels pushed to her limits by aspects of her caring role, frustrated and angry. This feels overwhelming to the point of helplessness and frightening. I wonder whether walking away was Yvonne's way of protecting herself and maintain her wellbeing.

4.4.3 Cultural View – Do you see what I see?

Cultural values and views were important elements in how the participants perceived themselves and related to others.

> *'I think it would be good for Black carers or another minority to talk about their problems more because. I think that we are expected to shoulder a lot. Especially like as a Black woman as you are instilled to be strong, you got to be strong from a*

> *very early age and you've got to shoulder your family's responsibility. Like even if it takes a back seat towards your needs and I think that sometimes … that needs to be talked about…'* (Tanya, L.109).

Tanya felt that Black carers needed to talk about their problems more and it seems was expressing that she would like the facilitative environment to talk about her difficulties more. She uses the expression 'to shoulder a lot' which seems to suggest that there she feels she has had to carry more than what she can bear. Whilst the values instilled in her at an early age helped her adapt to the responsibility of caring it seems that this schema left no place for vulnerability or to consider subjective needs. There was a sense of resentment and discomfort that Tanya's own needs had been forced to take back seat. In ascribing to this stereotype of having to be strong as a Black woman there seemed to be a sense of guilt and disappointment that she did not feel she could match up/maintain this ideal. Further, holding such ideal seemed to leave Tanya feeling isolated. For Tanya it appeared she felt there would be something to gain from talking about her experience with carers culturally and ethnically similar to herself.

Another participant made reference to feeling more comfortable seeking support from others who were culturally and ethnically similar conveying:

> *'Sometimes, I just want to say it as it is and know that person knows where I am coming from… as a Black person I don't always feel confident that my cultural differences are considered. I mean culturally, I don't think a white counsellor would know where to start with me, I feel I would have to explain myself and they might not know where I'm coming from. But I do think if I could talk about a lot of the things that pop into my head it would be really good for me'.* (Marsha, L.41-81).

Being able to feel comfortable being herself was important for Marsha, as well as being understood. It seems that this has not always been the case and there is a strong sense of disappointment and disillusionment. She expresses feeling dismissed as though her cultural perception is of no consequence. This appears to be ingrained in her life experiences, a sense of feeling misunderstood and devalued. Marsha is uncertain the diversity of her experiences can be contained by a white therapist. There is a sense of frustration and impatience around having to explain herself and the lived life experiences that have shaped her views. Like Tanya she feels that being able to talk about her difficulties would be helpful.

A participant from a Nigerian background expressed feelings of abandonment from her cultural perspective, expressing that she felt her cultural background was not fully understood by the professionals she had turned to for help:

> *'Now he understands but he a black man, would a black man even want to associate themselves with those kids. No some of them, I am not saying 100% you see they won't, so they, they just left, they left the woman to deal with it and where is this woman getting help from. Then this this woman needs to get help get from people that understand the background. Because it's easier to say, oh yeah, we need to get him arrested we don't do that but is that possible no, that person well do they know where they are coming from do they know the background, no…'* (Fola, L.136-142).

As previously stated, Fola had disclosed feeling abandoned by her husband and being left to deal with the added responsibility of caring for a disabled child. From her subjective standpoint she makes a statement about Black men, suggesting they do not accept disability/imperfection. This understanding appears to be fuelled by the pain of abandonment of being left to cope with a difficult situation alone. It seems that Fola's experience is that her husband could not cope with a disabled child through fear of his manhood being brought into question by being associated with a child that was 'damaged'. There is a sense of angry frustrated resignation here to being left to get on as a strong Black woman and 'deal with it'. Being left to cope, to deal with things also appears to have been an enormous perplexing traumatic struggle for Fola who turned to the available source within the host country.

In expressing her plight, it seems that there was confusion over understanding Fola's cultural background. Within the interview Fola had disclosed her husband had been domestically violent and she had shared her suffering with her GP. The GP's solution was to have the husband arrested however, whilst needing help Fola felt misunderstood. The arrest of her husband was not what she was seeking, criminalising him due to unacceptable behaviour in the host country was the easy part. Rather than feeling supported with her disclosure it seems that Fola felt more traumatised and wounded. When she states *'that person well do they know where they are coming from do, they know the background'* it is clear she feels misunderstood and misinterpreted at an ethnic and cultural level.

Fola highlights how important it is for her to feel heard as a Black carer and identify with other Black carers:

> *'I go to meetings … that is just me personally. Now, black people don't come out, I don't see them in meetings... Why they are not coming to carers meetings and groups, it could be…what can be done? the damage has been done what can be anyone do? I might as well be hiding in the corner of my room and have life. And I believe, they should do…Or the fear of 'me' a black person, what am 'I' going to*

> *say that will make any difference. But it might not be just be one voice, might be voices that will tackle it and they become more isolated really than any other'.* (Fola, L.136-142).

Attending meetings appears to be a venue where Fola can meet up with culturally and ethnically similar individuals. She seems not only confused but concerned that she is not seeing Black people within the meetings she attends. This is perplexing and as she reflects on the reasons as to why this might be, she reaches a conclusion, asking herself '*what can be done'*. The situation feels hopeless. I wonder whether she feels that through the neglect of the situation the damage has gone too far to be corrected. She makes a powerful statement *'I might as well be hiding in the corner of my room and have life'* whilst she is generalising this to all Black carers there is a sense that no matter what she says or does will make a difference to her situation since no-one listens. This feels isolating and I get the sense Fola feels to withdraw and is fighting hard against this lonely state. Another powerful reference is made that sheds light on her subjective experience *'me' a black person, what am 'I' going to say that will make any difference.'* There is something exhausting about this, tiring as though she has tried time and time again. Yet there is a strength and a hopeful vision that it will not just be her voice 'one voice' but 'voices' from other culturally similar carers that might bring light to their experience.

5 Discussion

As previously expressed and identified within the literature review there is a gap in the current knowledge about the experiences of carers who identify as 'Black'. 'Being black' is a subjective experience a topic that has been inadequately examined (Stevens, Bell, Sonn et al., 2017) in psychology literature. The purpose of this study was to explore the experiences of Black carers, a group that is thought to experience exclusion and marginalisation within existing services. These findings illustrate that whilst carers who identify as Black share similar experiences to White carers there are a number of unique cultural issues pertinent to their cultural identity.

The discussion chapter begins with a brief summary of the analysis and how the themes interacted with each other. The chapter will review the study's findings by presenting view of participant experiences presented in the analysis and contextualising them in current literature and illuminating the unique issues that emerge from the present study. A discussion of the present study's findings in relation to some theoretical models will be presented. Clinical implications in relation to the findings will be considered together with contributions in terms of theory, research and practice this research makes to counselling psychology. A critical evaluation of the present study that considers the study's limitations will be undertaken. This section ends with reflexive conclusions of the research.

5.1 Summary of the Analysis

In my attempt to understand the lived experience of carers who identify as Black in the United Kingdom, three master themes with ten subordinate themes emerged (Appendix K). As previously mentioned, although different from each other, each of the themes are also related to the other. For example, the theme 'Being a carer' is all part of the repertoire of ‘Being Black’ and ‘Being a Black Carer’. These master themes are not opposites, but different yet integrated parts of Carers who identify as ‘Black’. A description of each master theme with discussion is presented below:

5.2 ‘Being a carer’

The present study provides an insight into the multifaceted awakening of the participants in taking on the role. It explores what the experience means to the participants themselves, how they interpreted and adapted to the role. Assuming the role of caring was identified by some participants as not being something they had planned for but something that had crept up gradually. How the participants negotiated this role appears to be linked to their subjective familial connection. For example, the role of motherhood whilst supporting an adult dependent child. On the nature of motherhood, studies (Milliken, 2001; Valiquette-Tessier, Gosselin and Young, 2019) have found that biological mothers are often stereotyped as primary caregivers and regarded themselves as the person most capable of caring for their children.

This finding is consistent with the perspective of the participant Fola who had been primary carer for her disabled son for more than thirty-five years. As previously mentioned in the analysis, Fola was originally from Nigeria arriving in the UK in the 70’s in her late teens. Cultural beliefs and values seemed to play a part in the way Fola took on and adapted to the role of carer. From a cultural perspective it is possible that Fola felt stigmatised and punished by her husband beliefs as in many cultures’ disability has been associated with disease, curses, dependence and helplessness.

African beliefs concerning people with disabilities have been reported on much over the past few years. Existing research (Bunning, Gona, Newton et al., 2017; Ndlovu, 2016) suggests that African indigenous beliefs are part and parcel of an intricate network of ideas, knowledge, values, ethics, attitudes and social traditions. This author postulates that indigenous African beliefs concerning disability and people with disabilities can be depicted both negatively and positively. In feeling stigmatised, shame, lack of trust, language barriers and cultural perceptions have been reported to remain barriers in mental health (Greenwood et al., 2014).

Lack of information and misunderstanding about mental health could be a contributing factor behind the reason carers who identify as Black may continue suffering in silence. This could explain Fola's dilemma when she expressed, she felt Black women needed help from those that understood the background. From her perspective although she had been a victim of domestic abuse, arresting her husband was not a solution for her. Whilst I do not condone any form of domestic violence the likening of Black males with criminality is well documented within literature (Booth, 2007; Smiley and Fakunle, 2016). It is possible from this standpoint, that Fola felt information and education for her husband might have been a better preventive and supportive intervention.

This study illuminates that individuals who identify as Black experience subjective isolation. This may be due to cultural perceptions and values that one does not 'wash their dirty linen in public.' McKenzie-Mavinga (2016) suggests this to be a common analogy that can add to the elements of internalised oppression that uphold taboo in the Black family. In her clinical work on overarching processes that influence black individuals struggles and drives for actualisation Alleyne (2007) theorised the clinical concept 'the internal oppressor'. This clinical researcher suggests that internalised oppression is the process of absorbing consciously or unconsciously the values and beliefs of the oppressor and subscribing to the stereotypes and misinformation about one's groups.

5.3 'Being Black'

The participants in this study expressed their subjective experiences of 'Being Black' in intricate multifaceted ways. According to Bhavani et al., (2005) ethnicity can be defined as a result of a mix of cultural and other factors including one or more of language, diet, religion, ancestry and physical features traditionally associated with race" and is essentially a process of group identification pertaining to the collective group an individual "belongs to and either identifies with or is identified with by others. Within the context of psychological therapy when defining what it is to be Black, awareness of history is insufficient (Lago, 2011). From a counselling perspective this author asserts that the focus of many counselling approaches is on the present and argues that it must be recognised that in order to understand current events a relevant understanding of history is necessary. This suggests that whilst it is virtually impossible for people of the host population to fathom the complexity of pain, trauma and suffering as an outsider of an ethnic group, individuals can have an idea of oppression but not the experience. On attempting to define the lived experience of what it is to be 'black' this author draws on the Caribbean proverb 'he who feels it knows it'. Individuals within the UK of African Caribbean and Asian origin commonly refer to themselves as 'black' (Evandrou, 2000; Lago, 1996), a term underlying a common shared experience. The struggles of black individuals are not primarily fixed on the day-to-day impact of racial external interactions and racial oppression, but also with internal impacts.

The way the participants viewed their subjective identities in conjunction with their role of 'being a carer' was multifaceted. All of the participants were woman and most of them expressed they assumed the role of carer without question as there were certain expectations in relation to gender and race. This seems to fit with the findings of other studies investigating caregiving patterns in ethnic minority communities which reported that caregiving is significantly influenced by gender role stereotypes (Cloutterbuck & Mahoney, 2003; Townsend & Godfrey, 2001) with females providing care.

The role of religiosity appeared to help some of the participants cope with their carer role and seemed to be a protective factor an individual could tap into when pushed to emotional limits. This is consistent with the findings of Morano and King (2005) who reported a correlation between religiosity a coping strategy, carers perception of self-acceptance and levels of depression, indicating that some form of religious support could serve as a protective factor, especially with ethnically diverse caregivers. As put forward by one participant when her resilience was tested as she continued to try to have faith.

McLennon, Anderson and Epps et al (2018) in their qualitative research on African American daughters caring for parents found in their subordinate themes that family culture and values were inclusive concepts of religiosity, support and duty. These authors suggested that daughters integrated caregiving into their lives with acceptance.

Many of the participants welcomed and appreciated the idea of being signposted by professionals. Existing research (Reeve & Baker, 2005) suggests that identifying and signposting carers could make a significant difference to carer mental wellbeing experiences and outcomes. One of the participants in her engagement with local services found a commonality on attending a carers support group. Another participant felt unclear about the support she was receiving suggesting that she had been left to work things out for herself. This lack of information on support offered by local services could be viewed as bewildering for carers who need structure. This fits with the findings of Meyer (2018) who conducted a study on carer experiences accessing information on supports and services. This author reported on a tension between carer’s varying levels of knowledge and experience with the social care system.

Greenwood, Habibi and Smit et al., (2015) posited that some of the barriers to accessing services might not be ethnic or culture specific and some difficulties might be relevant to all carers. However, for some participants the notion of accessing local services for support evoked fears of being misunderstood and feelings of isolation. The vital importance of mental health has been widely acknowledged within literature. In their research on British African Caribbean women and depression Adkison-Bradley, Maynard and Johnson et al., (2009) emphasize that the stresses of everyday living and the experience of living in a racist society has taken its toll on Black women. The findings from this study suggest that for black carers feeling culturally at ease is an important factor and that culturally competent services are needed. This view supports and is supported by a study conducted by Greenwood (2018) who draws attention to the growing evidence within research which suggests that the experiences of black and minority ethnic carers are often different and may be more challenging than those of their white counterparts.

In this study, the stereotypical schemas of being a Black woman appear to have influenced not only the way the participants viewed themselves but the way they felt others perceived them. Similar to the schemas held for African American women, Black women within the UK have been subject to stereotypical images of the ‘strong Black women’ and ‘the angry Black woman’. Many of the participants expressed feeling pressure and stress as a result of the experienced burden they were juggling and indirectly concealing it. According to literature (Abrams, Hill & Maxwell, 2018) the strong Black woman schema carries beliefs and cultural expectations of incessant resilience, independence and strength that guides meaning making related to Black womanhood. The findings of these authors, that Black women as a result of continuously conjuring resilience in response to physical and psychological hardships often portray strength whilst concealing trauma, fits with the experiences of the participants. It would seem that the purpose of this schema is a coping mechanism for those women who identify as a strong Black woman facilitating them in the assumption of multiple responsibilities and roles. For example, some of the participants were mothers, carers and employees.

Feelings of judgment and feeling compelled to be ‘super polite’ regardless of how the individual was subjectively experiencing the situation was a disturbing thread from participant’s experiences. This feels not only overbearing but oppressive. One participant expressed fearing any objection might be seen as aggressive and intimidating on her part. The angry Black woman schema presents all Black women as ill tempered, illogical, overbearing, hostile, irrational, aggressive and negative despite the circumstances.

The historical and current infantilization of Black people has been well documented within literature (Field, 2014). One of the women described fearing being judged by her employers as having too much on her plate to deal with and being subjected to relegation to a lower post if her vulnerability was exposed. Within this element of stigmatisation and shame there is a sense of adulthood, autonomy and the right to self-determination being challenged here. Outrage might be a normal emotional response here. However, as mentioned in existing literature (Daniels & Jackson, 2014) Black women are frequently read as hostile, being loud and prone to public displays that nobody else wants to hear and cast in the role of ‘angry Black woman’. Ashley (2014) argues that such a stereotype is pervasive and parasitic affecting the self-esteem of Black women and how they are viewed by others. This is consistent with the experiences of this participant and others within this study of who appeared to be hypervigilant through fear of being viewed as the angry Black woman, minding her ‘p’s and q’s’, stifling her natural way of being.

The effects of such schemas have been linked to several destructive psychological outcomes including distress and depression (Watson & Hunter, 2016). Empirical research (Alleyne, 2007) suggests that that Black women who carry the proud image of the strong Black woman often deny themselves the needed space to be compassionate and considerate when it comes to managing issues of stress. This would suggest that such individuals require culturally competent services in order to reduce isolation.

5.4 'Being a Black Carer'

Whilst on the whole, most of the participants reported perceiving caregiving as the family's responsibility divergent and convergent experiences of being a Black carer were expressed. Participants described feelings of frustration, isolation and being left to get on with things. This could be described as the 'subjective burden' of caring (Brodaty & Donkin, 2009; Pelle, 2013) defined as the distress the carer experiences as a result of the emotional, physical and psychological effects on the carer through the process of caring.

The struggle of juggling and balancing aspects of life was a theme that also ran throughout the participant narratives. Although, Black women face similar struggles to White women, it can be argued that 'being a Black woman' is a complexity in itself (Hall, Everett & Hamilton-Mason, 2012) since issues of diversity as well as inequalities have to be faced (Hall, 2018). Integrating this reality within the carer role might be stressful resulting in stress related illnesses reported by some of the participants within this study. These findings add support to existing literature on the subjective health experiences of carers who identify as Black.

