Black Africans in the UK's experiences of treatment for common mental disorders and their strategies for maintaining their ongoing mental wellbeing

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Abstract

In the UK, mental health disorders are responsible for the largest proportion of the total burden of disease. Common mental disorders (CMD) such as depression, anxiety and stress related conditions are the leading cause of sickness absence.

The proportion of people with a mental disorder accessing treatment has increased, although it is estimated that c75% of people may not access treatment services. People from White British backgrounds are more likely to receive treatment (13%) compared to BAME groups (7%). The lowest proportion of people receiving treatment are Black ethnic groups compared to their population in England. In order to improve uptake, it is essential to understand what drives engagement with services amongst Black Africans and how they maintain their mental wellbeing. This thesis aims to contribute towards providing a more holistic picture of the pathway to care, treatment and ongoing wellbeing maintenance amongst Black Africans to further inform strategies, service planning and delivery.

A qualitative research methodology was adopted; in-depth interviews with sixteen participants were conducted to explore experiences of Black Africans with a CMD. Interviewees were split into four categories based on the theoretical framework used, Kleinman et al., (1978) model of healthcare system and explanatory model of illness. The categories were people with a CMD, family/friends supporting someone with a CMD, mental health professionals and traditional healer/faith leader that support people with a CMD.

The findings showed that perceptions of mental illness are key in how people make sense of the symptoms they experience. Stigma and fear of judgement is viewed as being present across the 'system' including healthcare, which impacts health seeking behaviour. Motivations for seeking support were based on the need to get 'fixed', as people reached a point of being unable to cope on their own or crisis point. Two approaches used to maintain wellbeing are coping strategies learnt through therapy and having a social support network.

Integrating statement

The DrPH programme aims to prepare its candidates with the experience to deal with key challenges of understanding and adapting scientific knowledge in order to achieve public health gains, in addition to the analytical and practical skills needed by managers and leaders in public health. It enables the development of both expertise to carry out and evaluate research and skills essential for leadership roles in public health policy and practice. This is what drew me to apply for the programme. As someone that was already working in a project management role delivering public health services, I felt the programme would give me the academic background I lacked, being a biological science graduate, to continue developing my skills and practice. With a keen interest in research, the DrPH course would offer me an opportunity to also develop those skills and contribute to a body of knowledge based on the interests I held.

One of the main pieces of advice imparted on my DrPH cohort during orientation was that the programme particularly the taught modules, are at a doctoral level and we will see a marked difference from masters level modules. The Evidence Based Public Health Policy & Practice (EBPHP) module was my first introduction to the programme and I quickly recognised that it would challenge my critical thinking, ability to synthesise large volumes of information, analyse and consider how it all sat in the context I operated in, as well as how I could begin to refine my practice. As a part-time student with a demanding job, the challenge of balancing that pressure with reading in preparation of the weekly lectures helped to focus and make me more organised. This pre-reading was essential in being able to contribute meaningfully to the discussions during lectures. The two assignments particularly conducting a systematic review, proved to be the most intellectually challenging piece of work to complete for the module. With no prior experience of carrying out such a review, on reflection over the years following, I appreciate the value of gaining that experience.

One of the difficulties of remaining employed throughout my DrPH was that I could not do both taught modules in the same semester. On completion of EBPHP, I registered for the Global Mental Health masters module in the following semester to take the opportunity to further my academic knowledge. With an intention to focus my thesis research on mental health, I felt this module would start preparing me for that part of the DrPH programme. Undertaking this excellent and well taught module really emphasized the step change of the DrPH modules' content. I also took the opportunity to attend some of the courses on the Transferable Skills Programme such as qualitative research skills, in preparation for other parts of the DrPH.

Understanding Leadership, Management & Organisations (ULMO) gave me an opportunity to reflect on my own practice as a professional. Perhaps one of the highlights of the module was the residential that I went on with others in my second cohort. It gave me an opportunity to look into different leadership styles including my own, working within teams more efficiently and examine how I could develop myself to reach the goals I wished to achieve. The lectures also gave an opportunity for further reflection on the management of organisations which I was immersed in through my work. This included looking at the importance of good governance structures and processes in the running of organisations.

Both the EBPHP and ULMO prepared me for the next phase of the programme, the Organisational and Policy Analysis project (OPA). I was keen to carry out my OPA at an organisation I was working at however, this coincided with very broad system-wide and organisational changes as a result of the Health and Social Care Act 2012. Public health teams from Primary Care Trusts transitioned over to the local authorities of the boroughs they covered from 2013. The transition process was very complex as adjustments to staffing structures were made and new ways of working adopted. This impacted on the process of getting approval to carry out my OPA when I joined Wandsworth Council. I had to pay particular attention to political sensitivities within the organisations. I carefully considered the topic on which to focus to ensure it would be welcomed or not objected to by senior managers. This process in itself was a great opportunity to improve my political astuteness, which is important in understanding how organisations are led and function. Getting a greater understanding of how the shift from operating within the NHS to being embedded in an organisation led by local politicians influenced how the public health team continued to carry out some of its services, became the basis for my OPA.

My project focused on Wandsworth Council and examined the influencing strategies used by the public health team to ensure continued investment on a number of its non-prescribed services that were being reviewed, due to spending cuts or required re-commissioning. I took a qualitative approach using documentary evidence, semi-structured interviews and participant and non-participant observation to gather the data. The findings illustrated that the public health team liaised with a wide range of stakeholders within the council and externally to execute its functions. The tools they utilised to influence decision making were based on aligning the team strategically in the council and embedding its agenda through allies particularly elected members. Carrying out the OPA gave me an opportunity to develop my qualitative research skills in preparation for this thesis research.

Focusing my thesis on mental health in Black African communities has been a passion project for me. I often reflect on the time I worked on my application to join the DrPH course through to meeting my supervisor for an interview to discuss my interests. I applied for the course a year in advance because I was very keen to embark on this professional development journey and contribute towards shedding light on the topic of mental health in the community I am a part of. The thesis process has allowed me to further develop my skills as I would like to be involved in research as my career evolves. I have drawn on my learning from the different stages of the DrPH to carry out this research. From refining my topic to keep within the scope of the DrPH, through to identifying the best means of collecting data and the analytical framework to adopt. I carried out the bulk of my data collection, analysis and report writing during the COVID-19 pandemic. This introduced many challenges with recruiting participants however, it also gave me time to be able to work on my write up due to the advantages of working from home.

Reflecting broadly on my experience of the DrPH, I can say I have wholeheartedly enjoyed this journey. The structure of the course allowed me to continue working whilst I learnt and developed my professional practice which was really important to me. I have also seen my personal growth which is partly as a result of this experience. Although I encountered many life challenges along the way, it has been a very rewarding experience. Transitioning from a biological science background to social science has been a big shift and it allows me to view things with different lenses. We often hear of people's difficult experiences of completing doctorate degrees because of the immense pressure and so many other factors. These stories can be daunting for novice researchers and during those difficult moments, it can make you question whether you will ever get to the finish line. I think one of the most valuable aspects of this journey, has been having the time and space to complete it at the pace that was right for me. This I feel is really important when you embark on such a journey.

Acknowledgements

The most important aspect of this journey has been keeping my motivation high and persevering through all the challenges. I would like to firstly thank my primary supervisor, Dr Nicki Thorogood, for her constant support, encouragement, motivation and guidance throughout my time on the programme. I also wish to thank my second supervisor, Dr Julian Eaton, for offering different perspectives, guidance and challenging me to examine different areas of my thesis even further. I thank Dr Mary-Alison Durand for taking the time out to review my thesis and provide valuable feedback.

I would like to thank all the interviewees that took part in this study and generously gave their time and shared their stories. My thanks also go to my former Wandsworth Council colleagues, that gave me an opportunity to carry out my OPA and their time.

My biggest gratitude goes to my parents, Dembo Fanta Bojang and Sukai Mbye Bojang. They invested in my education, nurtured and enabled me to reach a point where I am able to further invest in my personal development. I would also like to thank my siblings, cousins, aunties, uncles and friends for their continued encouragement, prayers and support. Also thanking my better half for being patient and supportive throughout the highs and lows.

I dedicate this thesis to my grandmothers, the matriarchs of my family, without whom, our lives will not be as rich and full. I thank them for their sacrifice, wisdom and nurturing throughout my life.

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Glossary

BAME	Black and Minority Ethnic
CAMHS	Child and Adolescent Mental Health Services
CBT	Cognitive Behavioural Therapy
CCG	Clinical Commissioning Group
CMD	Common Mental Disorder
CMHT	Community Mental Health Teams
EMPIRIC	Ethnic Minority Psychiatric Illness Rates in the Community
IAPT	Improving Access to Psychological Therapies
ICS	Integrated Care System
LTP	Long Term Plan
MHFYFV	Mental Health Five Year Forward View
NHSE	NHS England
NPoC	National Programmes of Care
NICE	National Institute for Health and Care Excellence
ONS	Office of National Statistics
SMI	Serious Mental Illness
VCS	Voluntary and community sector
WHO	World Health Organisation

Population profile – snapshot

1. *The 2011 census put a spotlight on the growing diversity of England and Wales' population. Amongst the 56.1 million residents in England and Wales, about 13% (7.5 million) were born outside of the UK. Forty-six percent of the population born overseas identified with a White ethnic group, 33% as Asian/Asian British and 13% as Black/African/Caribbean/Black British* (ONS, 2015).
2. *95% of Black Africans born outside the UK arrived after 1981* (ONS, 2015).
3. *Of the total population that were born overseas, 48% identified as Christian, 19% as Muslim and 14% cited not having a religion* (ONS, 2015).
4. *Black and minority ethnic groups are more likely to be concentrated in London and the Midlands* (GOV.UK, 2011).

1. Background and introduction

The WHO defines mental health as "*a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community*" (World Health Organisation (WHO), 2014).

1.1 UK prevalence and burden of mental health disorders

The burden of mental health disorders has increasingly been a topic of focus in developed countries. In the UK, mental health disorders are responsible for the largest burden of disease, 28% of the total burden, compared to 16% each for cancer and heart disease (Ferrari *et al.*, 2013). It is estimated that about 1 in 4 people in the UK will experience at least one diagnosable mental health problem in any given year (CentreForMentalHealth(forNHS), 2016). According to the Adult Psychiatric Morbidity Survey carried out in 2014 (report published in 2016), in England, 1 in 6 people reported experiencing a common mental health problem such as anxiety and depression, in any given week (McManus *et al.*, 2016). The Survey also provided estimates for bipolar, psychotic and personality disorders. Estimates for bipolar disorder, psychotic disorder and personality disorders are usually measured over a person's lifetime, rather than each year. Estimates can vary quite a lot but according to the survey findings, 0.7 in 100 people have a psychotic disorder, 2.0 in 100 people have bipolar disorder and 3.3 in 100 people have antisocial personality disorder (McManus *et al.*, 2016).

About half of all mental illnesses are established by the age of 14 and this rises to 75% by the age of 24 (CentreForMentalHealth(forNHS), 2016). The impact of mental illness on people's life experiences is considerable, resulting in suffering, distress and disability. There is also considerable impact on health and social care as well as a cost to the economy estimated at £105 billion a year (CentreForMentalHealth(forNHS), 2016). In the UK, it is estimated that 70 million days are lost from work each year due to mental ill health (i.e. depression, anxiety and stress related conditions), making it the leading cause of sickness absence (Davies, 2014).

People in marginalised groups are at greater risk of being diagnosed with a mental health condition. These include Black, Asian and minority ethnic (BAME) people, gay, lesbian, bisexual and transgender people, disabled people, people who have been in contact with the criminal justice system, and others. BAME households are more likely to live in poorer or over-crowded conditions, which increases their risks of developing mental health problems (CentreForMentalHealth(forNHS), 2016).

There are close ties between physical and mental health. A report by The King's Fund in 2012 stated that 30% of people with a long-term physical health problem also had a mental health problem and 46% of people with a mental health problem also had a long-term physical health problem (Naylor *et al.*, 2012). The public, private and voluntary sectors in the UK continue to develop initiatives aimed at improving access and provision of mental health services and in particular focusing on adapting services to make them more effective and meet the varying needs of a diverse population. All these developments are reliant on realistic estimates of the incidence and prevalence of mental illness amongst different population groups, as well as issues relating to how they engage with services (Rees *et al.*, 2016).

It is recognised that grouping people together under broad ethnic categories can create difficulties as it conceals significant differences within the categories (Aspinall, 1998; Bhopal, 2002). It is difficult to get a realistic picture of mental illness prevalence amongst different minority ethnic groups due to the limited availability of population surveys examining this, as well as the lack of focus on other mental illnesses besides psychotic disorders and individuals' contact with healthcare services for these conditions. This is largely due to limited access to surveying sufficient numbers of ethnic minority participants (Sproston and Nazroo, 2002).

There has been relatively little research on mental illness in primary care and community settings given that most common mental disorders (CMDs) are often treated at this level. Lloyd (2009) suggests that rates of CMDs may be underestimated in cross-cultural research as some psychological symptoms which could be presented as somatic symptoms in some ethnic groups, may be overlooked (Lloyd, 2009). The characterisation of certain CMDs such as anxiety and depression as part of everyday life and so therefore not serious enough to seek help, unlike serious mental illnesses, may, for instance, have an impact on the number of Black Africans presenting in primary or community care for these disorders. Fewer people are likely to present to primary care for CMDs (Lowenthal *et al.,* 2012). Lloyd (2009) proposed there may be other factors influencing presentation in primary care and whether symptoms can be attributed and diagnosed as a CMD such as language, age at migration, employment, sex and social position (Lloyd, 2009). For instance, in 2016/17, 64% of people referred for psychological therapies were women. Additionally, service level data in 2016/17 showed that people living in areas of deprivation were twice as likely to be referred for psychological therapies compared to those living in the least deprived areas, demonstrating that socio-economic status is a key factor in the referral for a CMD. People that are unemployed or economically inactive are significantly more likely to receive a treatment referral for a CMD compared to those that are employed (Baker, 2018). There is evidence that these contextual factors can adversely affect people's mental and emotional wellbeing (NHS England, 2016a).

Whilst it is difficult to get accurate records of the incidence and prevalence of CMDs particularly amongst ethnic minorities, there has been some research which offers an insight, one of the most notable being the EMPIRIC study (Weich *et al.*, 2004). The study found there was a relatively higher prevalence of anxiety amongst South Asian women (63.5%) compared to White women (28.5%). Outside of such studies, service level data is often used as a proxy measure of incidence. The recent political and media attention that mental health has received, may have led to an increase in referrals to services and better engagement therefore suggesting that incidence is on the increase (NHS England, 2016a).

In 2020, the COVID-19 pandemic caused a great deal of hardship for individuals, families and businesses. It has caused economic uncertainty and the deepest recession on record in the UK's history (HM Treasury, 2020). The pandemic has also shone a light on the number of people across the population that are struggling with a mental health disorder. BAME communities have been especially affected by the pandemic, not only in terms of health outcomes from contracting COVID-19 but also their mental health (Smith, Bhui and Cipriani, 2020). A survey carried out by Mind (mental health charity) of 14,000 adults during the pandemic, showed that existing inequalities in finances, employment and housing as well as other issues greatly impacted the mental health of people from BAME communities compared to people from White backgrounds (Mind, 2020).

1.2 Purpose of this thesis study

As noted above, the burden of mental illness can have considerable impact on the lives of affected individuals and their families. It also has implications on the national health, social care provision and wider economy. There is limited data and research on mental illness at a granular level that focuses on BAME groups and less so looking at groups within this broad umbrella describing many ethnicities. As already mentioned, people in marginalised groups of which BAME groups are one, are at greater risk of being diagnosed with a mental health condition. To improve outcomes for these groups, it is important to carry out research which specifically examines the experiences of individual ethnic groups, of managing their mental wellbeing and which takes it a step further by focusing on a group of mental illnesses, such as common mental disorders (CMD). This thesis focuses on one of the populations within the BAME umbrella, Black Africans. The study seeks to understand the key motivations that drive engagement with mental health services amongst Black Africans living in the UK once they receive a diagnosis of a CMD or define it themselves, assuming they do engage with services. The study also examines how people go onto maintain their mental wellbeing following treatment if received. The aim of this research is to contribute towards providing a more holistic picture of the pathways to care, treatment and ongoing maintenance of their health amongst this ethnic group living in the UK. Section 2 further details the research questions this thesis is seeking to answer.

1.3 Raising the profile of mental ill health in the UK

Over the last decade, there has been a number of high-profile campaigns which aimed to raise awareness of mental illness, improve the public's knowledge, challenge the stigma associated with it and encourage people to seek help early. One of the notable campaigns, Time to Change, focused on reducing public stigma and discrimination towards people with mental illness. The campaign featured the personal stories of a number of celebrities that had experience of mental illness. An evaluation of the campaign showed a "step change" increase in positive attitudes in some key areas such as prejudice and exclusion (Evans-Lacko *et al.*, 2014). In recent times, a member of the British Royal Family gave a televised interview discussing his experience of mental ill health. Such activities have been a key motivation for the development of national strategies, policies and guidance on how improvements could be made to services to better meet the needs of local populations. It has also been a driver for increased investment by the government into mental health care.

1.4 The five year forward view for mental health – Taskforce strategy

"The NHS needs a far more proactive and preventative approach to reduce the long-term impact for people experiencing mental health problems and for their families, and to reduce costs for the NHS and emergency services" (CentreForMentalHealth(forNHS), 2016).

February 2016 saw the publication of the mental health taskforce five-year strategy. It set out the state of mental health service provision in England and the ambition to deliver major improvements for 1 million more people with mental health illnesses, to access high quality care (CentreForMentalHealth(forNHS), 2016). The strategy sets out 58 recommendations to work towards the government's ambition to achieve parity of esteem between mental and physical illness, provide access to good quality mental health care and ensure people have a decent place to live, employment or good quality relationships in their local communities (CentreForMentalHealth(forNHS), 2016). The importance of reducing inequalities amongst people that are disproportionately affected by mental health illnesses such as those from BAME communities (see section 1.7 below for further details), people that live in poverty or are unemployed is strongly highlighted in the strategy. All recommendations in the strategy were accepted and the need for annual investments of £1 billion per year was identified to enable its delivery (CentreForMentalHealth(forNHS), 2016). Work has been underway to develop more responsive and accessible mental health services including improved access and reduced waiting times for psychological therapies.

At the end of 2018, the NHS Long Term Plan was published which made a renewed commitment to improve and widen access to care for children and adults needing mental health support. The plan aims to deliver the fastest expansion in mental health services in the history of the NHS. Thousands more adults will be able to access talking therapies for common disorders and mental health liaison teams will be expanded. It also plans to improve how people with serious mental illnesses (SMIs) are treated by the NHS, including during crisis. Additionally, it will ensure more mothers experiencing severe mental health issues get the treatment they need and, for the first time also see their partners offered mental health support. The funding committed to enable delivery of these services was extended to a minimum of £2.3bn a year by 2023/24, making it a faster increment rate than the NHS budget (NHS, 2019a). It is uncertain what impact the pandemic will have on future spending on mental health and other health services, as measures are put in place to recover the economy, once the pandemic is at significantly reduced levels (HM Treasury, 2020).

1.5 Commissioning of mental health services

The commissioning and delivery of mental health services is complex much like the organisation of a lot of health services. The commissioning models adopted have a subsequent impact on service delivery at a national, regional and local level. In England, some services are commissioned by NHS England/Improvement (referred to from hereon as NHSE) whilst others by Clinical Commissioning Groups (CCGs), local authorities as well as the third sector. Figure 1 below shows the organisations involved in the commissioning process in each local healthcare system across the country. Each local system has its own governance processes for making commissioning decisions and implementing services (NHS England, no date).

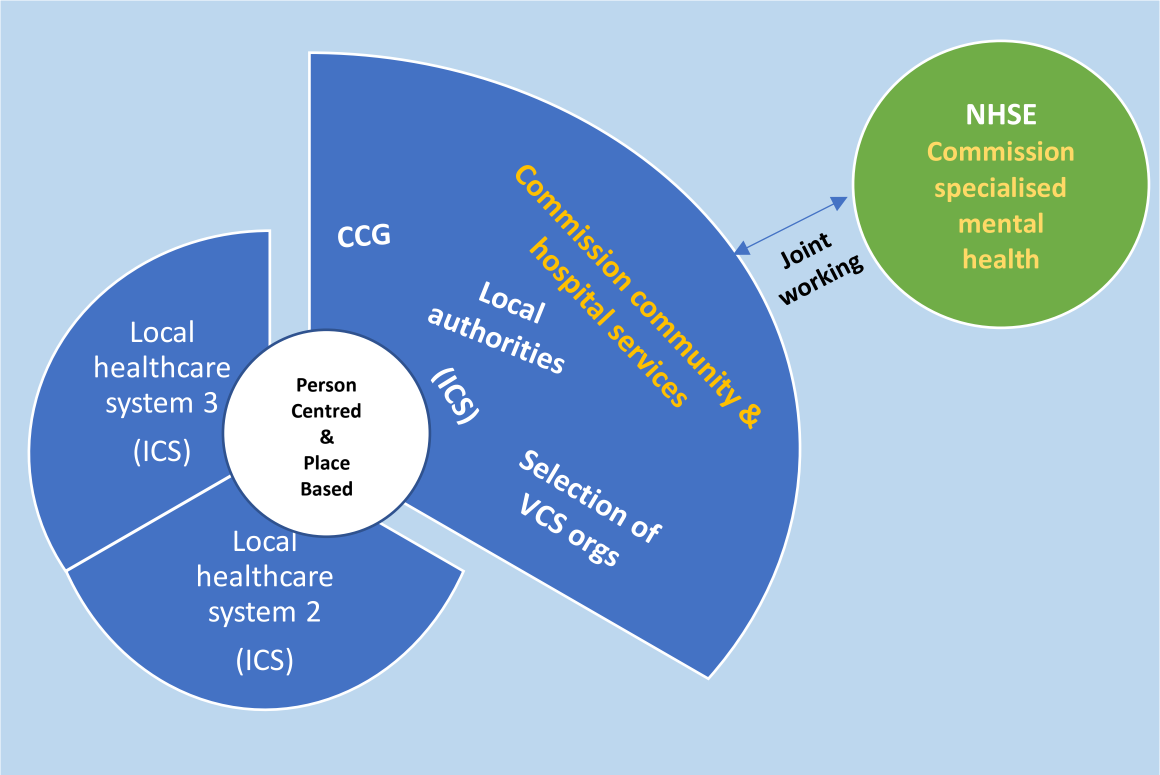


Figure 1. Overview of organisations involved in commissioning in local healthcare systems.

NHSE has the remit of commissioning specialised mental health services (NHS England, no date). CCGs commission most of the hospital and community NHS services in the local areas they are responsible for. This includes mental health and learning disability services, which are often coupled together. Although this responsibility has been discharged to CCGs, NHSE still retains an assurance role to ensure CCGs are making appropriate investments and decisions on health service provision, on behalf of their local population. As the health and care system continues to transform with local NHS organisations and local authorities working closer to deliver more joined up care, these will transform into Integrated Care Systems (ICS). Section 1.1 outlines the links between mental health problems and factors such as poor housing, homelessness, poverty, disability and long-term illness, experience of violence or abuse, immigration status (e.g. refugees and asylum seekers), veterans, the lesbian, gay, bisexual and transgender community (LGBT), looked after children, and some BAME groups (Local Government Association, 2018). As an ICS evolves, it will have greater freedom to manage the operational and financial performance of services in their area and deliver more joined up care (NHS England, 2019a).

Integral to mental healthcare provision, is the voluntary and community sector. The sector's main role in mental health services is in provision. An estimated 1.5 million people a year access CCG funded mental health services from this sector, making it the largest forum of provision (Bell and Allwood, 2019). The sector however has a role in commissioning as well, albeit this may be on a small scale when compared to the number of organisations involved in service provision. In most cases, the organisations that sit on forums where decisions are made on priorities to progress, services to commission, models of commissioning, often make these contributions on a pro-bono basis (Holder, 2013).

Challenges still exist in addressing complexities of service commissioning across the country such as effective partnership working. The NHS Five Year Forward View for Mental Health states services should deliver integrated physical and mental healthcare. The needs of local populations are currently tackled in isolation, which is not effective or efficient (CentreForMentalHealth(forNHS), 2016). Further information on service commissioning is provided in Appendix 1.

1.6 Mental health services delivered

Mental health services are delivered throughout the life course. As this thesis focuses on adult mental health, detail provided in this section will be on adult services. Much like the commissioning picture, delivery of mental health services is equally complex with different providers having responsibilities along the patient pathways. This section gives a brief overview of how services are typically arranged as it is relevant to findings in this thesis, specifically, the experiences of interviewees in navigating the system to access the support required. Further information on service delivery is provided in Appendix 2.

Service provision is largely divided into the categories of

- acute and crisis
- secure

- community settings

Providers of services include primary care, acute care, mental health trusts, community health trusts, voluntary and community sector as well as private providers. Services are sometimes delivered as a standalone although often done in partnership with other providers, such as a mental health trust working with ambulance services (NHS Providers, 2017). Figure 2 shows an example of mental health services that are commissioned and delivered by the local healthcare system. Partners in the public and voluntary sectors are delivering a mixture of services in Birmingham and Solihull ranging from peer support initiatives through to crisis response (Birmingham and Solihull CCG, 2017).

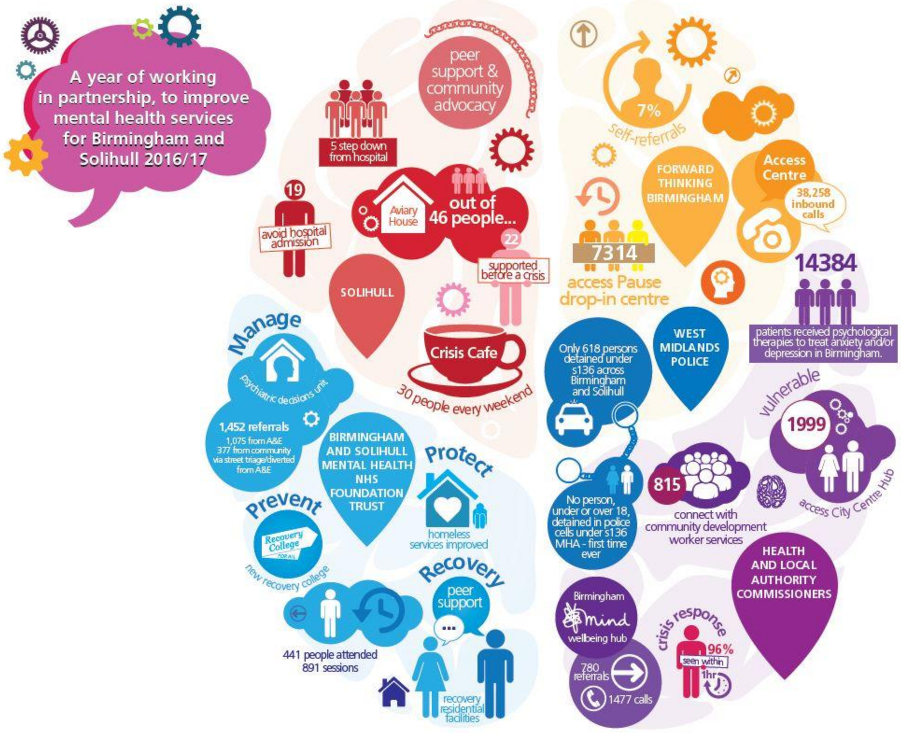


Figure 2. Joint commissioning and service delivery model in Birmingham and Solihull (Birmingham and Solihull CCG, 2017)

1.6.1 Acute and crisis services

Intensive support for people who are experiencing an acute or 'crisis' episode during their mental illness is provided by these services. Typical service models include the provision of short-term, intensive periods of support in a patient's home or in the community, to prevent an unnecessary hospital admission. If a short hospital stay is needed, healthcare staff work with patients to create a plan to get them home as soon as it is safe to do so. Patients have to be referred by a healthcare professional to access such support. There is an increasing move to provide as much treatment and support in the community as possible (NHS England, 2020). Figure 3 shows an example of a referral pathway to access acute and crisis services. This pathway is delivered in South West London (Merton Council, 2016).