Cultural beliefs about what is was to be a 'Black woman' seemed to play a role in the heavy demands some of the participants placed on themselves, alluding to the 'Superwoman' stereotype referred to by some researchers (Abrams, Hill & Maxwell, 2018; Woods-Giscombé, 2010). Black feminist writers have provided a rich discourse about the potentially negative impact of the Superwoman ideal on the interpersonal, social and emotional wellbeing on Black women. Consistent with this discourse a number of participants identified they felt their mental wellbeing had suffered as a consequence of their caring role. These results offer evidence of the impact of such harmful stereotypes on Black women's mental health and wellbeing.

Responsibility for the ongoing care of the cared for individual fell by default to the participants whose ages ranged from eighteen to sixty years old. What appeared to be a basic social issue identified by some of the participants was that although they assumed responsibility for their relative, neither mental health practitioners nor local government services appeared to recognise this. This lack of inclusion into decision making in regard to their loved one facilitated negative impacts such as caregiver stress, ultimately affecting the carers own health. Whilst it could be argued from previous research that the invisibility of care giving affects carers from all ethnic backgrounds. Research has also found that in accessing services, Black carers face additional barriers of ethnocentrism and racism and this forms part of their experience with services. For BME carers there are two relationships at play: the general relationship between carers and service provision and the relationship between BME communities and service provision. Within the UK, race is the basis of historical and continuing discrimination and the impact of racial oppression has long been theorized by scholars. Born out of discrimination and oppression are feelings of despair, loneliness, isolation and hopelessness threads that ran across many of the participants experiences.

Research suggests that whilst Black women face many of the same struggles as White women, Black women also have to face issues of diversity on top of inequalities (Hall, 2018). This appears consistent with the experiences of the participants within this study whom were all women. This could also explain the findings of existing studies (Greenwood, 2018) which suggest that Black carers are less likely to access and engage with formal services than their white counterparts, even though they report greater need for support.

Family constellations and dynamics were also thrown into the mix. Unlike previous perceptions of strong extended family networks/connections amongst the BME community that would be available to provide support the participants within this study were generally unsupported. Adamson and Donavan (2005) highlighted the need for co-operation between the state and the family for the provision of care. These authors suggest that the capacity of black families to provide informal care is overestimated. The findings of this study highlighted that Black carers are generally unassisted by extended family members suggesting that there is a need for support from other sectors for this group of carers. These findings provide some support for the findings of other studies (Parveen et al., 2011; Pound & Greenwood, 2016; Strudwick & Morris, 2010) who point out the common misconception that BME carers have an extended support network and therefore do not have support needs beyond the family. For example, many family networks may have become fragmented due to migration with extended family members being left behind.

5.5 Discussion of findings in relation to theoretical models

The findings of this study appear to be consistent with the stress process model proposed by Pearlin et al., (1990). This model describes the dynamics between three major components: sources of stress, mediators of stress, and manifestations of stress. This model is suggested (Hall, 2018) to be useful theoretical framework for understanding how discrimination on the basis of ascribed characteristics such as race and ethnicity affects mental wellbeing. Hall (2018) argues that to fully grasp coping strategies that Black individuals employ in stressful situations, it is important to know some of the underlying challenges. Although this author's seminal work is in the USA it is highly relevant to the experiences of individuals who identify as Black. This researcher argues that practices such as understanding how the individual gets along with mainstream society, dealing with racism, prejudice and discrimination need to be employed. The role of that understanding plays in the cultural needs and perceptions of the participants within the study in relation to how they coped in relation to their caring role appears to be important.

The socio-cultural stress and coping models have been used to illuminate ethnic differences in carer stress, coping styles, appraisals and outcomes (Knight, Silverstein, McCallum, & Fox, 2000; McCallum, Longmire, & Knight, 2007). As mentioned previously, on assuming the role of caring many of the participants identified this as not being something they had planned for but something that had crept up gradually. According to this model the effects of stressful conditions such as care recipient behavioural problems on the mental/physical health outcomes of carers, are mediated by the carers appraisal and ability to cope with those stressful conditions (Montoro-Rodriguez & Gallagher-Thompson, 2009). Grasping the reality of 'being a carer' after the penny drops was something of a struggle for the participants. The adverse effects on the psychological wellbeing of heavily involved carers was reported by Hirst (2005) to be most pronounced at the beginning when carers first undertook the role of carer.

According to Hall (2018) the core themes of Black feminism incorporate Black gendered oppression such as racism, misogyny and poverty and permeates them with the lived experiences of Black women's taken for granted, everyday knowledge. This researcher posits that Black women who experience gendered racism will experience significant stress. Cultural beliefs about what it is to be a ‘Black woman’ seemed to play a role in the heavy demands some of the participants placed on themselves. Many of the participants reported experiencing significant stress consistent with Hall (2018). These results offer evidence of the impact of harmful attitudes on Black women’s mental health and wellbeing.

Drawing on Klein’s ideas about the unconscious schizoid mechanisms for meaning and displacing anxiety in the application of psychodynamic concepts to race and culture some authors have discussed the paranoid nature of racism. From this perspective of psychodynamic theory an infant is in a state of panic and terror when their needs are not being met and from this viewpoint sees this as an attack on its life. Within this concept Frankland (2010) argues that the paranoid-schizoid position suggests that the ‘paranoid’ element refers to the anxiety and terror regarding perceived persecution or attack from the outside world. The study’s findings suggest that due to their subjective experiences carers who identify as black may adopt the paranoid-schizoid position whilst interacting with those outside their ethnicity.

African psychology and its application in therapeutic practice is suggested to be a strengths-based approach (Mapule-McInnis, 2018) taking into account the living conditions in which a Black individual exists (cultural context). The findings of this study highlight the significance of cultural context in attempting to grasp an understanding of the participants lifeworld. This theoretical framework assists contextualisation of the Black individual’s reality by considering the heightened experiences of worldwide oppression of Black cultures; understandings of self-introduced from such experiences; the development of multidimensional understandings of self beyond a Westernised perspective as a tool for resistance. Whilst not every individual who identifies as Black will need or appreciated this model, in agreement with Mapule-McInnis (2018) I agree it is useful to have as part of the therapist's toolkit of approaches.

5.6 Clinical implications and applicability to Counselling Psychology Practice

The current study has identified several potential recommendations for the therapeutic treatment of individuals who identify as Black. How these recommendations might be applied to professional practice and inform counselling psychologists will be explored. Farooq and Abbas (2013) reported that giving 'voice' and choice to clients who access psychological services is fundamental to the work of psychologists. These authors argue on the importance of developing culturally appropriate psychological interventions. McIntosh (2017), makes a good point when she argues that the lived experience of ethnic minorities may be impacted by the degree of acceptance, understanding, prejudicial attitude, stereotyping and ignorance that exists within the dominant culture where they reside. Thus, feeling accepted is important. Some of the recommendations for therapeutic treatment of carers who identify as Black support the existing clinical literature in working with those from BME communities. However, due to the shortage of information and knowledge of the experiences and needs in therapeutic treatment of carers who identify as Black, recommendations made here are considered valuable contributions in providing a deeper more holistic understanding.

In light of the current study's findings, it is suggested that counselling psychologists need to extend their knowledge of provision of care to an ethnically diverse population using a more multifaceted approach. This could start at the foundation of counselling psychology training in preparing White trainees to work in today's multicultural world through intensive training. Jackson (2018) in her article in Therapy Today draws on the experience of Counselling tutor Pam Peart, a trainer for 40 years who states in delivering training on diversity she feels in a constant battle to get her white, middle classed colleagues to see how their courses and their teaching skirt around the issues of race, prejudice and bias. It is clear that not only trainees but all practitioners working therapeutically with clients need to be challenged to leave their comfort zone in order to work with discomfort. Extending their knowledge of Black issues will help counselling psychologists engage with the client's frame of reference and build a stronger therapeutic alliance where the carers can feel heard and validated. Lago (2011) aptly argues that it is now well evidenced that 'it isn't the model of therapy that determines the outcome; it's the quality of the relationship between the therapist and the client'. Cultural competence pertains to the appropriate provision of care to a diverse population and whilst there has been some criticism around the application of cultural competency (Satel, 2000; Weinrach & Thomas, 2002) due to the emphasis on the ethno-cultural dimension of cultural competence is necessitated because of the implicit and explicit Eurocentric bias influence of western psychotherapy (Bassey & Melluish, 2013).

As Counselling psychologists, we have a significant part to play through enabling people to recognise and understand what constitutes and contributes to racism raising awareness is imperative in providing culturally appropriate services. This suggestion is supported by Solomos (2003) who argues that racism in a wider context is not a fixed phenomenon but an integral element of diverse social issues. This present study suggests that carers who identify as Black might be more likely to access support services that they felt met their cultural needs. Existing studies (Gallagher-Thompson & Coon; 2007; Elvish, Cawley & Keady, 2012; Lipinska, 2016) found that counselling and psychological interventions for carers can give an all-important, safe and confidential environment where individuals can vent feelings of anger, depression, grievances, create and try out different coping strategies and advocacy roles. Training practitioners to work with diversity along with the complexity appears to be of importance here.

The current study sheds some light on the emotional needs of Black carers, highlighting the lack of emotional support. This is supported by the findings of Cox (1995) who conducted a study that examined caregiving among black and non-minority white individuals caring for a relative with dementia. This researcher found that although neither group felt others understood their concerns, lack of emotional support had a significant effect only among the black caregivers.

For counselling psychologists an implication here is the phenomenon of race entering the therapeutic environment and how one as the practitioner interacts and negotiates this. Self-awareness is a crucial component, Alleyne (2009) points out that race enters psychotherapy in ways that parallel its workings in society as a whole and argues that whether racism is experienced as a one-off encounter or an ongoing experience, it can be damaging to the wellbeing of an individual. Further, it is well documented (McKenzie-Mavinga, 2016) that individuals/oppressed groups hold a tremendous amount of powerful feelings and rage that can remain unprocessed and unsupported due to fear, inhibition and concerns about mental health. In line with the principles of counselling psychology, counselling psychologists are alerted to the significance of building a strong therapeutic alliance with carers who identify as Black through an empathetic and supportive approach.

The present research has sought to inform professional clinical practice of multiple ways to design client-led therapeutic interventions, that appreciate and combine social and cultural factors that can work to understand carer experience of those individuals who identify as Black from their subjective frame of reference. Thus, cultural competency is an important aspect of clinical practice.

5.7 Conclusion and recommendations for future research

The purpose of this study was to analyse detailed descriptions of the ‘lived experience’ of carers who identify as ‘Black’ within the UK and how they cope in relation to their caring role. Although recruitment was not gender restricted, only females came forward to volunteer. Thus, the study ended up with six women participants. In adhering to the IPA’s idiographic emphasis (Smith et al., 2009), it important to note that this research does not make generalisation about all individuals who identify as Black. However, it offers a valuable contribution to the limited knowledge base of Black carers experiences of how they cope.

The current study is one of the few UK based studies that explores the experiences of Black carers and how they cope in relation to their caring role. The principle finding of this research is that the experience of wellbeing for Black carers is predominantly influenced by cultural identity and perceptions. Emergent themes included ‘Being a Carer’, ‘Being Black’ and ‘Being a Black Carer’ which illuminate the personal stories of the six women interviewed.

The carers interviewed had varied and composite life experiences that were entwined with their experiences of being a carer. Some were mothers, others were daughters and the resulting analysis showed that the carers interviewed viewed their role as occurring through cultural and social circumstances. In line with the literature exploring the experiences of African American women who identified as Black many of the participants faced similar struggles and stresses which were seen to have an impact on their wellbeing. Further, some of the participants interviewed expressed that adverse circumstances experienced led to them experiencing increased levels of stress undermining their physical and psychological wellbeing.

Replication of this study may be useful in consolidating the findings of the study and contributing further to this underrepresented area. Findings could add to the knowledge base informing counselling psychologists and healthcare practitioners/support services about how this group of carers navigate their mental wellbeing in relation to their caring role, in a way that might be useful. Primary, secondary care services and third sector services need to work towards providing more client-centred services, engaging and addressing the needs of communities that are hard to reach. Local health settings could work with local carers groups to establish service user advisory groups to identify barriers to accessing services.

One of the recommendations drawn from this research is that counselling psychologists and other healthcare professionals should seek to understand what constitutes and contributes to the experiences of carers who identify as Black, considering how ethnic identity and culture impact on the presenting issue using a pluralistic approach.

In engaging black and minority ethnic communities to access available services, providers might make services more accessible through using existing health services such as GP practices to promote services and identify Black carers offering them details of available services and/or make referrals. Several of the participants identified being unaware of the services available which may explain why some Black carers wait/or do not to seek help. A further source for engaging BME communities might be through disseminating information to local faith groups and work with voluntary sector mental health support services.

In conclusion, the findings of this research offer some useful implications for practice and service provision. Although this research contributes to the existing literature exploring the experience of carers who identify as Black and how they cope in relation to their caring role, there is still a lot more which needs to be explored. Further, qualitative exploration into the experiences of this group of individuals could be done using various frameworks in order to acknowledge the lived experience. For example, an intersectionality framework to explore and explain the complex and interconnected nature in the areas of cultural identity, gender, coping and mental wellbeing is much needed.

5.8 Strengths and limitations of the research

From a critical viewpoint all research can be deemed as having both strengths and limitations which need to be acknowledged. IPA is concerned with detailed examination of individuals lived experience and how individuals make sense of that experience (Eatough & Smith, 2008, p.179). This method of analysis was considered as appropriate since the interest within this research is exploratory and the emphasis is on understanding the carers subjective experience. Thus, the aim is to get as close as possible to the individual's personal experience.

Limitations of this research to gaining richer participant experiences might have been the interview schedule that was designed to be asked exactly as worded in a standardised format meaning that the same questions are asked to each participant in the same order. The first question on the interview schedule began by asking "First of all, could you tell me a little bit about how you came to be a carer and how long you have been a carer?" It was felt that possibly the consequences of phrasing the question in this way might have limited or shut down participant responses in terms of the emotional impact of their caring role. However, at the time of comprising the Interview Schedule it was felt such a question might be experienced as a soft opener since the second question to the participant requested "In as much detail as possible could you describe how you experience your role as carer?" allowing and encouraging the participant to express their experience more fully.

As mentioned within the Methodological reflexivity it was on reflection felt my assumption of Black ethnic identity led me to fill in explicit discourse about 'being Black' without the vocalisation. The interview questions were structured in an attempt to ensure that carers would express themselves and focus on their experience of the carer role. There was no mention of 'being Black', my presupposition was that this would emerge since blackness is a salient feature. This could be viewed as both a strength and a weakness in as much as it appeared that the experience of 'being Black' seemed to be an unspoken part of the interaction with the participants. They were expressing 'being Black' but not always including it within the dialogue assuming perhaps that since I the researcher was 'Black' I could grasp what they were expressing. Researchers have long posited about the issues of power and emotion within the qualitative interview situation (Edwards & Holland, 2013). These authors suggest that in a qualitative interview from a psychosocial perspective, power and emotions come together in both conscious and unconscious ways and from a psychoanalytic perspective the interview is the concept of a 'defended subject'. From this standpoint the implication of the researchers positionality (race) in relation to a participant is argued to be a significant focus of discussions with recurring themes being how shared race between researcher and participant might shape an interview. Moreover, the extent to which unspoken assumptions are a feature of such interviews where the researcher and the participant share membership of the same racial group (Edwards & Holland, 2013).

Within existing research (Bhavnani,1993; Bhopal, 1997) the debate on whether or not researchers who are researching individuals from minority ethnic backgrounds need to share 'race' with their participants in order to generate 'better or more authentic data' is ongoing. Within the research process of this research it appears that my 'sameness' with the participants might have brought about potential drawbacks in the 'shared collusion' of creating a comfortable space that also prevented the participants from disclosing further detail of their experiences.

One of the strengths of this research was that the analysis used facilitated the production of rich, detailed accounts of participants' experiences that were beneficial to the research aims. Throughout the process of analysis care was taken to ensue rigour within the study in order to capture participant experiences whilst developing a high level of interpretive engagement with their subjective accounts. It is emphasised the findings of this research resulted from the researcher's interpretations and efforts to make sense of how these individuals understand their experiences. This corresponds to the hermeneutic feature (Smith et al., 2009) of IPA suggesting that different themes from data might have emerged from another researcher's interpretation.

Through the vehicle of phenomenological analysis (Smith, 2004), IPA is an idiographic approach that does not aim to seek definitive answers or develop theory; thus, the aim of this research is not that it will say something about all carers who identify as Black. However, the transferability of the findings can be evaluated in terms of the insights it provides concerning the experiences of how carers who identify as Black cope with their mental wellbeing in relation to their caring role. Smith and Eatough (2006) suggest that in adopting this approach over time later studies can investigate other groups and generalization becomes possible through a steady accumulation of similar cases.

A challenge for this research was the recruitment of male carers who identified as Black. This suggests there is a need to raise awareness of how this group of individuals cope with their subjective wellbeing in relation to their caring role. This need is evident from the dearth of research and literature on the experiences of this group which is something that could be considered for future research.

Whilst it was not the intent to recruit all male, all female or an equally distributed gendered sample, the participants recruited were all female. The study sought to recruit participants using purposive homogeneous sampling. This approach to sampling is one that is selected for the recruitment of participants that have a shared characteristic or set of characteristics. For example, for the purpose of this research the researcher wanted to understand the experiences of carers that identified as Black, so they asked Black people about this. This is a homogenous sample created on the basis of race and can be considered homogeneous since they belong to a closely defined group for whom the research question held relevance and subjective significance (Breakwell, Hammond, Fife-Schaw & Smith, 2006). It can be argued that the 'belonging' to an ethnic group holds subjective meaning to the individual concerned. Whilst this might be viewed as a limitation it certainly adds a data rich source to the knowledge base. For example, the participants were women and they are Black, adding intersectionality among race and gender. A recommendation for future studies might be to recruit equal amounts of Black females and males. Again, this could add further rich data in terms of sociodemographic factors such as gender, socioeconomic status and ethnicity. However, views on validity are mixed whereby some researchers (Rollins, 1985) have challenged the validity of racially specific claims in studies of women of colour where there are not racially comparative groups included in the sample. Others (Cannon, Higginbotham & Leung, 1988) have critiqued studies using homogenous samples of white middle classed women for failing to explicitly recognise the findings reflect only the experiences of white middle classed women and exclude those of women of colour. Jager, Putnick & Bornstein (2017) argue that the greater the number of homogenous sociodemographic factors, the more homogeneous the sample and the narrower the sampling frame.

Whilst there is no direct answer to the question of how many participants are needed in a sample sizes, it has been recommended (Sandelowski, 1996) that qualitative should be large enough to allow the unfolding of a new and richly detailed understanding of the phenomenon being investigated but small enough for the 'deep, case-orientated analysis'(p.183) of qualitative date is not excluded. In determining sample size Morse (2000) suggests that factors which should be considered include the nature of the topic, arguing that fewer participants are needed if the topic is below the surface and intriguing but difficult to grab. She further suggests, Quality of data and Study design and the use of Shadowed data as other factors which should be considered. Morse (2000) recommends that if a phenomenological study is being conducted and the researcher is interviewing each person many times, there is a large amount of data for each participant and therefore the study requires fewer participants suggesting between 6 to 10. This fits with the proposition of Fade (2004) in regard to the sample size who argued that the basic IPA method was suitable for smaller samples of up to ten participants. This method is an 'idiographic case study approach' and this smaller can viewed as a strength. Smith (2004) points out that smaller samples when using IPA is a key area of development within health research since this approach brings us closer to significant aspects of shared humanity.

5.9 Final Reflections

Carrying out this research has been a difficult learning journey of being still, becoming totally absorbed and reflecting on the phenomena of the experiences of how individuals who identify as ‘Black’ within the UK, cope in relation to their caring role. As a practitioner with deeply grounded humanistic client-led roots, the process of research taught me to value and aspire to what Carl Rogers refers to as the importance of immersing oneself as a researcher in phenomena under study ‘this means a tolerance for ambiguity and contradiction, a resistance for closure, the valuing of unbridled curiosity’ (Rogers, in Kirschenbaum & Henderson, 1996, p. 269).

I came into this project with my own assumptions about the experiences of carers who identified as Black. This assumption was that this group of individuals experiences would be multifaceted and difficult. Through the course of conducting the interviews I found a lot to reflect on. As previously mentioned researchers within studies involving participant action research are often situated as insider and outsider, as they conduct research within their own community, workplace or social groups whilst occupying an outside position of the researcher (Crean, 2018).

Being an insider I was struck by the participants accounts of their lives and how they processed this. As I reflected on this, I realised that I sometimes shared experiences, perspectives and opinions with my participants, and at other times did not. There were times I felt close to tears at the sense of being left unsupported during what were clearly difficult times. For example, when one of the participants disclosed living with her son’s HIV diagnosis for twenty years and not feeling able to share her concern with anyone.

I realised that unsupported was how I often experience my own carer role. I acknowledge this as my own subjectivity and tried to aspire to the suggestion of Carl Rogers who spoke about subjective researchers and argued that subjectivity, far from being a weakness, is both inevitable and desirable (Kasket, 2012).

I found that during the analysis process reflexivity was very crucial in allowing me to develop my reflexive stance whilst grasping IPA's concept of the hermeneutic circle. Thoughts would emerge as I analysed each transcript writing in my reflective diary allowed me to express any emerging ideas and bracket them so not to impinge on the analytic process. I further found that there seemed to be a real-life conflict between research findings and applying these into service contexts. For me subjectively, I feel that the issue of being an insider/outsider carrying out research with carers who identify as Black has to do with the emotional aspect of the caring role. Caring for a family member with a variety of needs ranging from chronic illness, mild/severe disabilities or mental health can be a demanding task affection every decision made. The topic of conducting this research on carers who identify as Black has been of personal importance for me and I feel this has contributed to my own learning and development as a counselling psychologist.

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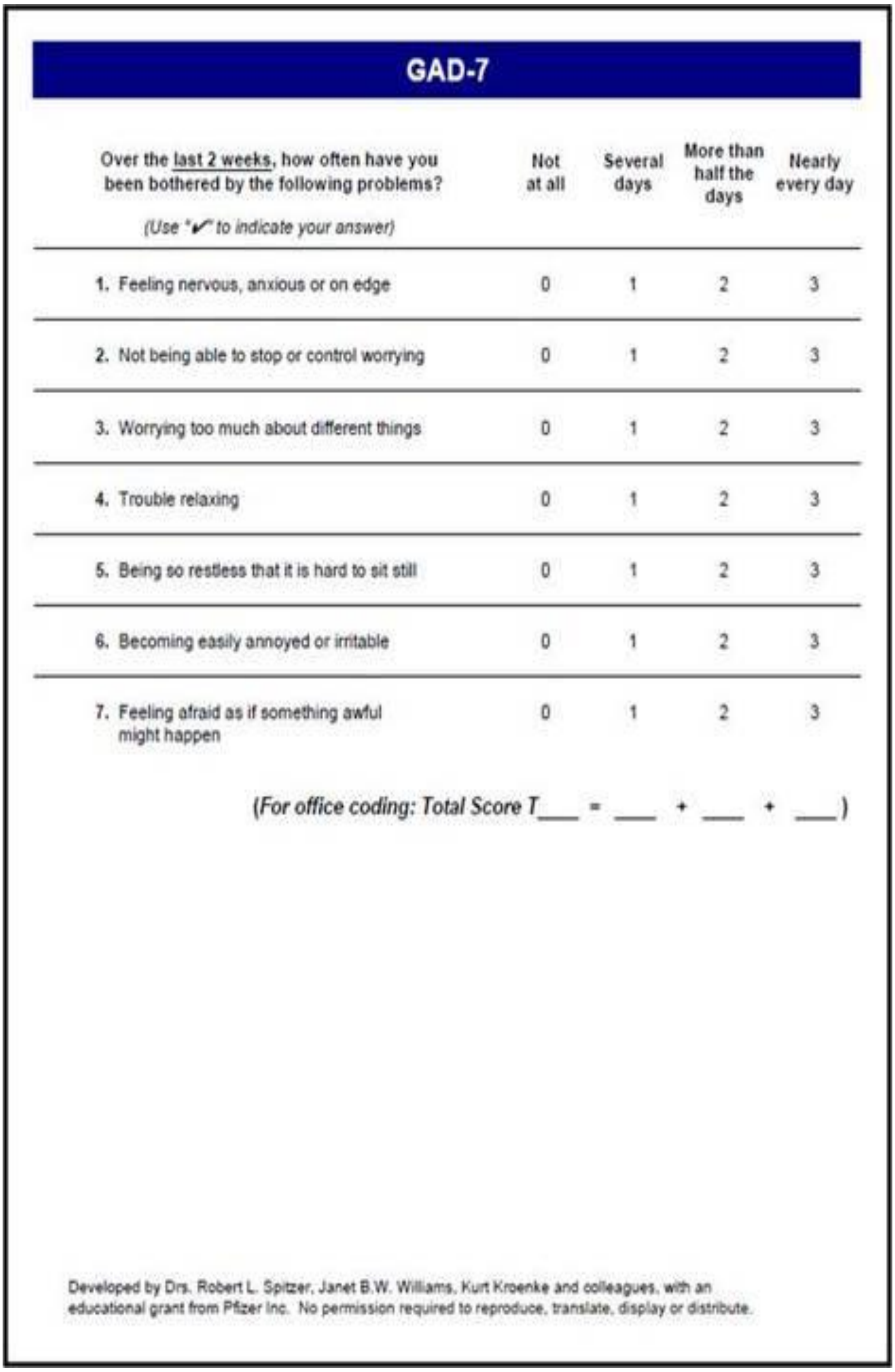
Appendices

Appendix A

General Anxiety Disorder-7



GAD-7

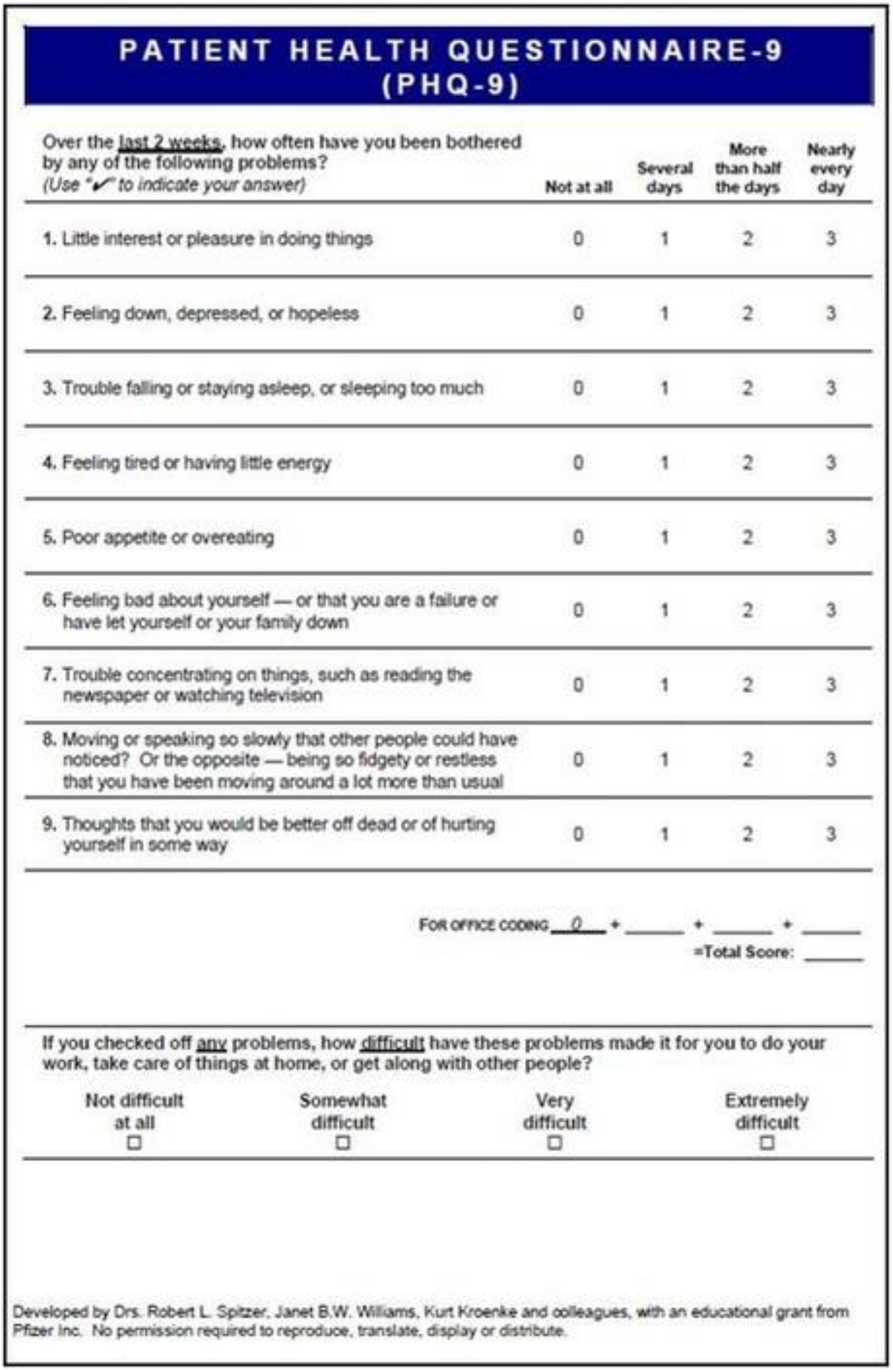
Over the last 2 weeks, how often have you been bothered by the following problems? *(Use "✔" to indicate your answer)*	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

(For office coding: Total Score T____ = ____ + ____ + ____)

Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc. No permission required to reproduce, translate, display or distribute.

Appendix B

Patient Health Questionnaire-9



PATIENT HEALTH QUESTIONNAIRE-9
(PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems? *(Use "✔" to indicate your answer)*	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING 0 + ______ + ______ + ______

=Total Score: ______

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
☐	☐	☐	☐

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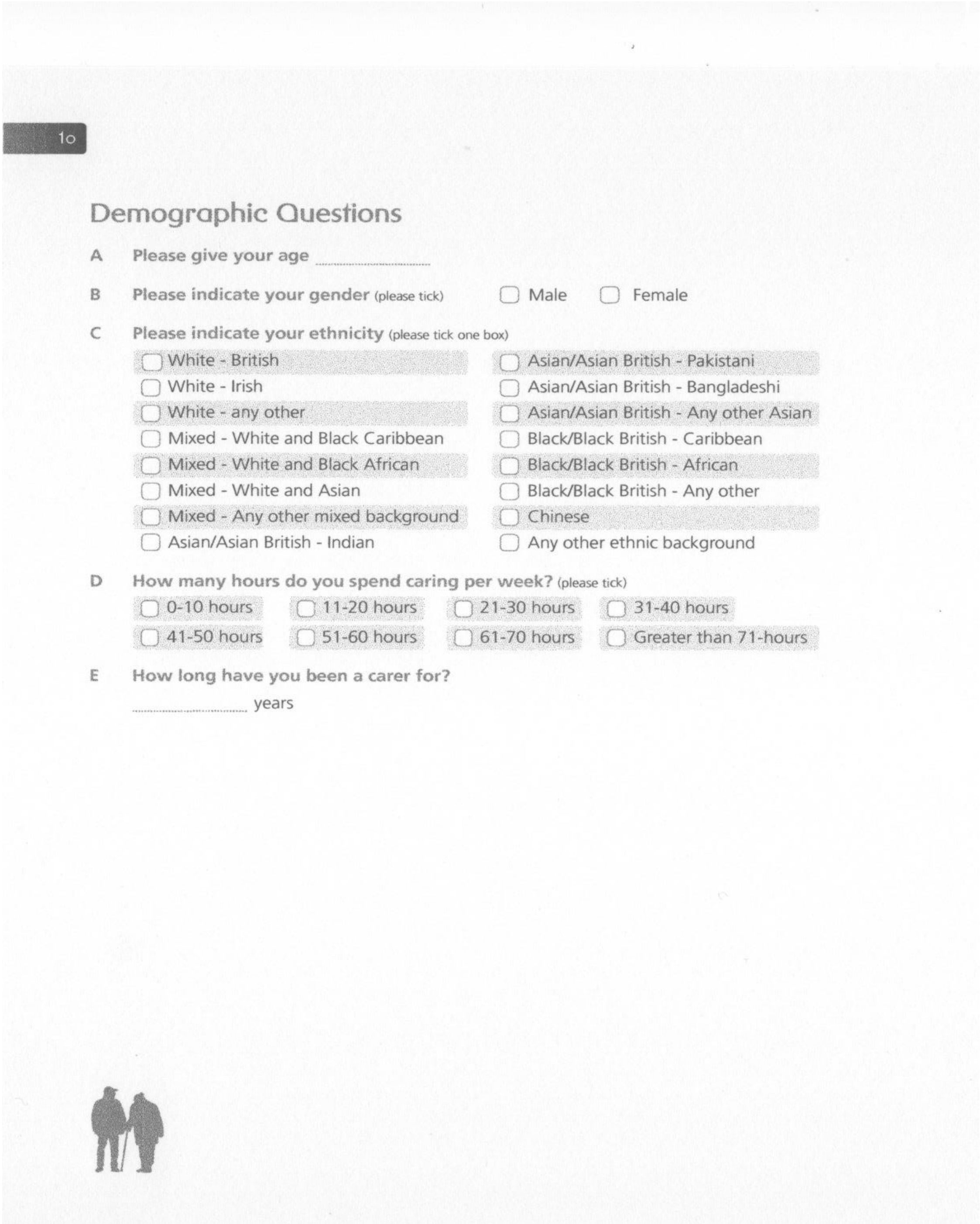
Appendix C

Adult Carer Quality of Life Questionnaire – Demographic Questions



10

Demographic Questions

A Please give your age ....