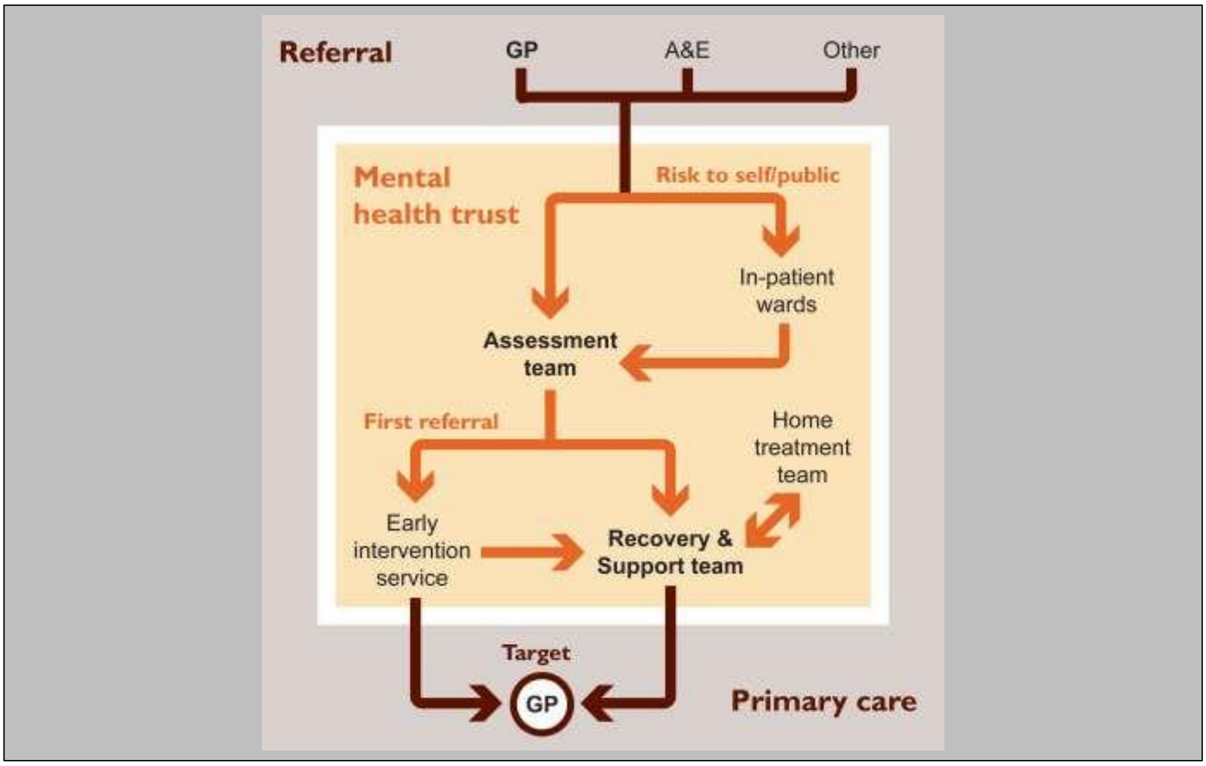


Figure 3. Referral pathway into mental health services in South West London (Merton Council, 2016)

It should be noted that several studies have highlighted the overrepresentation of Black people in psychiatric hospitals and that their need for mental health help is identified through crisis services and the Mental Health Act. This is at higher levels when compared to White populations (Bhui and Bhugra, 2002).

As with other commitments made in the Long Term Plan, over £200 million of national funding is to be allocated between 2020–2022, to enable local areas to transform their urgent and emergency mental health care pathways through a network of services. The funds will also enable the roll out of new or extended crisis services such as safe havens, crisis cafes and crisis houses in every region (NHS England, 2020). Such services are typically delivered by the voluntary sector and NHS organisations which are highly regarded by patients. Some of these organisations work in collaboration with others that deliver services mainly for BAME communities such as The Black, African Asian Therapy Network or run specialist services targeting for instance Black men, like the charity, Mind (Mind, no date; The Black African Asian Therapy Network, no date; NHS England, 2020).

1.6.2 Secure services

Secure / forensic mental health services provide accommodation, treatment and support in high, medium and low secure facilities as well as in the community, for people with severe mental health problems that are perceived to pose a risk to the public. Services predominantly work with people who have been imprisoned or admitted to hospital through the 1983 Mental Health Act following a criminal offence (Durcan, Hoare and Cumming, 2011).

High secure units admit people detained under the Mental Health Act and who need treatment in high security facilities because they are presumed to be dangerous, violent or have criminal propensities. Medium secure units were developed after the opening of high secure units, to bridge the gap between high secure and general psychiatric care (Duke *et al.*, 2018). Again, similar to acute and crisis services, BAME populations are overrepresented in secure units. Data shows that first admission rates into forensic settings for half of England and Wales were 5.6 times higher among Black men in comparison to White men. The rates of admission among Asian men were half of that of White men and Black women's rates were 2.9 times higher compared to White women. One of the reasons cited for the difference in admission rates observed is the lack of early intervention by community mental health services to minimise progression down this pathway (Bhui and Bhugra, 2002). Low secure services provide care and treatment to people that may be a significant risk of harm to others and whose escape from hospital should be impeded (NHS England, 2018).

NHS England pledged to invest during 2020/21 in improving pathways in and out of secure care with a focus on expanding community services for people that need them. This is intended to prevent avoidable admissions and support step down and ongoing recovery in the community where appropriate (England, 2016).

1.6.3 Community mental health services

Community mental health services play a crucial role in the delivery of care by providing support to people closer to their homes and communities. These services are delivered by community mental health teams (CMHTs) which were established 30 years ago. Most CMHTs are entirely based in secondary care and are multi-disciplinary, including clinical and non-clinical staff (NHS, 2019b). The main role of some teams include providing ongoing treatment and support for people suffering from severe and enduring mental disorders such as bipolar disorder, psychotic depression and treatment resistant anxiety spectrum disorders (Hertfordshire Partnership University NHS Trust, no date).

As with other mental health services, the MHFYFV and LTP have ambitions to transform and modernise community services by developing new, integrated care models of primary care and community mental healthcare. There are a range of services delivered in primary care and other community settings for CMDs, as they do not meet the threshold for the services described above. Additionally, services are delivered for people transitioning from those accessed through the CMHTs (Cambridgeshire and Peterborough NHS Trust, 2020).

1.6.4 Mental health services in primary care and other community settings

Service models differ across regions to meet needs of local populations. The premise of these services is based on a person's needs rather than their diagnosis. Pertinent to this thesis is the ranges of services delivered in primary and community settings for CMDs. Providing high-quality mental health care in primary care, including GP practices, can transform people's experiences and their outcomes as well as that of their carers' and professionals involved in their care (NHS England and Improvement, no date). Receiving mental healthcare in a GP practice or other primary care setting, in comparison to hospital or specialist settings can be less stigmatising for service users. This model is expected to go some way in helping achieve parity of esteem between mental and physical health, as an individual's mental health needs can be viewed as a long-term condition that requires ongoing primary care support, similar to conditions such as diabetes and respiratory diseases. It will help promote mental health awareness and faster diagnosis through identifying and addressing their needs more quickly, accurately, to reduce the number of repeat assessments and frequent attenders. It will also help minimise attendance through crisis settings (NHS England, 2016b). Additionally, it will help deliver joined up care in treating the physical and mental health needs of patients (NHS England and Improvement, no date). Achieving this objective will go some distance in improving experiences of some people with a CMD as findings in this study suggest. This is discussed further in Sections 5 and 6 and the conclusions proposed are directly informed by findings in this study.

As noted above, a range of services for CMDs are delivered in these settings as well. The main form of treatment for CMDs is psychological therapies which includes counselling, Cognitive Behavioural Therapy (CBT), computerised CBT, family therapy, Dialectical Behaviour Therapy and creative therapies. The service most broadly delivered is the Improving Access to Psychological Therapies (IAPT) programme. The programme was developed as a systematic way to organise and improve the delivery of, and access to, evidence-based psychological therapies within the NHS. It has broadened the access to psychological therapies available as part of the NHS. IAPT services largely provide support for low to moderate depression and anxiety disorders (Rethink Mental Illness, no date). In most cases, people access psychological therapies through referral or signposting by their healthcare professional. Some services can however be accessed without a referral. IAPT services are characterised by three key principles:

a. Evidence-based psychological therapies at the appropriate dose/intensity
b. Qualified and supervised workforce
c. Routine outcome monitoring to ensure people receiving therapy have regular information on their progress.

The approach to service delivery uses a stepped-care model which works on the principle that people are offered the least intrusive intervention that meets their needs as a first line. A lot of people with mild to moderate depression or anxiety disorders are likely to be offered low-intensity treatment. People who do not fully recover at this level are then to be stepped up to high-intensity treatment. The recommendation by NICE is that people with more severe depression, social anxiety disorder or post-traumatic stress disorder should receive high-intensity interventions as a first line treatment. IAPT services sit within the wider healthcare system and are commissioned by CCGs. They are required to work closely with other health and care services to ensure people with needs that cannot be met by IAPT can access care at the right place and time (NHS, 2019c). Some participants that were interviewed for this thesis accessed psychological services through the IAPT programme and had varying experiences of access and the intervention provided to them. This is explored in the Findings section.

Outside of psychological therapies delivered by the NHS, similar services can be accessed in the voluntary sector. As of September 2018, there were over 168,000 registered charities in the UK delivering a broad range of services and initiatives for people (Charity Commission, 2018). There are many charities that solely focus on delivering mental health services whilst others have a broader remit of which mental health is one of them. Well known charities for instance Mind, operates in several regions offering services such as counselling and CBT to the local communities they serve. Additionally, they provide other supportive services that are not typically provided by public sector mental health services therefore complimenting this work. These include employment advice, training, benefits advice, befriending/peer support and support for carers to name a few (Mind Croydon, 2020). Work done by this sector is important but often an unacknowledged part of mental health care.

1.6.5 Non-commissioned mental health care support

As outlined in the above section, work done in the voluntary sector is not widely acknowledged as part of mental health care and accounts for a very small volume of the services commissioned. Similarly support provided through other means such as faith organisations and community groups are also often unacknowledged. However, the importance in mental health prevention, recovery and ongoing wellbeing of having a social network such as these organisations can provide is widely recognised (Memon *et al.*, 2016). A number of religions are practiced in the UK with the predominant ones being Christianity, Islam, Hinduism, Judaism and Sikhism (Office for National Statistics, 2020). There are huge numbers of faith organisations with varied membership. Some of these organisations take a very active role in providing informal social support to their members particularly around mental wellbeing (The Church of England, 2020). Some research studies have found that people from BAME communities often seek help from faith services before seeking medical support. This support is usually initiated by family and friends (Islam, Rabiee and Singh, 2015). These services are generally not part of the commissioned package; but are offered by such organisations as part of the roles they adopt in their communities. There are also an unknown number of small community groups running activities in local neighbourhoods, as arrangements governing their work is very often less formal. Activities they organise and run include leisure such as local walks / trips intended to give people an opportunity to socialise, through to coffee mornings and volunteering roles that give individuals meaningful work to carry out. These groups provide a support network to people especially those that may not have a broad family and friend network (Resource Centre, 2018).

Unpaid/informal care is another aspect of mental health care that does not form part of the formal commissioning or service delivery model. Again, the importance of social support is well recognised in the recovery of individuals (Parliament UK, 2018). Approximately 6.5 million people in the UK provide care worth an estimated £57 - £100 billion per year and this number varies across the country. These caring roles are often carried out by family, friends and neighbours (Parliament UK, 2018). The role of faith organisations, community groups, family and friends in the access to health care is explored further in the following sections.

Further information on service delivery is provided in Appendix 2.

1.7 Uptake of mental health services

There has been a gradual increase in the use of mental health services over the last number of years with data collection using a number of approaches enabling year on year increase to be tracked. According to the Adult Psychiatric Morbidity Survey in 2014 (McManus et al., 2016), 13% (original survey report noted 12.1% but this was corrected in 2017) of respondents reported receiving mental health treatment at the time of interview, with medication being the higher form of treatment compared to psychological therapies. For people with a CMD, 39% reported having treatment at the time of the survey (data corrected in 2017) (NHS Digital, 2020).

According to NICE, the proportion of people with a CMD that access mental health treatment has increased significantly in the last several years. Figure 4 shows an example of the growth in the number of people with a CMD accessing treatment following a referral to the IAPT programme. In 2012/13, around 450,000 people received treatment following a referral to IAPT and by 2017/18, this figure has almost tripled (NICE, 2019).

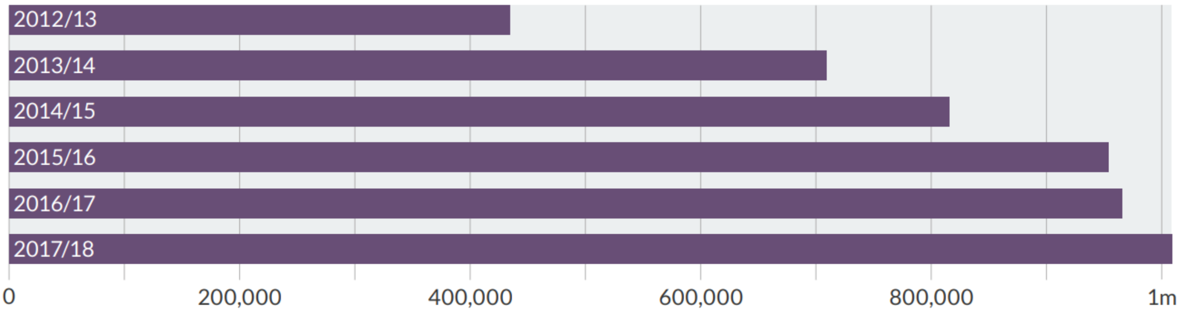


Figure 4. Number of people receiving treatment following referral to IAPT services between 2012/13 to 2017/18 (NICE, 2019)

Despite the huge increase in uptake of treatment for a CMD, it is estimated that about 75% of people with mental health problems in England may not access treatment services which has been one of the criticisms of the IAPT programme. The targets set for the programme are deemed to be low therefore not challenging the service enough to reach more people; additionally the period of time that people are engaged for should not be based on parameters set by commissioners, rather their needs (Clark, 2018).

In addition to the gap in number of people not accessing treatment, women are more likely than men to get care for all mental health conditions, with 15% of women having treatment compared to 9% of men according to the Adult Psychiatric Morbidity Survey (McManus et al., 2016). According to the Survey, people from White British backgrounds are more likely to receive mental health treatment (13.3%) in comparison to BAME groups (7%). The lowest proportion of people receiving treatment were Black adults (6.2%) (McManus S, et al., 2016). Data looking at the levels of IAPT service usage in 2013/14 amongst Black Africans relative to their population, suggests they are amongst the groups of ethnicities with the lowest usage (57.4%). Similar data on other BAME groups suggest for instance Black Caribbeans access IAPT services at a rate of 121.4% compared to their population (Anthony, 2015). The Adult Psychiatric Morbidity Survey in 2007 proposed that rates of CMDs amongst Black Africans are at least as high as in other populations, suggesting therefore that there are other factors at play influencing their access of psychological therapies which is vital to understand if we wish to facilitate their access to services (McManus *et al.*, 2009). This thesis is aiming to understand some of the factors that may be at play. The mental health taskforce five-year strategy pledges there will be increased provision of psychological therapies in order for 25% of people with CMDs to access services each year, so it would be important to increase uptake across all ethnic groups (CentreForMentalHealth(forNHS), 2016).

There are many factors that influence whether or not people seek help and how they may or may not choose to access services. As this research is focused on experiences of Black Africans and the previous section shows that uptake is lower amongst some BAME communities for some services, the following section will examine factors impacting uptake in more detail. It should be noted that there are limited studies specifically examining the CMD experiences of Black Africans in the UK, however available studies (generally include other ethnic minority groups within the BAME umbrella in addition to Black Africans) do offer valuable insight.

1.8 Barriers, pathways and facilitators to accessing mental health services amongst BAME groups

Research studies and service level data have shown that individuals from White ethnic groups are more likely to seek mental healthcare services early compared to BAME communities. Studies also suggest that levels of first contact with treatment services for psychotic illnesses are significantly higher in Black Caribbean people compared to other ethnicities (Sproston and Nazroo, 2002). Evidence also shows that people of African descent have lower levels of engagement with mainstream health services, are more likely to access them through adverse pathways and subsequently have poorer experiences and outcomes (Morgan, 2006). Socio-cultural factors such as social exclusion, racism, acculturation and differing descriptions of distress are often given as reasons for the differences observed in rates of psychotic illness. These factors are however also associated with increased risk of common mental disorders (Lloyd, 2009).

It is important to understand the key barriers, facilitators and pathways that BAME groups and specifically Black Africans experience in accessing mental health services in order to improve outcomes for this group, as this will be inextricably linked to how they maintain their ongoing wellbeing. Research studies have highlighted the themes outlined in the sections below.

1.8.1 Barriers

As mentioned above, there are disparities in the access to mental health services amongst BAME communities which cannot be attributed to low prevalence levels of mental illness. It is still unclear whether this variation is based on needs of BAME populations or the result of institutional, cultural and/or socioeconomic exclusion factors, which are known to disadvantage these groups (Mclean, Campbell and Cornish, 2003; Bhui *et al.*, 2003). Some evidence indicates that hard to reach groups including BAME communities are less likely to obtain mental healthcare due to certain barriers. In the study carried out by Memon *et al.*, (2016) looking specifically at the perceived barriers to accessing mental health services amongst BAME groups living in Brighton and Hove City, there were key themes that emerged which the authors classified broadly as personal and environmental factors, and relationship between service user and provider. The authors further expanded these categories to provide more detailed descriptions about the perceived barriers from their research findings:

1. **Symptom recognition** – An inability for individuals to recognise and attribute their symptoms to mental illness which is also the case in other communities. There is also a lack of awareness of mental illness compounded by the cultural belief that mental illness should not be discussed openly particularly with family members.
2. **Stigma and cultural identity** – Stigma towards mental illness within some communities made individuals reluctant to openly acknowledge their symptoms, therefore, restricting access to services. Family members may also be reluctant to seek help on behalf of their loved one due to stigma of being associated with someone that has a mental illness. Cultural background and identity defined acceptable responses to mental health problems and appropriate coping mechanisms. Some communities perceive mental illness as everyday challenges and therefore individuals should be able to cope with these challenges.
3. **Social networks** – For those with social networks, this is often the first point of contact for support and therefore providing an alternative to professional services. On the other hand, having a strong social network can also be a barrier, as it can be viewed as a viable alternative to accessing professional mental health services, especially if there is distrust within the community of formal healthcare services. For people that

do not have a broad social network, this is equally a barrier as there is no enabling support to help them access professional services.

4. **Waiting times** – Lengthy waiting times for assessments and services were identified as having a negative impact on outcomes for individuals as their mental illness was allowed to escalate in severity. Long waiting times is not only applicable to BAME communities but also other ethnicities.
5. **Recognition and response to needs** – Healthcare professionals' lack of recognition or empathetic response to needs of patients was cited as a barrier. The healthcare system is viewed as lacking flexibility and was therefore unable to support individual or cultural preferences especially in relation to available therapies. Non-medical approaches such as expressive writing workshops were not encouraged by healthcare professionals.
6. **Culture** – The lack of healthcare professionals that are from BAME communities who are perceived as understanding the needs and realities of BAME individuals is highlighted as a barrier.
7. **Awareness of services** – An unawareness amongst healthcare professionals of other services that could be accessed is highlighted as a barrier. Healthcare professionals are viewed as not having a wide knowledge of community organisations providing mental health support that individuals can be signposted to. This means the full range of treatment options available to service users cannot be discussed.

Three additional barriers highlighted by the authors included language, finances and communication. These are further articulated in Appendix 3. The findings of the Memon et al., (2016) study are consistent with that of Weich *et al.*, (2004), Tabassum *et al.,* (2000) and Arthur *et al.,* (2010) with a particular emphasis on barriers around language, communication and stigma.

A community development project delivered in the London Borough of Redbridge in 2008 to understand barriers to accessing mental health support amongst BAME groups also found similar barriers to the study by Memon et al., (2016). Barriers included not acknowledging symptoms being experienced, attributing symptoms to social issues rather than medical, reliance on family support instead of accessing help from healthcare professionals, perception that accessing primary care services will be difficult or may be inappropriate and lack of access to alternative therapies (Keynejad, 2008).

In the study conducted by Anthony (2015) examining Black Africans experiences of navigating pathways to access IAPT services, the barriers highlighted were stigma/shame, reluctance to disclose information to others to help dispel myths, a lack of knowledge and information about mental health issues and services, different world views about prevalence of CMDs amongst Black Africans and negative experiences of accessing services (Anthony, 2015). Stigma and shame were key issues that influenced the other barriers highlighted. Participants in the study by Anthony (2015) related it to a fear of being rejected by their community if their mental health issue was disclosed which then influences whether they seek help and attempt to improve awareness (Anthony, 2015).

Brown et al., (2011) examined the differences between Black African and White British women's perceptions of depression and help-seeking, and found that Black women held stronger beliefs that depression would not seriously impact their lives, assumed it would be less chronic, and less responsive to treatment (Brown *et al.*, 2011). They also linked fewer symptoms with depression and were more likely to deem it as a social issue rather than medically caused. This in turn influenced their help-seeking decisions. One of the main help-seeking barriers highlighted was GP-consultation difficulties as it was felt that GPs would not understand the issues, lack empathy and they were not the right people from whom help should be sought (Brown *et al.*, 2011).

All the studies above share some commonalities in their findings about BAME populations and specifically Black Africans. These are largely around stigma/shame, not associating their symptoms with mental illness, lack of awareness of suitable services to access, a perceived lack of empathy from healthcare professionals, the role of their community and culture and acceptable forms of managing mental illness. A number of the findings in this thesis research are also consistent with these studies as described in further detail in Sections 5 and 6.

1.8.2 Pathways

Pathways to mental healthcare services have been described as "the sequence of contacts with individuals and organisations prompted by the distressed person's efforts, and those of his or her significant others, to seek help as well as the help that is supplied in response of these efforts" (Rogler and Cortes, 1993). The AESOP study noted that there was variation in the pathways and patterns of use of mental health services between ethnic minorities and White British populations (Morgan *et al.*, 2005). Ethnic minorities were less likely to engage with their GP about mental health issues within a 12-month period for prescriptions of anti-depressants or referral for specialist services (Bhui *et al.*, 2003). As previously mentioned, individuals from BAME communities often access services at the point of crises such as detention under the Mental Health Act or via the police/judicial system (Bhui *et al.*, 2003; Fearon *et al.*, 2005).

Studies into the pathways to mental health care rarely examined other forms of help seeking aside from contact with statutory services which provides a one-dimensional view. A study by Gater *et al.*, (1991) carried out across 10 countries, suggests that traditional healers were often accessed for support by Black Africans particularly in areas of low service provision, which led to delays in receiving formal treatment. The use in African countries of traditional healers' services to address issues such as health concerns is presumed to be widespread (Ae-Ngibise *et al.*, 2010). Kleinman's (1978) model of healthcare systems as indicated in Figure 5 below takes a broad view of different help seeking avenues and people's perceptions of illness, which includes seeking help from traditional healers. The model is proposed to depict the total healthcare system of any society. It considers help seeking through traditional practitioners and healers (Folk Sector) as well as mainstream healthcare services (Professional Sector). In this model, the Professional Sector adopts a bio-medical perspective while the Folk Sector functions using cultural and religious interventions to treat disease. The Popular Sector entails the general population and in particular family and friends of those that have an illness, who are a key part of the decision-making on where the individual should seek care from (Fenenga *et al.*, 2016). Kleinman proposed that between 70% and 90% of illness is managed solely within the Popular Sector. Additionally, most decisions concerning when to seek help from the other sectors, whom to consult and whether to comply and evaluations of the efficacy of treatment are also made within this sector.

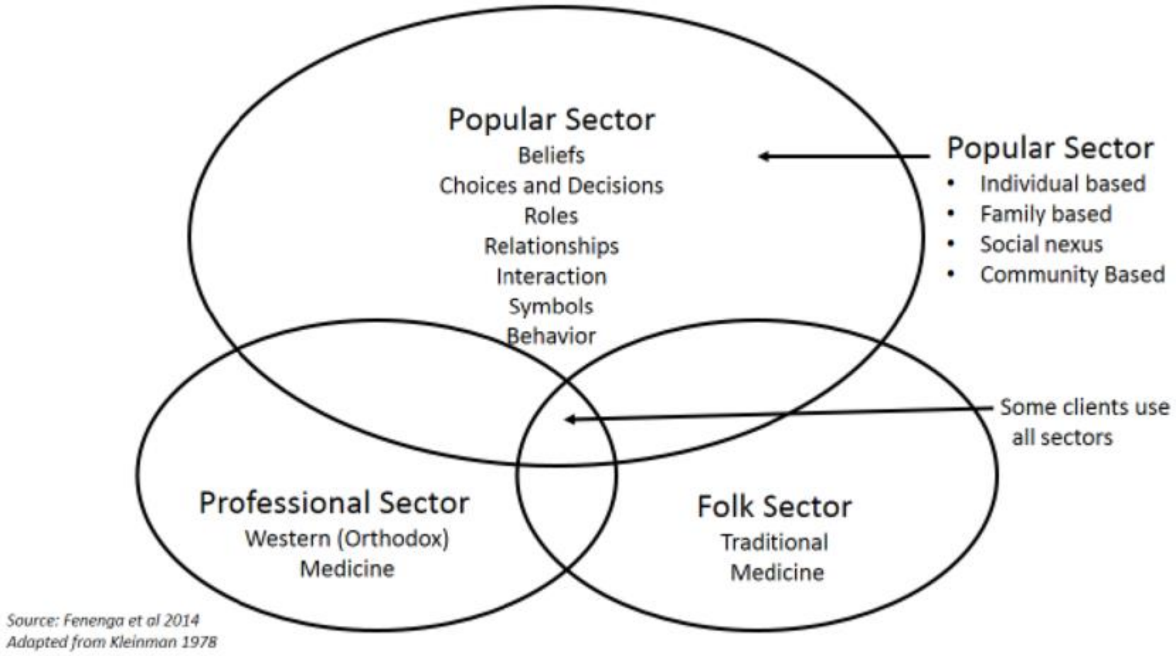


Figure 5. Kleinman's model of healthcare systems (source Fenenga *et al.*, 2014, cited in Fenenega et al., 2016)

Further to Kleinman's work on the model of healthcare system, he also developed an explanatory model of illness to enable physicians improve their understanding and the patient's experience of care. The model aimed to respond to patients' feedback that reported "dissatisfaction, inequity of access to care and spiralling costs" (p251), issues which Kleinman regarded as being unable to be solved through traditional medical approaches. Kleinman defined illness as being flexible across cultures and individuals whilst disease has a fixed definition and diagnosis. This means that every patients' experience of a certain disease may be felt, described and understood in a different way, therefore causing patients with the same disease to classify themselves with a different illness (Kleinman, Eisenberg and Good, 1978). This is also true of the way patients perceive and describe their mental illness and so is an important factor in how and where they seek care and support. The explanatory model of illness has been widely critiqued by anthropologists as being limited in its breadth and not sufficiently capturing the role culture plays in illness and disease. It still however continues to be used in the biomedical community for topics such as mental health disorders and somatic diseases (Skelly *et al.*, 2006; Kokanovic *et al.*, 2008). Kleinman's (1978) model of the healthcare system and the explanatory model of illness is important in framing some of the findings in this thesis and will be further explored in Section 3.

In the study by Anthony (2015), pathways to accessing IAPT services were described in detail by participants. One of the main similarities highlighted by participants about their pathways to accessing IAPT services was that their GP was the last contact prior to receiving support from the service. GPs made the referral to IAPT (Anthony, 2015). This is consistent with the study by Brown et al., (2011) as noted in the previous section, where women did not immediately seek help from their GP as it was perceived that they will be unable to help (Brown *et al.*, 2011). Anthony (2015) found that participants generally went from seeking help in the popular and folk sectors to the professional sectors, however this was not across the board. It should be noted however that all participants in the study by Anthony (2015) were recruited via the professional sector and there is limited detail on participants' help-seeking experiences prior to accessing IAPT services (Anthony, 2015). Nonetheless, this highlights that some people may use all three sectors to manage their wellbeing.

The study by Rabiee and Smith (2014) examining the experiences of accessing services amongst African and Caribbean service users and carers, noted participants valuing the ability to access support from voluntary organisations alongside statutory services. This helped them extend their social network and provided them with support to be able to cope with everyday activities (Rabiee and Smith, 2014). For some participants, being able to access medication through health services was positive as it helped them manage at least one of their symptoms, e.g. insomnia. Experiences that were deemed to be negative by participants included lack of continuity of care, lack of equity in accessing resources such as talking therapies, the attitude of staff such as feeling overlooked, not understood and respected. Participants also shared that mental health services do not take a holistic approach, in particular, paying attention to people's circumstances, culture and beliefs (Rabiee and Smith, 2014). Some of the findings in this thesis is consistent with the themes highlighted in the studies by Anthony (2015) and Rabiee and Smith (2014). These are discussed in Sections 5 and 6.