B Please indicate your gender (please tick) ☐ Male ☐ Female

C Please indicate your ethnicity (please tick one box)

☐ White - British
☐ White - Irish
☐ White - any other
☐ Mixed - White and Black Caribbean
☐ Mixed - White and Black African
☐ Mixed - White and Asian
☐ Mixed - Any other mixed background
☐ Asian/Asian British - Indian
☐ Asian/Asian British - Pakistani
☐ Asian/Asian British - Bangladeshi
☐ Asian/Asian British - Any other Asian
☐ Black/Black British - Caribbean
☐ Black/Black British - African
☐ Black/Black British - Any other
☐ Chinese
☐ Any other ethnic background

D How many hours do you spend caring per week? (please tick)

☐ 0-10 hours ☐ 11-20 hours ☐ 21-30 hours ☐ 31-40 hours
☐ 41-50 hours ☐ 51-60 hours ☐ 61-70 hours ☐ Greater than 71-hours

E How long have you been a carer for?

.... years

Appendix D

LONDON
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Participant Information Sheet

Title of research: The experience of the role of being a caregiver for carers who identify as ‘Black’: An IPA study.

My name is Debra Powell, I am a trainee counselling psychologist at London Metropolitan University, and I am currently carrying out (Doctoral) research to discover more about the experiences of Black carers. Very little is known about the topic and there seems to be a lack of comprehensive research on the ‘lived experience’ of caregivers who identify as ‘Black’ and how they ‘cope’ in relation to their caring role. My hope is that by carrying out this research we will be able to gain a better understanding of Black carers experiences of their caring role and ‘give voice’ so that BME carers can get the support, help and services they need within their local communities.

Invitation to Participate

I am writing in the hope that you will be interested in helping me in this endeavour and share your experience of being a caregiver by participating in an interview. The interview would last approximately 1 hour and will be voice recorded. Data from your interview will be used for my Doctoral level counselling psychology project. Participation is entirely voluntary. If you choose to participate you are free to withdraw up to two weeks from the date of interview without question.

Interviews will be voice recorded and strictly confidential. All recordings will be kept securely stored in a locked filing cabinet and destroyed once the project is completed. All information that is collected about you during the course of the research will be kept strictly confidential. Your name or any identifying information will be removed from the data and will not be quoted in the study. The consent forms will be kept separately from the data and will only serve to verify that proper consent has been obtained. The name of this Carers centre will not be mentioned in the study. (Please note that confidentiality might not apply in certain circumstances, e.g., if information is disclosed that indicates a risk to someone’s safety).

This study has been approved by the Research Ethics Review Panel at London Metropolitan University and will be conducted in accordance with the ethical guidelines provided by the British Psychological Society. If you have any questions, comments or complaints about this study please get in touch with me, either in person, via phone or email. Alternatively, you can contact my director of studies, Dr Angela Ioanna Loulopoulou on 020 7133 2667 or email at A.Loulopoulou@londonmet.ac.uk

Thank you very much for your time and interest, it is much appreciated. If you are interested in taking part in this study, please contact me either in person, via phone or email. My details are below. I look forward to hopefully hearing from you soon.

Kind regards,

Debra Powell
Email: dep0276@my.londonmet.ac.uk
Phone: [redacted]

Appendix E

LONDON
METROPOLITAN
UNIVERSITY

Informed Consent Form

Title of research: The experience of the role of being a caregiver for carers who identify as 'Black': An IPA study.

Description of procedure: In this research you will be asked a number of questions regarding your experience of being a carer within a voice recorded interview.

- I understand the procedures to be used.

- I understand I am free to withdraw at any time before the interview and until two weeks after the interview without question.

- I understand that participation in this study is anonymous. My name will not be used in connection with the results in any way, a pseudonym will be used on the digital voice recording and all information that may otherwise identify me (e.g. address, friend's names) will be changed prior to transcription. There are limits to confidentiality however; confidentiality will be breached if any information is disclosed that indicates a risk to safety.

- I understand that the results of the study will be accessible to others when completed and that excerpts from my interview (minus explicit identifying information) may be used within the study.

- I understand that I may find this interview upsetting and that it may evoke a number of difficult and distressing feelings for me. I will be offered support and the opportunity to discuss these feelings at length post interview with the researcher. The researcher will also give information on further support available if required.

- I understand that I have the right to obtain information about the findings of the study and details of how to obtain this information will be given in the debriefing form.

- I understand that the data will be destroyed once the study has been assessed.

Signature of participant: ……………... Signature of researcher: ………………

Print name: ………………
Date: …………………

Print name: ………………
Date: ………………………

Appendix F

LONDON
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Debriefing Form

Thank you for taking part in this research study. This is part of a Doctoral project that the researcher is conducting.

If you are interested in the results of the study, or if you have any questions about this study, or if you wish to withdraw, please contact the researcher on the following email addresses: Dep0276@my.londonmet.ac.uk

Emails will be checked regularly. Please remember that if you wish to withdraw your date from this study, you need to do it at the latest up to two weeks from your interview date

Equally, if you have any questions or concerns you are more than welcome to address them now.

If you have any complaints regarding any aspect of the way you have been treated during the course of the study please contact my research supervisor Dr Angela Ioanna Loulopoulou on 020 7133 2667 or email at A.Loulopoulou@londonmet.ac.uk

If participation has raised any concerns or issues that you wish to discuss further, you may want to contact your GP, or alternatively, the agencies listed below can provide advice and support in confidence.

- The **CarersTrust** national charity provides free help, advice and support to carers. They can be contacted on 0300 772 9600 or accessed via https://carers.org/contact-us
- **Mind** provides information and support to help promote understanding of mental health issues. They can be contacted on 0845 766 0163 or accessed via www.mind.org.uk
- **The Samaritans** offers a safe place to talk 24 hours a day, 365 days a year. Their national helpline phone number is: 116 123 or accessed via http://www.samaritans.org/

Appendix G

Interview Schedule

Welcome and introduction by researcher, housekeeping rules i.e., mobile phone off and distress protocol indicators. Review of information sheet and informed consent.

<u>Questions</u>

1. First of all, could you tell me a little bit about how you came to be a carer and how long you have been a carer?

2. In as much detail as possible could you describe how you experience your role as carer?

3. Can you tell me about the difficulties, if any you face in your experience as main carer?

- How do you support yourself?

- What type of support do you get for your physical/practical needs?

- What type of support do you get for your emotional needs?

4. Do you think being a carer affected/affects your life choices? If so how?

5. How do you understand/perceive your own mental wellbeing?

- How do you take care of yourself?

- Have you ever considered counselling?

    - If yes, what was your experience

6. What things, if any would like to add or talk about that you think might be relevant to our discussion of your experience or this topic?

7. What has doing this interview been like for you?

<u>Further Prompts</u>

- What do you mean when you say…?

- Can you tell me a bit more about…?
- That’s an interesting point, how do you think it relates to…

N.B. Bullet points are potential prompters/further questions if the interviewee does not cover such areas in their answer; these may be refined or altered post pilot study.

Appendix H

Distress Protocol

This protocol has been devised by a qualified mental health nurse for the purposes of research into PTSD (Cocking, 2008) to deal with the possibility that some participants may become distressed and/or agitated during their involvement. It is not expected that extreme distress will occur in the interviews, nor that the relevant action will become necessary. However, this protocol identifies three stages of distress that the researcher will look out for and take the necessary action should it arise.

1. Mild distress:

Signs to look out for:

1) Tearfulness
2) Voice becomes choked with emotion/ difficulty speaking
3) Participant becomes distracted/ restless

Action to take:

1) Ask participant if they are happy to continue
2) Offer them time to pause and compose themselves
3) Remind them they can stop at any time they wish if they become too distressed

2. Severe distress:

Signs to look out for:

1) Uncontrolled crying/ wailing, inability to talk coherently
2) Panic attack- e.g. hyperventilation, shaking, fear of impending heart attack
3) Intrusive thoughts of the traumatic event- e.g. flashbacks

Action to take:

1) The researcher will intervene to terminate the interview/experiment.
2) The debrief will begin immediately
3) Relaxation techniques will be suggested to regulate breathing/ reduce agitation
4) The researcher will recognize participants' distress, and reassure that their experiences are normal reactions to abnormal events and that most people recover from PTSD
5) If any unresolved issues arise during the interview, accept and validate their distress, but suggest that they discuss with mental health professionals and remind participants that this is not designed as a therapeutic interaction
6) Details of counselling/therapeutic services available will be offered to participants

3. Extreme distress:

Signs to look out for:

1) Severe agitation and possible verbal or physical aggression
2) In very extreme cases- possible psychotic breakdown where the participant relives the traumatic incident and begins to lose touch with reality

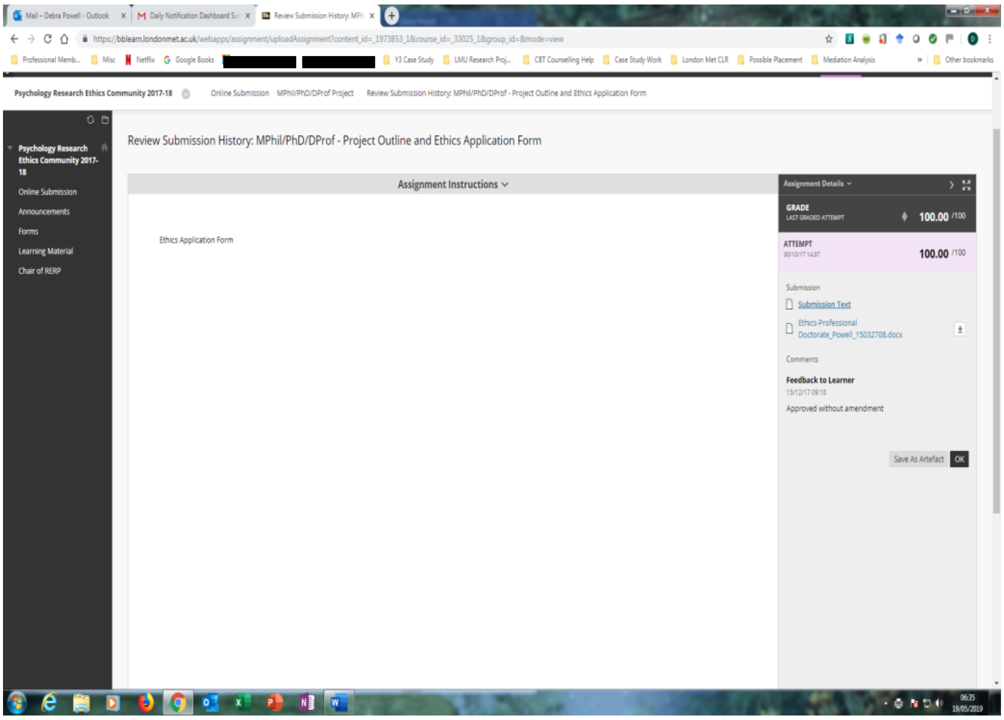
Action to take:

1) Maintain safety of participant and researcher

2) If the researcher has concerns for the participant's or others' safety, he will inform them that he has a duty to inform any existing contacts they have with mental health services, such as a Community Psychiatric Nurse (CPN) or their GP.
3) If the researcher believes that either the participant or someone else is in immediate danger, then he will suggest that they present themselves to the local A&E Department and ask for the on-call psychiatric liaison team.
4) If the participant is unwilling to seek immediate help and becomes violent, then the Police will be called and asked to use their powers under the Mental Health Act to detain someone and take them to a place of safety pending psychiatric assessment. (This last option would only be used in an extreme emergency)

Appendix I:

Ethics Approval



Psychology Research Ethics Community 2017-18 Online Submission MPhil/PhD/DProf Project Review Submission History: MPhil/PhD/DProf - Project Outline and Ethics Application Form

Review Submission History: MPhil/PhD/DProf - Project Outline and Ethics Application Form

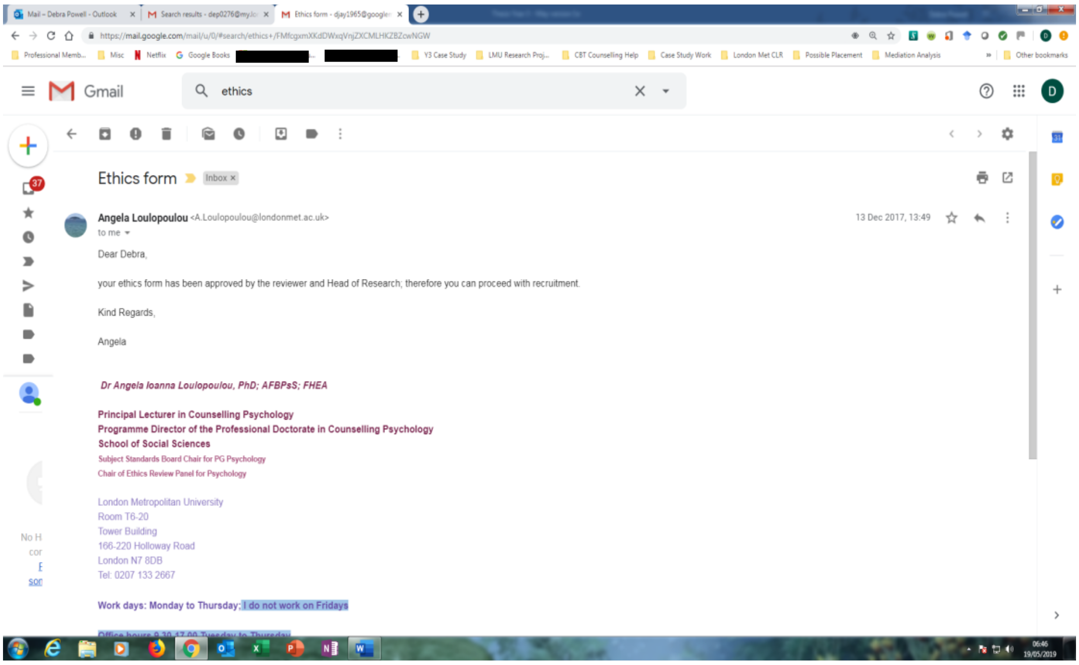
Ethics Application Form

GRADE
LAST GRADED ATTEMPT 100.00 /100

ATTEMPT
30/10/17 14:37 100.00 /100

Submission
Submission Text
Ethics-Professional Doctorate_Powell_15032708.docx

Comments
Feedback to Learner
13/12/17 09:18
Approved without amendment



Ethics form

Angela Loulopoulou <A.Loulopoulou@londonmet.ac.uk>
to me
13 Dec 2017, 13:49

Dear Debra,

your ethics form has been approved by the reviewer and Head of Research; therefore you can proceed with recruitment.

Kind Regards,

Angela

Dr Angela Ioanna Loulopoulou, PhD; AFBPsS; FHEA

Principal Lecturer in Counselling Psychology
Programme Director of the Professional Doctorate in Counselling Psychology
School of Social Sciences
Subject Standards Board Chair for PG Psychology
Chair of Ethics Review Panel for Psychology

London Metropolitan University
Room T6-20
Tower Building
166-220 Holloway Road
London N7 8DB
Tel: 0207 133 2667

Work days: Monday to Thursday; I do not work on Fridays

Office hours 9.30-17.00 Tuesday to Thursday

Appendix J

Participant Interview Transcript Themes

1 (Fola) Themes Table

Participant 1

THEMES	Page/Line	Key words
Disbelief	**P1, L3**	*I did not even know*
Educational enlightenment	**P2, L40**	*My GP stopped me*
Son 'damaged' at birth	**P1, L5**	*My boy was damaged*
Questioning role	**P1, L3 - 6**	*I didn't even know … taking care…as a mother… working*
Long time coming	**P1, L7**	*…about 3 years ago before I realised…*
Multiple roles	**P1, L5 - 7**	*…as a mother…working… realised, I was a carer*
Going through a lot	**P1, L11**	*…if I say …'cracked up'*
Illness and Stress	**P1, L16**	*I became really ill and stress related illnesses…*
Support from Social Services	**P2, L48**	*Who would help to say….*
Local services	**P3, L108**	*...there was none there for me*
Grateful	**P1, L21**	*So I am really grateful to her (GP)…to be quite honest*
Feeling heard	**P1, L21**	*If not for her …*
No time to be crippled	**P3, L93**	*...best not be crippled*
Going with the flow	**P3, L85-L86**	*If not because I was thinking about my son…*
Caring role	**P1, L15**	*Caring for my son…and other children*
More counselling needed for women like me	**P3. L98-99**	*I think that we need more counselling than anyone else…*
Courage to talk about experience	**P3, L107**	*I just have the courage recently to talk…*
Cracking up	**P1, L11**	*'bout if I say like cracked up…'*
Work overload	**P1, L11-12**	*Because of the workload…I became very ill….*
Suffering abuse	**P3, L107**	*…I even went through domestic abuse*
Responsibility	**P1, L13**	*….and there was so much responsibility*