1.8.3 Facilitators

The issue of enabling factors that make it easier for individuals from BAME communities to access services has not been as widely researched as that of barriers to accessing services. The main facilitators highlighted are social or family support and previous positive experiences of health services (Gulliver *et al.*, 2010). Additionally, acknowledging the need for help has also been highlighted as being an important facilitator generally for access to mental healthcare services (Ayalon and Alvidrez, 2007). Social support may be regarded as one of the social determinants of health in a general population. People that do not receive as much social support as others are more likely to suffer from poorer quality of life including depression (Grav *et al.*, 2012).

The findings from the studies by Gulliver et al., (2010), Ayalon and Alvidrez (2007) and Grav et al., (2012) are all consistent with the findings from the study by Anthony (2015) and the report by Keynejad (2008). Anthony (2015) found that facilitators which enabled or encouraged participants to access help centred largely around others encouraging help seeking, accessing valuable information from reputable sources, recognising the need for help as it becomes difficult to cope and having a positive experience of services. People encouraging help seeking included family members, contacts from church and GPs. In the project by Keynejad (2008), participants proposed facilitators could include statutory services taking a more holistic approach to include options such as providing advice on employment. Another suggested facilitator is better integration of services from the voluntary sector and faith services to be better rounded (Keynejad, 2008).

Studies by Ae-Ngibise et al., (2010) and Ruane (2010) focusing on Black African communities suggest that integrating African world views into treatments and collaborating with non-healthcare practitioners such as traditional and faith leaders may improve the use of services (Ae-Ngibise *et al.*, 2010; Ruane, 2010). The WHO defines traditional medicine as “the sum total of the knowledge, skill, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness.” (World Health Organisation (WHO), 2013). The WHO published its strategy on Traditional Medicine in 2013 to support member states in developing proactive policies and putting in place action plans that strengthens the role of traditional medicine in keeping populations healthy. The strategy draws attention to the existence of traditional and complementary medicine in almost all countries across the world and the importance of identifying safe means of integrating them into mainstream services (World Health Organisation (WHO), 2013). Further information is detailed in the discussion (Section 6) of this thesis on the role of traditional medicine in maintaining wellbeing.

1.9 Characterisation of mental illness by different populations

Different populations and cultures hold various beliefs about and explanations for mental illness. These beliefs underpin how people choose to access support and services, if at all, for the treatment of mental illnesses (Arday, 2018). This is particularly relevant to findings in this study, where people’s characterisation of mental illness influenced the decisions they made about accessing professional support. This is further explored in the Findings and Discussion sections.

Attitudes and beliefs about mental illness are influenced by people’s knowledge based on what has been shared through their personal networks, knowing and interacting with someone with mental illness, cultural stereotypes, as well as through stories in the media and other outlets (Choudhry *et al.*, 2016). Understanding cultural context is key to understanding different beliefs about mental illness. These lay belief systems are not only held in BAME communities but are found amongst all cultural communities and backgrounds. In a meta-synthesis on beliefs and perceptions about mental health issues by Choudhury et al., (2016), a study on Jewish populations highlighted that mental illness is seen as an opportunity to receive divine messages, a means of forgiveness and to improve people's souls (Choudhry *et al.*, 2016). In a South Asian study, it was shown that people perceive mental illness as a normal part of experiencing difficulties in life that is predestined for them. In contrast, Southeast Asian cultures perceive mental illness as being the result of supernatural forces/phenomena and the wrath or denial of spirits or deities. This belief is held by other communities including some Western cultures. A study carried out in Switzerland with patients that have a mental illness showed that demons were considered the main cause of mental health problems by the patients (Choudhry *et al.*, 2016). Cultural differences exist in relation to the aetiology of mental illnesses and the maintaining factors. In the same meta-synthesis, studies within Asian populations highlighted the belief that somatic and organic factors lead to emotional issues, therefore, people prefer treating the physical symptoms. In Chinese culture, mental illnesses and their causes are perceived to be as a result of an imbalance of cosmic forces. It is therefore treated by restoring the balance through diet, exercise, interpersonal relationships and cognitions. This is similar to the explanatory system found amongst patients and their families in a study conducted in Nigeria (Choudhry *et al.*, 2016). The belief systems held by different cultures largely determines how and where they seek help as per Kleinman's model of healthcare systems (Kleinman, Eisenberg and Good, 1978).

As shown in the narrative from the sections above, mental health care pathways are very complex. To stay within the scope of this thesis, the next section will delve further into the established care pathways for CMDs in the UK.

1.10 Identification and pathways to care for CMDs

In the UK, majority of depression and anxiety disorders are diagnosed and treated in primary care however most individuals do not seek treatment early and CMDs can go unrecognised for considerable lengths of time. Identification of anxiety disorders is particularly poor in primary care and small numbers receive treatment for it (Bhui *et al.*, 2014). The National Institute for Health and Care Excellence (NICE) published guidelines in 2011 focusing on primary care to drive improved access to services, identification and recognition of CMDs, provision of advice on treatment and referral and development of local care pathways (NICE, 2011). The guidelines were updated in May 2018 and it focuses on promoting and preventing premature mortality of BAME groups. It builds on the importance of providing services in accessible community-based settings such as a person's home or other residential settings, community centres and social centres that are more appealing and culturally sensitive. It also stresses the importance of services needing to be visible and responsive to the local population (NICE, 2018). The role that these pathways play in ensuring that a CMD is identified early and appropriate treatment recommended is explored in Section 5.4. The set-up of pathways is particularly important in influencing the experiences of participants in this study.

1.11 Experience of recovery from CMD

There are different means of capturing information on people’s experiences of recovering from mental illness and maintaining their wellbeing. This ranges from studies specifically examining people’s experiences which this thesis is aiming to do, through to collecting feedback directly from service users such as NHS experience surveys.

In the study by Tuffour (2020) looking at the role of religion in recovery from SMI amongst Black Africans in England, participants highlighted the importance of relying on their faith (Christianity in this case) as well as drawing on the traditional African worldviews about mental illness. The study suggests that for some Black Africans recovering from SMI, providing support that draws on the biomedical model as well as religious and traditional systems, will help meet their needs (Tuffour, 2020).

Within NHS services, one means of understanding people’s experiences is through the Community Mental Health Survey. The survey asks a sample of service users from each hospital trust questions about their experiences (Nuffield Trust, 2020). Due to the COVID-19 pandemic and different changes made to service delivery by hospitals, survey data collected in 2020 is not comparable to previous years however, it still provides some insight to people’s experience.

The survey asks service users to rate their overall experience from very poor to very good. There have been small changes to overall experience between 2014 and 2019; data from 2020 is not comparable. In 2019, 17% of service users rated their experience as very good and 3% as very poor. In 2020, 19% rated their experience as very good and 3% as very poor. When compared to other national patient surveys, community mental health service users rate their experience less favourably (Nuffield Trust, 2020).

Additionally, service users are asked about support provided to access help or advice for other aspects of their lives. Respondents reported being best supported to access help for their physical needs but less for e.g. finding or keeping work, financial and benefits advice. Results from 2019 and 2020 showed similar experiences (Nuffield Trust, 2019, 2020).

All respondents were asked if services involved their family member or someone close to them, as much as they would have liked. Just over half (53%) indicated that a family member or someone close to them was ‘definitely’ involved as much as they wanted. Eighteen per cent of respondents noted ‘no, not as much as I would like’ (Nuffield Trust, 2020).

The report also highlighted concerns about the inequalities in accessing mental health services and recovery rates of people from BAME communities, noting that these inequalities have been exacerbated as a result of the pandemic (Nuffield Trust, 2020).

2. Research aims

As outlined above, the burden of mental illness can have a huge impact on national health, social care provision and on the wider economy. It can also have huge implications for the lives of affected individuals and their families. Much research has focused on psychotic disorders, late presentations to healthcare services and subsequent poor outcomes experienced by minority ethnic groups particularly those from African communities. Adjustments to service planning, delivery and strategy have been made in an effort for them to be more accessible to groups at most risk of poorer outcomes and that have higher and later presentation to services.

There is limited research available on uptake of psychological therapies and other services for CMDs by ethnic minorities as demonstrated above and even less so at the more granular level than is usually available from the data. As mentioned in Section 1.2 and sections that followed, it is important to understand the factors that contribute to the lower rates of access to services seen amongst Black Africans. This has in part been addressed by the various pieces of research carried out on the barriers, facilitators and pathways to accessing mental health services amongst minority ethnic groups (Morgan *et al.*, 2005; Gulliver *et al.*, 2010; Anthony, 2015; Memon *et al.*, 2016). Section 1 outlines the rationale why further exploration is needed to understand the key motivations that drive engagement with services amongst Black Africans once a diagnosis of CMD is received or is self-defined, and how they subsequently maintain their mental wellbeing following treatment, assuming they do. Additional research is also needed to understand the motivations for accessing other types of support. As noted, research on mental health experiences of Black Africans have focused on serious mental illnesses or included other ethnic groups within the BAME umbrella therefore, this thesis will be the first to focus on Black Africans only and CMDs. The aim of this research is to contribute towards providing a more holistic picture of the pathways to care, treatment and ongoing maintenance of their health amongst this ethnic group living in the UK. This would enable more informed strategies, service planning and delivery and so facilitate access.

Research questions

This DrPH thesis explores the experiences of Black African individuals living in the UK that have self-defined or received a diagnosis of CMD and may or may not have subsequently received treatment. The thesis explored these experiences seeking to answer the following questions:

1. What is the experience of Black African people after they self-define or receive a diagnosis of CMD?
2. What is the experience of Black African people that receive a treatment for CMDs?
3. How do they conceptualise their treatment and its impact?
4. What do they do (or not) to maintain their ongoing mental wellbeing?

3. Theoretical framework

As noted in Section 1.7.2, Kleinman's (1978) model of the healthcare system and explanatory model of illness provides a lens through which some of the findings discussed in Section 6 of this thesis can be examined. Whilst Kleinman's model of illness has been critiqued by anthropologists, the model of the healthcare system is recognised as being important in broadening the definition of a system that both includes the biomedical view but also recognises the role of culture within the professional sector and general approach individuals take in maintaining their wellbeing (Kleinman, Eisenberg and Good, 1978; Scheper-Hughes, 1990). Kleinman et al., (1978) estimated that between 70% and 90% of self-recognised illnesses are managed in the Popular Sector which has been deemed to remain reflective of most societies to this day (Kleinman, Eisenberg and Good, 1978; Kolling, Winkley and von Deden, 2010).

Kleinman et al., (1978) proposed that the Popular and Folk Sectors provide a substantial amount of care. It was suggested that physicians (Professional Sector) treat 'disease' which is defined as 'abnormalities in the structure and function of body organs and systems', whereas patients suffer 'illness' which is defined as 'experiences of disvalued changes in states of being and in social function; the human experience of sickness'. These two definitions do not stand in one to one relation (Kleinman, Eisenberg and Good, 1978). Kleinman et al., (1978) went on to suggest that illness is shaped by people's culture in terms of how they perceive it, their experiences and coping mechanisms are all based on one's explanations of sickness and the social positions they hold in their systems. These have an influence on people's expectations and perceptions of their symptoms, the way certain conditions are labelled through to how they are evaluated, and the subsequent responses taken all stem from these labels. The means by which health problems are discussed, when help is sought, from whom, the level of engagement and how this experience of help or care is evaluated are all influenced by cultural beliefs. Each of the Sectors hold a different explanatory model of disease and illness due to their cultural beliefs (Kleinman, Eisenberg and Good, 1978).

As noted above, the explanatory model of illness has been critiqued largely as being limited in its breadth and not sufficiently capturing the role culture plays in illness and disease. Kleinman's view of the model has equally evolved over time to a position of being less structuralist and more focused on narratives of experiences of illness (cited in Weiss, 2001). However, the explanatory model of illness continues to be widely used by clinical practitioners and cross-cultural psychiatric researchers (Kokanovic *et al.*, 2008). Anthropologists on the other hand, have moved towards a more organic and nuanced concept of culture (Scheper-Hughes, 1990). Kleinman's (1978) explanatory model of illness builds on Engel's 1977 biopsychosocial model (cited in Wade and Halligan, 2017), where Engel suggested that psychiatry should adopt the proposed model. Similar to Kleinman, Engel recognised that the biomedical model did not allow enough scope within its framework for the social, psychological and behavioural aspects of illness. The biopsychosocial model proposes that illness develops through the complex interaction of biological factors such as genetics, psychological factors such as personality and behaviour and social factors which include culture and family (cited in Wade and Halligan, 2017). Whilst this model continues to be used and has been built on by other scholars, it has also been criticised as for instance lacking philosophical coherence (Benning, 2015).

The majority of work that has looked at healthcare systems has focused on the professional sector/biomedical view. Decisions about healthcare systems are largely made using the biomedical model (Wade and Halligan, 2017). The four widely used systems are the Beveridge Model, Bismarck Model, National Health Insurance Model and Out-of-Pocket Model. These are all based on the objective of providing services for a country's population from the professional sector mainly. The UK adopts the Beveridge Model which means healthcare is provided and financed by the government through tax payments (Wallace, 2013).

When completing this thesis and reflecting specifically on the interviews, it is clear that culture plays a fundamental role in how participants view their CMD and the decisions they take to improve and maintain their wellbeing. The four models of a healthcare system listed in the previous paragraph, do not take a strong holistic view of healthcare, but are instead focused on biomedical services. A much wider lens is needed in which to examine how Black Africans with a CMD maintain their wellbeing to begin understanding some of the patterns of use of healthcare services. Using Kleinman's (1978) model of healthcare system and explanatory model of illness, brings together two concepts that provide a framework which offers a degree of nuance that is needed when examining the data. Additionally, it is a good fit for my own conceptual framework of how Black Africans living in the UK conceptualise their experiences of mental ill health and go about maintaining their wellbeing. This is based on the fact that people utilise both biomedical and traditional medical services in almost all African countries. This therefore forms an important component of how Black Africans view health and steps they take to maintain it (Mokgobi, 2014). Through analysing data from this research, some reflections have been made on the breadth of the explanatory model of illness which is explored in Section 6.5.

4. Methodology

This section outlines the methodology adopted in this study. A rationale is provided for the study design used and a detailed outline of the sampling strategy and approach to recruitment is given. This is followed by a description of the demographics of the participants and the process of carrying out interviews. Lastly are details of the ethical process, limitations of the methodology, approach to data management, a reflexive account and researcher's positionality.

4.1 Study design

The study took a qualitative research design, using in-depth semi-structured interviews. Qualitative research is a more holistic approach that aims to capture and preserve the complexities and intricacies of perception and experience, which is essential when trying to understand the experiences of a section of the population that is known not to engage with mental health services relative to their population level (Buston *et al.*, 1998). Some other studies focusing on understanding the experiences of BAME people of mental health services collected data through focus groups. As stigma is a documented issue within many communities including Black Africans, taking a focus group approach in this study would have likely made it difficult to recruit participants and explore discussions in-depth (Livingston, 2013).

Semi-structured interviews are helpful for researching issues that people may be uncomfortable discussing. More relevant data can be collected when interviewees' confidence and comfort around the discussion topic grows particularly when interviews are conducted in a comfortable environment (Burnard *et al.*, 2008). In-depth interviews can provide detailed data on individuals' experiences, views and feelings. It is often guided by the participant which enables the researcher to assess issues that are of particular importance to them, to explore further (Burnard *et al.*, 2008). It was concluded therefore that semi-structured in-depth interviews would be the best method to adopt for this study.

4.2 Study sample

Sixteen participants were recruited to participate in the study. Interviews were carried out between early March 2020 and November 2020. Four groups of participants were recruited for the study:

1. People that self-defined or have/had a diagnosis of a CMD from an African background
2. Professionals providing mental health support or care in community organisations
3. Family and friends of people with a CMD that have provided support
4. Traditional healers and faith leaders that provide mental healthcare support

All participants were aged 18 years and over. Selecting the study sample was based on the key players articulated in Kleinman et al.'s, (1978) model of healthcare systems. The sample size of 16 allowed for a range of perspectives to be collected within the scope of a DrPH thesis.

This number is considered to be adequate when examining a very focused research question before reaching saturation (Green and Thorogood, 2004). Additionally, it also allowed for thorough analysis to be carried out.

For the first group, that is people that have/had a CMD, and are of Black African ethnicity, effort was made to recruit participants from different age groups and genders. Participants were interviewed in order to gather data on their feelings and experiences following their diagnosis or self-definition of a CMD. For those that subsequently received treatment or accessed professional support, the interviews also delved into their experience of the treatment and/or support they received.

Professionals that deliver support or care in community organisations were recruited to provide their perspective on the engagement, and particularly support offered for CMDs amongst Black Africans. Also important in the journey of individuals that have a CMD is the response of and impact on family members and social network. Family members and friends of people with a CMD were also interviewed to gain their perspective of providing support and the experience of the person with a CMD in their wellbeing journey. As outlined previously, some literature cites traditional healers and faith leaders as a group from whom Black Africans seek healthcare support and may often be the first point of contact. This was an important group to include in the study sample to get a better understanding of how the interventions they provide may or may not complement the treatment of CMDs amongst some Black African populations and maintenance of ongoing wellbeing. Ten participants in total were recruited for these three categories – professionals providing support through community organisations, traditional healers/faith leaders and family members/friends.

As mentioned above, a qualitative research approach tries to understand and articulate individuals' perspectives and experiences particularly where sample numbers are small. It seeks not to make generalisations as each perspective and experience typically has unique elements to each individual. People that have a CMD, their family and friends represent the popular sector. Professionals providing support in community organisations represent the professional sector and the traditional healer/faith leader represent the folk sector. This approach to sampling gives a more holistic view particularly as some people use all three sectors when seeking support (Fenenga *et al.*, 2016).

4.3 Participant recruitment

Recruitment took a multi-pronged approach. Community organisations and groups that provide a range of services were engaged. The organisations and groups can be categorised into the following. Provision of:

- Mental health support to all populations
- Support services for BAME groups including mental health
- Wider health and wellbeing services
- General social and leisure activities

- Support to carers

Faith organisations were also approached. As a large proportion of the Black African population in the UK identify as being Christians, outreach was mainly aimed at churches, however, mosques were also included (Office for National Statistics, 2011). Personal networking was a key part of the recruitment strategy giving the nature of the research and the sensitivities about discussing mental health experiences. It was important to use this network as gaining potential participants' trust is a major factor in determining whether they choose to participate or not. A large proportion of Black Africans live in big UK cities such as London, Manchester and Birmingham so most recruitment took place in these locations (See Appendix 4 for participant recruitment materials). Organisations and faith groups that were contacted were largely based in these three cities and surrounding areas.

The following section provides an in-depth description of each recruitment approach. It should be noted the COVID-19 pandemic influenced some of the adjustments made to the recruitment approach, to align with government guidelines and changes to service delivery across many settings.

4.3.1 Recruiting through community organisations and groups

Community organisations and groups were approached to recruit participants mainly in three of the groups – people with a CMD, family and friends providing support to someone with a CMD and professionals providing mental health support in community settings. To compile a list of relevant organisations to contact, an internet search was carried out to identify those meeting these criteria. Organisations that did not have a website or contact information were excluded. A review of the services offered by the organisation was carried out through reading information on their site or other related sites that hosted the details. Organisations that are run in partnership with NHS organisations were also excluded as ethical approval for the study does not cover them. The above listed organisations were contacted via email introducing the research and a request for the information to be shared with relevant individuals. The email also included an offer to speak to the relevant people within their organisation, to share further details on the study and answer any questions they may have. It was also noted that interviews would be carried out virtually once national restrictions were in place, to reassure people that steps were being taken to carry out research activities in a safe manner. A log was kept with information of whom within the organisation was contacted, dates of correspondence and outcome. Logging the information aided in highlighting which contacts needed follow-up.

A number of organisations requested a follow-up call or face to face meeting to discuss the research further. Some of these organisations included the Mind charities. This was important to the organisations as they were particularly keen to understand what participation would mean for their service users and staff. The face to face visits also gave an opportunity to meet some service users to introduce the research topic to them and assess their interest in participating. The organisations also provided a tour of their facilities and offered for the interviews to be carried out in their premises if there were any interested service users. It should be noted that these visits were carried out prior to the COVID-19 pandemic. They were no longer possible to do during the pandemic, so discussions moved to phone calls and videoconferences.

By the end of participant recruitment, a total of 67 organisations were contacted of which there was a response from 15. Two organisations declined to share details of the study with their staff or service users as they had limited capacity to participate in research or it would have a negative impact on their relationship with service users. Those that responded positively, agreed to disseminate the participant recruitment materials provided to them (See Appendix 4) in their staff and service user newsletters/bulletins. An undelivered or error message was received for emails sent to two organisations. No response was received from the remaining organisations even after being followed up to three times during the period of participant recruitment. Follow-up was interspersed as national and regional restrictions during the course of the COVID-19 pandemic meant that some organisations were unable to continue running their services (as noted on some websites), therefore, would not respond. Demands on some organisations' services also meant they had less capacity to field and respond to queries relating to research which some noted in their automatic replies.

4.3.2 Recruiting through faith organisations

Faith organisations were approached to recruit to all groups. Similar to recruitment through community organisations, an online search was carried out to find religious organisations. Groups that did not have a website or contact information were removed. The search primarily focused on Black African and Caribbean majority churches however churches with large mixed congregations were also included on the list to contact. Some large churches have multiple branches so their head offices were contacted in order to be able to get a response that would cover all of them. Again, an introductory email was sent about the research and a request for the information to be shared with relevant individuals and branches. The email also included an offer to speak to key people within their organisation, to share further details on the study and answer any questions they may have. A log was kept with information of whom within the organisation was contacted, dates of correspondence and outcome. Logging the information aided in highlighting which contacts needed follow-up.

Some of the organisations also requested for a phone call or face to face meeting with their leaders to discuss the project further before any information was shared with their congregation. These meetings were also carried out prior to the COVID-19 pandemic.

Again, by the end of participant recruitment, a total of 22 faith organisations were contacted of which there was a response from 4. Those that responded agreed to disseminate the participant recruitment materials (See Appendix 4) provided to them and had a follow-up call or meeting with the researcher prior to circulating the information to their staff, congregation and other contacts. No response was received from remaining organisations. Similar to the approach taken in recruiting through community organisations and groups, follow up correspondence was sent up to three times and interspersed during the period of participant recruitment.

4.3.3 Recruiting via personal networks

People that have a CMD were largely recruited through personal networking and faith organisations. Family members and friends that have or still provide support to someone with a CMD were also mainly engaged through personal networking, as were faith leaders/traditional healers. Engaging people through this involved speaking to colleagues, acquaintances and friends about the study to find out if people within their network would have an interest in participating. Those that met the criteria of the study were invited to take part. Once people took part, they were encouraged to approach suitable people in their network about participating and put them in touch with the researcher to discuss it further.

All these approaches to recruit participants were taken to have a good breadth of interviewees. Additionally, as the focus of the study is very tightly defined, a wide net had to be cast in order to recruit the target numbers. With mental health being a topic that is not openly discussed in many communities including Black African, it was essential to reach out to many networks.

4.4 Data collection

Demographic data such as age, ethnicity and gender of participants with a CMD were collected, as well as data about education and profession because these are known factors that impact on health seeking behaviours. Collecting these data allowed the researcher to extend recruitment efforts to ensure there was a broad range of participants. In the case of ethnicity (i.e. Black African) of participants with a CMD, this was defined as being a migrant from Africa or a first-generation Black African living in the UK (i.e. parents migrated from Africa). As previously mentioned, according to the 2011 census, 95% of Black Africans arrived in the UK after 1981 (ONS, 2015) therefore participants are likely to be migrants and first-generation Black Africans living in the UK.

The semi-structured interviews used to gather data from participants were an iterative process and data were analysed as they were being collected to refine the focus of the study. Topic guides (See Appendix 5) were developed which continued to be refined as the study progressed. Interviews carried out during the first national restrictions included questions about changes to service delivery. These questions were included following an interview with the first professional in a community organisation as it was topical at the time. As more interviews were done, there was less focus on effects of the pandemic as most restrictions had been lifted and there was a broader understanding that services may continue to be delivered differently for some time.

Interviews were recorded and transcribed by the researcher, and thematically analysed. Interviews were carried out in English and Wolof (a local language spoken in The Gambia and some other parts of West Africa). The researcher is of Gambian descent and speaks Wolof fluently which lends itself to being able to carry out interviews in Wolof if that is preferred by a participant. Section 4.7 provides further information on the approach taken to translation of interviews fully or partially carried out in Wolof. As part of the data management, all participants were given a participant number, rather than using their names, to preserve anonymity.

4.5 Participant demographics

Of the 16 participants that were recruited, key demographic information was collected which included age, gender, education, religion, occupation, length of time living in the UK (where relevant) and how they describe their ethnicity. Table 1 provides a breakdown of the demographic information of each participant.

The categories and definitions used to present the demographic information in the table is as follows.

- **ID** – each participant has been given an ID that starts with a 'P' followed by sequential numbers, to preserve anonymity.
- **Participant group** – this is defined as per the category outlined in Section 4.2 Study sample. The groups are:
    - People that have a self-defined CMD or received a diagnosis – denoted in the table as diagnosed/self-defined CMD.
    - Professionals providing mental health support or care in community organisations – denoted in the table as MH Professional.
    - Family and friends of people with a CMD that have provided support – denoted in the table as family/friend.
    - Traditional healers and faith leaders that provide mental healthcare support – denoted in the table as traditional healer or faith leader.
- **Diagnosis/self-definition** – this is the diagnosis received by individuals from a healthcare professional or self-defined based on their understanding of the symptoms they experienced. Where the information is not applicable, it is indicated as N/A.
- **Sought care** – this indicates whether a participant with a CMD sought care. It also indicates if family/friend supporting a person with a CMD sought care on their behalf.
- **Age** – this is provided as 5-year ranges. As all participants are aged 18 and above, the first category is 18-24, followed by 25-29, 30-34 and so on. Where the information is not available or not relevant, it is indicated as N/A.
- **Gender** – this is defined as male or female based on how participants identified their gender.
- **Education** – this is defined as the highest level of education attained. The levels are degree; A Levels; GCSE; no formal education; where the information is not available or relevant, it is indicated as N/A.

- **Occupation** – this is defined as professional which relate to non-routine jobs; non-professional which relate to routine jobs; unemployed; student.
- **Religion** – the categories are aligned to those utilised by the Office for National Statistics (Office for National Statistics, 2011). The main religions listed in this category are Christian, Muslim, Jewish, Buddhist, Sikh, Hindu, No religion and Any other. Where the information is not available or not relevant, it is indicated as N/A.
- **Time in the UK** – this is the period of time spent living in the UK continuously. It is also provided in 5 year ranges with the exception of the first category which is 'since birth', representing those that have been living in the UK all their lives. The next category is 0-5 years, followed by 6-10, 11-15 and so on. Where the information is not available, it is indicated as N/A.
- **Ethnicity** – the ethnic categories are aligned to those utilised by the Office for National Statistics (Office for National Statistics, 2011). For the purpose of this study, the main ones are Black African, Black Caribbean, Mixed: White and Black African and White British. A further indication has been made where the participant migrated to the UK or is a first generation British.

These categories have been set out to preserve the anonymity of participants.

Table 1. Breakdown of participant demographics

ID	Participant Group	Diagnosis/self -definition	Sought care	Age range (yrs)	Gender	Education	Occupation	Religion	Time in the UK (yrs)	Ethnicity
P01	Diagnosed/self-defined CMD	Anxiety	Yes	35-39	Female	Degree	Professional	Christian	21-25	Black African (Emigrated)
P02	Family/ friend	Unknown	Yes	35-39	Female	Degree	Professional	Christian	21-25	Black African (Emigrated)
P03	MH Professional	N/A	NA	18-24	Female	Degree	Professional	N/A	Since birth	Black African (First generation)
P04	MH Professional	N/A	NA	35-39	Female	Degree	Professional	N/A	0-5	Black African (Emigrated)
P05	Family/ friend	Depression	Yes	35-39	Female	Degree	Professional	Muslim	16-20	Mixed: White and Black African (First generation)
P06	MH Professional	N/A	NA	N/A	Female	Degree	Professional	N/A	NA	Black Caribbean
P07	MH Professional	N/A	NA	N/A	Male	Degree	Professional	N/A	NA	White British
P08	Family/ friend	Depression	Yes	35-39	Male	Degree	Professional	N/A	Since birth	Black African (First generation)
P09	Diagnosed/self-defined CMD	Anxiety, panic attacks	Yes	18-24	Male	Degree	Professional	Muslim	0-5	Black African (Emigrated)
P10	Faith leader	N/A	NA	40-44	Male	N/A	Non-professional	Muslim	11-15	Black African (Emigrated)
P11	Diagnosed/self-defined CMD	Anxiety, panic attacks	Yes	30-34	Female	A Levels	Non-professional	Christian	16-20	Black African (Emigrated)
P12	Family/friend	Depression	Yes	30-34	Female	A Levels	Non-professional	Christian	16-20	Black African (Emigrated)
P13	Diagnosed/self-defined CMD	Anxiety, panic attack	Yes	40-44	Female	Degree	Student	Muslim	16-20	Black African (Emigrated)
P14	Diagnosed/self-defined CMD	Postnatal depression	No	35-39	Female	Degree	Professional	Muslim	6-10	Black African (Emigrated)
P15	Family/ friend	Suspected schizophrenia	Yes	35-39	Female	Degree	Professional	Christian	Since birth	Black African (First generation)
P16	Diagnosed/self-defined CMD	Depression	Yes	35-39	Female	Degree	Professional	Muslim	16-20	Mixed: White and Black African (First generation)

4.6 Interview process

A suitable time was arranged with each participant to hold the interview and their preferred method – face to face, phone or videoconference. During the COVID-19 pandemic, no face to face interviews were held. All interviewees were emailed a copy of the participant information sheet (See Appendix 6) and consent form (See Appendix 7) prior, to read and ask any questions beforehand or on the day of the interview. If they had no questions, a signed copy of the consent form was given in person or emailed.

As noted above, the interviews were recorded and a field notepad was kept to take notes during and after the interviews. Interviews lasted between 22mins and 72mins with most on average lasting 40-50mins. The notepad was also used to capture discussions and follow-up actions from meetings held during the participant recruitment process. Below is a detailed account of the interview process for each group. Topic guides were devised for each group of participants to ensure the semi-structured interviews were relevant and would draw out information relating to the participants' experiences.

4.6.1 People that have/had a CMD

The topic guide focused on capturing details of participants' experiences, their perceptions of their mental wellbeing and strategies they use to maintain it. Discussions centred around understanding the beginning of participants' journeys, what prompted them to seek healthcare or made them recognise they needed mental health support, the type of support accessed and how it has or has not aided their recovery, role of their family, friends and wider social network, the strategies they use to maintain their wellbeing and services/support they believe would further enable them to stay well. With the COVID-19 pandemic being such a topical issue that has impacted many people, it was pertinent to ask participants how it may have affected their wellbeing if appropriate or if it came up and any further support or strategies they have drawn on to cope (Kola, 2020).

Disclosing information about medical history particularly to do with mental health can trigger difficult memories or emotions for some individuals. The researcher was cognisant of this and information was kept on hand to signpost participants to support services if required however, none of the participants needed the information. Participants were also informed at the beginning of the interview to only share information they felt comfortable to and that the interview could be paused at any time if they did not wish to proceed, or it was best to halt it.

4.6.2 Professionals providing mental health support or care in community organisations

For these interviews, the topic guide firstly picks up on professionals' current work and relevant previous experiences of providing mental health support services particularly to people from Black African communities. The guide goes on to focus on understanding services provided and users that engage in them, uptake amongst Black Africans and any variation observed, adaptations that are made to engage different sections of the population/target group. It then delves into the journey and experiences of Black Africans that have been provided mental health support, the role of family, friends and wider social network in the recovery process and ongoing wellbeing of individuals, the role of religious organisations and traditional medicine and on a broader picture, changes that could be made to policies and service delivery to better support Black African communities. The impact of COVID-19 on the delivery of services and the wellbeing of their clients was also explored during interviews that were carried out at the time of the first national lockdown as it was very topical, however it became less so in interviews that were done when most restrictions were lifted. These questions helped to understand how professionals adapted to provide the support needed.

4.6.3 Family and friends of people with a CMD that have provided support

This topic guide aimed to gain the perspectives of family members and friends on their role in supporting someone with a CMD, the journey taken and experiences encountered. It begins with getting background about the interviewees and whom with a CMD they support. Discussions then go on to focus on how a CMD was identified, services that may or may not have been sought, motivations for doing so and how these were engaged, and experiences throughout the journey of providing support to the person affected. It was key within the guide to understand their role, how decisions were made and what prompted them and the subsequent impact they had. Equally key was the strategies used to ensure ongoing mental wellbeing and their view on how effective it had been. As more interviews were carried out, it became increasingly clear that it was also important to understand how providing care and support affected them, because this has been cited in lots of literature (Parliament UK, 2018) as having profound impact on carers' wellbeing. Participants also reflected on what services or support they felt is essential in supporting people affected by a CMD and the people caring for them.

Similar to interviews with the other groups, the topic guide was expanded to include questions about the impact of the pandemic on the mental wellbeing of their family member or friend that has a CMD where appropriate or if it came up, as well as their own wellbeing. Again, discussing experiences about mental illness can trigger difficult memories or emotions for some individuals so a similar approach to interviews with people with a CMD was taken on having signposting information to hand and sharing details they felt comfortable to.

4.6.4 Traditional healers and faith leaders that provide mental healthcare support

For this interview, the topic guide focused on understanding the type of support offered, how it is provided and strategies used by people engaged in the services, to maintain their ongoing wellbeing. It starts by understanding the fundamental teachings or beliefs that guide the type of support provided and how it is delivered. Generally, traditional healers are viewed as people that perform healing using herbal remedies guided by ancestral teachings and spirits.

Faith leaders are viewed as receiving guidance from God and their practice of providing healing is informed by religious teachings. Some faith leaders, however, also use herbal remedies as part of their healing process. The definition and distinction between the two often differs a little depending on the cultural context. Some individuals are viewed as both traditional healers and faith leaders depending on their standing in the community and how intertwined traditional African religious practices are with that of other major religions such as Christianity and Islam (Mokgobi, 2014).

The topic guide goes on to look at the stages at which people choose to access this support. Within the topic guide, it was important to understand how the balance of support is struck with care that an individual may be receiving through Western medical services. It goes on to explore the role family and friends play in supporting individuals to access their service and any ongoing involvement they may have.

4.7 Data management and analysis

Data collected were held securely and confidentially on the LSHTM network and anonymity was preserved as far as practicable and as agreed with the participant (See Appendix 8 for data management plan). Data analysis commenced immediately after collection started to identify any additional information required to refine the study. NVivo 12 was used to hold all recorded interviews for transcription and analysis. As noted above, a field notepad was used to capture some of the interview notes and to act as a reminder during the course of discussions to prompt for further information where required. The notepad was also valuable in capturing discussions during the process of recruiting participants such as the meetings held with faith and voluntary sector organisations, to provide further information about the research and what participation entailed.

The NVivo Transcription tool was used to complete the first round of transcription to shorten the process. This is an ‘add-on’ functionality that was introduced by the company. Whilst the tool is able to transcribe interviews of up to an hour in less than 30mins, an additional round of cleansing and corrections was required. The researcher reviewed the transcripts and made all edits as needed before finalising the file in NVivo. This approach proved to be a more efficient means of transcribing some of the interviews as it took significantly less time. For interviews where the audio quality was not high enough, the researcher transcribed them without using the transcription tool. Where the interview (fully or partially) was carried out in Wolof, the researcher was able to translate and transcribe it due to being a native speaker of the language. Translating and transcribing conversations in Wolof took significantly more time compared to interviews carried out in English as it was a two-step process that had to be carried out fully by the researcher instead of using a transcription or translation tool. There are no reliable electronic translation tools that could have been used to reduce the length of time in completing it. It was important to take this approach to ensure that the interviews were captured accurately when translated in order to not miss or misunderstand vital information. Each part of the interviews was listened to several times to ensure it is accurately translated.

A number of qualitative data analysis methods are available with key differences between them based on what could be learnt from people's verbal accounts. They all aim to understand a person's perspective or experience (Berkwits and Inui, 1998). For this study, thematic analysis was utilised as a means of understanding people's experiences of maintaining their wellbeing and how their social and community network also enable this. Thematic analysis gives a framework for reviewing information gathered from interviews to compare and classify them into common themes. It highlights the validity of a person's lived experience which may differ from others as it is individual to them. The importance of the nature of social processes that influence and shape particular phenomena also form a key part of understanding the information gathered (Charmaz, 2006).

As outlined above, key demographic information was collected from participants. Commencing the interviews by asking this information provided a means of easing participants into the interview to feel more comfortable and to also gather information that may be valuable to ask about during the course of the interview, which may have ordinarily not been touched on e.g. professionals mention other jobs they may have which offers direct experience to the topic being discussed.

A broad coding scheme was developed after the transcription of the first three interviews to help refine the topic guides. The first three interviewees were a person with a CMD, family/friend and a professional working in a community organisation. As most of the introductory sections of this thesis were written when interviews were being carried out, it provided an opportunity to be inductive and deductive, as the researcher had familiarity with the literature available. As new themes emerged with additional interviews, this was added to the library of tree nodes that were created. There were ongoing discussions about the emerging themes with the researcher's supervisor to verify findings and any further refinements or additional data that needed to be collected. It initially appeared there was minimal recurrence of themes when the first three interviews were carried out, however, on conducting further interviews and refining the coding, the main themes across the different groups interviewed were similar. This is further explored in the findings section.

Coding of all interviews was carried out in two steps. The interview transcripts were printed out and coded on paper first before transferring this information into NVivo. Taking this two-stepped approach to coding lends itself to being able to easily re-code sections of the transcript iteratively. During coding, the interviews were being listened to at the same time to gain a full understanding of the discussions. Intonations play a valuable part in understanding interview data and by reading just the transcript, these elements will be missed. Once coding was completed, each tree node was thematically analysed and in some cases re-coded where it fit better into another category. The nodes created from each of the four participant groups interviewed was examined to identify recurring themes. This was done within and between each group of participants. Where tree nodes do not have any branches, they were left as standalone nodes. Variations between participants' experiences and views were also noted even where they conflicted. This is further elaborated on in the Findings section.

To draw out key information from the analysis, specifically, where people with a CMD and family/friend interviewees gave in-depth descriptions of their feelings about their experiences, this has been represented as a Wordle/word cloud in the Findings section. A Wordle tool which is freely available online was used to generate the image. Using this visual representation, gave greater prominence to words that appeared more frequently in the interviews to help with framing and discussing the findings (McNaught and Lam, 2010).

4.8 Ethical approval

Ethical approval for the study was sought from the LSHTM Research Ethics Committee. Informed consent from all participants was obtained (See Appendix 7). Participants were provided with an information sheet (See Appendix 6) describing the details of the study and what their participation entailed, to enable them to make a decision about whether to take part. They were assured that all discussions will be confidential, however, if they disclosed information that suggests they or someone else was at serious risk, then it will have to be raised to the appropriate service or authorities. If such an instance arose, the participant will be informed and the information passed on to someone who can provide help. No such instances arose during the interviews. Outside of such circumstances, their anonymity and participation in the study will be maintained. Participants were informed they could withdraw from the study at any stage if they chose to however, all participants remained in the study.

4.9 Research quality and rigour

Carrying out qualitative research acknowledges the fact that the researcher's perspective is brought into the process; from the methodology adopted through to how the findings are interpreted and reflected on. This is helpful in giving the research some depth in the quality and reliability of the analysis as well as the rigour (Green and Thorogood, 2004). Key considerations that informed my reflexivity include the methodological approach, theoretical framework and an awareness of the context in which the research was carried out both at a micro and macro level. My own subjective position in the research is also outlined in the reflexive and positionality sections below.

4.10 Limitations of the study

As with any research study, there are limitations to the design which need to be acknowledged. These are explored in this section and Section 4.11.

One of the limitations is the breadth of participants that took part. Whilst every effort was made to recruit participants (people with a CMD and family/friends) that broadly reflect the Black African population in terms of age, gender, length of time spent living in the UK, education attainment and occupation, as outlined in Table 1, all participants are aged between 18 and 44 years, have high educational achievements and largely work in professional roles. This represents a segment of the Black African population living in the UK. Highly educated professionals are more likely to participate in research. They are also more likely to seek healthcare services which is illustrated by the accounts of interviewees in this study as detailed in the Findings and Discussions section. The study has therefore not captured accounts from others that may be thought to not seek help or at least not do so early or experience barriers that those who participated did not e.g. difficulty communicating as they speak low levels of English. Participants' experiences and views may or may not differ to such individuals. Nonetheless, this thesis offers an insight into the experiences of this segment of the population.

As mentioned previously, when recruiting participants, organisations and groups that do not have information online about their services were excluded. This means that many grassroots community groups that do not have the infrastructure of that of more established organisations were excluded. Such groups are often said to provide services and support to people in communities that are harder to reach through for example mainstream services. Excluding them therefore limited the breadth of sources where participants could be recruited from.

The majority of the recruitment process for the study was carried out during the COVID-19 pandemic. This introduced many challenges due to the national restrictions in the delivery of services as well as people's ability to engage in their usual day to day activities. Mental health is a sensitive topic in most communities and that is very much the case in Black African populations. The initial approach to recruitment taken was to reach out to services and different communities such as churches to introduce the research topic. This was then followed up by meeting the service leads and for instance pastors to discuss the study in detail and answer questions. These meetings were requested as they wanted to be assured that the research will be well received by people accessing their services or activities due to the sensitive nature of it. A level of trust needed to be built with the leads before they agreed to disseminate information about the research and encourage people to take part. The national lockdown made it difficult to proceed with this approach and meetings had to be cancelled as soon as it came into effect. Although a lot of services moved to providing their activities virtually, this happened at different paces depending on the infrastructure they had in place. Places of worship for instance took the longest to move their activities if they were able to. Contacts that were generated which may have potentially led to recruiting more participants with diverse backgrounds were lost due to the impact of the pandemic. People had an interest in the study but were very much focused on responding to the pandemic, therefore sustaining engagement to progress discussions became challenging. This negatively impacted on the ability to reach potential participants from different backgrounds to get broader views and understanding of people's experiences.

Another limitation is recruitment could not be extended to NHS services or even community organisations that ran services in close partnership with the NHS as this would have required getting additional ethical approval. Ethical approval to carry out research involving NHS organisations can be a complex and lengthy process which would have impacted on the timescales for carrying out this study. This limitation means that organisations delivering mental health services relevant to the study e.g. Recovery Colleges, could not be approached for participant recruitment. Again, this limits the breadth of participants that can take part. People accessing these services will likely be from a range of Black African communities and have experiences which may be distinctly different to the study participants.

The aim was to recruit at least one faith leader and one traditional healer or two faith leaders or two traditional healers from different religious backgrounds. This was however a challenge due to the pandemic. The most effective way of engaging the faith community or African traditional healers is to meet face to face to discuss work being carried out for them to feel reassured to participate. There was interest from three faith leaders that were engaged through three churches however, prior to discussions of their participation and their support in recruiting participants from their congregation being finalised, national COVID-19 restrictions were put in place. As noted above, due to the pandemic restrictions being in place for a few months, it was difficult to get them to re-engage and also to establish new contacts. Only one faith leader took part in this research which limits the breadth of data that can be collected. Although there are many similarities between the major religions practiced in the UK however, there are fundamental differences in their teachings which influence the world view and practices of their leaders, that shape how CMDs are perceived and treated. Whilst the interview with the faith leader was very insightful, it does not represent the teachings and practices of all the major religions or indeed Islam (religion of the faith leader). Additionally, there are differences in practice amongst faith leaders determined by their education, experience and where applicable, the denomination within their religion.

Although sample size is not a key factor in this research and a minimum number is not required, it should be noted that the experiences of participants described in the Findings is very much individual to them. It does not necessarily represent the experiences and views of other Black Africans. Recruitment was concluded once 16 participants were interviewed as it was deemed a sufficient number before saturation was reached.

4.11 Advantages and disadvantages of research methodology

As noted above, the study has a number of limitations, which are linked to the approach taken in recruiting participants. There are a number of advantages and disadvantages to the methodology adopted, which is explored in more detail in this section.

One the biggest advantages of using Kleinman's model of the healthcare system as a framework for sampling, is that it captures different perspectives of the journeys of people with a CMD, through the eyes of those that play an integral part in providing support to affected individuals. Other research studies examining the mental health experiences of Black Africans or BAME populations, typically only recruit one, two or three participant groups; people with a mental illness, family/friends and healthcare professionals (Brown *et al.*, 2011;

Lamb *et al.*, 2012; Rabiee and Smith, 2014; Anthony, 2015; Memon *et al.*, 2016). Based on review of published literature, only one community development project by Keynejad (2008) carried out in the London Borough of Redbridge, drew participants from four groups, across multiple BAME ethnicities, discussing barriers to help seeking (Keynejad, 2008). This thesis is the first study to bring together participants from four groups to examine the experiences of Black Africans only, in an attempt to draw on a more representative network that individuals surround themselves with, in managing their CMD. This allowed a degree of triangulation of interview data to be carried out, to get more in-depth and rounded views. This thesis draws on professionals working in the community that provide an extended level of support for people with a CMD instead of those working in the NHS including affiliated organisations, whom are largely funded to deliver most mental health services (NHS Providers, 2017). This is another advantage of the methodology as these professional networks are very important to tap into. Due to the way their services are designed, they often have protracted contact with their service users, which is important in some people's management of their ongoing wellbeing (Islington Mind, 2020). This contrasts the model in other settings, where there is an emphasis to equip people with tools to manage their wellbeing, which is often driven by service commissioning arrangements (Clark, 2018). Yet another advantage is the breadth of participants experiences owing to the combination of approaches taken to recruit them. Using a variety of sources meant that participants with different journeys took part. If participants were largely recruited from for example the membership database of one or two organisations, this may have limited the breadth of data collected as there will be similarities in people's experiences, due to their use of the same services. Owing to difficulty in recruiting participants, some studies such as those carried out by Anthony (2015), Memon et al., (2016) and Rabiee and Smith (2014), adopted the approach of recruiting from selected organisations or databases (Rabiee and Smith, 2014; Anthony, 2015; Memon *et al.*, 2016).

One of the main disadvantages of the recruitment approach taken in this study was the inability to extend it to NHS services due to ethical approval not being sought. This potentially impacted on the breadth of participants with a CMD and professionals that took part in the study. Recruiting from NHS services may have enabled the demographic profile of these participants to be broader such as including more males, people over the age of 44 and those with lower educational attainment or not working in professional roles. People of this demographic are likely to have different experiences to those that participated in this study therefore, their perspectives would have influenced the findings. Additionally, professionals working in the NHS provide support to people with a CMD at a particular point in their journey, for varying lengths of time. Their perspective particularly how they think the design of their services influences the engagement of Black Africans, would have offered a valuable insight to influencing commissioning decisions. Whilst it is noted that this is a drawback, the normal timescales for securing ethical approval to carry out research in the NHS would have impacted the timescales of this study. The COVID-19 pandemic further affected approval timescales, as ethics applications for NHS related studies focusing on COVID-19 were prioritised. It is likely that if recruitment were extended to NHS organisations, more participants with a CMD could be recruited however, this is not certain as the COVID-19 pandemic greatly altered how services were delivered, which meant it was harder to engage professionals and users in non-essential services.

4.12 Reflexivity

Whilst it was challenging to recruit some of the participants in this study, those that participated were very keen to do so. They were enthusiastic about two aspects of the study, the fact that it focuses on mental health as this is a topic not widely discussed and it is solely trying to understand the experiences of Black Africans living in the UK, instead of the broad umbrella of BAME communities. It was felt that it is very much needed and for that reason, participants were happy to share their experiences and views, in the hope that it will lead to some form of change.

In carrying out this research, I was acutely aware that discussing sensitive or difficult experiences can be very emotional for some individuals and perhaps unearth certain thoughts and feelings they will then need to deal with at the end of the interviews. I had a degree of nervousness and sensitivity about approaching participants to be interviewed, particularly as almost all except two interviews had to be done via phone or videoconference due to the pandemic. I was conscious that in the event any participants broke down during the interviews, it would be challenging to provide them with reassurance or some form of support whilst not being in the same physical space as them. Whilst holding almost all the interviews virtually was not my expectation of how the research would be carried out when I commenced participant recruitment, it also lent itself to the quality of the research in many respects. As noted, discussing mental health is a sensitive issue for most and also being interviewed by someone unfamiliar and being recorded may be uncomfortable. The stigma of mental illness is very prevalent in Black African communities therefore, it is not discussed very widely or openly (Alang, 2016). Having the discussions over the phone particularly without the use of video (option was given to participants to use or not use video) was a conscious attempt to make interviewees feel comfortable to be able to take part and not have a fear of being judged. So, in some respects, the approach had advantages, in encouraging participation once people got to the point of being sufficiently interested.

As I am of African descent, I was also conscious that it may deter some people from wanting to take part in the study, however, it could also be a facilitator as some participants may feel more comfortable speaking to a person they feel will have the cultural understanding of their experiences. Culture and tradition play a huge part in African societies and the way communities interact with each other. African communities in the UK are relatively tightknit particularly where people have established networks they previously held in their home countries. I was cognisant of how these factors will play into the research as some individuals may be reluctant to be involved in the study or will share limited information due to concerns of stigma and confidentiality. Nonetheless, the research still benefited from my position due to my understanding of African societies, knowledge of some networks that were tapped into to join the study, as well as my ability to speak one of the local languages fluently (Wolof).

This offered an opportunity for the interviews to be held in a language that the individual may feel most comfortable speaking.

4.13 Positionality

Throughout this research, I was conscious of my own position within it, being that I am Black African and have been living in the UK for most of my life – I meet the participant demographic profile, I am an immigrant. As I mentioned in my integrating statement, carrying out this research has been a passion project for me. My world view is shaped by my experiences of growing up in The Gambia and the UK. My first memories of conversations about different types of mental illness were when I was in primary school in The Gambia. I began to observe and enquire about mental health conditions; I was particularly interested in understanding people’s beliefs about the causes and how they perceive and treat individuals with a mental health condition. One of my observations was that culture and religion played a big part in how people characterise mental health issues and how society attempts to provide support to individuals and families. My degree studies in neuroscience offered me a different perspective; the Western explanations of the biology of different illnesses and treatment options. I continue to hold two explanatory models of illness – the biomedical view and the traditional/religious view. I was aware of how holding both views shaped the participant groups I chose to interview and most importantly, the conceptual framework which I leaned on to analyse and discuss my findings.

5. Findings

To help frame this section of the thesis, it is useful to outline again the four questions this research is seeking to answer.

1. What is the experience of Black African people after they self-define or receive a diagnosis of CMD?
2. What is the experience of Black African people that receive a treatment for CMDs?
3. How do they conceptualise their treatment and its impact?
4. What do they do (or not) to maintain their ongoing mental wellbeing?

On completion of coding and analysis of the interview transcripts, a number of strong themes emerged. These themes typically follow the journey of people with a CMD or those providing support to someone with a CMD, from the point at which they started experiencing feelings or a recognition of symptoms indicating some form of a change in their wellbeing. This is followed by the steps taken by interviewees to manage their wellbeing or provide support needed and the strategies that have been adopted to maintain ongoing mental wellbeing. These themes have been presented under the following headings which will be explored individually.

1. Characterisation of symptoms
2. Perceptions of mental health disorders
3. Impact of common mental disorders
4. Health seeking and support
5. Treatment
6. Service delivery
7. Maintaining ongoing wellbeing
8. Improving experiences and outcomes

The findings under the above headings are briefly discussed in this section and further elaborated on in the Discussion section.

5.1 Characterisation of symptoms

The journey of each interviewee that had experience of a CMD was different and so was that of family/friends that provided support to someone with a CMD. One key finding from this research is how the characterisation of symptoms is integral to decision making on whether people affected by a CMD seek care. This was an interesting finding that showed an intricate link between characterisation of symptoms and maintenance of wellbeing which is further explored in Section 5.4. This largely determined people’s journey to seeking or not seeking treatment, when they chose to seek help and from where, and how they maintain their wellbeing. It also allows people with a CMD to ‘make sense’ of their feelings and experiences and interviewees were keen to share this, which was a recurring point in conversations. This is further discussed in Sections 5.2 and 5.4. Particular descriptions of symptoms mainly featured in interviews with individuals that have a CMD, family/friends and the faith leader. It was not a key part of interviews with professionals. Interviews with professionals instead focused on how they support people to ‘make sense’ of their experiences rather than what these are or how they are described by people. This is explored further in Sections 5.2 and 5.4.

There was also a distinct difference in how symptoms were described during interviews with people with a CMD and the faith leader in comparison to family/friends. People with a CMD and the faith leader described symptoms based on feelings experienced during the most difficult points in individuals’ journeys. Detailed accounts of how they felt, how they tried to ‘make sense of’ or understand what they were experiencing was given by the interviewees. Participant P01 described her symptoms as:

“I was scared. I wasn’t sleeping. And for me, it was my fear. So, my anxiety was that if I went to sleep, I was going to die.” (Participant P01; female; diagnosed/self-defined CMD)

The faith leader interviewed described symptoms of some people he has provided support to based on the feelings they typically experience:

“Symptoms can include signs of stress, not being in the right frame of mind, feeling sad, wanting to be alone, losing the sense of time, laughing or crying about different circumstances which may not warrant that type of reaction, feeling emotional, not looking after their personal hygiene, getting angry easily or quickly.” (Participant P10; male; faith leader)

Figure 6 gives a depiction of the words used by interviewees with a CMD to describe symptoms they experienced. The words that appear bolded or larger in size indicate how often they recurred in the interviews. For interviewees that reported suffering from anxiety, description of their symptoms very much focused on the fears they held. For some it was a fear of dying which then led to other feelings or symptoms such as insomnia. Interviewees that shared they suffered from depression recalled the symptoms that had the most impact on them was ‘dark times’, where they were unable to remain hopeful and see an end to the feelings they experienced. The experiences were seen by participants with a CMD as ‘going through a period of feeling emotional’.

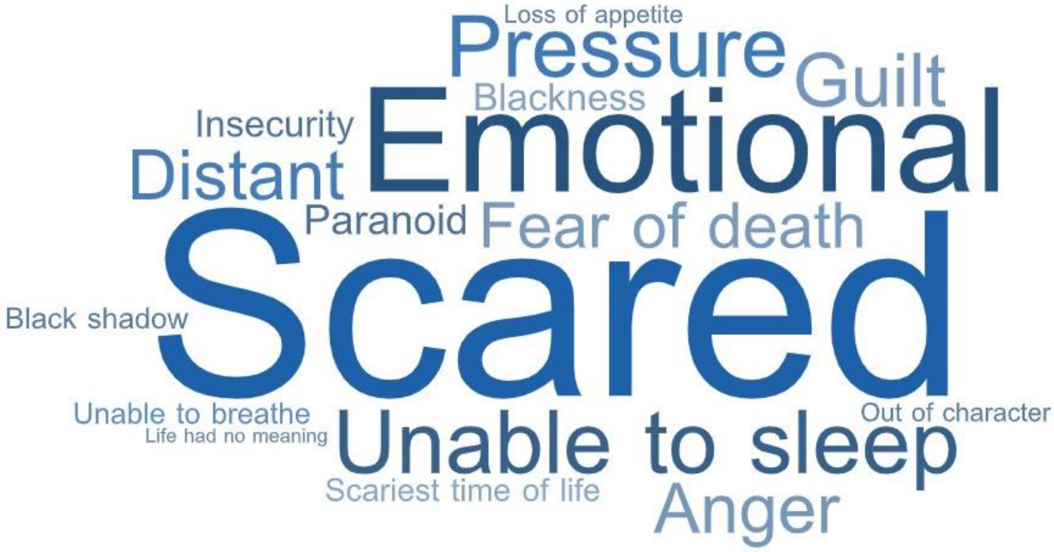


Figure 6. Description of CMD symptoms experienced by interviewees

In contrast, family/friends described symptoms in the form of changed behaviour and actions instead of how the person with a CMD felt:

"She was distributing a lot of odd behaviours even at home, you know……I can even go back as far as saying she was distributing certain behaviour that was alarming. Back then to my mum, it was just my sister misbehaving in school." (Participant P02; female; family/friend)

The possible significance of these differences is discussed further in Section 6.2.

5.1.1 Mental health literacy

Mental health literacy has been defined as 'knowledge and beliefs about mental disorders which aid their recognition, management or prevention' (Jorm *et al.*, 1997, p.182). Jorm et al., (1997) further stated that it 'includes the ability to recognise specific disorders; knowing how to seek mental health information; knowledge of risk factors and causes, of self-treatments, and of professional help available; and attitudes that promote recognition and appropriate help-seeking' (Jorm *et al.*, 1997, p.182). Amongst the interviewees, specifically people with a CMD, family/friends and the faith leader, there was a general recognition of feeling unwell or of experiencing something different that was unlike anything felt before. These descriptions relate to the first wave of CMD symptoms experienced. Again, as interviews with professionals focused on the support provided as people try to 'make sense' of their experiences, there was not an emphasis on how people felt, and each experience is unique to the individual. This distinction is further explored in Sections 5.2 and 5.4.