Have to be strong	**P3, L89**	*I felt like sitting down and I want to throw up…*
Pressure to provide	**P2, L35**	*…the only way I could do it, is to work hard to have the resources…*
Don't pity me	**P2, L72**	*…in a way they might kind of look down on me thinking that…*
Fulfilling role as a mother	**P2, L49-50**	*…it's like wow, I want my son to be able to live independently...*
Important to succeed in life	**P2, L58-59** **P2, L64-65**	*I've always been so much ambitious* *...all I wanted to do was to be at the top of every whatever I need to do*
Left a career to do a job	**P2, L61**	*…so, I left my banking career to go into retail…*
Black people can't handle responsibility	**P2, L72-73**	*…thinking that I won't be able to hold the responsibility…*
Relegation	**P2, L66-67**	*…because they might tell me to be on a lower rank…step down.*
Equality – what equality?	**P2, L66**	*…I did not tell them I had a child with a disability*
Who am I going to talk to anyway	**P3, L109**	*…but they never came to talk…*
Isolation	**P3, L81**	*..at the back of my mind which non-one can take away…*
Fear of judgement	**P3, L110**	*It's going to be an argument…just going to take your son away…*
Feeling misunderstood	**P4, L119-120**	*He's looking at it in a normal way…but cultural differences*
Benefit of feeling heard	**P1, L21-22**	*Because if not for her maybe I won't be where I am today, I won't be sitting here. I would be somewhere else*
Needing help	**P3, L111-112**	*so that is what I mean by we need more, and we need more help… looking back into my own situation I just believe black women need more help*

Ostracised/Unsupported	**P4, L138**	*…they left the woman to deal with it…*
A struggle	**P4, L116-7**	*if you felt as though your culture was understood, it would make things it would have made it easier for you to ask for help*
Where do I begin	**P1, L26**	*Ok yeah maybe because l, (Laughs)I didn't answer the question straight away*
Cultural understanding	**P4, L114-115**	*so perhaps if I had seen somebody who understands my culture ...*
Easier to criminalise people	**P4, L140**	*Because it's easier to say, oh yeah, we need to get him arrested*
What is acceptable?	**P4, L120**	*He's looking at it in a normal way. but cultural differences*
Difference & Diversity	**P5, L186**	*It's not about pride, it's not about whatever diversity or whatever anyone might call it.*
I am acculturated	**P5, L158**	*...I been in the country for 45 years or going to 50 years, it's more like my childhood or my teenage life was spent here.*
Black people don't seek help	**P1, L13 -16**	*…taking up very challenging work…at the same time being a Black woman…*
Not wanting to seek help	**P2, L36**	*And the only way I could do it, is to work hard, to have the resources*
Pressure of caring for someone with complex needs	**P2, L35**	*…that put pressure my, that put pressure on me*
What if I wasn't heard?	**P1, L22**	*I won't be sitting here. I would be somewhere else*
What would happen if there is no one around?	**P2, L50-51**	*what would happen if no one is around to take care of him?*
No one to help	**P2, L53-54**	*there was nothing. I used to walk, I just walk*
No help	**P2, L55**	*there is no one there for me to help. I wish you know, like when you wish things could be better…*

Left by one’s family	**P3, L102-103**	*my own husband, he went out there while all this crisis to be with other women*
Cry for help	**P2, L54**	*when I am really, really down I just cry like ‘ouwh’*
Abandoned, rejected	**P4, L136-137**	*but he a black man, would a black man even want to associate themselves with those kids*
Left to deal with it	**P3, L104-105**	*so that alone is a chunk of pressure*
Self-sacrifice	**P2, L69**	*Never going and saying look I’m going for two weeks holiday or three weeks holiday*
Not a burden, a concern	**P5, 190-191**	*should I say burden no, you know that sort of i feel concerned about over the years especially the last five three years.*
Importance of having access to services	**P3, L79-80**	*I become to, aware of what services that are out there ....I could walk in and talk to them.*
Counselling has helped me	**P3, L97**	*…the counsellors, yes, they have helped me.*
Need help from people that understand background	**P4, L139-140**	*Then this woman needs to get help get from people that understand the background*
Don’t tell me how it is for me	**P2-3, L73-75**	*…when they are not there I have to as a manager ... be able to hold my branch. So, looking at that within me I didn’t ask them,*
Black people have a right to seek support	**P4, L148-149**	*I go to meetings because I believe that whatever we are enjoying now, somebody must have fought for it…*
Lack of support information	**P2, L45-46**	*I wasn’t even supporting myself because I did not even know about people take care of carers like, C.... C..... I didn’t know, I didn’t know anything about them.*

More help needed for Black carers	**P4, L150**	*…black people don't come out, I don't see them in meetings…*
I just want to tell my story	**P1, L28**	*and so, it's like a story to me, yeah I just like to tell my story.*
One voice against other voices	**P5, L155**	*what am 'I' going to say that will make any difference*
It's about reality	**P5, L186-187**	*It's just about reality we have to see things the way it is.*
Differences in care standards	**P5, L169-170**	*I have been in a meeting where by they have said you know what the way we black people take care of ourselves and the people that we care for, the white people don't do that.*
Difference in how care is given/received	**P5, L173-174**	*So, when we are talking about their care and all of that it seems there's some kind of tension*

2 (Precious) Themes Table

THEMES	**Page/Line**	**Key words**
Was strange to me	**P1, L4-5**	*It started with him stripping turning the furniture upside down which was strange to me….*
This was not planned for	**P1, L3-4**	*I have been a carer ... since he was only 17 and he is 48 now, you can imagine.*
Struggles	**P1, L3**	*and the struggles*
No end to problems	**P3, L96-97**	*you can't see an end to the problems*
Frightened	**P2, L59**	*frightens me because he has been attacked so many times*
Anticipation	**P1, L14**	*Yes, I'm still waiting…*
Panic	**P3, L124**	*…something had happened…*
Apprehensive	**P1, L10-11**	*…there would come a time when the suffering yeah may become burnt out*
High & low feelings	**P1, L14**	*sometimes it is high, sometimes it is low…*
Waiting for the day	**P1, L12**	*I am still waiting for that day.*
Worry someone outside might see	**P1, L21-22**	*I would not like people to see him outside*
What if something happened to me	**P4, L143**	*what if anything happened?*
What will happen when I go away?	**P3, L123**	*I just thought let me leave him and go and see.*
Worry about change in loved one	**P1, L20**	*I am seeing a kind of an enigma,*
Professional don't listen	**P2, L40-41**	*I mean people like the doctors and maybe the student they don't think I should know what is going on.*
Concerns unheard	**P2, L44**	*Obviously, I am going to worried, why? they will not tell me*
Wants to be consulted/involved	**P2, L47-48**	*I would like professionals to ask carers to let me know what is going on.*
Talk to me	**P2, L61-62**	*I want them to talk to me.*
My opinion matters	**P2, L53**	*My knowledge of him matters.*

Feeling misunderstood	**P2, L41**	*They think I am an interfering mother.*
Undervalued	**P2, L81-82**	*They don't want to know that we as carers we have knowledge of our people*
Sitting with other carers rewarding	**P3, L94**	*And believe me it helps a lot*
Groups help	**P3, L100-101**	*I have to be there for my son then I have to look after myself…so it does help*
Some carers very experienced	**P3, L105**	*some of them are very experienced*
Shared commonality	**P2, L79-80**	*what I am going through is not unique all the carers have the same issue*
Learn how to handle different situations	**P3, L109**	*anything like that can happen how you can handle it*
Feels a part of something	**P2, L78**	*they are now involving us in consultation,*
Gain latest information	**P2, L77-78**	*the latest thing in mental care is being brought to us in that group*
I encourage him	**P1, L21**	*you need somebody to encourage him to look after himself…*
Acceptance of cared for autonomy	**P3, L115-116**	*"mummy go, he's not a baby, he's not a baby anymore."*
Stepping back	**P1, 37-38**	*I want to see that to encourage him to be independent as much as possible I want to step back a bit*
Appreciation of son	**P4, L135-136**	*He is doing his own bit too, so I can't put him down as if he is totally useless, no he is helping me as well*
Independent of me	**P1, L27-30**	*He has a flat… he goes to his flat to stay a few days…*
Pressure – have to take him	**P4, L129**	*If I want to go, I have to take him*
Want people to accept him	**P4, L131**	*If I am sure where I am going, people who know him, they accept him for what he is*

Not every group knows the whole story	**P4, L132-133**	*…I am somebody who doesn't like washing my dirty linen in public.*
Bad knees	**P3, L91**	because of my arthritis
Prevents doing a lot	**P4, L126**	it stops me doing a lot that I should be doing at this stage
Affects personally	**P3, L97**	*you can't see an end to the problems so it kind of affects you personally*
Stressful	**P2, L57-58**	*Very, very stressful. This is me, I don't know how I can express myself than to say what I have observed.*
Saddened	**P1, L24**	*avoid situation like that which can really sadden me very much*
Sleepless nights	**P2, L63-64**	*I know that is what is not helping me when you lose sleep in the day*
Depressed	**P4, L140**	*I will say a bit depressed, a bit depressed.*
Lost interest in life	**P2, L70--71**	*I just felt I lost interest in life…I think that tipped me over the edge…*
Anxious	**P4, L141**	*Anxious, anxious you know in that, what will eventually happen…*
Weighed down	**P1, L23**	*…avoid situation like that which can…weigh me down*
Shame	**P4, L150-152**	not everybody knows that…, I have never said that before.
Embarrassment	**P4, L150-151**	*Because in our group you can't sit down and say I am *** I am mother to *** who as HIV*
Stigma	**P4, L148-149**	*Because apart from the mental health he also has this problem with HIV*
Private – not talking about things	**P4, L156-157**	*Is that what mummy has been keeping from us?*
Keeping things in	**P4, L157-158**	*"You have been keeping this since 1999" that's about 18 years ago, so all that is there that HIV thing*

Carrying the weight - This has been on my mind	**P5, L192-193**	*What have I’ve brought forth in some ways has come out*
Draining to live with	**P4, L155-156**	*That thing is draining to live with everyday*
Speaking the unspoken	**P4, L155**	*have never spoken about the other thing.*
Nobody will support	**P4, L141-142**	*because I have said before nobody will support ***,*
Who will look out for him?	**P4, L143-144**	*Who will look out for him and when you think which is me all the time*
Support network	**P3, L114-115**	*they have their own life now, they have moved on, which I don’t blame them*
Family dismissive	**P3, L115-116**	*"mummy go, he's not a baby, he’s not a baby anymore."*
What will eventually happen	**P4, L141**	*anxious you know in that, what will eventually happen…*
Counselling helped	**P5, L170-171**	*I think all of those counselling help me in some way…*
Historically I would have cried with these questions	**P5, L187-188**	*Before, if you are asking me questions like this maybe I should have started crying*
Can talk about things	**P4, L154-155**	*I know mental illness is coming so we talk about it…*
Being able to speak	**P5, L196**	*Saying it out makes me know that it's not able to go on.*
Being involved with the groups strengthened	**P5, L188-189**	*definitely being involved in these various groups has strengthened me a lot,*
Talking about things does help	**P5, L191**	*but talking about things does help*
Hope even in this situation	**P5, L189-190**	*is not the end of the world. That even in this situation some things can be salvaged...*
I am not the only one with problems	**P4, L163-164**	*…so, I am not the only one with some other problem. I know there are so many other people without meeting them*

3 (Chantelle) Themes Table

THEMES	**Page/Line**	**Key words**
Inadvertent experience of caring role	**P1, L2**	*I started when I was 17, my mum use to care for my uncle*
Overstretched	**P1, L12-13**	*"how can I take care of those daily needs" as well as like the medical and then like taking them out and I've been overstretched in that sense*
Role has rewards	**P1, L13**	Being a carer kind of has its rewards as well
Don't want to be overstretched	**P1, L14**	*but I just don't want to be overstretched*
Setting boundaries	**P1, L14-15**	*you have to put boundaries up sometimes and say maybe I can't do it and someone else might be involved*
Goes day by day	**P1, L37**	*I think like I go day by day,*
Practical help	**P2, L53-54**	*"I get a lot of support ... have helped us a lot…Last year was a total mess"*
No time for own pursuits	**P2, L54-55**	*my wellbeing yeah, I think ...I'm like sorting out social needs for my mum and my uncle so I think that's still pending*
This was not planned for	**P1, L5-6**	*gradually erm my mum became sick…*
Acceptance of cared for autonomy	**P1, L18-19**	*My uncle… might not want that certain thing, but he needs it…I'm younger*
Meeting cared for needs	**P2, L67-68**	*I do ask often that if this is what you want and how can I like improve your life*
Want to do a good job	**P2, L68-69**	*so it's not just like me seeing it from one perspective and they see it another*
What I give I get back	**P3, L85-86**	*So, I think in that sense caring is how I respond to my mum and uncle and how they want to respond back to me.*
Feeling unheard	**P1, L26-27**	*I think was about just getting recognition that erm that they were sick, I had to struggle a lot with the doctors*
Responsibility	**P1, L3-4**	*I would always be like checking if he had the right stuff if going to the appointments*
Routine stressful	**P1, L9**	*being a carer can be stressful if you don't have like, me ... daily meetings.*
Need to be organised	**P1, L10**	*if you're not organised and if you're not doing things that need to be done on like on a daily*
Pushed to the limit	**P1, L11**	*it can push you to your limits. I have been stressed*

Need help	**P1, L14-15**	*maybe I can't do it and someone else might be involved*
Like a battle	**P1, L17-18**	*it's like a fight sometimes… it can put a strain in the mix*
Knowledge of cared for	**P1, L19-20**	*I know what's happening and other people might not*
Powerless struggle	**P2, L25-27**	*I think was about just getting recognition that erm that they were sick… my mums' requirements are not met*
Own health issues	**P2, 40-41**	*some days I suffer with severe asthma so like some days I can't breathe*
Have to push self	**P2, L41-42**	I still have to like push myself to do the certain stuff
Things have to be done	**P2, L46**	somewhat but things have to be done if that makes sense
Seeking help difficult	**P2, L48-50**	*she hasn't really been forthcoming …I do need to go to see the doctor*
Holiday/social plans backburner	**P2, L56-57**	*me and H** want to be going on holiday but I can't find anyone to look after mum or uncle*
Somebody has to be around	**P2, L58**	*someone always has to be home or both of us*
Improved holistically	**P2, L71-71**	*I've improved like me and H** do have time for our self now like I have to find time…*
Counselling has to be willing participation	**P3, L76-78**	*it depends on what you want like how you are willing to improve. Erm, like if I'm not willing to do it what is the point of going? ... it has to be a willing participation between both*
Rankless task	**P3, L81**	*caring can be like a challenge but it's also, it can be a rankless task*
Role complexity	**P1, L2-6**	*care for my uncle who has hydrocephalus….my mum became sick, so she had seizures an*
Role reversal	**P1, L2**	*my mum use to care for my uncle*
Respect	**P1, L17**	*my uncle ... might not want that certain thing*
No definite solution	**P1, L27-28**	*mums' requirements are not met… I don't really have a definite solution for my mum's illness*
Work against grain	**P1, L28**	*I have to work against the grain …they shut down a lot of services*
Struggle to find adequate services	**P1, L29-30**	*and so like I have to go everywhere just to care, adequate care that she deserves so yeah*
Don't know how I support myself	**P1, L37**	*I don't know the answer to the question. That one was hard, yeah…*

Stressful	**P1, L37-38**	*I find it very stressful like yeah that, that one's hard*
Wellbeing pending	**P2, L53-54**	*my wellbeing …so I think that's still pending*
No back up caring support	**P2, 56-57**	*but I can't find anyone to look after mum or uncle*
My decision impacts others	**P2, L62-63**	*I'm not just making decisions just for myself, I'm making it for the erm people that I care for…*
Pressure – needs to be right decision	**P2, L63-64**	*so it has to be the right decision but sometimes it could be the wrong decision but that's life*
Caring role a challenge	**P3, L81**	*caring can be like a challenge*
Been fun telling my story	**P3, L87**	*it's been fun, tough questions, tough questions*

4 (Tanya) Themes Table

THEMES	Page/Line	Key words
Assuming carer role	**P1, L4-5**	*I was in college full time but my mum got really sick with seizures, so she was unable to look after my uncle, so it was just me*
Voice for cared for	**P1, L32-33**	*but I just have to double check like okay this is what we want but let me say it in a different way so that they can get the proper help*
Life not perfect	**P2, L56-57**	*sometimes it's like 'oh' but I realise that life is not maybe perfect,*
Role assumption	**P1, L8-9**	*well I see my role as a carer, so I will make the decisions and I kind of either agree with it or just like add on to*
Cultural belief	**P1, L16-17**	*the difficulties I face is erm like when talking to my mum and my uncle about things sometimes they don't want to take directions from me*
Cultural perception	**P1, L17-19**	*Difficult because I am like younger than them, so they think treat I am trying to dictate their lifestyle. Sometimes I just see it as like another viewpoint*
It's hard	**P2, L19-20**	*Like a problem can be looked at another way, you can't attack it from like one angle you have to go from different perspectives. So, I think that it's hard*
Unheard/Unseen	**P1, L23-24**	*talking to health professionals and because they sometimes like glaze over me*
Ignored	**P1, L24**	*…so they will be like addressing it to my mum or my uncle.*
Angry black woman	**P1, L28-30**	*I am super polite because I don't want to intimidate them, and they be like 'oh she came off really aggressive' stuff like that*
Swallowing things	**P1, L27-29**	*I think that I have to also, when I am talking to health professionals or whatever I have to make sure I am super polite*
Oppression acceptance	**P1, L30**	*So, I have to make sure that I be on my p's and q's always.*
Fear of victimisation	**P1, L30-32**	*I always try to be polite but I always try to like go the extra mile so they don't hinder my mum and my uncle health like their administrates*