People with a CMD did not associate their symptoms with mental ill health with the exception of one interviewee that eventually did after a period of time, due to having worked in the field and in learning disability settings. Other interviewees felt their symptoms were somatic or temporary:

"I thought I had a heart problem. I thought I would just drop down and die one day. I had never experienced that in my life. I felt like I couldn't breathe." (Participant P11; female; diagnosed/self-defined CMD)

Some interviewees opted to seek help depending on how heightened their feelings were or chose to delay in the hope they would feel better over time. Symptoms not being associated with a CMD is partly due to interviewees' understanding and definition of mental illness as someone experiencing psychosis or a crisis:

"Before this interview, I think I would have classed mental health as someone literally having a breakdown like the Britney Spears or the person running around with something, that's what I would have classed mental health as. Or maybe someone that tried to commit suicide, because I always think when I hear suicide, what was that person going through mentally. So, someone attempting suicide and someone literally having a breakdown, I would class as a mental health and nothing in between." (Participant P01; female; diagnosed/self-defined CMD)

Only symptoms of serious mental illnesses are understood to be linked to mental ill health:

"You don't realise that's what it is until it has passed. I didn't know that's what it was, so it was after a while my husband drew my attention to it and then I reflected on it….but before then it was just me, when I came home, very, very moody all the time, I broke down, I don't know why….I just know that was not myself, I was just down, I couldn't pinpoint what it was because it's not like I was in pain and you cannot explain it, you just know you're not yourself." (Participant P14; female; diagnosed/self-defined CMD)

Similarly, family/friends interviewed also did not recognise the presence of CMD symptoms early on until it reached crisis point. This realisation was reached due to the person they supported reaching a point where there were noticeable changes in their behaviour, which prompted family and friends to act:

"My friend's friend….she received some random text messages from him that were very, very abusive. For the years that I've known this guy, I've never ever seen or heard him being abusive. He's a very calm gentleman. It turned out he wasn't himself. I called his phone and I

spoke to him, by the way he was to me on the phone, he seemed to be off." (Participant P05; female; family/friend)

"I think she recognised she was going through something but I don't think she had the language for it at that time." (Participant P02; female; family/friend)

Upon reflection, this group of participants recognised there were early signs of the people they supported having a CMD. This only became evident once they knew of what triggered their change in behaviour and signs eluding to the person requiring support.

All non-health professional interviewees were familiar with depression and anxiety. It was felt by some that the terms are often used loosely in everyday language but that there was little understanding of the symptoms associated with it as noted above. For interviewees that experienced anxiety, these symptoms had a significant impact on their lives, day to day activities, relationships, mood and general wellbeing. The symptoms were experienced for prolonged periods of time prior to accessing psychological support, up to 6 months for two of the interviewees. For interviewees that expressed suffering from panic attacks, they weren't familiar with this terminology neither were they aware of the symptoms until after their first experiences. On reflection, one participant felt you can only understand what the terminology means and the symptoms associated with it through lived experience:

"I heard of it [panic attacks] but I didn't know if something actually affects you physically and all these symptoms you have along with it. I feel unless you experience it, you don't really know about it or maybe you don't even hear about it. So, you don't do too much research, thinking that won't happen to me….you just don't think about it." (Participant P11; female; diagnosed/self-defined CMD)

The symptoms of a panic attack were therefore thought to be physiological which prompted health seeking. When help was sought, it was described as physical issues which then triggered medical investigations to be carried out to identify the cause. These interviewees, with the exception of one also shared their family and friends were unaware of the signs of a panic attack and therefore also assumed the cause was physiological. In the case where the interviewee's family was familiar with the signs, this was due to them being medical professionals. It should be noted however that despite family members being in the medical profession, the symptoms were not immediately linked to mental ill health, instead, it was thought to be physiological. Section 5.4.1 goes into further detail about the motivating factors for seeking mental health support and the complex process to eventually reaching that decision.

As previously mentioned, research suggests there are differences in symptom patterns and concepts of mental illness across cultures as noted in the meta-synthesis by Choudhury et al., (2016). The way people characterise their symptoms may also be influenced by how services are configured and the most effective means of seeking help (Lloyd, 2009). Whilst this may have been a factor that impacted on interviewees' understanding of their experiences and motivations for seeking help, mental health literacy may have also been a factor. There is a large body of published literature on mental health literacy featuring studies that aimed to assess knowledge, attitudes and help-seeking. The vast majority of these studies however did not use assessment tools of acceptable psychometric properties. Most also used diagnostic vignettes as an assessment tool but limited their scope by including only a few types of mental health conditions. Additionally, there is a huge focus on carrying out these assessments amongst student populations. This offers a limited view of knowledge of mental health symptoms, distinction between CMDs and serious mental illnesses and mental health promotion (Kutcher, Wei and Coniglio, 2016). There is little published data available on the assessment of mental health awareness across the general public, despite the wealth of health promotion activities delivered in the UK. Data is however captured about attitudes to mental health problems with a particular focus on stigma and mental wellbeing (Dean and Phillips, 2015). Jorm et al., (1997) noted that if mental disorders are to be recognised early across the population to enable appropriate health seeking, then levels of mental health literacy need to be raised (Jorm *et al.*, 1997).

5.2 Perceptions of mental health disorders

Perceptions of mental health disorders is an important aspect of people's experiences that came across strongly in interviews. It helped determine the decisions people made about the treatment to access or not to access, the route and degree of engagement. The way interviewees characterised symptoms was inextricably linked to their perceptions of mental health disorders. Perceptions ranged from people's belief systems through to societal structures and norms which to a large extent dictated what type of support people accessed as detailed in the next section. The stigma of mental illness in African populations influences people's decisions on how they choose to manage their experiences (Kakuma *et al.*, 2010). This was a finding in this thesis and influenced whom interviewees' felt they could trust and rely on for support; this was the case for most of the interviewees with a CMD. Difficult experiences over prolonged periods that remain unaddressed or untreated often are unrecognised as mental ill health at the time people are going through their most difficult periods. On reflection, individuals realise they have been struggling to deal with it. This is similarly highlighted by family/friend networks and professionals. Each of these themes are explored in greater detail in the following sections.

5.2.1 Medical vs non-medical views of mental health disorders

Interviewees hold different beliefs about the causes of mental health disorders or symptoms experienced which therefore determines the ‘treatment or support’ sought. The professionals that were interviewed recognised and emphasised the importance of not pathologising people’s experiences of mental illness and allowing individuals to work through it themselves with support. This is reflected in the structure of the services they deliver through their community organisations to support people that have experience of mental illness:

“The overall ethos of the projects has to take a non-pathologising approach. We don’t use labels and we encourage service users to develop and then come to their own understanding of their experiences. If they find it helpful to identify with the label as a way of beginning to make sense of their experiences, that’s fine, we wouldn’t challenge that. But on the other hand, we wouldn’t insist that people sort of make sense of how their lives are through diagnostic categories either. So, it’s a mixture of both.” (Participant P07; male; MH professional)

Professionals also acknowledge and respect that the views people may hold could be driven by the teachings of their faith. It is also recognised that these beliefs can influence when people choose to seek support and how engaged they remain if they are in touch with services:

“A lot of people coming from Nigeria that end up in therapy, from my understanding is usually due to religion, culture and peer pressure. A lot of that pressure is so immense for them to achieve from what I’m seeing that it’s quite overwhelming. It’s a very status driven society…..It is such a push pull thing with the church and the wider society. It is huge. Their capacity to be authentic, to be their true self is very, very limited, there is no space…..it’s either church or business.” (Participant P06; female; MH professional)

As previously mentioned, some cultures perceive mental illness as being the result of supernatural forces or phenomena and the wrath or denial of spirits or deities. Some religious teachings also hold similar views about causes being linked to supernatural forces or phenomena. The approach in which support is provided using religious teachings as the underpinning principle can vary depending on the religion and the faith leader. In this study, the faith leader interviewed holds the belief that certain health symptoms particularly physical ones should be treated using Western medical practices as the causes are physiological. In their interpretation, the teachings of the religion also emphasise this:

"God asks people to put their trust in Him. However, He says people should explore all opportunities available to them first before putting their trust in Him. Putting trust in God therefore means asking Him to aid you so that the medical treatment you are receiving works. We have prayers that people can say to get better if they feel unwell but an individual shouldn't use it as the only line of treatment and opt not to take any medication. God says that people should seek any beneficial knowledge……and this includes seeking medical care from people trained and specialised in that discipline" (Participant P10; male; faith leader)

These teachings also extend to the treatment of some symptoms of CMDs. Where CMD symptoms could be treated using Western medical practices if the cause is physiological, then people should opt to seek this help. There are instances in which these symptoms are believed to be linked to spiritual causes therefore the treatment should be through religious practices or a combination of Western and religious practices. This is based on the Islamic teaching that there are different causes of diseases. Some causes are physiological whilst others are not:

"Jinns are a form of energy, they do not have a form, unlike human beings. Jinns can affect human beings as they can occupy different spaces. This can cause symptoms in people when they are affected by jinns. Science does not recognise this. People can have stress and anxiety due to factors not connected to jinns but they can also have these experiences which are connected to jinns. If an individual is feeling unwell, first and foremost they need to explore every avenue medically to look for a solution…..if you go for a period and your symptoms persist and medical professionals are unable to help, then you should put your trust in God and seek alternative options." (Participant P10; male; faith leader)

There are some similarities, but also differences, in the views about the role of religion and its teachings amongst other interviewees. Having trust in God is a common view held by some of the participants that have a CMD and this played a key part in how they chose to manage their symptoms and maintain their ongoing wellbeing.

"Me being a Christian, your faith is supposed to carry you through no matter what the situation." (Participant P01; female; diagnosed/self-defined CMD)

"It is clearly written in the Quran that Allah will test all with trials and tribulations and a lot of things. Even anxiety is there, you will be scared of things and all that but all you have to do is rely on God. So, some people are of the opinion that if you are very close to Allah, then you are not supposed to experience anything like that." (Participant P13; female; diagnosed/self-defined CMD)

Interviewees with a CMD that practice a religion expressed the challenge of holding the belief that one's faith should be able to help them get through any difficulties they experience in their lives. It made it tougher to reconcile the symptoms they were experiencing and their desire for it to be addressed for example:

"I am religious, I'm a Muslim. Prayer was not more than it was generally in my normal life. I mean, I would pray, I guess I would pray more." (Participant P09; male; diagnosed/self-defined CMD)

Despite the struggle that interviewees with a CMD experienced to align their religious beliefs or the teachings of their faith with that of medical views, what was clear is they did not quickly link their symptoms to mental ill health, even when there is a presence of medical knowledge within their support network. Those links were only made once they sought professional help. From the view of the faith leader, this link is also made once people receive some form of medical reassurance or counselling support. This suggests the views interviewees' hold separates the mind from the body. As previously noted, the way symptoms are characterised is linked to people's perceptions of mental health disorders. Figure 7 below illustrates the transition experienced by interviewees with a CMD from the point where they start to feel symptoms which they try to make sense of, through to the point they arrive at when they had time to work through it and more importantly, professional support. This is echoed by the professionals interviewed and the faith leader. This illustration is constructed from the description of this process in the journey of the interviewees in this study. Accessing this support and working through the symptoms experienced suggests that it allowed interviewees to reach a point of either attaching a label (as a mental illness) to their experiences or recognising that the professional support accessed was needed.

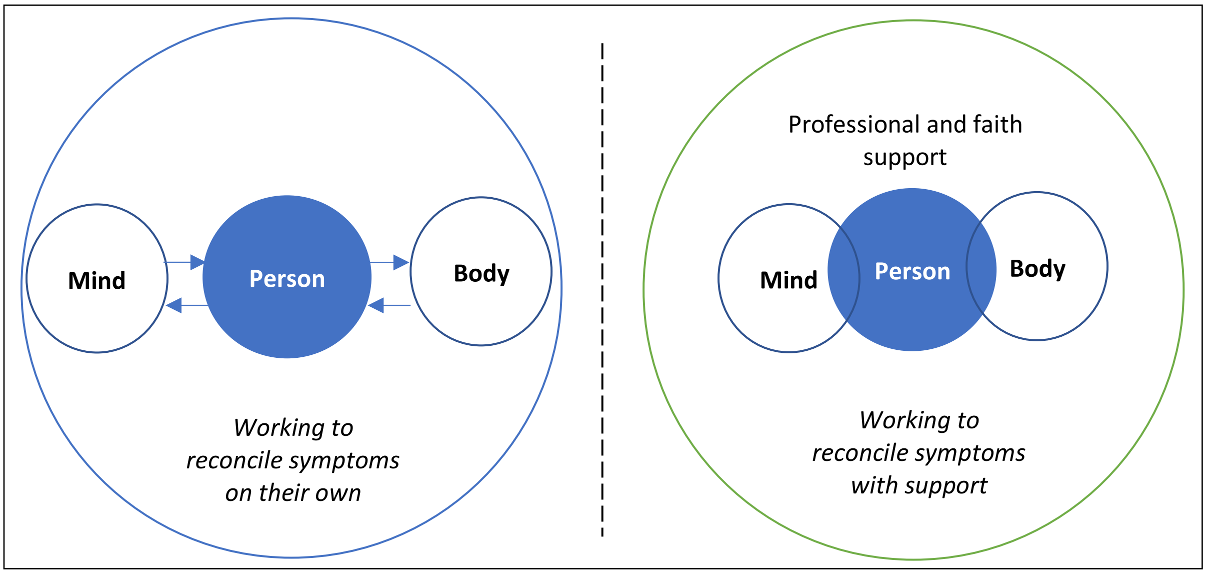


Figure 7. Transition through different phases as people seek to understand the symptoms they are experiencing at each stage of their journey.

A meta-synthesis by Choudhry et al., (2016) noted that some study participants believed that the explanations for the causes of common mental disorders are rooted in science but this varies amongst people, groups and cultures. Beliefs about the explanations for mental disorders then determined their preferred choice for treatment and support. For example, those who believe the cause is linked to supernatural factors therefore lean on their faith and that network for support (Choudhry *et al.*, 2016). This will be further delved into the following sections when health seeking and treatment/support options are discussed as well as in Section 6.

5.2.2 Myths and misconceptions about common mental disorders

Many myths and misconceptions exist about mental illness across different populations and cultures. One widely held misconception is that 'mental health problems are rare' (Time to Change, 2020). As this study focuses on Black Africans, there are certain myths and misconceptions shared that are perhaps unique to this community. Interviewees were cognisant of these myths and misconceptions especially people with a CMD, who's decision-making process on when, where and how to seek support took these into consideration as detailed further in Section 5.4. It also played into how they conceptualised their symptoms and experiences as noted earlier.

One of myth is that Black people do not suffer from CMDs and depression is most cited as an example. Another is that Black Africans are viewed as strong people that are able to cope with a myriad of challenges, therefore there is an expectation to always display signs of strength:

"Nobody wants to say I'm depressed. There's this thing that Black people don't get depression…I think people see you as being weak or something, so nobody would want to admit it even if they knew…..that word depression is not something that's in our African dictionary." (Participant P14; female; diagnosed/self-defined CMD)

Another notion viewed as a misconception by some of the interviewees in the study is what religious leaders characterise as mental illness (only serious mental illnesses considered as an illness) and the symptoms they recognise as being linked to it. This characterisation shapes the sort of advice they give to individuals experiencing symptoms of a CMD that seek their support:

"If the religious leaders themselves don't tell us oh no, no, no, don't worry, you cannot be depressed, you just pray and you will be fine. That is the issue, they tend to do that a lot. And tell you there's no problem or tell you that there's no problem that prayer can't solve, just pray about it and you will be fine. So, once we have that conflict of always pray, pray, pray, we have a big problem in our community." (Participant P14; female; diagnosed/self-defined CMD)

A study carried out by Alang., (2016) in the USA, noted similar findings amongst African Americans. Interviewees conceptualised depression as a weakness. Mental illnesses were not seen as consistent with having strength. This is thought to lead to silence about depression or symptoms that might be thought of as being at odds with perceptions of harmony, resilience and strength. This view appears to contribute to mental illness stigma within the Black African community by fostering silence, judgement and shame (Alang, 2016). These views are further discussed in the next section.

5.2.3 Stigma, fear and judgement

Stigma is primarily a psychological and social phenomenon. It has been defined as "the co-occurrence of its components – labelling, stereotyping, separation, status loss, and discrimination – and it is further indicated that for stigmatisation to occur, power must be exercised" (Link and Phelan, 2001, p.363). Livingston., (2013) additionally explained this definition as "labelling refers to the social process of constructing and applying oversimplified, socially salient categories of human difference. Through this process, labelled persons are believed to be distinctly different. Stereotyping involves cultural endorsement of the association between social labels and undesirable characteristics. In the next component, separating 'us' from 'them', persons bearing a stereotyped label are set apart and isolated from the rest of society. Thus, a 'stigmatized them' is created. The preceding components can then lead to devaluation, rejection, and exclusion of certain groups, which creates social disadvantage and loss of social status" (Livingston, 2013, p.3).

Stigma is indicated to exist at three levels that are interrelated – self, social and structural. Self-stigma is defined as internalising the stigmatising perceptions of others by the people that hold stigmatised attributes. People with stereotyped characteristics, for instance mental illness, are often socialised into believing they are devalued members of society, which means they assume negative feelings about themselves and encounter feelings of shame and reduced self-efficacy (Adams *et al.*, 2014). Felt stigma is the internalised sense of shame and the discrimination by others based on being viewed as being imperfect (Scambler, 2004). Social stigma relates to members of a community deciding that certain characteristics are outside of their norms and then proceed to behave in a way that may be harmful towards people they perceive to fall within this category. It then provides an ideal environment from which self and structural stigma can arise (Adams *et al.*, 2014).

Analysis of interviews with participants with a CMD suggests that this definition of stigma resonated with them. It was a key factor in how people chose to manage their symptoms and if, how, when and where to seek support from when unable to cope. The fear of being stigmatised was also a factor in the decision-making process reported by family/friends that were interviewed, when seeking to get support for the person affected by a CMD. Similarly, professionals and the faith leader were acutely aware of the role stigma plays in people's mental wellbeing journey. This is not unique to Black Africans however there may be aspects that are more present within these communities.

Amongst interviewees with a CMD, all but one strongly highlighted how stigma influenced the way they felt and how they chose to manage their symptoms. They were fearful and conscious of the judgement they could face if they disclosed what they were experiencing particularly to people they perceived may not understand. This concern extends to confiding to family and friends that interviewees thought may also not have a full understanding of how such difficult experiences could be affecting their wellbeing or not regard it as being serious. It also extends to professionals:

"I feel like when I started talking, when I started going for the counselling, then I think I started judging myself too much, too much, I was judging myself. I was thinking I don't want it to get out that I was feeling like this because if it got out, then people will judge me, especially like in my faith community, they might think like maybe you are not that close to God, maybe you have something in secret you're doing that's not good." (Participant P13; female; diagnosed/self-defined CMD)

Amongst family/friend interviewees, the stigma of mental illness and the impact they believe it has on service delivery, how Black people are perceived and treated by the 'system' was a key consideration when trying to make a decision on which actions to take to support the individual experiencing CMD symptoms. This not only speaks to the stigma that exists within Black African communities but also the perceived broader stigma (through stereotyping and structural discrimination) across different institutions, which could impact on the outcomes of individuals affected by mental illness. Trust in the 'system' also factors into this conversation:

"We were worried about contacting services to get him help. We didn't want his details in the system and didn't know how he would feel about his details being out there. We were also worried about how it might affect his visitation rights to see his child. If it came out that he was struggling with mental illness, then he may not be allowed to see his child. These were all the things we were debating between us because we could not reach an agreement." (Participant P05; female; family/friend)

"Africans don't want their business to be in the system so most of the time they avoid going there like the plague. It's like street guys not wanting to talk to the Police, same thing." (Participant P08; male; family/friend)

Professionals interviewed also noted the role stigma plays and how it impacts people's ability to discuss their experiences, to seek help and to disclose experiences of the treatment or support they received. The silence about mental illness (mainly serious mental illnesses) is intrinsic in Black African communities which means that 'mental illness unspoken about = mental illness treatment unspoken about'. It is a taboo to discuss mental illness openly and other health issues are considered to be a private matter. This was also echoed in the interview with the faith leader:

"Whenever you have a disorder that actually incapacitates you, it still becomes stigmatising and that's not something you walk around telling people about. People still try to cover it up. In our society, I think anything that has to do with people's privacy and I think health in general, that's not something you feel comfortable talking about….But mental health somehow is something that is always very, very much taboo, something you cover up, because this comes with this belief that it might have been the result of a curse or something you might have done or that someone in your family or somehow through your family transmission that you are paying for." (Participant P04; female; MH professional)

"I grew up in a home where children should be seen and not heard. I grew up in a home where you didn't speak really, you didn't ask questions, so I guess that kind of stems from there really." (Participant P02; female; family/friend)

In addition to the above relating to the taboo of discussing mental ill health, it is surmised that African communities are of the belief that they have long developed coping strategies to manage mental illness within family structures therefore, there is less motivation to discuss it and seek help:

"Within the family, people have developed a strategy to kind of cover up for it or to hide this family stain. And so, it becomes all the more difficult to reach out and ask for help because we've been managing this within the family for years and we've found ways to manage the symptoms for years. So why would you out of nowhere say that now you are going to go and seek Western solutions when we are telling you that." (Participant P04; female; MH professional)

Also related to the above statement and quote, it was noted largely by the professional interviewees, that stigma and the beliefs which shape these views can continue to be passed down from one generation to another within the Black African community. This is particularly relevant to how widely mental illness is then discussed within family and community structures. Again, this has a profound impact on the experiences of people affected by mental illness and their family/friend network:

"The assumption was that there was some sort of curse like the person was cast if they suffer from a bad mental health. And I think maybe this just kind of continued over the generations and still is quite stigmatised and not spoken about because they don't know how to address it or they see bad mental health as being like a curse or something that's happened because God isn't pleased with you." (Participant P03; female; MH professional)

People with a CMD and the perceptions they hold about stigma and the fear of judgment from different people also extends to their family and friends. This fear of judgement also stems from the belief that having a CMD may not be viewed as being a serious issue and is part of normal everyday activities, therefore should be able to cope (Lloyd, 2009). The underlying factors leading to someone suffering from a CMD may also be linked to the expected reaction and support from family/friends. Certain traumatic experiences as an underlying factor is perceived by one participant as being a more justifiable reason for suffering from a CMD:

"I didn't speak to any of my family members and my mum, my dad, my siblings. I didn't speak to them because I think I felt like they wouldn't understand. And also, I've got a brother that's been through war. They've been through war and you know, and he was getting on with his life. And you know, what have I been through? Oh, I'm scared I'm going to die. And when I did speak to my friends about it, I'm not sure why, but I didn't let them know how serious it was." (Participant P01; female; diagnosed/self-defined CMD)

"If I went to my mum, I said that I've got anxiety, she would've overlooked it. It would've been nothing. But if I had tried to commit suicide, she would've said why didn't you tell me. You know, but I did try and tell you. I told you that I have anxiety." (Participant P01; female; diagnosed/self-defined CMD)

People with experience of mental illness are thought to endure greater stigma compared to any other health issue (Mantovani, Pizzolati and Edge, 2017). This is thought by some to be linked to low mental health literacy levels across the general population despite efforts to address this issue with campaigns such as Time to Change and PHE's Every Mind Matters, as well as through policy changes, to shift the direction of travel towards achieving social justice and equity (Mantovani, Pizzolati and Edge, 2017; NHS, 2020a). Adams et al., (2014) noted there is evidence that people with a mental illness face ethnically based prejudice and discrimination by healthcare professionals. This impacts on the levels of engagement in services within these communities as well as the pathways in which they enter these services (Adams *et al.*, 2014). As noted in the quotes from Participants P05 and P08, mistrust in services is a factor in delayed help-seeking. This is also noted by Adams et al., (2014). In the study carried out by Anglin et al., (2006), they proposed that stigma stemming from and reinforced within ethnic minority communities, is linked to stigmatising attitudes to messages about mental illness conveyed by families.

Based on interviews with participants in this thesis, it is clear they believe these three levels of stigma exist within themselves, in their communities and the society at large. As previously mentioned, this conceptualisation plays a very integral part in the steps people take to manage their experiences and seek the type of support they feel is best for them, that is, reliant on not being judged, their issues not being trivialised, and the impact of stigma may not be felt as much. This is discussed in more detail in Sections 5.4 and 6.2.

5.2.4 Traumatic experiences

Trauma has been defined as resulting from “an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or threatening and that has lasting adverse effects on the individual’s functioning and physical, social, emotional, or spiritual well-being” (Center for Substance Abuse Treatment (US), 2014, p.7). It can affect people irrespective of their ethnicity, age, gender, sexual orientation or psychosocial background. People can have traumatic experiences through a single event, a series of events and/or a chronic condition such as abuse or neglect. It can affect individuals, families, communities, specific cultures and generations. Trauma can often overwhelm a person or community’s ability to cope and can cause a fight, flight or freeze response during the course of the event. It can create a sense of vulnerability, helplessness and fear (Center for Substance Abuse Treatment (US), 2014).

Interviewees raised the role traumatic experiences played in the journey of people that are affected by CMDs. Family/friends, professionals and the faith leader all felt there was a connection to past trauma amongst the people they supported, with the experiences they endured leading to them needing help:

“I’ve had mute sessions, like a whole 45 minute session. So, I sit in silence because somebody had gone through trauma. The few words I would put in there every two to three minutes allowed them to feel safe and trustworthy and trusting. And after a while, we realise that they had been raped when they were children until they got to a point where they could no longer be themselves and they dissociate.” (Participant P04; female; MH professional)

“Sometimes people’s anxiety might be triggered by a series of events culminating over time. It could be down to grief and being stricken by it. It could be down to marital problems over long periods of time that breakdown. These can all accumulate over time.” (Participant P10; male; faith leader)

People with a CMD that disclosed previous traumatic events during the interviews also reported that they did not link these events to their CMD at the time. For some, they were only able to make that connection once they sought help:

"The therapy didn't get to that point, to kind of explore why I had gotten to that point. And to be honest with you, I'm aware now that there might have been something else I was probably trying to avoid, but I can't say what it is. I'm not sure how I got there." (Participant P01; female; diagnosed/self-defined CMD)

"I just saw a lot of people were dying. There was my cousin's death. The car crash, that one really affected me. And then there was the Grenfell Tower. It was around the time of the Grenfell fire that it started. I started having nightmares that I was actually in the house….and I was in different places in the house because I lived there, so I know what it's like, what the layout was and everything. But I don't know why I was dreaming about that." (Participant P11; female; diagnosed/self-defined CMD)

For people that felt their CMD was triggered by periods of extreme stress or pressure, no connections to previous traumatic experiences have been made or if they have, it was not shared with the researcher. What is perhaps interesting with interviewees who felt their CMD was triggered by stress or pressure is all but one, did not use these words (stress, pressure) when describing their experiences and what they felt may have triggered their CMD:

"I had a bit of an issue a couple of years back. Whilst I was going through that tough time, I started having panic attacks. I knew because of the tough times I was going through, I was trying to cope on my own, I was reading my Quran and all that." (Participant P13; female; diagnosed/self-defined CMD)

Some interviewees noted they were interested in understanding the root of their CMD experience as part of their journey to help identify how to manage their condition, whilst for others, their goal was to have the tools or coping mechanism to continue living their lives as much like 'normal' as they could, without needing to understand any underlying causes. The rationale for focusing on managing their condition is further discussed in Section 6.2.

5.2.5 Acceptance

As discussed previously, there are different factors that influence how people characterise and come to understand their experiences. From the recognition of symptoms and attributing it to a CMD, through to fear of judgement, stigma and recognising the role traumatic events may have played in their lives. This means different people identify differently with a diagnosis of a CMD or descriptions of their experiences as relating to mental ill health. This can again impact on whether people choose to seek help, where they access it from, how and when they get that support and most importantly, the degree to which they engage with it. The process of working through one's feelings and trying to make sense of their experiences to finally reaching some form of acceptance was highlighted by all interviewees. For some they were able to reach the point of acceptance once they received a formal diagnosis and for others, they prefer not to adopt, or do not recognise, the label of a CMD even if they sought professional help.

"The amount of relief I felt, I think that helped or changed things. Because now I knew what was wrong with me. Not knowing what was wrong was so scary." (Participant P11; female; diagnosed/self-defined CMD)

"I'm not sure if I was diagnosed but I was suffering. I did have really bad anxiety. And I did go to my GP and I got referred for therapy. So, I don't know if that meant if I was diagnosed or not." (Participant P01; female; diagnosed/self-defined CMD)

"So, he went into hospital for like a week and then he was released. When he came out, he was in denial with everything that was going on. He said he was okay. He said it was an experiment he was trying to conduct. And he still wasn't himself." (Participant P05; female; family/friend)

The professionals interviewed in this study noted the importance of allowing people the time and space to work through and make sense of their experiences to reach some form of acceptance. This is reflected in how their services are designed. Service users are not required to accept a diagnostic label neither are they dissuaded from identifying with it.

"Some people come because they've had experiences of the statutory mental health system and they've acquired a diagnosis through that and they disagree with it but they want some sort of support and they find other services pathologising potentially some people. Some people do come and say I've just gone through a crisis in my life, my life has been upended, I've got this diagnosis, what do I do." (Participant P07; male; MH professional)

Acceptance of illness has been defined as being "a psychological indicator of the quality of adaptation to life with a disease" (Janowski *et al.*, 2013, p.2). Some people may hold different levels of acceptance of their illness, which may indicate how well they tolerate its burden. It has been proposed that people with high acceptance levels of their illness, may feel more inclined to take up or continue behaviour that helps them maintain the lowest possible impact of the illness on their lives (Janowski *et al.*, 2013). Rethink Mental Illness recommend that people explore acceptance as part of their recovery journey because it may help them make positive changes and reach new goals (Rethink Mental Illness, 2020).

5.3 Impact of common mental disorders

The wider impact of CMDs on affected individuals and their support network was a key part of people's experiences. It again helps determine how people seek help and support, conceptualise their experience, and the decisions taken in maintaining their ongoing wellbeing. All interviewees with a CMD highlighted the impact their experiences had on their relationships with family, friends and broader social network. This was echoed by family/friends that supported someone with a CMD and professionals. Relationships in some cases became strained or completely broke down partly due to the difficulty of navigating these experiences and trying to provide support during crucial time points. This strain on relationships was also attributed by some interviewees to a lack of or breakdown in trust:

"One of the most difficult things for me then as well was my husband did not understand how I felt. It's not his fault though, sometimes even for myself I did not understand, I just knew I wasn't fine. So, he didn't really know how to deal with it and I think that was one point that we didn't really talk much. I didn't really know what to tell him and he didn't understand. He felt we were on top of everything and everything was going to be okay so why would I feel any different and what was actually making me feel like that within myself." (Participant P13; female; diagnosed/self-defined CMD)

"I feel very, very, bad for calling the health service and the police to come and take him away. I feel very guilty for doing that. So, it's been a bit of a challenge emotionally trying to deal with that. But at the same time, he was a friend and he still is a friend, and I feel like I've lost a friend because I don't see him getting better or getting any help. So, it's not been easy." (Participant P05; female; family/friend)

People with a CMD also took steps to distance themselves from some people within their network in an effort to conceal the difficulties they were experiencing. There was a fear that if they continued to interact with people as they normally would, there was a likelihood that someone may recognise the challenges they were trying to navigate and link it to mental ill health. For some interviewees, distancing themselves was a means of controlling the level of 'negative' advice, interactions and conversations they may have with people perceived to not understand their experiences. It was also a means of controlling access to information that was equally perceived to be negative:

"My mind was just negative. I had to stop watching the news. I mean I went off Instagram and all social media for like six months or a year because every time I went on it, it was like bad, bad, bad. I had to stop all of that." (Participant P11; female; diagnosed/self-defined CMD)

"What I did then was just to move a little bit away, I thought it was better not to attend some programmes and then people, I just decided not to meet my network, my circle was smaller, I didn't talk to many people. It was just what I had to do to get myself better, pick myself up and be able to keep going. And then I didn't want to listen to any negative lectures or anything that will tell me that maybe I've sinned a lot." (Participant P13; female; diagnosed/self-defined CMD)

The impact of CMDs also extends to people becoming reliant on family/friends to provide them with support or care, which then impacts on the day to day activities of the individuals providing this help:

"It's been a big strain on my mum. It's been really, really, really tough. Not only is she seeing her daughter go through that, having to care for her, stop everything she's doing to care for her two children. She's meant to be at that time where all her children are grown up now so she can go where she wants, come where she wants but she's had to become a mother again. That was hard." (Participant P15; female; family/friend)

The impact is not only on perhaps carrying out day to day tasks as part of the support provided but also financial aid. This can have profound effects on some particularly when public funds cannot be accessed. Family members have to continuously find means of meeting their own financial needs as well as that of the person they are supporting.

"Usually at a time when social services come into your life, it's at a time of crisis. As a family, all you want to do is protect, protect, protect. The last thing you want to hear is foster care or being removed. So, at the time, you do whatever it takes. So, at the time we were like the kids are with us, you don't need to worry, we can look after them. Obviously as time went on, we realised we need financial support. These kids are expensive. School uniforms, activities, everything. Child benefit doesn't cover it, it's like £20 a week….My mum is retired, so had it not been for the family, I don't know what it would be like for the kids." (Participant P15; female; family/friend)

From the perspectives of family members and friends that provide support to people with a mental disorder, their experience of being part of an individual's journey and the direct impact it has on them and their lives, also shaped the level of support provided. This experience also shaped how relationships are delicately managed, which are an essential part of one's network and ultimately wellbeing. Figure 8 gives a depiction of the words used by interviewees to describe how they felt when providing support to someone with a CMD. The words that appear bolded or larger in size indicate how often they recurred in the interviews.

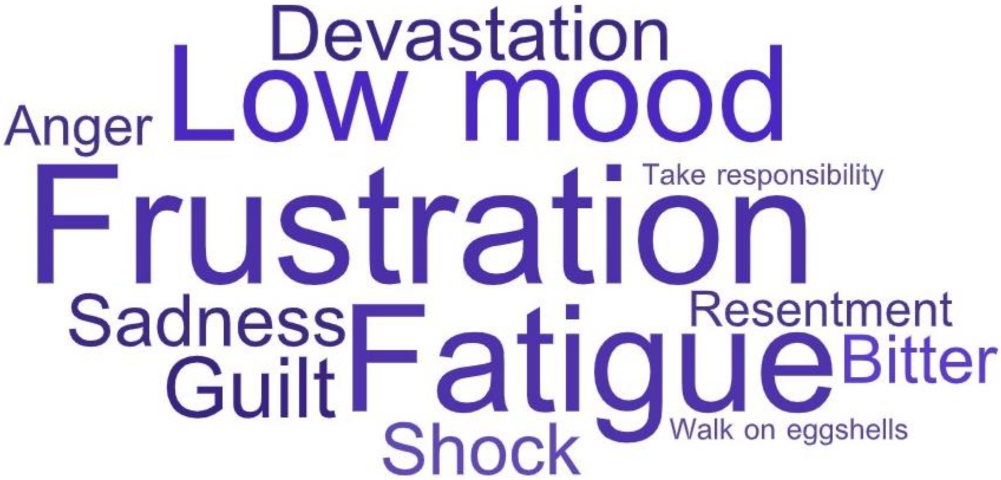


Figure 8. Impact of CMD – Description of the feelings of family and friends of an individual with a CMD

There is a degree of similarity in some of the feelings experienced by family/friends and people with a CMD as illustrated in Figure 6. Feelings such as anger, guilt and low mood or being emotional are common across both. Whilst there is some overlap, it should be noted that based on the interviews carried out, there did not appear to be a shared understanding of this, and the root of the emotions is also different. As noted in section 5.1, people affected by CMD characterised their symptoms based on their feelings whilst family/friends described them based on changes in behaviour.

Family/friends interviewed recognise the challenges being experienced by the person with a CMD they support, however, it appeared they have difficulty reconciling this knowledge with their feelings towards the situation. There is an appreciation that difficult mental health experiences can mean an individual does not recognise or is not always aware of how it impacts on others such as family or friends that may be trying to support them. Provision of support also has an impact on the wellbeing of these individuals and over time, could lead to relationships between them and the person with a CMD getting strained. This highlights the importance of those people who are providing support to someone also needing to access some form of support or respite for themselves in order to maintain their own wellbeing. The emphasis and attention often is on the affected individual therefore the need for this wider support can go undetected or unaddressed. The experience of providing mental health support can sometimes be traumatic for family/friends:

"For me, it hit me hard. I know mental health is a selfish illness. People are self-centred, those that are going through the mental health are very, the world is all about me and they don't see the impact on other people. I know she can't help it but I can't help taking it personally. So, because of that I don't have much of a relationship with her. We talk, she calls me a lot and we speak but I feel that my role is to make sure that her children are okay and she's secondary to be honest. I don't go to see her because I don't want to. I am still very bitter about the whole thing because it didn't just impact mum's life, it impacted everybody else's life, it impacted my life." (Participant P15; female; family/friend)

As detailed earlier, family/friends can take on the responsibility of providing practical day to day, emotional and financial support to someone with a CMD. As a result, without very much proper preparation or the knowledge of health professionals, they often experience significant changes in their life. Positive and negative effects of family/friends providing care and support is not always visible (Schulz and Sherwood, 2008) however, the data presented here show that it can lead to high levels of burden and could eventually have consequences on the wellbeing of the caregivers and supporters.

5.4 Health seeking and support

The type of treatment and support people sought was driven by how they characterised their symptoms and their perceptions of mental illness and its impact. People's experiences varied from making a decision on their own to seek help through to needing support from their network to access treatment. Time played an important role in when people chose to access treatment as did the knowledge of services available and, even more so, how they can be accessed. Trust or the lack of it in the healthcare and statutory systems, and family/social networks, also played a big role in the process of deciding to seek treatment and support. One of the biggest drivers however in motivating individuals to seek treatment and support was their need for the symptoms they are experiencing to be 'fixed'.

5.4.1 Motivations

Motivations to access some form of professional support differed between people with a CMD and family/friends of someone with a CMD. It is usual for someone with a form of illness or experiencing symptoms, to go through periods of monitoring changes in their health, to try to establish the cause and take steps to manage them as best as they can (Kleinman, 1978). As outlined in previous sections, interviewees went through this process and for most of them, took steps to try and 'manage or cope' with their symptoms for different lengths of time before they either decided to seek help, or reached a point of receiving a diagnosis.

The process of weighing up whether to seek professional help or not was a complex process for interviewees with a CMD. On the one hand, symptoms they experienced at some points in their journeys were so overwhelming, particularly for people that disclosed struggling with anxiety and panic attacks, that their desire to 'live' and not feel the symptoms they had, was key in helping make that decision:

"My son and the fact that I didn't want to go crazy or die young and leave him behind." (Participant P11; female; diagnosed/self-defined CMD)

On the other hand, there was a fear of the impact of continuing to feel scared. This feeling was difficult to keep at bay and manage:

"And what made me go, to be honest with you, I was scared of being scared. I can't really explain that feeling and I just can't put it into words but I was scared of being scared. So, for me, I went more or less with the mentality of fix me." (Participant P01; female; diagnosed/self-defined CMD)

For interviewees that knew of someone that has a serious mental illness (SMI) and the way it impacts on their life, the fear of their own symptoms escalating to the point of becoming that 'serious', was also a strong motivator for seeking help:

"I thought I had a heart problem. I thought I was about to just drop down and die one day. I had never experienced that in my life. I felt like I couldn't breathe. Then I thought I was going mental. My cousin had mental health problems and I've been there experiencing the whole thing with her. My biggest fear was I was going to turn into her." (Participant P11; female; diagnosed/self-defined CMD)

For the majority of interviewees with a CMD, the characterisation of symptoms as relating to mental ill health did not happen at the beginning of their journey. However, where it was recognised as being possibly linked to CMD, due to experience of working in the mental health field, it was one of the factors that motivated health seeking:

"One of the things is that it was a bit tough for me to accept in the beginning that this is what is happening to me until I was thinking the world is closing in on me. I was like, no, this can't happen to me, this can't happen to my family. So, I knew the signs but why am I not able to deal with it. Or am I just imagining it in my head and is it like my imagination running wild or is this actually happening. And then I realised, this is actually happening to me, I'm having panic attacks and I should go somewhere." (Participant P13; female; diagnosed/self-defined CMD)

The need to remain in, or regain control of one's life, feelings and thoughts was important to interviewees as part of how they coped with their symptoms. It was also a driving force in wanting to receive professional help, even if it was unclear what type of support was needed due to symptoms not being attributed to a CMD. Reaching the point of acknowledging the need for healthcare services was an important step in people's journey:

"I was really worried about going out because I would feel disorientated……it was definitely exacerbated by my anxiety. So, I would feel like I was going to pass out every time even when I really knew I wasn't, so I wasn't exactly trying to go out……I felt like there was always the risk of me just passing out or having a panic attack or something. So, I tried to avoid having that happen in public." (Participant P09; male; diagnosed/self-defined CMD)

"And just wanting to be able to control it because it was crazy. I thought I was losing my mind. It was just the negative feelings in your chest and your body, just feelings." (Participant P11; female; diagnosed/self-defined CMD)

The lack of trust in the 'system' which includes both healthcare and non-healthcare was a consideration for some interviewees. There was a fear that certain sensitive information should not be disclosed to healthcare professionals and instead a selective approach should be taken in what is divulged. Disclosing mental health issues in particular should be approached carefully as it will be held on record. An aspect of this view relates to the discrimination, unfair treatment and racism that is believed Black people face from the 'system' when they have interactions with them. This extends to not just healthcare services but particularly the criminal and justice system (The Sainsbury Centre for Mental Health, 2006):

"I think probably if I had known there were other services, I probably would have gone for that rather than my GP. Because I know in the past that I have been told don't go to a GP for everything because, you know, especially with mental health, when you go through, they have things on record and things like that." (Participant P01; female; diagnosed/self-defined CMD)

"If I was in my car right now and you pull me over, being a Black man, you make up whatever law you want to get me out of the car and put me in jail." (Participant P08; male; family/friend)

"I think he sees it as something negative because now he's on the police database. The second time around, they said they won't file an investigation. So, I just don't want his name

tarnished but at the end of the day, his health is more important than having his name tarnished." (Participant P05; female; family/friend)

The motivation of family/friends to seek support for an individual was also a complex process. As the people they support are all adults, this has implications for the services that can be accessed on their behalf or the degree to which they can be encouraged to engage with and continue to do so. Striking the balance in the decision-making process was delicate. Respecting the person's right to access a service they wish to be engaged with was key. However, so was actively encouraging them to do so even if they did not recognise the need, as this was deemed the best decision for their wellbeing by family/friends providing support. Additionally, protecting the individuals considered at risk was also stated as important. Decision making involved considering different options, appraising them and negotiating to reach a consensus amongst everyone involved in the family/friend network. Reaching the point where the network felt unable to continue helping manage symptoms or the fear the person would be of harm to themselves, was a strong motivator for seeking help:

"So, all of his friends, we all came together and I set up a group chat so that we could communicate easily and we all decided to go and pay him a visit…..we came to the agreement that he needed to get some help." (Participant P05; female; family/friend)

"She was fine and then all of a sudden she started getting paranoid. So, the trigger was that she wouldn't let the kids go to school because she felt that someone was going to kill them. It was at that time the oldest child, he was able to call my mum to let her know. My mum just popped over to the house and then intervened. My sister wouldn't leave the house." (Participant P15; female; family/friend)

Professionals interviewed in this study work in the community, so the perspectives they shared are with this view. They indicated that in their experience, people accessing support through community organisations do so at different points in their journeys. For some, it is during the time where they are still trying to 'make sense' of the symptoms they are experiencing, whilst for others, they received a diagnosis and are working through it. In some cases, the motivator is that they have tried accessing a number of statutory services or leaned on their family or social network, however, still need further support from professionals:

"Some people come because they've had experiences of the statutory mental health system and they've acquired a diagnosis through that and they disagree with it but they want some sort of support and they find other services pathologising. Otherwise, some people do come

and say I've just had, just gone through a crisis in my life. My life has been upended. I've got this diagnosis. What do I do?" (Participant P07; male; MH professional)

There are individuals whose motivations for engaging with these services is to build their social network, or to get involved in meaningful activities so as to keep a routine that allows them to maintain their ongoing wellbeing:

"Our main aim is basically to just promote social inclusion amongst the community wherever we're based. So, one of the main things that we do….is just basically a social group that has all the mental health service users who want to come along. And it's just a place for them to be able to talk to other people, maybe not speak if they don't want to and just kind of sit around and relax. We obviously serve food and there's also activities, especially in the afternoon, such as art, we have in our training room a movie that is being played so people can go and watch that." (Participant P03; female; MH professional)

According to the faith leader interviewed, people's motivations for seeking support from religious figures are broad. They may seek this support themselves or family/friends may do so on their behalf. For some individuals, they do so because part of their belief is that the cause of their symptoms is not medical. It is instead a result of a form of 'spiritual imbalance' or 'curse'. Individuals have at times reached a point of crisis when they seek help:

"In some extreme cases, for some people, they are driven to seek help because their condition is caused by a jinn and the jinn instructs them to take their own life, so, they are suicidal. An example is there's an Arab woman that was introduced to me by her friend. She asked me to pray for her. Whenever her symptoms re-emerge and become overwhelming again, she calls on me and asks me for help as she was suicidal. During that whole period, she had been seeking medical help but the doctors could not diagnose her. They would admit her for a little while and release her again. Her condition was caused by a jinn." (Participant P10; male; faith leader)

For others, their motivation is driven by their inability to reach a resolution after seeking support from healthcare services:

"An example, there's a woman I supported who's well educated. She had some difficulties in her life and started going for counselling in the early stages. During her period of going for counselling, she also used to contact me for support. After some time, she decided to terminate her counselling sessions which I found out about later on. She shared with me that what she could not work out was why during her counselling sessions, she used to leave the

sessions feeling stressed and crying. However, when she receives 'counselling' from me, her mind is at peace. She said, I am nearly back to my normal self, based on the sessions I've been having with you; since I stopped going to the other counselling sessions, that was when I started feeling better and having peace." (Participant P10; male; faith leader)

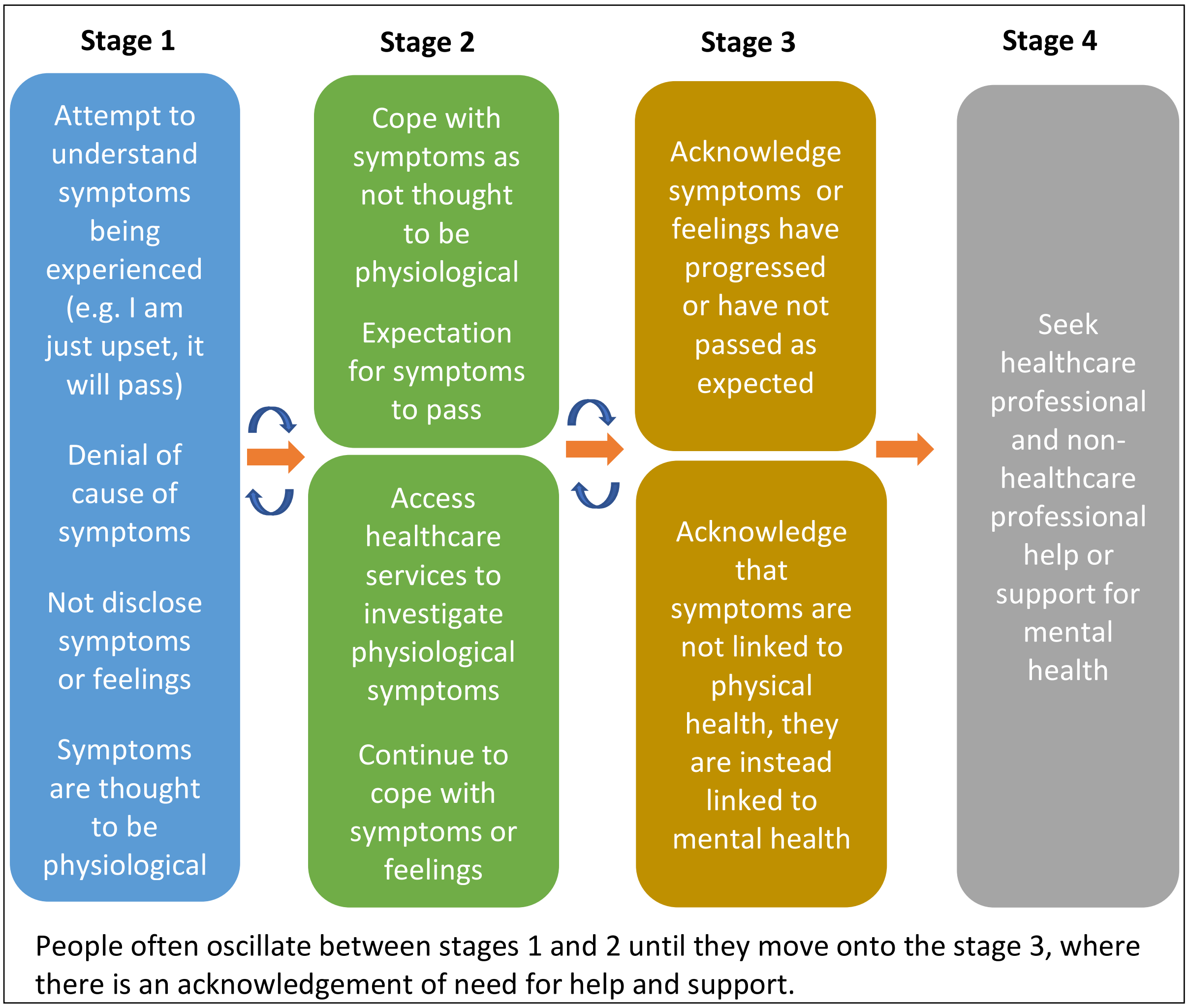
Whilst most of the interviewees with a CMD in this study, either diagnosed or self-defined, chose to seek support, one did not. This, according to the interviewee, was because the symptoms experienced were not attributable to a CMD. It was eventually recognised by them as a CMD following sharing their experiences with their GP much later on but at that stage, the interviewee felt able to cope and had continued to maintain their wellbeing:

"It's later on when I reflected on what was happening and my husband drew my attention to it, that's when I realised what I was going through. At the time when it was happening, I didn't think about it as depression. I didn't know what was happening. At the time I didn't know. I thought I was emotional, getting angry over nothing…..I talked about it with the GP because I was asked how I was feeling. So, I didn't think about going to share it with anybody, I didn't even know it was an issue…..it was just me not feeling happy but I didn't think it was something to report to anybody at the time." (Participant P14; female; diagnosed/self-defined CMD)

The following sections give a more in-depth account of the journey and process people go through to finally acknowledge and seek help outside of their family/friend network, and what happens once they access it. It covers the timeline ('when') to getting help, where people then decide to get this help and how they do so.

5.4.2 'When'

As previously mentioned, people may experience their symptoms for significant lengths of time before they take steps to seek mental health support outside of their family or social network. For others, their journey to accessing support commences or is triggered by a need to investigate symptoms thought to be physiological that may require urgent treatment. The stages that people typically go through based on accounts of interviewees with a CMD in this study can be described as per Figure 9 below. People that attribute their symptoms or feelings to physical health take a slightly different path in their journey to eventually seek mental health support. Whilst this figure illustrates the journey in a linear form, it should be noted that people oscillate between the first two stages and in some cases also stage 3 before reaching final acknowledgement for the need to seek mental health support. This figure has been constructed using the accounts of interviewees in this study.



People often oscillate between stages 1 and 2 until they move onto the stage 3, where there is an acknowledgement of need for help and support.

Figure 9. Depiction of the stages people with a CMD progress through in their journey to acknowledging the need for help and then accessing it.

During the first stage, people go through the process of trying to ‘make sense’ of the feelings or symptoms they are expressing. There is a belief the symptoms will be short term and eventually go away. For that reason, no immediate action is taken to seek help neither are the symptoms attributed to mental health:

“Even if I was aware of the services that were there, it still would’ve, I think personally, taken me that long to seek help. Because you go through something, it’s like, okay, you’re upset, you’re upset for a period of time. You’re angry for a period of time. So that is the steps. I don’t think I would’ve gone for help any sooner if even I did know about it to a certain degree.” (Participant P01; female; diagnosed/self-defined CMD)

For interviewees that thought their symptoms were due to a physiological reason, they attempted to cope with it for a much shorter period of time however, then decided to seek help to investigate their symptoms. For the interviewee quoted below, they sought help immediately after having their first panic attack (stage 2), but this was after experiencing other symptoms they could not directly link to a cause:

"I thought I was having a heart attack or a health condition…. So, after the first panic attack, I went to the doctor, they did an ECG…..then I did a scan and I had to come home with this machine for three days. And this was all before they told me about anxiety or panic attacks. But they did all of that. So, it took a few months." (Participant P11; female; diagnosed/self-defined CMD)

For interviewees that did not attribute their symptoms to their physical health, they continued to try and cope and manage until they reached a point where their symptoms had progressed/worsened or had not passed as expected. As indicated previously, the period of trying to cope before seeking help could last up to 6 months (stage 3):

"Six months. Because it was like six months I couldn't sleep. I remember that. I remember thinking it'll be six months now. Now I need to do something about it. So, it took me that long. I knew I needed help but it took me six months to acknowledge that I need help." (Participant P01; female; diagnosed/self-defined CMD)

"I knew that I needed help because I couldn't deal with it on my own. I wanted to but I knew as a professional myself that I need to…..I saw myself like a bowl, you're pouring water inside the bowl and I was so full that now I was overspilling." (Participant P13; female; diagnosed/self-defined CMD)

Where the first step to seek help is to have physical health investigations, the acknowledgement of the need for mental health support then comes via healthcare professionals that have been involved in the process of looking into these symptoms. Interviewees shared they acknowledged and accepted the initial CMD diagnosis as it was by a health professional:

"When I went to my GP at one time and I just had it in front of her, she was like you're having a panic attack and anxiety. And then it switched from hospital to the other side, to the therapist." (Participant P11; female; diagnosed/self-defined CMD)

For family/friend interviewees, the insight they gained into the journey of the person they supported did not typically commence at stages 1 and 2, it was instead at stage 3. This acknowledgement by the person requiring support was not always shared with the family/friend interviewees however, on reflection interviewees recognise there were indications that the person may have needed mental health help:

"I don't see why she wouldn't have wanted the help because there was a few times she did voice out that she was tired of feeling the way she did but she never said what she was tired of." (Participant P02; female; family/friend)

The other difference however, being that the acknowledgement of symptoms having progressed to the point where mental health services needed to be engaged did not come from the person with a CMD. The person with a CMD was felt to have reached crisis point, they were exhibiting behaviour that was uncharacteristic and needed immediate professional mental health intervention:

"I got a call from my friend, I was in the library….and she said your cousin is being weird. So, I called my dad and said I think you guys should go and check on XXXX. So, when they called her, they found out that she had gone and taken her kids out of school. She was driving recklessly. So, I came down the next day and by then, my dad had taken her to the hospital." (Participant P12; female; family/friend)

As previously noted, professionals interviewed fed back that people typically engage services delivered by their community organisations once they reach a point of either having a diagnosis from statutory mental health services, they feel their mental disorder is manageable, have tried other services but wish to seek alternative options, are at a point of crisis or in some cases, they are still trying to make sense of their experiences (stage 3). Similarly, the faith leader interviewed reflected people engage based on the points above:

"I would say it is normally when they have got their mental health disorder under control. So, it's when they're not really a threat to themselves or others. Am obviously talking about more mild versions of mental health when it's something like depression and anxiety." (Participant P03; female; MH professional)

5.4.3 'Where'

Again, based on whether people with a CMD perceived their symptoms to be linked to their physical health or not, it helped determine where they chose to seek help (stage 4). The following were cited as the first point of professional health services that were accessed.

a. GP services

b. Specialist services
c. Workplace services

There were particular prerequisites that people factored into their decision making when identifying where to seek help. The services have to be confidential, non-judgemental and offer a safe space to disclose sensitive information. It should be noted that GPs are viewed as the ‘gatekeepers’ of the healthcare system therefore, to access specialist services, the pathway commences from that point. GPs also have a broad knowledge of services that would be most suitable to which to refer the individual. This also influenced where people felt they needed to go as their first port of call. Another reason for GP services being accessed was because it offered familiarity which in itself could be viewed as being a safe space for some interviewees. People with a CMD’s lack of awareness of other services was also a factor:

“And I did go to my GP and I got referred for therapy…..and I think what led me to the GP was that I didn’t know what else to do….so, I didn’t know what I was going to expect….And I think for me going to my GP as well, it was someone familiar. I mean, it is a bit difficult to go to tell a stranger and say this is what’s going on with me.” (Participant P01; female; diagnosed/self-defined CMD)

For the interviewees that accessed specialist services, they proceeded to the relevant discipline they felt the symptoms were associated with. For instance, Participant P09, saw one specialist, which then triggered a series of investigative tests until a mental health diagnosis was reached:

“Initially the focus was on me feeling dizzy or feeling disorientated. So, I went to see a neurologist and then cardiologist and then other doctors. And then when the results showed that I didn’t have any problems that could be attributed to that, I then saw a therapist….based on the recommendation of the neurologist.” (Participant P09; male; diagnosed/self-defined CMD)

As noted in the previous section, family/friends felt that by the time the person they supported accessed services, they had reached crisis point. This means they reached out to emergency services to get immediate help:

“We called the ambulance and they came over with the police and they decided that he didn’t need to be taken away because of not being harm to himself or anyone else around….his condition wasn’t getting any better, it started to get worse….so the police were called back again. They came back and said we’ll have to say he was being aggressive in

order for him to be arrested and taken away. So that's what happened and that's how he was taken away and went into hospital." (Participant P05; female; family/friend)

There are a number of organisations across the country that deliver helpline support services that can be accessed by the public. Many employers also have health and wellbeing support services for staff. These services are also confidential and viewed by many as being a safe space to disclose information (Mental Health Foundation, 2012). One interviewee opted to seek initial support through their employer when they acknowledged need for help:

"My organisation I was working for then, they had like a counselling line, so, I think I woke up in the middle of the night one day and I just called them. I was really crying and I just needed someone to talk to, and my partner wasn't around. Even if he was around, he has never worked in mental health so he doesn't even know how to deal with it or anything. So, I called the line and thankfully someone picked up. So, I started crying, I can't even remember what I was saying, I was talking to her for like 15mins, I was just saying things and she just kept quiet. I think I must've exhausted myself and then I kept quiet for a while." (Participant P13; female; diagnosed/self-defined CMD)

Mental health support services delivered by community organisations may not be the first point of access for most service users that are seen however, there is a proportion that do engage at the beginning of their journey to getting professional help:

"We do get people who have just gone through initial first crisis and that can be younger people, people a bit older. It depends when they experienced their first crisis….I would say it's probably more that people who've been living with particular experiences of the world and have really struggled to make sense of it and find appropriate support, who turn to us." (Participant P07; male; MH professional)

Support through a faith leader may or may not be the first option that people choose to explore depending on whether they have attempted to access other services (likely Western), how they characterise their symptoms and their perceptions of what may be the cause, therefore appropriate 'treatment'.