What I have been through is emotional	**P3, L122-123**	*when you actually think about the things you have been through its kind of emotional.*
Loss of independence	**P1, L36-38**	*So, then I didn't support myself for like 11 months I didn't have any money….was just living at the mercy of like my family members, … a very difficult time*
A struggle	**P3, L88**	*But I don't think I look after myself. Like, yeah, it's a struggle*
Anxiety	**P1, L40**	*I had a lot of anxiety over it and I felt really bad*
Low self-esteem	**P1, L41**	*I wasn't able to support myself. So yeah, I was, I felt really low about that*
Would like change	**P3, L118-119**	*what I would like to change like to have like a group or where we could talk about specific issues*
Unseen	**P2, L48-49**	*Even though I wanted to become my uncles advocate like he (housing officer) would not talk to me, he wouldn't t engage with me*
Faith helps	**P2, L54**	*I'm like a Christian, so I pray a lot, I try to pray and like to have faith*
Cultural Family values instilled	**P2, 60**	*Because I have always been instilled to have like family value*
Mental Health = Super depressed	**P2, L71**	*…think like 2 years ago I was super depressed*
Mental Health – crying all the time	**P2, L71**	*I was like crying all the time*
Pressure	**P2, L71-72**	*but like I am the type of person a bottle until it rises to a fizz so everything comes out…*
Hard to explain problems	**P3, L99-100**	*The guy was really nice but erm it was kind of hard to explain my problems*
Hard to explain how people view me society	**P3, L100-101**	*sometimes it's like hard to say how people view you in society*
Uncomfortable about how I am viewed	**P3, L101-103**	*So, like yeah it's like it was kind of hard and its sometimes I don't think health professionals realise how people, they view like a Black woman in society like they think, I don't know, it's just hard*
Strong black woman	**P3, L110-111**	*Especially like as a Black woman as you are instilled to be strong,*
Okay to talk	**P3, L113**	*I think that needs to be talked about like it's okay*

Can’t carry everything	**P3, L114-115**	*like we're not mules we're not horses we can't carry everything and I think that needs to be talked about*
Opinion doesn’t matter	**P3, L117**	*like my family like they see it as my role whether I love it,*
Expected of me	**P3, L110**	*I think that we are expected to shoulder a lot.*
Role reversal	**P1, L20-21**	*I think that it's hard that they trust me but to a point because they are older than me*
Ignored by professionals	**P2, L48**	*before he was not talking to me at all.*
Stabbing in the dark	**P2, L51**	*before we were like stabbing in the dark.*
Not a burden a concern	**P2, L64-65**	*it was always in my plan like to always help my mum because she always like put herself last and then me and my sister first.*
Realisation of what is happening	**P2, L75-76**	*But I realise that now, I have still got a depression anxiety…*
No time for self	**P2, L79-80**	*all my things and I don’t mind it have gone to a back burner*
Heath at risk	**P2, L81**	*sometimes like I'm ill and I have to like to put my health at risk*
Loneliness	**P2, L82-83**	*it feels very lonely even with my sister there*
Isolation	**P3, L84-85**	*I've realised that like sometimes I’m not feeling her emotionally, she's not feeling. Cos someone can't be everything to a person.*
Left to cope	**P3, L117**	*my family like they see it as my role…*
Struggle to look after self	**P3, L88-89**	*it's a struggle but I'm trying, it's a struggle.*
Don’t feel professionals understand	**P3, L102-103**	*I don’t think health professionals realise how people, they view like a Black woman in society like they think,*
Hard to think	**P3, L103**	*It was hard to think and then we had family counselling because my sister has been sick*
Would be good for black carers to talk	**P3, L109**	*I think it would be good for Black carers or another minority to talk about their problems more*
Family structure – cultural perception	**P3, L115-116**	*…our family structure …. needs to be addressed*
Would like a group	**P3, L118-119**	*like to have like a group or where we could talk about specific issues*
Difficult to talk	**P3, L121-122**	*kind of hard to erm like erm talk about when you actually think*

It good to be listened to	**P3, L123**	*It's been really good to actually someone to listen and ask questions*
Not feeling judged important	**P3, L123-124**	*and like not coming from a judgemental base. i guess it's been good*
Effects of caring role	**P2, L59**	*it definitely affects, because it's like you can't make a step without thinking about them*
On waiting list for counselling	**P2, L53**	*they set me up with a counsellor but it's like a long waiting list*
Support from services	**P2, L42**	*I have a case worker and she supports me a lot,*
Health issues	**P1, L35**	*…like myself is Syncope, so like I faint a lot, like I faint all the time,*
Historically counselling	**P3, L94**	*I have it like when I was like 15/13 because I was like really depressed*
Counselling changed nothing	**P3, L97**	*just felt like it wasn't really changing things*

5 (Yvonne) Themes Table

Participant 5

THEMES	Page/Line	Key words
Role assumption	**P1, L5-6**	*So, I just thought that on that day that I didn't think that she could manage on her own anymore*
Support from paid carers	**P2, L45-46**	*… having the carers there, that is a support.*
Lifestyle changes stressful	**P2, L61-62**	*Like having to try to renovate her whole home to make it comfortable for her as well. So that was definitely quite stressful.*
No recognition	**P4, L135-136**	*But I've just learnt and now that you know what non-one's really going to do that*
Don't get anything back	**P3-4, L126-127**	*it is what it is you're not going to get anything back from it*
Draining	**P2, L79-80**	*Very rarely, you might get a thank you and that kind of thing so it's emotionally, emotionally draining*
Stressful	**P1, L28**	*you there were times when it was extremely, extremely stressful to*
Strain – pressure	**P4, L142-143**	*you don't realise how much strain it probably is putting on you cos you just get up, you just keep on going.*
Frustrated	**P3, L114-116**	*I have felt like frustrated with the whole thing and when you are frustrated with the whole thing sometimes I have just learnt to just walk away.*
Extremely difficult	**P2, L54-55**	. *It's been extremely difficult at times but I've just had to get on with it*
Stigma	**P3, L121-122**	*…there's a lot of people on social media that don't know that I'm you know a carer for my mum …I have not really said anything.*
Just get on with it	**P2, L74-75**	*I suppose there are just times when you've got things to do so you've just got to have to get on with it.*
Getting on with it	**P2, L53-54**	*I just think that I have not really had any support I've just had to get on with it.*
Just push through	**P3, L100-101**	*I kind of knew what I needed to do in terms of was just push through and get through.*
role juggling	**P2, L66-68**	*every weekend Saturday morning I would have to get up really early to do*

		her personal care. Go back to do her lunch,
Self-identity	**P3, L84**	*I work full time. I am in a job that I actually love.*
Left to cope – no support	**P2, L53-54**	*I just think that I have not really had any support I've just had to get on with it.*
No offer of counselling	**P3, L95-96**	*I don't know if it was really offered to be honest with you. Erm, nobody's ever offered me counselling in this particular situation in my life*
Faith helps	**P1, L32-33**	*I have my faith and I believe that my faith has really been a strong tower of support.*
Accepting own limitations	**P3, L115-116**	*sometimes I have just learnt to just walk away. You know, just leave it.*
Selfcare	**P3, L84-85**	*I actually do enjoy the nice things in life in terms of like I said my holidays.*
Self-compassion	**P3, L117-119**	*she's been soaking wet and then I've just thought you know what I can't be asked sometimes, it's morning how much difference is it going to be if I get there 10am.*
Self-Awareness	**P2, L73-74**	*I think I am quite in tune with myself, I know when I am tired which is most of the time. I know what my triggers are*
Taking breaks helps	**P4, L37-138**	*will be off on holiday next week for half-term and that literally, you know that's how I do it. That's just how I do it.*
Ways of coping	**P3, L119-120**	*it's literally things like that I've just had to learn strategies to look after myself and I'm just trying to.*
Burden of care	**P4, L143**	*You just do it because, you know you just do it but, it is a lot.*
From whence will my help come	**P1, L32-33**	*I have my faith and I believe that my faith has really been a strong tower of support.*
Fed up – getting on my nerves	**P3, L113-114**	*this is getting on my nerves so I'm fed up of this*
Happy cross – burden of care	**P1, L36-38**	*I have quite a nice active social life which I have just had to make sure I do that in order to maintain my happy cross.*
Need to get away - Very stressful	**P1, L36-37**	*But there were times when it was quite stressful when the only thing I could do which meant that I had time for*

		myself was to actually just pick up and travel
No compensation for strain	**P4, L143-144**	*It absolutely is a lot; it is a lot and you know you can't compensate for that.*
Living it	**P4, L147-149**	*I feel emotional now which I wasn't beforehand ... I suppose when I'm living it ...*
Feelings of resentment	**P3, L124**	*you can become resentful*
Emotionally draining	**P2, L57**	*It's been difficult in terms of emotionally draining*
Need a balance	**P3, L110-111**	*really important that you are able to have a balance. Like my balance is I can up, and I can go to work even though my job is a busy job,*
Importance of looking forward	**P3, L86-87**	*I just make sure that I do things for me so I tried to do things for me even if it's going to the cinema or you know there's a Nando's at the top of the road…*
Boundaries – invasion of space	**P1, L58-59**	*It meant that I then had carers coming into my home and in my space so that was difficult*
Be prepared for the unexpected	**P2, L58-59**	*if you're caring for someone you need to make sure that all your documents are in order.*
Realisation of role	**P4, L141**	*Oh my God, you do all of this 2 all of these things, erm and wow are you doing all of this?*
Left to cope by family	**P3, L107-108**	*I've got two siblings but to be honest with you they don't do anything in terms of caring for my mum*
When Is it going to end?	**P2, L125-126**	*Sometimes I think "Oh God, when is this going to end?" then I might make jokes at work like you know that kind of thing*
Telling my story	**P4, L140-141**	*I'm talking to you and I'm feeling a little bit choked up because and again it's like "Oh my God, you do all of this*
Always in role/on duty	**P2, L66-68**	*…every weekend Saturday morning I would have to get up really early to do her personal care. Go back to do her lunch, go back in the evening go back to put her to bed*
Good to talk	**P3, L109**	*it's really good to have people that you can talk to.*
Friendship relationships help	**P2, L50**	*It's really my faith and my friends*

Support Network	**P3, L109-110**	*People that can support you erm through the process*
Encouragement helps	**P4, L135**	*I suppose its small, small things that people might say just to encourage me.*
Support seeking	**P2, L70-71**	*I've had to say no I need to make a change so I just do every other week now which means that I can then get a break.*
Support received	**P3, L90**	*I have people around me that I can offload on if I chose to.*
Complexity of role	**P1, L15-17**	*my role has changed …there was a time when I was literally doing quite a lot … but erm that's changed now*

6 (Marsha) Themes Table

THEMES	**Page/Line**	**Key words**
Multiple Roles – mother, carer, employee	**P1, L17-18**	*I was told I was a carer twice over…*
Role assumption – the penny drops	**P1, L4**	*It happened in kind of an in a sort of roundabout way…*
Disbelief	**P1, L6**	*I thought no not mum she's just so strong.*
Long journey	**P1, L15 - 16**	*It's been such a long journey.*
Get head round it - Perception	**P1, L27**	*…it's getting your head around it*
Multitasker	**P1, L25 - 26**	*Keep appointments, take her for check-ups – make sure she looks tidy*
Balancing act	**P1, L31**	*difficult balancing that with caring for my family*
Have to be available	**P2, L52**	someone always has to stay back with mum.
Role sometimes rewarding	**P1, L15**	*I experience the role in itself as sometimes rewarding, sometimes stressful*
Role sometimes stressful	**P1, L108**	*I experience the role in itself as … sometimes stressful*
Emotional rollercoaster	**P2, L66-67**	*can feel emotionally up and down*
Role reversal	**P1, L24**	*…like I've become my mums mother, I*
Friends dwindled	**P2, L70-71**	*friends at that time, but over the years they've kind of dwindled*
No time for self	**P2, L72**	*I know I should be looking after myself more, it's just the time really*
Restricted independence	**P2, L51-52**	*Oh definitely, I can't work, someone has to be around for mum. I mean we don't get to go out as a family*
Emotional*	**P3. L93**	*I forgot some of the journey I've been on and how much of a struggle it's been. It's been really emotional*
Being a 'mother' Just being mum	**P1, L17-1**	*Around the same time my daughter got a diagnosis*

		for Asperger's and I was told I was a carer twice over but caring for her is different in the way that I see myself
Strong Black woman	**P3, L74-75**	*I had a really strong Caribbean upbringing where the women are strong and carry everything*
Superwoman	**P2, L69**	*Just get on with everything, the school runs, waiting for the transport to take mum off*
Fear of recrimination	**P3, L89-90**	*I suppose I just stifle things so that at least mum gets some services.*
Needing help	**P2, L62-63**	*I know I need help sometimes … I come to the centre but it's very generic*
Worry about being understood	**P3, L76**	*I suppose I worry that if I had counselling, I won't be understood.*
Cultural understanding	**P3, L76**	*I mean culturally, I don't think a white counsellor would know where to start with me,*
A struggle	**P2, L47**	*it's been a struggle generally*
Lost independence	**P2, L69-70**	*I stopped work to care for mum*
Difference and diversity	**P3, L79**	*they might not know where I'm coming from*
Swallow things	**P3, L89-90**	*I just stifle things so that at least mum gets some services.*
Culturally natural	**P1, L12**	*Culturally, this seemed natural to me, mum had taken care of me for so long*
Faith helps	**P1, L34**	*But I am a Christian which helps, I really feel God gives me that extra support*
Really hard	**P1, L34**	*It can be really hard at times*
Cultural differences	**P2, L44-45**	*as a Black person I don't always feel confident that*

		my cultural differences are considered.
Overlooked	**P2, L45-46**	*Maybe it's just me, but sometimes I feel the way services respond to me is not the way they might if I were white.*
Shutdown	**P3, L48-49**	*Sort of use to no-one listening.*
Struggle to have needs met	**P2, L46-47**	*it's been a struggle to get mum culturally acceptable services.*
Angry black woman	**P2, L47-48**	*I mean if I make a fuss then I'm just that angry black woman*
Silenced	**P2, L48**	*…so I just tend to shut up for peace sake*
Others don't understand	**P2, L63-64**	*but I don't think people sometimes understand my dilemmas*
Worry about being misunderstood	**P3, L75-76**	*I suppose I worry that if I had counselling, I won't be understood.*
Don't ask for help	**P2, L63**	*I mean, I just try and blend in…*
Assertiveness*	**P2, L58**	*sort of put my foot down last year*
Pressure of responsibility	**P2, L52**	*someone always has to stay back with mum.*
Lack of appropriate support	**P2, L53** **P2, L65-66**	*most of the time the hours don't always work* *I don't really get that support.*
No help	**P2, L40**	*Nothing really, I know there are carers groups but they don't seem to be that diverse.*
Importance of having access to services	**P3, L84-85**	*lack of services for black people, it would be good to have a group I could go to erm and just not have to explain myself*
Left by one's family	**P2, L64-66**	*I don't have a good relationship with my siblings ... I don't really get that support.*

Subjective reality	**P2, L41-42**	*Sometimes, I just want to say it as it is and know that person knows where I am coming from*
Differences in care standards	**P3, L87-88**	*it's like people don't know where I'm coming from when I talk about the type of care my mum needs.*
Difference in how care is given/received	**P3, L88-89**	*It's like I'm making a fuss, but this is how I was brought up to care for people.*
Not a burden, a concern	**P1, L9-10**	*kind of fell on me and like I said I wanted to do it.*
Family help not forthcoming	**P1, L33-34**	*Not my siblings … they are not forthcoming in offering help.*
Support groups not diverse	**P2, L40**	*I know there are carers groups but they don't seem to be that diverse.*
Shut up for peace sake – internalised	**P2, L48**	*so I just tend to shut up for peace sake.*
Talking would be good	**P3, L79-81**	*But I do think if I could talk about a lot of the things that pop into my head it would be really good for me*
Good to have a group	**P3, L84-85**	*it would be good to have a group I could go to erm and just not have to explain myself, if you know what I mean*
More help needed for Black carers	**P3, L84**	*I think maybe services or the lack of services for black people, i*

Appendix K

Master Theme table

MASTER THEMES	SUBORDINATE THEMES
1. **BEING A CARER**	The penny drops – awareness of 'being' a carer.
	Can I get my head around this?
	Help seeking/Accessing Services
2. **BEING BLACK – 'he who feels it knows it'**	Suffering in silence
	Being a Black woman
	From whence will my help come?
	Going against the grain
3. **BEING A BLACK CARER**	Internalised pressure and the boiling pot
	Walk of despair
	Cultural view – Do you see what I see?