5.4.4 'How'

The way in which people seek help will depend on the different factors listed previously such as how they characterise their symptom. Once interviewees with a CMD accepted a referral for mental health support, they felt the pathway was fast. The waiting periods were much shorter than the interviewees expected based on the disclaimer given about typical waiting times. They did not delay engaging with the psychological therapies services once contacted to book in for an appointment:

"When I went and they said, go and speak to someone, and for me it was like oh, but at the same time, even though it was surprising that they said go and speak to someone, at the same time I was expecting something from them but just didn't know what….I didn't have to wait long. The therapy was meant to be 8 weeks or 8 sessions, not necessarily every week." (Participant P01; female; diagnosed/self-defined CMD)

As detailed previously, family/friends experiences of providing support and accessing professional services was at the point of crisis, when the person's disorder had progressed significantly. Whilst this may not be the preferred route for accessing services, it was felt there were limited options available to them. Navigating health services was cited as a challenge; especially to identify the appropriate teams that are best placed to respond. Contacting emergency services was therefore the only option available to guarantee the person with a mental illness will receive care:

"I remember spending a whole day calling one place. The process is long to get help started. They'll give me a number to call another place, I'll call them, they'll give me another number to call. The whole day, I was going from one place to another to another to another. So, the whole process is long. All you should need to do is just call one place and get help straight away. It's long winded and at the end of the day, you don't even know what you're doing. You are back at one again." (Participant P05; female; family/friend)

It should be noted that once individuals accessed services via this route (crisis point), they were likely to have repeat contacts before eventually accepting some form of support:

"Services were involved in the beginning but they stepped back because she wouldn't consent to engage with them and is competent. So, you know, they respected her wishes and they backed off. So, from 13 years ago to now, she's probably been sectioned about 5 times. These last 3 years has been the longest not to be sectioned." (Participant P15; female; family/friend)

When people opt to engage with community organisations providing mental health support, they can do so following a referral from a health professional or they can self-refer. One of the key aspects of the services is ensuring that it offers stability so it can be relied upon by service users. People have the flexibility to utilise services when they need to and during periods when they disengage, it is ensured their ‘place’ remains open for when they decide to re-engage in future.

There was some similarity in experiences amongst interviewees; the fact that in most cases, people ‘ping ponged’ between services before eventually engaging in the one most suited to their needs. This is true for people whose first contact with health services was to investigate physical symptoms, as well as those that accessed mental health services.

Health or care seeking behaviour has been defined as “any action undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy” (Ward, Mertens and Thomas, 1997). Prior to health seeking behaviour is the decision-making process that is determined by individuals and/or their family/friends, community norms or cultures, and expectations as well as service delivery related characteristics (Oberoi *et al.*, 2016). The health belief model suggests there are two major factors which influence whether individuals take a certain health behaviour. The first is the extent to which the illness is seen as a threat and the degree to which taking an action will lead to a positive health outcome. The perceived threat is determined by whether a person believes they are likely to get the illness and the severity to which it will affect them. The second is the perceived effectiveness of taking action to prevent having a negative outcome and this involves considering how much effort, time and resource it may take (Oberoi *et al.*, 2016). This aligns with the process that interviewees went through as they sought to make a decision on whether to seek help and if they do, when, where and how to do so.

5.5 Treatment and support

People with a CMD and family/friend interviewees stated that their expectation when accessing mental health services was for the problem to be ‘fixed’ once they engaged. Their expectations of the potential outcomes from engaging in these services is very much aligned to what patients expect when they seek professional help (Kleinman, 1978). The treatment of physical ailments typically focuses on alleviating symptoms and in most cases, the cause as well. The emphasis from interviewees was very much that symptoms be alleviated and there was less importance placed on engaging in the service, in order to understand the potential factors that may have led to their CMD:

“So, for me, I went more or less with the mentality of fix me.” (Participant P01; female; diagnosed/self-defined CMD)

“The GP was like you’re suffering from anxiety and panic attack and I was looking at him like what’s that. I was literally crying, can’t breathe. It was very stressful. But then having that helped. But now it’s, I know the problem, how do we fix it?” (Participant P11; female; diagnosed/self-defined CMD)

“For me, I was just happy that someone had stepped in. And for me, it was just like fix my sister. I didn’t wonder how she was gonna get better or how it was gonna get done. For me she was in the hospital, okay, thank God, they’re gonna fix her.” (Participant P02; female; family/friend)

The following sections explore in more depth interviewees’ experience of engaging in ‘treatment’. It also details experiences of family/friends and the perspectives of the professionals and faith leader, based on their practice.

5.5.1 Engagement in treatment

Once therapy was commenced by people with a CMD, engagement was high. All except one interviewee completed the series of sessions that were offered. Their experience of receiving therapy was positive; it was felt to be helpful and allowed them to achieve what they wanted out of it or at least felt it offered some form of outcome so they could move on. The sessions offered a safe space that was non-judgemental and confidential. It allowed people to have the space and time for reflection to begin to ‘make sense’ of their experiences:

“I had the counselling sessions, it was really good. That was when I realised the importance of communication. I do realise it in my line of work but I never knew how powerful it is to be able to talk to someone that is not judging you. So, each of the sessions if you go in there, because I am a person of faith, I use hijab. So, initially I remember asking my GP if I go in there the way I dress, will the person look at me. He said no, no, they don’t do that, they’re well trained and anyone can have any issue at any point in time.” (Participant P13; female; diagnosed/self-defined CMD)

“The whole thing, actually going to therapy gave me time out. Because I was actually very busy doing stuff and that was like my hour every week to just chill, unwind and just reflect on me.” (Participant P16; female; diagnosed/self-defined CMD)

For some of the interviewees, it gave them the opportunity to begin to understand and work through difficult previous experiences, feelings and thoughts they believed to have previously dealt with but did not connect it to their CMD:

“She made me realise there were so many baggages that I was I was still carrying. Like I lost my mum three months before my wedding, so she was like you have not even grieved for your mum, do you know that. I was like no, I did, after I got married. She was like no, you thought you had done that but you haven’t. Because when you started to talk you were like I

miss my mum, I miss my mum…..this was my first point of, she made me realise that I had a lot of things that I thought were done." (Participant P13; female; diagnosed/self-defined CMD)

For some interviewees, engaging in therapy challenged them to work through their feelings and thought processes to make sense of it, in order to reach a point of acceptance or breakthrough, learn and adopt coping strategies that could help them maintain their mental wellbeing:

"But looking back now, she didn't really do anything. One day in the therapy session, obviously after weeks of saying, I'm scared of dying, I'm scared of dying, I don't know if she was fed up of me or it was part of the session or the technique for her to get me to see things differently but she literally said to me when I said, well, I'm scared I'm going to die, she's like but why. Well, I won't be here anymore. She's like why. I said my kids, they will be sad. She's like why, I said, I don't want to die. She's like, so what if you die. I remember being really upset in that moment. I'm thinking what do you mean what if I die, I'm gone, I'm no longer here. I don't want to die, I want to live. But I remember leaving the therapy session that day and I felt alive. It is very weird. I felt alive. In that moment when she said that, I was upset. How dare you say that. I'm supposed to be here. You are supposed to be helping. You are supposed to be fixing me…..But I remember when I walked outside, I felt so refreshed…..And after months of not sleeping, I slept well that night. I just remember thinking in my head, just sleep, so, what if you die." (Participant P01; female; diagnosed/self-defined CMD)

It also allowed interviewees to work through feelings they did not know they had, which meant the sessions focused on issues they felt were different to their reason for engaging the service in the first place. This, however, did not deter them from continuing to engage as it was found to be a valuable process to work through:

"And then I went from being very depressed, that's the reason I did my therapy. So, by the time I actually got to do the sessions, I became very angry. So, half of my therapy was about anger management rather than depression." (Participant P16; female; diagnosed/self-defined CMD)

One of the things that came across really strongly from all the interviewees was their fighting spirit and determination to work through the difficult feelings and thoughts they experienced, in order to get better and be able to stay well. They focused their energy on getting better and this included for one interviewee, making other changes to their lifestyle:

“There’s a fear you know, so it’s like fighting that. So, when I start thinking negative, I just talk to myself. It’s the breathing, it’s just changing my mindset…..I changed my diet, I tried to be more healthy….I started exercising as well, like going to the gym every morning helped and just keeping myself busy.” (Participant P11; female; diagnosed/self-defined CMD)

For all interviewees with a CMD that sought treatment, none of them disclosed being given medication. In fact, three interviewees shared that they were not prescribed medication and the disclosure of this information was unprompted. It was felt that their symptoms were not severe enough to require medication:

“I’m going there and then they tell me I might not need to be on medication. You know, you have to fill in the questionnaires if you’re suicidal and all these things. And I wasn’t on that level. I wasn’t thinking that. I was thinking I want to survive. I want to live.” (Participant P11; female; diagnosed/self-defined CMD)

Family/friend interviewees’ experiences of the person they supported was very different to that of people with a CMD as detailed above. As mentioned earlier, there’s a shared expectation both groups hold; that accessing mental health services will essentially ‘fix’ the difficulties/issues the person with a CMD had. One of the key things that most family/friend interviewees found difficult to manage as part of the support they provided, was keeping the person engaged with services consistently and adhering to the recommended treatment options. This was compounded by the fact they felt there were limited options to ensure there was engagement, as the individual is an adult and without their consent, no further actions could be taken:

“It was my mum that would go to adult mental services and say look she needs a support worker and so forth. And every time my mum would go there, they would accept the referral, the worker would go to my sister and my sister would say, no, thank you, I don’t need your help. Sometimes she wouldn’t even let them in and they said, well, she’s competent, and she clearly knows what she wants, so we’re closing the case. And that will happen like five, six times to the point where they won’t bother anymore.” (Participant P15; female; family/friend)

Where the person engaged particularly in instances of multiple contacts with mental health services, maintaining adherence to medication regimens was found to be challenging and there were limited means of monitoring it. Engagement in therapy was also a challenge:

"And then when she got back home (from hospital), just giving her meds and to get her to eat, it was the most difficult thing. It was like I was taking care of a child….Her medication, she was refusing to take it. She pretends that she takes it." (Participant P12; female; family/friend)

Family/friend interviewees became aware of the person with a CMD's need for mental health support once they reached crisis point. Through the process of getting them the help needed, they learnt more about the individual's experiences that led them to the point they were at:

"When she had her youngest child, she had postnatal depression. They had been writing to her asking her to go for therapy and counselling and she didn't. But no one, none of us knew that she had that. And I think she found out that she had diabetes or high blood, one of them." (Participant P12; female; family/friend)

Whilst family/friends are the ones that take steps to access mental health care for the person they are supporting, they had little involvement in the process of planning their treatment. Where adherence was particularly difficult to maintain, it was felt there was no support from health services to address this. There is an acknowledgement it is due to restrictions around confidentiality and what information can be disclosed, however, it still left them in a position of having to continue providing support with little to no influence of what it should entail:

"I understand there's a lot relating to data protection in the UK but I was the one that registered him with the doctor. I was the one that called the health services to come and get him to take him away and all of that. So, for them to turnaround and tell me that I don't have any rights to know what's happening to him is a little bit unfair. He did not have a GP, I had to register him with the GP and even that was a challenge in itself." (Participant P05; female; family/friend)

For the professionals and faith leader interviewees, ensuring the people they provided a service to engaged and benefitted from it was reliant on them creating a safe, therapeutic, flexible and non-judgemental space. This allowed them to build trust with their clients and run a person-centred service:

"So, in those groups, I created a very cathartic, safe space, talking about confidentiality, respecting people's opinion created such a powerful, therapeutic group." (Participant P04; female; MH professional)

"The confidentiality is very important. There are some people that are suffering and don't have anyone to speak to. So, when they turn to you, they trust that you being an Imam, you will keep discussions confidential and not disclose it to anyone. And that's how it should be." (Participant P10; male; faith leader)

5.5.2 Coping mechanisms whilst in treatment

During the period of having therapy sessions and their general recovery journey, interviewees with a CMD took a number of steps to facilitate this process. For those that are religious, prayer was important to them and they turned to it:

"I would pray, I guess I would pray more." (Participant P09; male; diagnosed/self-defined CMD)

Whilst prayer offered a sense of hope and comfort to those that turned to it, interviewees separated their faith from their religious community. Where they were previously very involved with their religious network, they took the decision to maintain a level of distance to focus on their wellbeing. This was partly due to the fear of being judged, not wanting people to get an insight into what they were going through and being surrounded by advice and conversation perceived to be negative. For one of the interviewees, the process of disengaging also made them question religious teachings and beliefs:

"I read my Quran, I pray a lot….I realised what I needed to do, I needed to develop resilience….I wasn't thinking about talking to anyone in my faith community….I wasn't comfortable telling anyone…..I knew they would not be my first point of call. To be fair all this, I never shared it with my faith community….What I did was move a little bit away, I just decided not to attend some programmes, and then for people, I decided to make my circle smaller, I didn't talk to many people. I just did what I had to do to get myself better, pick myself up and be able to keep going. And then I didn't want to listen to any negative lectures or anything that would tell me that I have sinned the Lord or something like that." (Participant P13; female; diagnosed/self-defined CMD)

Not only was there disengagement from their religious network, interviewees also distanced themselves from others in their family and social network. This was again due to the above reasons in addition to feeling that their network will not understand their experiences. They maintained a very small number of people in their circle to disclose information to:

"I didn't really want to talk to anyone, I didn't want to talk to anyone that I knew….I tried to shut most people out. I had a few people calling me to check on me which I really appreciated and to be honest, I think they helped me get through it but if I had my own choice, I wouldn't even talk to a single person…..I just wanted to be left alone to be in my own little hole." (Participant P16; female; diagnosed/self-defined CMD)

Professional interviewees echoed similar details relating to people with a CMD turning to prayer during their recovery process, the difficulty they experience walking the fine line of maintaining a distance from their religious network, family and friends. For some individuals however, they still maintained engagement with their religious network, but this could introduce challenges working out which should be prioritised, getting support through their network or through professional services:

"Sometimes the tension potentially within the black community within church, they come from a Christian community and sort of being a part of that and what's maybe their sort of family are suggesting would be a good way to respond or to help them to manage their struggles in life. And what doctors and psychologists and people are saying might be helpful for them to manage their struggles in life, that can be a tension." (Participant P07; male; MH professional)

In the case of family/friend interviewees, they were aware of the person with a CMD restricting the information they shared and did not challenge it even in instances where they were privy to sensitive details, they did not disclose it to the individual. There was not a very open discussion with the person with a CMD, or within the social network, about any significant events that occurred relating to their illness:

"She's never said, I've never asked. I mean, I've wondered but I feel uncomfortable in asking…..No one said anything. I mean, we all I guess, we gossiped about it, what could have made her do this and that [attempt suicide] but that conversation was never with her, it was always behind her back. I personally never had that conversation with her." (Participant P02; female; family/friend)

5.5.3 Outcomes

Once people with a CMD completed their therapy sessions, they felt their mental health had improved and they were in a much more positive place in their journey. They learnt strategies they could apply in their life to maintain their wellbeing, manage their disorder and had an insight to their triggers so they could intervene early. Tools they added to their box to practice included meditation, breathing exercises, challenging negative thoughts and trying to focus on positive ones. Strategies that people draw on is discussed further in Section 5.7.

For family/friend interviewees, where engagement has somewhat been maintained and there is some level of adherence to treatment, this has been highlighted as positive because their main concern of managing the individual's symptoms was achieved, even if there are challenges at times. Additionally, the process of having some form of engagement with mental health services enables them to also gain knowledge and tools to better provide support. They recognise the triggers of the person with a CMD and are able to act swiftly. Whilst ensuring the person they support adheres to their treatment regimen is a long-term challenge, they continue to persevere in the hope of making progressive improvements over time:

"It's been fantastic. She went from being this miserable person, everyone, even family and friends knew her for being miserable to now her being happy. And everyone actually seeing the difference in her, making comments and just seeing her just be happy in general and living her life freely." (Participant P02; female; family/friend)

"Now when she's talking a certain way or certain thinking, I know that she's on the way, like something's been triggered. Before, I couldn't have told, I wouldn't have known at all because I just thought she was just trying to live her best life, not knowing that was out of character for her…..And when she comes home, we try and get her to take her medicine and eat, decide the best thing for her." (Participant P12; female; family/friend)

From the perspective of the professional interviewees and faith leader, helping people to have some form of supportive network if they opt to and equipping them with knowledge (e.g. importance of seeking help from a range of avenues), is key in ensuring the tools learnt from their experience of the service could be continued and there is a recognition of their triggers:

"So, we would always take a service user led approach. So, if it comes up in the work and they approach us and say it would be helpful, if you could think about involving my family in some sort of way to support me. We would go with that." (Participant P07; male; MH professional)

Studies have examined people's expectations of the outcomes of engaging in treatment. Outcome expectations is defined as 'patients' beliefs about the consequences of receiving treatment, such as the belief that treatment will lead to improvement' (Snippe *et al.*, 2015). It has been suggested that outcome expectations can influence the degree to which people engage in therapy. This is based on the idea that if people's expectations are high, they are more likely to put in effort to achieve the outcome they desire, whereas if their expectations are low, they are unlikely to. Engagement in treatment will be less consistent with low levels of expectations and it could lead to complete disengagement (Snippe *et al.*, 2015). Research carried out looking into expectations of patients as a predictor of engagement in CBT for anxiety and depression, showed there is a correlation between the two. Outcome expectations is not only suggested as influencing levels of engagement but also the degree to which people take onboard suggestions made during treatment such as exercises given to practice as part of a coping strategy. This is important for therapies such as CBT where practicing tools and strategies recommended by therapists is an essential aspect of the delivery model (Greenberg, Constantino and Bruce, 2006).

As noted earlier, interviewees approached engagement in mental health services with the mindset of being 'fixed' so therefore had an expectation that by continuing with the service, it will lead to the desired outcome. This also motivated them to take onboard recommendations made by the therapists to add to their coping tools.

5.6 Service delivery

Services delivered by community organisations are rooted in the values of promoting social inclusion, offering a variety of activities and therapeutic services in which people can engage in an informal setting (Mind Croydon, 2020). The most important tenets of their services are being non-judgemental, taking a non-pathologising approach, providing a safe space that is confidential and private, service-user led as well as flexible and adaptive to the landscape they operate in. The approach to delivery also extends to setting up specialist services that respond to the diverse needs of the populations they aim to serve. The flexibility of these services includes swiftly changing delivery models to respond to an unexpected change in the landscape such as the COVID-19 pandemic.

5.6.1 Specialist community services

Service level data indicates that people from BAME groups have lower levels of engagement in mental health services and often when they do, it is at crisis point (Bhui *et al.*, 2003). Community organisations providing mental health and supportive services recognise an unmet need in the communities they are based in. To address this, specialist services are set up. These include running BAME only sessions or drilling down to an even more specific level to hold sessions aimed at, for example, just the Black community and in some cases, Black men (Islington Mind, 2020). This is in an effort and response to the fact that within each ethnic community, certain approaches need to be taken to engage them and maintain it. It is also in recognition that different ethnic minority groups may have certain experiences or needs that is specific to their community and may not apply to other BAME groups. For community organisations that have multiple locations they operate from, this entails assessing the needs of communities and run services accordingly. Services are not necessarily universal across all locations:

"The BME aspect of the service is relatively new. It hasn't grown specifically to reflect the sort of concentrations of different populations across London. It's been growing more where we have historically been based but nevertheless that has kind of roughly coincided with larger BME populations. And it would certainly be something that we would be open to in the future. Maybe having a base in northeast or more east so, to better serve and to reach those communities." (Participant P07; male; MH professional)

5.6.2 Service model

To create an effective holistic, non-judgemental, non-pathologising, person-centred, and confidential service, it is important to understand who the typical service users are. For the service provider interviewees in this study, their clients are diverse, therefore needing a varied offer of activities they can be involved in. Activities delivered range from counselling sessions through to social and peer to peer sessions. For people that are unemployed, engaging in meaningful activities is integral to maintaining their wellbeing. This includes having a social network they build a relationship with through the activities they attend:

"Majority of them are unemployed. I think a lot of them are actually trying to find something to do and maybe something to look forward to during the day or during the week….It's also a space where they feel safe and obviously understood and they get to kind of occupy their time rather than staying at home and maybe not speaking to people." (Participant P03; female; MH professional)

Service providers recognise that their clients are at different points in their journeys. Some are still working on understanding their experiences, others are perhaps seeking an alternative approach that fits better with their world view or meets their needs:

"This is my experience, this is how the world is to me, and I look in the world and these are my beliefs about the world. So, it can go all the way from that and we wouldn't challenge that, we would find ways of working with that and helping to make that a way of understanding the world for somebody." (Participant P07; male; MH professional)

The priority of the services is building relationships and trust is at the heart of this. This is highlighted as being essential because in some cases, clients feel they have been let down by the professional sector therefore, there is a lack of trust. It also extends to the loss of services they have previously depended on being no longer available:

"It's all about staying with the client, it's all about going on their journey, you don't challenge their difficult beliefs, that's not encouraged. Because if they think you are part of the enemy then that could be quite threatening for them. You want to develop a relationship of trust. It's quite tricky, you're not their friend, you're not their family. Sometimes it takes a while to establish what's really going on with them…..so the trust thing is important." (Participant P06; female; MH professional)

There is a drive to have a diverse workforce particularly professionals of a Black ethnic origin, to deliver an inclusive service where people from Black communities feel comfortable to engage and are understood. Having staff from backgrounds representative of service users' ethnicity is felt to be important, as it provides cultural understanding of users' experiences:

"Some don't have an understanding of how impactful and how determining this cultural understanding is to client's behaviour…..the therapist hasn't even thought of the cultural thing, it's not the first thing that comes to mind." (Participant P06; female; MH professional)

"In terms of what we do, I think the one thing that I noticed immediately, we've got a workforce of eight people and six of us are Black. And I did wonder when I started, does this help to kind of engage people from Black, especially African backgrounds." (Participant P03; female; MH professional)

It should be noted that amongst interviewees with a CMD, ethnicity of service providers, especially their therapist, was not a factor in their decision making. The aspects most important to people was the competence of the therapist, having a safe space that is confidential, private and non-judgemental and being reassured that this will be maintained:

" My therapist, she was one of those that studied anxiety….And then she could actually understand what I was saying, that helped. I felt like she knew what she was saying and then she gave me all these little things that I could do." (Participant P11; female; diagnosed/self-defined CMD)

The COVID-19 pandemic severely impacted service delivery. Providers responded swiftly to maintain some of their services to continue supporting clients. Professional interviewees cited several examples of how they adapted their services to ensure essential contact and support with clients was maintained. At the time, it was expected the restrictions will only last a few weeks and services will return to some form of normality:

"All of our work has migrated to being online and to be done remotely. Some clients prefer to have video conferencing sessions, others prefer to have it over the phone.....We've replaced some sessions with virtual coffee hours on Zoom.....The art group is running online. We also have a dance and movement therapy group running online." (Participant P07; male; MH professional)

As outlined, the services discussed in this study take a non-pathologising approach to how they provide support. There has been an ongoing debate in recent times about the extent to which 'ordinary life difficulties' are pathologised as mental health problems (Maj, 2012). Whilst some people do identify and find it helpful to have their symptoms 'pathologised', it should be noted that not everyone identifies with it and can be a barrier to seeking help or disclosing one's experiences to people that are perceived to not understand it (Maj, 2012). This is discussed further in Section 6.4.4.

5.7 Maintaining ongoing wellbeing

The tools that people with a CMD use to maintain their wellbeing are broad according to interviewees in this study. As touched on in the earlier sections, for those that access therapeutic services, the strategies they are taught are carried through and become a lifelong asset that they draw on. For most, they recognise what triggers their episodes and steps to take to minimise its impact through the support they receive from mental health professionals. Broadly, the way in which people maintain their mental wellbeing can be categorised into coping strategies and support network, based on what interviewees reported. They each are a contributor that together make up the package people rely on as shown in Figure 10. The illustration in this figure has been drawn from information highlighted in this study by participants.

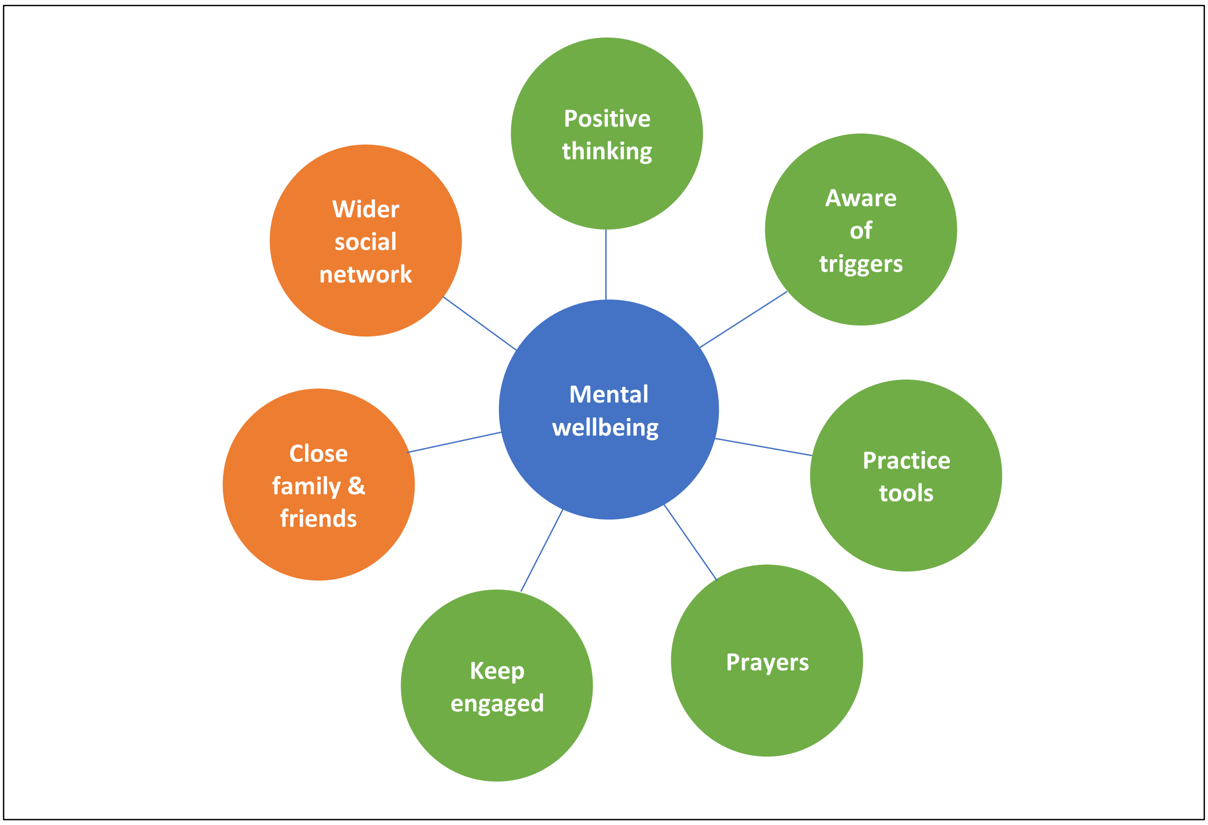


Figure 10. Maintain ongoing wellbeing through coping strategies and reliance on family, friends and broad social network.