Master table of themes for the group

Being a Carer

The penny drops – awareness of 'being a carer	***Page/Line***
Fola: *Right I have been a carer for about over 35 years specifically, but I did not even know I um about it, was a carer. Um, cos to me, my boy was damaged at birth and I'm taking care of my son and um, as a mother and um working*	**P1, L3 - 6**
Precious: *I am a carer for my son and erm and I have been a carer to him and the struggles that it brings since he was only 17 and he is 48 now, you can imagine. It started with him stripping turning the furniture upside down which was strange to me I had to call the doctor in.*	**P1, L3-5**
Chantelle: …*and I would always be like checking if he had the right stuff if going to the appointments, checking what he needs in the household and then how I could like take care of his needs and then gradually erm my mum became sick…*	**P1, L3-6**
Tanya: *I was in college full time, but my mum got really sick with seizures, so she was unable to look after my uncle, so it was just me…*	**P1, L4-5**

Yvonne: *So, I just thought that on that day that I didn't think that she could manage on her own anymore* **P1, L5-6**

Marsha: *I had noticed she was a bit more forgetful than usual but I just didn't think. I thought no not mum she's just so strong. I just put it down to stress.* **P1, L5-7**

Can I get my head around this?

Fola: *Then at the same time being a black woman caring for my son. Yeah, and other children anyway, and um yeah, I became really ill and stress related illnesses. Yes* **P1, L15-16**

Precious: *Because it just affect you sometimes you can't change your life you look and everything is just green though you can't see an end to the problems so it kind of affects you personally.* **P3, L95-97**

Tanya: *Like, I'm like a Christian, so I pray a lot, I try to pray and like to have faith ... So that's how I maybe cope with my emotional needs. But sometimes it's like 'oh' but I realise that life is not maybe perfect, but I continue to try to have faith.* **P2, L54-57**

Marsha: …*Yeah, it's sort of like I've become my mums mother, I have to get everything right, remember everything…* **P1, L24-25**

Help seeking/Accessing Services

Fola: *Yeah, so, I'm really grateful to her to be quite honest. Because if not for her maybe I won't be where I am today, I won't be sitting here. I would be somewhere else.* **P1, L21-22**

Precious: *I found what I am going through is not unique all the carers have the same issue with the cared they are offering their family the problem is with professionals they don't want to know that people have something to say.* **P2, L79-81**

Chantelle: *"I get a lot of support ... have helped us a lot…Last year was a total mess"* **P2, L53-54**

Yvonne: *I got carers for my mum now and my mum has moved into her own home. I suppose the support that I get is the support of having the carers there, that is a support. But other than that I've just had to figure it out.* **P2, L44-46**

Being Black

Suffering in silence

Fola: *Um because ...I was ill, maybe 'bout if I say like, cracked up, yeah because of the workload (pause) and I become very ill because I had been having been in a very um taking up a very challenging um work and there was so much responsibility*	**P1, L11-13**
I did not tell them I had a child with disability because they might tell me to be on a lower rank, you know or step down ... In a way they might kind of look down on me thinking that i won't be able to hold the responsibility	**P2/3, L65-75**
Precious: *I just felt I lost interest in life…I think that tipped me over the edge a bit…*	**P2, L70--71**
Chantelle: *...it's like a fight sometimes, like sometimes with my uncle like he might not want that certain thing but he needs it, so cos I'm younger it's obviously, and then his nieces it's obviously taking direction from that and it can put a strain in the mix*	**P1, L17-19**
Tanya: *I think like 2 years ago I was super depressed, I was like crying all the time and but like I am the type of person a bottle until it rises to a fizz so everything comes out, I would hold things in and then 6 - 8 months later everything will come out.*	**P2, L71-73**
Yvonne: *you don't realise how much strain it probably is putting on you cos you just get up, you just keep on going. You just do it because, you know you just do it but, it is a lot. It absolutely is a lot; it is a lot and you know you can't compensate for that.*	**P4, L142-144**
Marsha: *... so I just tend to shut up for peace sake. Sort of use to no-one listening.*	**P2, L48-49**
Being a Black woman	
Fola: *Yes, so, I think that pressure actually 'cos working hard all I know, is that I want to be able to provide for him. And the only way I could do it, is to work hard, to have the resources but I was wrong, so that put pressure my, that put pressure on me.*	**P2, L35-37**
…they left the woman to deal with it…	**P4, L138**
Tanya: *when I am talking to health professionals or whatever I have to make sure I am super polite because I don't want to intimidate them, and they be like 'oh she came off really aggressive' stuff like that. So, I have to make sure that I be on my p's and q's always. I always try to be polite but I always try to like go the extra mile so they don't hinder my mum…*	**P1, L28-31**
Precious: *I have never spoken about the other thing. That thing is draining to live with everyday what if after I am gone, they get to know - he is my only son. Is that what mummy has been keeping*	**P4, L155-158**

from us? But they must be upset you see "You have been keeping this since 1999" that's about 18 years ago… so all that is there that HIV thing

Chantelle*: *So, like, if you’re not organised and if you’re not doing things that need to be done on like on a daily, like activities and stuff erm it can push you to your limits. I have been stressed. Like “how can I take care of those daily needs” as Ill as like the medical and then like taking them out and I’ve been overstretched in that sense. **P1, L9-13**

Yvonne*: *I suppose there are just times when you’ve got things to do so you've just got to have to get on with it. That’s what I’ve been taught growing up. Definitely as a black woman. **P2, L74-75**

Marsha*: *I had a really strong Caribbean upbringing where the women are strong and carry everything **P3, L74-75**

From whence will my help come.

Fola*: *But I live for my son, so that is what I mean by we need more, and we need more help. Cos looking back into my own situation I just believe black women need more help. We need more help **P3, L111-112**

Precious*: *Anxious, anxious you know in that, what will eventually happen because I have said before nobody will support ***, he hasn’t got a personal friend that I’m going to sort out to see. So, I am the friend, I am everything. So anxious, about that, what if anything happened. Who will look out for him and when you think which is me all the time it causes me to be depressed. **P4, L141-144**

Chantelle*: *Being a carer kind of has its rewards as Ill I like doing it but I just don’t want to be overstretched, you have to put boundaries up sometimes and say maybe I can’t do it and someone else might be involved, so that's what I'm learning. **P1, L13-15**

Tanya*: *Like a problem can be looked at another way, you can’t attack it from like one angle you have to go from different perspectives. So, I think that it's hard that they trust me but to a point because they are older than me and sometimes, they think that you’re trying to take their power away from them but it’s not the case I want the best for them and sometimes they put themselves in danger **P2, L19-23**

Yvonne*: *I just think that I have not really had any support I've just had to get on with it. **P2, L53-54**

I don’t know if it was really offered to be honest with you. Erm, nobody's ever offered me counselling in this particular situation in my life **P3, L95-96**

Marsha: *I know I need help sometimes … I come to the centre but it's very generic.* **P2, L62-63**

Going against the grain

Tanya: *she rang him up and explained the situation further and that's how he actually talked to me cos before he was not talking to me at all. Even though I wanted to become my uncles advocate like he would not talk to me, he wouldn't t engage with me but until K***was like okay let me ring him. K** rang him up and then that's how it got sorted out. C*** C*** has been a massive help before we were like stabbing in the dark.* **P2, L47-51**

Chantelle: *I have to work against the grain, if that makes sense erm like they shut down a lot of services and the type of epilepsy that my mum has erm they don't do it anymore and so like I have to go everywhere just to care, adequate care that she deserves so yeah…* **P1, L28-30**

Being a Black Carer

Internalised pressure and the boiling pot

Fola: *I become very ill because I had been having been in a very um taking up a very challenging um work and there was so much responsibility. Then at the same time being a black woman caring for my son. Yeah, and other children anyway, and um yeah, I became really ill and stress related illnesses.* **P1, L12 -16**

Tanya: …*all my things and I don't mind it have gone to a back burner… sometimes like I'm ill and I have to like put my health at risk…* **P2, L79-81**

Marsha: *… I mean, I just try and blend in, but I don't think people sometimes understand my dilemmas.* **P2, L63-64**

Yvonne: *I have quite a nice active social life which I have just had to make sure I do that in order to maintain my happy cross. But there were times when it was quite stressful when the only thing I could do which meant that I had time for myself was to actually just pick up and travel. Just get away…* **P1, L36-39**

Sometimes I think "Oh God, when is this going to end?" then I might make jokes at work like you know that kind of thing **P2, L125-126**
I'm talking to you and I'm feeling a little bit choked up because and again it's like "Oh my God, you do all of this **P4, L140-141**

Walk of despair

Fola: *I used to walk, I just walk and sometimes, but when I am really, really down I just cry like 'ouwh' there is no one there for me to help. I wish you know, like when you wish things could be better, yeah that was how I use to feel.*	**P2, L53-56**
Tanya: *it feels very lonely even with my sister there I've realised that like sometimes I'm not feeling her emotionally, she's not feeling. Cos someone can't be everything to a person.*	**P2, L82-85**
Marsha: *I don't have a good relationship with my siblings ... I don't really get that support.*	**P2, L64-66**
Chantelle: …*me and *** want to be going on holiday but I can't find anyone to look after mum or uncle F* so I have to put that on the back burner and like for instance erm just like events like going out for parties and stuff like someone always has to be home or both of us*	**P2, 56-58**
Yvonne: *this is getting on my nerves so I'm fed up of this" or you know there have been lots of times where I have felt like frustrated with the whole thing and when you are frustrated with the whole thing sometimes I have just learnt to just walk away.*	**P3, L113-117**

Cultural View – Do you see what I see?

Tanya: *I think it would be good for Black carers or another minority to talk about their problems more because .. I think that we are expected to shoulder a lot. Especially like as a Black woman as you are instilled to be strong, you got to be strong from a very early age and you've got to shoulder your family's responsibility. Like even if it takes a back seat towards your needs and I think that sometimes ... that needs to be talked about*	**P3, L109**
Marsha: *Sometimes, I just want to say it as it is and know that person knows where I am coming from… as a Black person I don't always feel confident that my cultural differences are considered.*	**P2, L41-45**
I mean culturally, I don't think a white counsellor would know where to start with me, I feel I would have to explain myself and they might not know where I'm coming from. But I do think if I could talk about a lot of the things that pop into my head it would be really good for me.	**P3, 78-81**
Fola: *Now he understands but he a black man, would a black man even want to associate themselves with those kids. No some of them, I am not saying 100% you see they won't, so they, they just left, they left the woman to deal with it and where is this woman getting help from. Then this this woman needs to get help get from people that understand the background. Because it's easier to say, oh yeah, we*	**P4, L136-142**

need to get him arrested we don't do that but is that possible no, that person well do they know where they are coming from do they know the background, no…

I go to meetings ... that is just me personally. Now, black people don't come out, I don't see them in meetings... Why they are not coming to carers meetings and groups, it could be…what can be done? the damage has been done what can be anyone do? I might as well be hiding in the corner of my room and have life. And I believe, they should do…Or the fear of 'me' a black person, what am 'I' going to say that will make any difference. But it might not be just be one voice, might be voices that will tackle it and they become more isolated really than any other. **P4/5, L148-156**

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Counselling Psychology Review
Cover Page

Title: The Experience of the Role of Being A Caregiver for Carers Who Identify as 'Black': An Interpretative Phenomenological Analysis

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Abstract (Research) - word count: 243/250

Background/Aims/Objectives - Carers who identify as 'Black' are a group that is thought to experience exclusion and marginalisation within existing services. It is documented that little is known about knowledge or awareness and uptake of counselling services. Thus, the present study is concerned with the experience of Black carers with a focus on wellbeing and how they 'cope' in relation to their caring role.

Methodology/Methods - Semi-structured interviews were conducted with a purposive sample of six carers who identified as Black. Participants accounts of their lived experiences were recorded, verbatim transcribed and analysed using Interpretive Phenomenological Analysis (IPA),

Results/Finding - Three themes were identified: 'Being a carer', 'Being Black' and 'Being a Black Carer'. Although, separate from each other each theme is all part of the repertoire highlighting that although they are different from each other, they are also related to each other. These master themes are not opposites, but different yet integrated parts of Carers who identify as 'Black'.

Discussion/Conclusion - The principle finding of this research is that the experience of wellbeing for Black carers is predominantly influenced by cultural identity and perceptions. This research supports existing literature on carers who identify as Black. The findings of this research offer some useful implications for practice and service provision. Seeking to understand what constitutes and contributes to the experiences of carers who identify as Black.

Publishable Article

The Experience of The Role of Being A Caregiver for Carers Who Identify As ‘Black’: An IPA Study

Debra Powell

Background: *Carers who identify as ‘Black’ are a group that is thought to experience exclusion and marginalisation within existing services. It is documented that little is known about knowledge or awareness and uptake of counselling services. Thus, the present study is concerned with the experience of Black carers with a focus on wellbeing and how they ‘cope’ in relation to their caring role.*

Method: *Semi-structured interviews were conducted with a purposive sample of six carers who identified as Black. Participants accounts of their lived experiences were recorded, verbatim transcribed and analysed using Interpretive Phenomenological Analysis (IPA)*

Findings: *Three themes were identified: ‘Being a carer’, ‘Being Black’ and ‘Being a Black Carer’. Although, separate from each other each theme is all part of the repertoire highlighting that although they are different from each other, they are also related to each other. These master themes are not opposites, but different yet integrated parts of Carers who identify as ‘Black’.*

Conclusion: *The principle finding of this research is that the experience of wellbeing for Black carers is predominantly influenced by cultural identity and perceptions. This research supports existing literature on carers who identify as Black. The findings of this research offer some useful implications for practice and service provision. Seeking to understand what constitutes and contributes to the experiences of carers who identify as Black*

Background

Within literature, it has been widely acknowledged that the experience of caring for a family member with a variety of needs ranging from chronic illness, mild/severe disabilities or mental health can be a demanding task. In the United Kingdom (UK) it is estimated that there are “half a million carers from Black and Asian ethnic minorities (Carers UK, 2011).

Whilst, there is some research that explores caregiving attitudes, experiences and needs of BME family carers, it is well documented (BACP, BPS, Mind, Rethink et al., 2013; Pacitti, Hughes, Statter, Alvarado-Rivero & Chaddha, 2011) that individuals from Black Minority Ethnic (BME) groups are less likely to access counselling services than

White British people. Previous reviews have mentioned the existence of variations in health outcomes and access to services and reported that there appears to be a tendency for poorer health outcomes for BME populations and lower than expected uptake of services (Botsford, Clarke & Gibb, 2011; Szczepura,2005).

Although, it is recognised that counselling can be beneficial to carers (Lipinska, 2016), this appears to suggest that an understanding of the support needs of carers who identify as Black appears to be limited, including from a Counselling Psychology perspective. As a consequence, there is a dearth of knowledge to support practitioners working within this field

Burman, Gowrisunkur and Sangha (1998) posited that the approach of psychology towards ethnicity and culture has been oversimplified and makes assumptions on the universal generalizability of early human experiences. In their report ‘Beyond We Care Too: Putting Black Carers in the Picture’ the (NBCCWN, 2008) argue that needs are universal and point out that solutions may be different. The report suggests that although carers from BME communities mostly have the same needs as others, culturally sensitive ways of enabling access to services was vital to enable BME communities to engage with available services.

Eleftheriadou (2010) suggests clients from different cultural backgrounds have often been viewed as so ‘different’ they are ‘untreatable’. For BME carers this could mean they are overlooked for services such as psychological therapies because it is felt that more ‘specialist services’ are required. Moodley (2000) postulates that in terms of the small number of BME individuals who seek therapy a ‘not-knowing ‘mode seems to underlie much of the practice leaving BME clients ‘disenchanted with psychotherapy because of the failure to address fundamental issues. Issues such as illness presentation, therapist-client differences, client-therapist alliance and pigeonholing and stereotyping individuals.

In agreement with Moodley (2000) I would argue that the issue of BME groups remain outside, foreign and immigrant in theory, practice and research.

Dryden and Reeves (2008) suggest that the increasing presence of cultural diversity within clients presenting for counselling necessitates that counselling psychologists must increase their awareness of how cultural difference affects their clinical work. The BME population contains multiple sub-populations with rich historical, sociocultural values and experiences.

As previous research has demonstrated, it would seem that ethnic background appears to account for differences in experiences of caregiving (Fernando, 2005) and that the psychosocial effect of caring in different cultures is under-explored (Bunting & Jenkins, 2016). Farooq and Abbas (2013) reported that giving 'voice' and choice to clients who access psychological services is fundamental to the work of psychologists. These authors postulate that conducting research is one way to unmute the voices of those groups that are not heard. Further, they argue that as a result develop culturally appropriate psychological interventions. Additionally, it would appear that findings from existing academic research suggest that it is important and therefore relevant for counselling psychologists to understand carer experience from the carers subjective frame of reference and design client-led interventions that appreciate and combine social and cultural factors. Thus, cultural competency is an important aspect of clinical practice.

The purpose of the study

When researching the topic, I found that much of the literature pertaining to the caring experience of BME carers is theoretical in nature drawing on Eurocentric concepts to explain ethnically diverse cultural experiences.

Several empirical papers highlight the lack of culturally sensitive services but do not capture the potential internal conflict of BME carers coping with their caring role. The literature review identified a gap in the current knowledge about the experiences of carers who identify as ‘Black’. ‘Being black’ is a subjective experience a topic that has been inadequately examined (Stevens, Bell, Sonn et al., 2017) in psychology literature. Thus, the present study is concerned with the experience of Black carers, a group that is thought to experience exclusion and marginalisation within existing services. The aim is to explore the experiences of carers who identify as Black within the UK and how they cope with their subjective wellbeing in relation to their caring role.

Method

The present study adopted the Interpretative Phenomenological Analysis (IPA) as method of analysis. This approach was considered the best approach since the interest within this research is exploratory and the emphasis is on understanding the carers subjective experience. Through the vehicle of phenomenological analysis (Smith, 2004), IPA is an idiographic approach that aims to study individuals through giving voice to their subjective experiencing. Fade (2004) argued that the basic ‘idiographic case study approach’ IPA method was suitable for smaller samples of up to ten participants. As this method is particularly suited to exploratory research it was felt to be the ‘best fit’ for this study. Whilst I the researcher am not professing that this research will say something about all BME cultures, what I hope this research will provide is detailed descriptions and commentary about one particular community BME carer group, ‘carers who identify as Black’. The ethical considerations for this project were produced in agreement with the British Psychological Societies Code of Human Research Ethics Guidelines (2014).

Participants

The participants were six women who identified themselves as being ‘Black, aged over 18 and the primary carer of someone who was dependent on them. Additional information on each of the participants is provided below:

Table 1:

Summary of participant’ details

Participant (pseudonym)	Age	Ethnicity	Generation	They care for	Length of time as Carer
Chantelle	18-25	BC	2nd Gen	Mother	5
Tanya	18-25	BC	2nd Gen	Mother & Uncle	3.5
Yvonne	26-40	BC	1.5 Gen	Mother	10
Marsha	26-40	BC	2nd Gen	Mother	15
Precious	41-60	BA	1st Gen	Son	31
Fola	41-60	BA	1st Gen	Son	35

BC, Black Caribbean, BA, Black African

Procedure

Informed consent was obtained prior to interview from each participant. Participants were interviewed within a safe, quiet and confidential space at their convenience e.g., a counselling room within the Carers support organisation. Semi-structured, open ended questions were used to assist the researcher to gain insight into the participant’s unique phenomenological world. From the researcher perspective, this approach to collect data has the advantage of allowing the researcher to explore unanticipated or interesting avenues of questioning. All interviews were audio recorded with permission from the participant and later transcribed. At the end of the interview participants were thanked for their participation in the research and given a verbal and written debrief.

Data analysis

Interpretative Phenomenological Analysis is the chosen method of analysis. Yardley (2017) suggests that sensitivity to the data in qualitative analysis is crucial and researchers should employ a selection of credibility checks to enhance the study's validity. A reflective diary was kept supporting the research process, allowing the researcher to 'bracket' any preconceptions/expectations. The analysis involved each individual case being recorded, fully transcribed and analysed using IPA as outlined by Smith et al., (2009). Initial exploration of themes; identifying and labelling themes, master theme identification and examination of commonalities. This was followed by cross case analysis and a final theme table. The final themes translated into a narrative account.

Table 1: Master table of Master themes and related subordinate themes.

MASTER THEMES	SUBORDINATE THEMES
4. **BEING A CARER**	1.1 The penny drops – awareness of 'being' a carer. 1.2 Can I get my head around this? 1.3 Help seeking/accessing services
5. **BEING BLACK – 'he who feels it knows it'**	2.1 Suffering in silence 2.2 Being a Black woman 2.3 From whence will my help come? 2.4 Going against the grain
6. **BEING A BLACK CARER**	3.1 Internalised pressure and the boiling pot 3.2 Walk of despair 3.3 Cultural view – Do you see what I see?

Reflexivity and epistemology of the researcher

My interest in the experience of carers who identify as Black came from my subjective experience as a carer who identified as 'Black'. In my years as a carer I was faced with many challenges of over different issues and cultural values whilst navigating available services as I cared for my father. I attributed these to the fact that I came from a Caribbean background and whilst I had been born in the UK, I had been raised in a completely different culture with a different value system.

Through this study I was hoping to find out what it was like for other carers who identified as Black. I acknowledged that it was a different experience for those who had migrated from the African continent, those who had migrated from the Caribbean and those who had been born here. Indeed, there was a complexity there in itself about those who identified as Black and were first, second or third generation.

During the interview process I was aware of a need to be ‘therapist’ to challenge some of the things shared by the participants. Kavle (2007) mentioned the metaphor of the ‘traveller researcher’ and drawing on this proposition was able to ‘wander with’ the participants on their journey. For me, this journey has been emotional and inspiring, discovering the different experiences of the participants. As I reflect on this, I am moved to thanking the participants for sharing their personal experiences with me and their contribution to this research.

Findings

The analysis emphasised separate themes highlighting that although they are different from each other, they are also related to each other. For instance, the theme ‘Being a carer’ is all part of the repertoire of ‘Being Black’ and ‘Being a Black Carer’. These master themes are not opposites, but different yet integrated parts of Carers who identify as ‘Black’.

Being a Carer

How individuals adapt to becoming a carer is a phenomenon which lacks consensus in the wide variability of the experience of caregiving. Heidegger (1962/1927) posited that only through the lifeworld do individuals have access to experience of themselves. He suggests that individuals understand themselves and their existence by way of the activities they pursue and the things they take care of.

The penny drops – awareness of 'being' a carer.

Becoming a carer is often not a planned occurrence and can happen gradually or very suddenly, lasting for days or years (Marie Curie, 2018). When asked when they became a carer it seemed on conceptualising the question that there was an element of surprise in the participants' subjective experience in their acknowledgement of 'being' a carer.

> *'Right I have been a carer for about over 35 years specifically, but I did not even know I um about it, was a carer. Um, cos to me, my boy was damaged at birth and I'm taking care of my son and um, as a mother and um working…'* (Fola).

Central to most of the narratives was the element of awareness of 'out of the blue' change in behaviour of the cared for and the increased need for support that seemed to coincide at some level with an awareness of the vacancy for the role of carer.

> *'I was in college full time, but my mum got really sick with seizures, so she was unable to look after my uncle, so it was just me…'* (Tanya).

Can I get my head around this?

After the penny drops and the participants realise that there is a point of no return now, in that their loved one has extra/different needs, they are talking about getting their heads round the changes in their circumstances. They integrated the role of carer into their lives through acceptance, family and culture values some of which came at a cost.

> *‘Then at the same time being a Black woman caring for my son. Yeah, and other children anyway, and um yeah, I became really ill and stress related illnesses. Yes…’* (Fola).

Help seeking/Accessing Services

In dealing with difficult times participants described various experiences of help seeking and accessing services.

> *I got carers for my mum now and my mum has moved into her own home. I suppose the support that I get is the support of having the carers there, that is a support. But other than that, I've just had to figure it out.* (Yvonne).

Others described feeling supported:

> *“I get a lot of support … have helped us a lot…Last year was a total mess”* (*Chantelle*).

> **‘***Yeah, so, I’m really grateful to her(GP) to be quite honest. Because if not for her(GP) maybe I won’t be where I am today, I won’t be sitting here. I would be somewhere else.’* (Fola).

Being Black – ‘he who feels it knows it’

An inescapable link between a person and their society is posited by Berzoff, Flanagan and Hertz (2008) and is a concept that is fundamental to the understanding of race and racism.

Suffering in silence

Recognising the signs and symptoms that their mental wellbeing was being impacted was a thread that ran through the participants narratives.

> *'I think like 2 years ago I was super depressed, I was like crying all the time and but like I am the type of person a bottle until it rises to a fizz so everything comes out, I would hold things in and then 6 - 8 months later everything will come out' (Tanya*).

> *'I just felt I lost interest in life…I think that tipped me over the edge a bit…' (Precious*).

> *'… so, I just tend to shut up for peace sake. Sort of use to no-one listening'. (Marsha*)

Being a Black woman

The subjective theme of 'being a Black woman' and portraying strength whilst concealing trauma was apparent in the narrative and a thread that ran across several of the participants experiences.

> *'Yes, so, I think that pressure actually 'cos working hard all I know, is that I want to be able to provide for him. And the only way I could do it, is to work hard, to have the resources but I was wrong, so that put pressure my, that put pressure on me'.* (Fola).

Cultural perspectives were shared

> *'I suppose there are just times when you've got things to do so you've just got to have to get on with it. That's what I've been taught growing up. Definitely as a black woman'.* (Yvonne).

> *'I had a really strong Caribbean upbringing where the women are strong and carry everything…'* (Marsha).

Another participant expressed feeling pushed to adjust her expressions through fear of judgment.

> *‘When I am talking to health professionals or whatever I have to make sure I am super polite because I don't want to intimidate them, and they be like 'oh she came off really aggressive' stuff like that. So, I have to make sure that I be on my p's and q's always. I always try to be polite but I always try to like go the extra mile so they don’t hinder my mum…’* (Tanya).

From whence will my help come.

Many of the participants described how important they felt their role was and needing more help specific to their needs and the needs of those they were caring for.

> *But I live for my son, so that is what I mean by we need more, and we need more help. Cos looking back into my own situation I just believe black women need more help. We need more help…’* (Fola).

> *‘Anxious, anxious you know in that, what will eventually happen because I have said before nobody will support (name of cared for person), he hasn’t got a personal friend that I’m going to sort out to see. So, I am the friend, I am everything. So anxious, about that, what if anything happened. Who will look out for him and when you think which is me all the time it causes me to be depressed’* (Precious).

Going against the grain

For some of the participants seeking information or accessing adequate care was likened to going against the grain. Meaning that this was an uphill struggle.

> *'…she rang him up and explained the situation further and that's how he actually talked to me cos before he was not talking to me at all. Even though I wanted to become my uncles advocate like he would not talk to me, he wouldn't engage with me but until (support worker) was like okay let me ring him. (support worker) rang him up and then that's how it got sorted out. (Support worker) has been a massive help before we were like stabbing in the dark.'* (Tanya).

> *'I have to work against the grain, if that makes sense erm like they shut down a lot of services and the type of epilepsy that my mum has erm they don't do it anymore and so like I have to go everywhere just to care, adequate care that she deserves so yeah…'* (Chantelle).

Being a Black carer

Whilst previous research has demonstrated that the invisibility of care giving affects carers from all ethnic backgrounds it has also found that Black carers face additional barriers to accessing services.

Internalised pressure and the boiling pot

A number of participants identified they felt their mental wellbeing had suffered as a consequence of their caring role. Subjective cultural expectations were expressed here.

> *'I become very ill because I had been having been in a very um taking up a very challenging um work and there was so much responsibility. Then at the same time being a black woman caring for my son. Yeah, and other children anyway, and um yeah, I became really ill and stress related illnesses.'* (Fola).

> *'… I mean, I just try and blend in, but I don't think people sometimes understand my dilemmas.'* (Marsha).

Different to the rest of the participants Yvonne put forward a strategy for coping with the internalised pressure she experienced in her caring role:

> *'I have quite a nice active social life which I have just had to make sure I do that in order to maintain my happy cross. But there were times when it was quite stressful when the only thing I could do which meant that I had time for myself was to actually just pick up and travel. Just get away…'* (Yvonne).

Walk of despair

Feelings of despair, loneliness, isolation and hopelessness were themes that ran across many of the participants experiences.

> *'I used to walk, I just walk and sometimes, but when I am really, really down I just cry like 'ouwh' there is no one there for me to help. I wish you know, like when you wish things could be better, yeah that was how I use to feel'.* (Fola).

> *'…it feels very lonely even with my sister there I've realised that like sometimes I'm not feeling her emotionally, she's not feeling. Cos someone can't be everything to a person'.* (Tanya).

Cultural View – Do you see what I see?

Cultural values and views were important elements in how the participants perceived themselves and related to others.

> *'I think it would be good for Black carers or another minority to talk about their problems more because. I think that we are expected to shoulder a lot. Especially like as a Black woman as you are instilled to be strong, you got to be strong from a very early age and you've got to shoulder your family's responsibility. Like even if*

> *it takes a back seat towards your needs and I think that sometimes … that needs to be talked about…'* (Tanya).
>
> *'Sometimes, I just want to say it as it is and know that person knows where I am coming from… as a Black person I don't always feel confident that my cultural differences are considered. I mean culturally, I don't think a white counsellor would know where to start with me, I feel I would have to explain myself and they might not know where I'm coming from. But I do think if I could talk about a lot of the things that pop into my head it would be really good for me'.* (Marsha).

Discussion and Implication for practice

These findings illustrate that whilst carers who identify as Black share similar experiences to White carers there are a number of unique cultural issues pertinent to their cultural identity.

The participants in this study expressed their subjective experiences of 'Being Black' in intricate multifaceted ways. Within the context of psychological therapy when defining what it is to be Black, awareness of history is insufficient (Lago, 2011). From a counselling perspective this author asserts that the focus of many counselling approaches is on the present and argues that it must be recognised that in order to understand current events a relevant understanding of history is necessary. This suggests that whilst it is virtually impossible for people of the host population to fathom the complexity of pain, trauma and suffering as an outsider of an ethnic group, individuals can have an idea of oppression but not the experience. On attempting to define the lived experience of what it is to be 'black' this author draws on the Caribbean proverb 'he who feels it knows it'. The struggles of black individuals are not primarily fixed on the day-to-day impact of racial external interactions and racial oppression, but also with internal impacts.

The way the participants viewed their subjective identities in conjunction with their role of 'being a carer' was multifaceted. All of the participants were woman and most of them expressed they assumed the role of carer without question as there were certain expectations in relation to gender and race. This seems to fit with the findings of other studies investigating caregiving patterns in ethnic minority communities which reported that caregiving is significantly influenced by gender role stereotypes (Cloutterbuck & Mahoney, 2003; Townsend & Godfrey, 2001) with females providing care.

Cultural beliefs about what is was to be a 'Black woman' seemed to play a role in the heavy demands some of the participants placed on themselves, alluding to the 'Superwoman' stereotype referred to by some researchers (Abrams, Hill & Maxwell, 2018; Woods-Giscombé, 2010). Black feminist writers have provided a rich discourse about the potentially negative impact of the Superwoman ideal on the interpersonal, social and emotional wellbeing on Black women. Consistent with this discourse a number of participants identified they felt their mental wellbeing had suffered as a consequence of their caring role. These results offer evidence of the impact of such harmful stereotypes on Black women's mental health and wellbeing.

What appeared to be a basic social issue identified by some of the participants was that although they assumed responsibility for their relative, neither mental health practitioners nor local government services appeared to recognise this. This lack of inclusion into decision making in regard to their loved one facilitated negative impacts such as caregiver stress, ultimately affecting the carers own health. Whilst it could be argued from previous research that the invisibility of care giving affects carers from all ethnic backgrounds. Research has also found that in accessing services, Black carers face additional barriers of ethnocentrism and racism and this forms part of their experience with services. For BME carers there are two relationships at play: the general relationship between carers and service provision and the relationship between BME communities and service provision. Within the UK, race is the basis of historical and continuing discrimination and the impact of racial oppression has long been theorized by scholars. Born out of discrimination and oppression are feelings of despair, loneliness, isolation and hopelessness threads that ran across many of the participants experiences.

Research suggests that whilst Black women face many of the same struggles as White women, Black women also have to face issues of diversity on top of inequalities (Hall, 2018). This appears consistent with the experiences of the participants within this study whom were all women. This could also explain the findings of existing studies (Greenwood, 2018) which suggest that Black carers are less likely to access and engage with formal services than their white counterparts, even though they report greater need for support.

The current study has identified several potential recommendations for the therapeutic treatment of individuals who identify as Black. Farooq and Abbas (2013) reported that giving ‘voice’ and choice to clients who access psychological services is fundamental to the work of psychologists. These authors argue on the importance of developing culturally appropriate psychological interventions. McIntosh (2017), makes a good point when she argues that the lived experience of ethnic minorities may be impacted by the degree of acceptance, understanding, prejudicial attitude, stereotyping and ignorance that exists within the dominant culture where they reside. Thus, feeling accepted is important.

In light of the current study’s findings, it is suggested that counselling psychologists need to extend their knowledge of provision of care to an ethnically diverse population using a more multifaceted approach. Extending their knowledge of Black issues will help counselling psychologists engage with the client’s frame of reference and build a stronger therapeutic alliance where the carers can feel heard and validated. Lago (2011) aptly argues that it is now well evidenced that ‘it isn’t the model of therapy that determines the outcome; it’s the quality of the relationship between the therapist and the client’.

As Counselling psychologists, we have a significant part to play through enabling people to recognise and understand what constitutes and contributes to racism raising awareness is imperative in providing culturally appropriate services. This suggestion is supported by Solomos (2003) who argues that racism in a wider context is not a fixed phenomenon but an integral element of diverse social issues. This present study suggests that carers who identify as Black might be more likely to access support services that they felt met their cultural needs. Existing studies (Gallagher-Thompson & Coon; 2007; Elvish, Cawley & Keady, 2012) found that counselling and psychological interventions for carers can give an all-important, safe and confidential environment where individuals can vent feelings of anger, depression, grievances, create and try out different coping strategies and advocacy roles. Training practitioners to work with diversity along with the complexity of the appears to be of importance here.

Conclusion

Consistent with previous research, the findings overall seem to suggest that cultural awareness is important and primary and secondary care services need to consider what constitutes and contributes to the experiences of carers who identify as Black, considering how ethnic identity and culture impact on the presenting issue using a more pluralistic approach.

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