5.7.1 Coping strategies

One of the coping strategies that people with a CMD use is positive thinking. It is felt that when they went through difficult parts of their experience, thinking negatively was a strong aspect of it which had profound effects on them and how they then behaved. Therefore, turning potential negative thoughts into positive ones allows them to keep moving forward. To achieve this, positive affirmations are also used. Family/friend interviewees also echoed this as a key strategy:

"One thing now that I am very good at, I'm now more aware of when the symptoms start to set in. I know how to talk myself out of it. Like if I start panicking….I say well, you are already doing the best you can so what are you scared about. So, I know how to talk myself out of a situation. And then there are some apps, my university was very good with mental wellbeing." (Participant P13; female; diagnosed/self-defined CMD)

People that engaged in therapy feel they developed an awareness of their triggers. When they are going through difficult periods, they are able to spot this and take the necessary action early. Equally family/friends are able to also identify the triggers of the person they support which enables them to get help. Professional interviewees ensure this is incorporated as part of the sessions they run, so people develop an awareness to their triggers. Where their family has been involved by the service, this network is also equipped with the information:

"If I have an off day, I think about why I have an off day…..and then I think, it's normal, I will be alright. So, I always try to find a reason why I'm feeling the way I'm feeling…..It's just part of me, I need to know my body." (Participant P16; female; diagnosed/self-defined CMD)

"Mum knows my sister's triggers, she can know when she's going downhill. The excessive shopping, she knows the pattern. So, after the second time, mum started realising what the signs are and once she sees it, she would make contact with adult services." (Participant P15; female; family/friend)

Through therapy sessions, people are taught a number of different tools they can practice as part of their daily activities or utilise them during periods when they begin to struggle. These include e.g. breathing exercises, meditation and yoga, to focus their minds and give them a sense of calm:

"I had a meditation app and herbs for sleeping, they help a lot, more than I would've thought. I still have it till now. Basically, I will do that in the morning, afternoon and evening, just use digitally enhanced meditation…..and I still pray." (Participation P09; male; family/friend)

Interviewees that expressed actively practicing their religion, doing their prayers regularly is a big part of maintaining their wellbeing. There is a belief that having a strong faith in God gives one the strength and capability to deal with life challenges therefore, you have to build and maintain a relationship with God so that you are guided during difficult periods. The faith leader interviewed echoed this. The professional interviewees also highlighted for some clients, practicing their religion and relying on it, gives them a sense of hope:

"Me being a Christian, your faith is supposed to carry you through no matter what the situation." (Participant P01; female; diagnosed/self-defined CMD)

"I had the faith that things would get better." (Participant P13; female; diagnosed/self-defined CMD)

For some individuals, they have therapy sessions for extended periods of time, years for some. Leaving the door open to have additional therapy sessions or to disengage when either the person feels they are able to rely on other coping strategies or are perhaps going through a difficult time, is an important aspect of people's wellbeing journey. Professional interviewees indicated shaping their services in a way that offers clients that flexibility. Similarly, the faith leader also takes the same approach to supporting people:

"So, we offer open ended therapeutic work. And very often that means our service users will sort of come for quite a long time and they might disengage for a while." (Participant P07; male; MH professional)

"It depends. For some people they don't need to carry on with the counselling or support I give them but they always know that there's someone they can call on if they go through difficulties again. They can come back because sometimes their experiences are intermittent." (Participant P10; male; faith leader)

5.7.2 Support network

The role of people's support network is varied and involves family members, friends and associates. People with a CMD highlighted the importance of having a support network of family and close friends they can talk to when experiencing some difficulties. Whilst they may not share the full extent of their feelings or challenges they are going through, it is nonetheless important to have people they can confide in:

"I do have certain people that I do kind of tell everything to. But even then, sometimes I don't want to sound silly or someone that's like just silly….I'm not scared of being judged, I'm more like maybe, I'm not taken seriously now…..sometimes it depends, I will say everything and sometimes I will just say something little and make it into a joke. So, it's like I've said it but that person doesn't really know how I'm feeling deep down inside." (Participant P01; female; diagnosed/self-defined CMD)

Additionally, maintaining a broader network of people to socialise with informally through groups and associations was also deemed to be important. This ranges from sports groups through to associations that bring people together from a specific country or local region, to socialise and deliver initiatives that will help the country or area they or their family emigrated from. There are hundreds of such associations across the UK and a large proportion of them are registered with the Charity Commission (Charity Commission, 2018). Religious groups are also a key network that is relied upon:

"I think it helps a lot, it helps a lot. We meet often and have our events. That really provides an avenue for people to socialise. Sometimes, they are social networks that were already formed at home that people bring here and continue. Sometimes, they are new ones. People love that, that social network they have. There are so many groups, we call them hometown groups….that's really helpful to the Black community" (Participant P14; female; diagnosed/self-defined CMD)

Professional interviewees also shared similar details on the role that these social groups play in helping people with a CMD maintain their wellbeing. The associations in particular are a replication of the networks that some people who emigrated, had in the countries they are originally from:

"There are ways in which people replicate the community model in the Western societies where they have associations….replicate the sense of community and those communities' functions." (Participant P04; female; MH professional)

Family/friend interviewees viewed their role as centring on taking a non-judgemental approach, monitoring their progress particularly if they take medication, being sensitive about their previous experience and knowing when to seek help early to minimise the likelihood of symptoms getting worse:

"Always aware not to push her too much because she feels that she's going to push her to the point where she was before….but people in the household with her are walking on eggshells with her. Just scared not to break her again." (Participant P02; female; family/friend)

The process of coping is described as 'handling the external or internal stress that is reflected as difficult or exceeding own resources' (Holubova *et al.*, 2018, p.73). People's choice of coping strategies are normally used over extended periods of time for different situations. The way in which people lean into these strategies has an impact on the experiences they go on to have with their disorder (Holubova *et al.*, 2018). Coping strategies have been split into different categories. Strategies are divided into active and avoidant by Compas et al., (2001) whereas Folkman et al., (1986) split it as emotion-focused and problem-focused. Active coping strategies refer to protective approaches that may be taken to mitigate or eliminate the stress and has been linked to lower anxiety, depression and stress symptoms. It is deemed to be more efficient where the individual's condition is chronic. Where avoidant coping is opted for, the individual does not seek to eliminate the source of the stress, instead try to reduce their own negative reactions to the situation they face. Due to the source not being addressed, the negative emotions persist. People that take a problem-focused approach to how they cope with difficult experiences are thought to try to give meaning to normal daily challenges in order to have a psychological distance to the source of their stress. They are more flexible towards unexpected changes and have the ability to seek social support (Holubova *et al.*, 2018). Interviewees in this study shared that they take an active approach with the coping strategies they use and have found it to be beneficial in maintaining their wellbeing. The coping strategies drawn on by interviewees with a CMD at different points in their journey is further discussed in Sections 6.2 and 6.3.

5.8 Improving experiences and outcomes

Maintaining one's mental wellbeing is a lifelong journey. For that reason, interviewees in this study are eager to see changes in society that will provide a supportive system which enables everyone to thrive and go some distance in overcoming challenges they experience. As detailed in earlier sections, the stigma of mental health influences decisions made on health seeking, support, treatment and ongoing maintenance of one's wellbeing. Although the research questions in this study did not set out to explore in-depth improvements that could be made to help people maintain their wellbeing, interviewees were unanimous in their recommendations of changes needed. The proposed changes broadly fall under improving mental health literacy and revamping service delivery. These inform recommendations made in Section 7.

5.8.1 Improving mental health literacy

Improving mental health literacy is believed by interviewees to be integral to shifting perceptions and attitudes about mental health in Black African communities. A number of suggestions were made such as working with community and faith leaders to empower them to be mental health advocates. Where appropriate, linking the learning to teachings of the respective religions was suggested by three interviewees with a CMD:

"Our religious leaders themselves need the education first. The people that have a lot of influence on the community. Pastors and Imams have a lot of influence on the congregation. If they are educated to understand that it's okay to be depressed and if you are this is where you can go, then it will have a trickle-down effect on the congregation. So, I think we need to start with our leaders…..A lot of people go to their religious leaders rather than their GP. A lot of people speak to their religious leaders first. They try prayers, prayers first and it's when prayers don't work, that they now go to health facilities….If they are properly educated, know some of the signs and symptoms then they can signpost to relevant places to get some help. I think that will go a long way to help the community." (Participant P14; female; diagnosed/self-defined CMD)

It should be noted that despite interviewees wanting to see this change, they have so far not taken steps even where there was an opportunity to, to share their experiences, as a means of educating people in their community. Additionally, the suggestion (and assumption) that some people seek support from their religious leaders first, is not in line with the steps they took to manage their own CMD.

Some interviewees suggested that whilst these conversations are deemed necessary with community and faith leaders due to the platform and influence they have, it is also important to have them within family, friend and extended social networks. Also key in these dialogues is active listening as well as normalising or validating people's feelings. This again speaks to the issue of needing to address stigma and judgement:

"One thing is communication and the use of language…..the stigma, we're not talking enough about it…..there should be open discussions…..active listening skills is quite important but sometimes people just want to be heard, I just wanted to be heard. " (Participant P13; female; diagnosed/self-defined CMD)

Lastly, advocating for 'providing support without judgement' even when one is not completely privy to what an individual with a CMD may be experiencing or perhaps hold a different view, the priority is placing the needs of the person requiring support first:

"Be supportive, be empathetic…..we need the support and without the feeling of being judged." (Participant P13; female; diagnosed/self-defined CMD)

5.8.2 Revamping service delivery

Whilst some interviewees hailed the psychological services they accessed, others noted the difficulties they experienced in getting the help needed and most importantly maintaining it. Professionals raised how service delivery models can negatively impact the experience of some service users. Interviewees were keen to see the delivery of more accessible, local and broadminded services but most importantly, decisions on delivery of these services that are not financially driven:

"I think the problem with sort of counselling, psychotherapy, mental health services, they're sort of Cinderella services. They tend to be when times get hard, some of the first things that get cut…..We need more easy to access community spaces where people can sort of drop in without necessarily an appointment….in a non-judgemental way." (Participant P07; male; MH professional)

Family/friend interviewees felt this is an important factor in improving services to ensure people have access to therapy services and support to adhere to medication regimen:

"He needs to have therapy. He needs to be checked on maybe twice a week, maybe every week. He needs to go to a place where he has to check in and for meetings, therapy, make sure he's taking his medication. He needs help figuring out certain things as well." (Participation P05; female; family/friend)

Service integration is very topical as outlined in Sections 1.4 and 1.5 and this was the case in some of the interviews in this thesis. Interviewees felt there is still significant work that needs to be done to truly progress the agenda to improve their experiences of services. This will potentially minimise the degree of 'ping pong' between services that people go through, before eventually being referred to mental health services:

"I think with them recognising what it was earlier, that would have helped to save me from going for these treatments and hearing all these diagnoses." (Participant P11; female; diagnosed/self-defined CMD)

6. Discussion

As outlined earlier, service level data and research literature highlighted the lower rates of engagement in some mental health services observed amongst BAME communities. Delving further into the limited data available suggests that amongst BAME populations, Black Africans for instance have some of the lowest levels of engagement in psychological therapies relative to their population. Whilst they have low levels of engagement in some mental health pathways, they are over-represented in others – crisis routes. It is important to understand the factors that contribute to the lower uptake rates to begin shifting this pattern. This research aimed to contribute towards providing a more holistic picture of the pathways to care, of treatment and ongoing wellbeing maintenance amongst this ethnic group living in the UK, to enable more informed strategies, service planning and delivery.

The Findings section gives an in-depth outline of data from the interviews with participants, that have experience of CMDs either personally or through providing support. The key elements have been briefly discussed in the context of existing literature. The discussion section will now pull together all these strands to consider how they sit within the broader literature on engagement of BAME communities, especially Black Africans, in mental health services and how they maintain their wellbeing. Threaded through the discussions are the researcher's reflections on the findings and how they also sit within the context of other research. Additionally, the Discussion section details how this thesis adds a unique contribution to a growing body of knowledge on people's experiences of CMDs particularly amongst Black Africans, how they maintain their wellbeing and what could be done to ensure services and informal support meet the needs to these communities.

6.1. Summary of key findings

This summary sets the scene for the following sections including the conclusion. It follows the same order as the findings presented in Section 5.

a. Characterisation of symptoms

The way in which symptoms of CMD was characterised differed by type of interviewee. People with a CMD characterised their symptoms based on how they felt during their most difficult periods. Symptoms ranged from feeling scared, to being emotional, fear of dying, insomnia and so on. Professionals and the faith leader interviewees characterised symptoms in the same way. Family/friends however described symptoms in the form of changes in behaviour. What was consistent amongst people with a CMD and family/friend interviewees was the fact that symptoms were not attributed to a CMD.

b. Perceptions of mental health disorders

Perceptions of mental illness are a key in how people make sense of their symptoms. For those that consider themselves to be religious, there was a tension between reconciling religious teachings about having a strong faith during difficulties and the symptoms they were experiencing. Professionals articulated the importance of taking a non-pathologising approach to supporting people to ‘make sense’ of their symptoms. From the perspective of the faith leader, both Western and non-Western views of mental disorders and treatment are valid, have a place in society and should be complementary of each other.

c. Stigma, fear and judgement

Stigma, fear and judgement of people with a CMD is very much at the forefront of most interviewees’ minds and informs the decisions they take as a result of it. The impact of stigma and judgement is viewed as not only being present within one’s community but also across services including healthcare. As a result, people develop strategies to hide mental health disorders.

d. Traumatic experiences

For some interviewees, they did not recognise how previous traumatic experiences might be associated to their CMD experience. Through accessing mental health support, some interviewees report these experiences being explored during therapeutic sessions and the potential links there might be to their CMD.

e. Acceptance

Accepting that symptoms being experienced may be linked to a CMD is a big factor in people’s journey. For some interviewees, they reached this point when they received a diagnosis from a healthcare professional; for others, it was when they were referred for mental health support. From the perspective of the professionals, the use of diagnosis labels to help people work through and accept their experiences, is neither encouraged nor discouraged. The process of reaching acceptance appeared to be more difficult for people that reached a crisis point.

f. Impact of common mental disorders

The impact of mental health disorders are broad. They affect people’s family and social relationships. These relationships can become distant and strained. Other pressures it places on for instance families, could extend to financial and physical, especially where support for daily tasks is needed. Whilst there is a recognition of the difficulties the person with a CMD is experiencing, this was hard for family/friend interviewees to reconcile and accept emotionally.

g. Health seeking and support

Participants motivations for seeking mental health support were focused on needing to get ‘fixed’, as people reached a point of being unable to cope on their own or they felt their family member or friend had reached crisis point and needed immediate help. The time taken to seek help depended on whether symptoms were characterised as being emotional or physiological. There was a greater emphasis on working through emotional difficulties over prolonged periods. Where the cause was felt to need medical investigation as it was thought to be physiological, help was sought much earlier through different avenues including GPs.

h. Treatment and support

The level of engagement in services was driven by whether the point of acceptance of CMD symptoms was reached. Engagement in services was via GPs, specialist services, workplace services or emergency services. Interviewees with a CMD had positive experiences of the therapeutic support received and benefitted from the knowledge and tools gained. During the engagement process, they also took additional steps to improve their wellbeing. From the perspective of family/friend interviewees, services were difficult to navigate, engagement was difficult to sustain consistently as they would have liked.

i. Service delivery

The approach to service delivery within community organisations (according to professionals interviewed in this study) is to be person-centred, non-judgemental, non-pathologising, holistic, adaptable and flexible. These interviewees highlighted the importance of supporting individuals on their own journeys and not challenging their views. Supporting people to manage their wellbeing did not just centre on providing therapeutic services but also supportive ones such as social inclusion activities.

j. Maintaining ongoing wellbeing

Interviewees with a CMD noted two main approaches they use to maintain their wellbeing – coping strategies learnt from their therapy sessions and having a strong family and friend support as well as a wider social network. For interviewees' that support an individual with a mental health disorder, the focus was on being aware of their triggers in order to respond swiftly to access professional support. Additionally, working together to encourage medication adherence and support to e.g. manage finances. The professional and faith leader interviewees took the approach of always 'leaving the door open' for the possibility of re-engagement when needed.

k. Improving experiences and outcomes

All interviewees expressed an appetite to see changes in service delivery and the way mental health disorders are viewed and understood by the Black African community. Interviewees felt that improving mental health literacy is fundamental and some of the starting points include working with community and faith leaders. Making pathways to access mental health services much easier to navigate may improve health seeking but at the least, improve experiences.

6.2 Experience: The road to 'diagnosis' and treatment

This DrPH thesis explores the experiences of Black African individuals living in the UK that have self-defined or received a diagnosis of CMD and seeking to answer the following questions:

1. What is the experience of Black African people after they self-define or receive a diagnosis of CMD?
2. What is the experience of Black African people that receive a treatment for CMDs?
3. How do they conceptualise their treatment and its impact?
4. What do they do (or not) to maintain their ongoing mental wellbeing?

As mentioned in the Findings section, the precursor to understanding these experiences is the journey prior to getting a diagnosis or self-defining, as it greatly shapes it. This section discusses a number of key themes drawn from the Findings section, that relate to people's journey up to when they received treatment for their CMD.

Sections 1.7.2 and 3 provided an overview of Kleinman's (1978) model of healthcare systems and explanatory model of illness and the rationale for using it as a framework to discuss the findings. As outlined in the Methodology section, the selection of interviewees is based on the key actors identified in Kleinman's model. Interviewees with a CMD and family/friends in this study are the key actors in the Popular Sector. Professionals from community organisations are the main actors in the Professional Sector and the faith leader the actor in the Folk Sector. It should be noted that statutory services and the people delivering them as described by interviewees as where they sought help from, are also actors in the Professional Sector. Choosing to interview participants from across the three arms of Kleinman's model allowed a more holistic view to be captured in the data.

6.2.1 Role of the Popular Sector

As described in the Findings section, people with a CMD spent significant proportions of their journey in the Popular Sector before they sought help from the Professional Sector. The time spent in this sector was mainly to work through symptoms that were being experienced to try and 'make sense' of them. Interviewees developed their own strategies for coping with the symptoms. The process of trying to 'make sense' of their experiences is rooted in cultural beliefs as indicated by Kleinman et al., (1978). The tension between mind and body, trying to reconcile what they were feeling with cultural and religious beliefs was a challenge. Compounded by this is a lack of awareness of how these symptoms are characterised and labelled as relating to mental illness by the Professional Sector. As noted previously, in the early stages all interviewees with a CMD except one did not recognise or understand their experiences as relating to mental illness. Little is known about mental health literacy levels relating to CMDs in the general population. Studies measuring literacy levels have not been broad enough to assess this, however, there are suggestions that recognition of SMIs is generally high (Kutcher, Wei and Coniglio, 2016). This is in line with findings in this study, where interviewees have a better knowledge of symptoms linked to SMIs than those of CMDs. Additionally, in the study by Memon et al., (2016) looking at the perceived barriers to accessing mental health services amongst BAME groups in Brighton and Hove City, they also found that participants did not recognise and attribute their symptoms to mental illness (Memon *et al.*, 2016). Similar findings were detailed in the studies by Keynejad (2008) and Anthony (2015) examining the barriers and facilitators that Black Africans/BAME service users experienced in accessing help, as well as the study by Brown et al., (2011), examining the differences between Black African and White British women's perceptions of depression and help-seeking (Keynejad, 2008; Brown *et al.*, 2011; Anthony, 2015). In this study, no conclusions can be drawn about potential differences in knowledge of CMD amongst participants based on for instance gender, due to the limited numbers that took part.

In addition to the lack of awareness of mental illness, this was compounded by the cultural belief that mental illness should not be discussed openly. Participants with a CMD were keen to keep their experiences private therefore, shared limited information with their families, friends, religious leaders and wider network. This is due to health and illness especially mental illness being viewed as a private matter in Black African culture and not to be discussed openly (Berwald *et al.*, 2016; Memon *et al.*, 2016). In relation to religious leaders, participants felt that they often provide support and are the first point of contact for many people with a mental illness. Additionally, they felt that religious leaders are integral to building awareness of CMD amongst Black Africans and that they disseminate information on the provision of adequate support to people expressing mental distress. Whilst this was their expressed view, it is in stark contrast to the decisions they made where it pertained to their own circumstances. As participants leaned on their faith to help them cope and continue to do so, it could be assumed that they would equally lean on their religious network particularly leaders, for advice, guidance and support, through the lens of the religion they practice. They instead drew on their cultural beliefs and practices about keeping their CMD private and did not use it as an opportunity to raise awareness in their community. Keeping their experiences private was more important to them as they feared that knowledge of their CMD could influence their standing in the community, particularly if people from their religious network belong to the same social networks and communities. This very conscious decision about restricting information influenced participants' overall experiences; when they chose to seek help from healthcare services and how they continued to maintain their mental wellbeing. This tension that participants felt is further explored in Section 6.2.3.

Rooted in people's belief systems is their acute awareness of stigma relating to mental illness even if they had not reached the point of characterising their symptoms as relating to mental ill health. They understood that the symptoms represented some form of change in their general wellbeing. For interviewees that are religious, the belief that their faith should be strong enough to get them through most obstacles, meant they found it difficult to confide in people in their network, due to the fear it would be assumed that their faith was not strong enough. The fear of stigma and judgement also extends to how actors in the wider 'system' both within healthcare and non-healthcare will perceive their illness and treat them. Stigma is suggested to exist at three different levels and this includes the wider 'system' which represents stigma at a structural level (Adams *et al.*, 2014). Memon et al., (2016) also found that stigma towards mental illness made study participants reluctant to openly acknowledge their symptoms, therefore, hesitant to access services. Cultural background and identity defined acceptable responses to mental health problems and appropriate coping mechanisms (Memon *et al.*, 2016). It could be inferred that the explanatory model most interviewees in this thesis leaned on to conceptualise their illness was based on their experiences being linked to whatever life challenges they had at the time, which they expected would be temporary. Leaning on their faith and religious beliefs would then give them the strength and capability to manage their symptoms until they eventually disappeared. Relying on one's faith gave a sense of hope and at the same time, shifted the burden of solving the issue to a higher power. There is a belief in religions such as Christianity and Islam that challenging issues should be placed in God's hands, as He will deliver a resolution once this step is taken, despite the period of time it may go on for (William *et al.*, 2019). Tuffour (2020) found that participants recovering from SMI, have a strong reliance on their religion (Christianity) in addition to drawing on traditional African worldviews (Tuffour, 2020). Where symptoms were also physiological, the explanatory model focused on these symptoms led interviewees in this thesis to perceive their condition as being serious and therefore needing investigation from the Professional Sector.

Choices and decision making happen in this sector. As mentioned in the Findings section, people with a CMD in this study oscillated between three stages before they made a decision to seek help from the Professional Sector. The decision was largely taken on their own even though there was support from family and friends to manage some aspects of the difficulties they had. As noted earlier in this section, this was driven by not wanting to disclose the extent to which their illness affected them and also the perception that someone that has not experienced the symptoms or is not a health professional, will not understand what they were going through. Health and illness is viewed as a private matter in the Black African community and should not be discussed openly (Memon *et al.*, 2016). This is especially the case for mental illness and other conditions that may not appear to have 'visible signs'. Serious illnesses where there are signs are also kept private (Berwald *et al.*, 2016). As noted in Section 5.2.3, some interviewees indicated being keen to access support and they made a conscious decision to give just enough information to some family members or friends to highlight their difficulties but did not go beyond that to indicate the seriousness of it. There was an awareness of a change within them although it was not immediately linked to their health. As mentioned previously, in the study by Brown et al., (2011) a higher number of Black African women in comparison to White British women, associated their symptoms of depression with social rather than medical issues (Brown *et al.*, 2011). In the case of interviewees in this thesis that associated their symptoms with a physiological cause, the decision to seek help and where to go was made with the help of their family members. They were quick to flag the seriousness of their symptoms and desire to seek help immediately. This suggests that participants felt more comfortable to seek help for symptoms associated with their physical health but where it relates to issues that cannot be tied to a part of their body that will require investigation, the response is much slower. In the study by Memon et al., (2016), participants that have social networks often used this as their first point of contact for support and therefore providing an alternative to professional services (Memon *et al.*, 2016). This reinforces Kleinman's (1978) view of the proportion of illnesses managed within the Popular Sector (Kleinman, 1978).

Family/friend interviewees also spent time in the Popular Sector but much less in comparison as at the point where they became involved in providing support, the person's illness or symptoms had progressed to the point of crisis therefore, needing urgent help from the Professional Sector. They went through the same stages as that of people with a CMD as described above however, this was condensed down to days and at most, a couple of weeks. They did not have the same amount of time to work through and try to understand the symptoms of the person with a CMD, to come up with coping strategies that could be managed within this sector. They instead progressed very quickly to the point of considering the choices available and made a decision. This was through a process of negotiation and finally agreement on what the best course of action was based on the limited information they had at the time. It is widely recognised that family involvement in mental health services can take different forms. It could be as minimal as providing information on services through to providing consultations, interventions and therapies (Eassom *et al.*, 2014).

Whilst the focus is mainly on the individual in need of mental health support, family/friends also experienced a range of feelings during this period. There is an aspect of shock as they witness their loved one go through a crisis and what feels like a sudden change in behaviour. This was a troubling and difficult experience for them particularly where police or social services were involved. They had to again go through the process of making sense of what the individual is experiencing, accept it in order to act swiftly to access help. The whole process of trying to understand the cause of change in behaviour or symptoms the individual with a CMD was experiencing as well as working through their own feelings, was a difficult and emotional process for family/friends. Being in a reactive rather than proactive mode meant family/friends often felt frustrated trying to deal with a situation that presumably came out of nowhere, because they did not recognise the signs early on. Family/friend interviewees also hold their own explanatory model of illness which is different to that of the person they are supporting. They concluded that symptoms the individual experienced were linked to a mental illness which informed their decision making. As mentioned in the Findings section, the decision to seek help from the Professional Sector is a complex one. This was largely due to the lack of trust in the Professional Sector and the broader 'system'. It speaks to the complex relationship and nature of racial inequality across different parts of the system including health, care, criminal and justice, which some perceive will impact on the quality of care they receive (The Sainsbury Centre for Mental Health, 2006). The issue of trust in the system will be explored further in the following sections.

The process of decision making by interviewees with a CMD and family/friend participants is aligned with Kleinman et al.'s, (1978) suggestion that decisions of where and when to seek help, how long to engage for and how to assess impact of the treatment are made in this sector. It should be noted that people with a CMD and family/friend interviewees are from professional backgrounds with degree level education with the exception of two. All but two are females. High education attainment and being employed in a professional role is often correlated with better, early and proactive health seeking compared to people with lower education attainment and unemployment or being in routine/manual work (Jansen *et al.*, 2018). Educational attainment and type of employment is also often linked to higher levels of health literacy although this is not always the case (Jansen *et al.*, 2018). Women have also been found to be twice as likely to seek help for CMDs compared to men (Call and Shafer, 2018). Whilst this study was not trying to compare how quickly different participants recognised their symptoms and sought help, based on other research on the role qualifications and profession plays, it would have been expected that most would seek help early or perhaps linked their symptoms to mental illness. This was a surprising finding which suggests that other factors play a more significant role amongst participants in this study, than education attainment and profession. Firstly, people with a CMD characterised their symptoms in the beginning as challenges they were experiencing which in time, they expected will get resolved. This characterisation meant that they did not feel the need to seek support at first. Additionally, relying on their faith and resilience was key in the process of working through their experiences. These two factors appear to play a more important role than general knowledge of help seeking.

The professionals and faith leader interviewees appreciate the value and large role the Popular Sector plays in people's experiences, understanding and management of mental illness, as well as how decisions are subsequently made to seek their service and expectations of what the outcomes will be. They are therefore respectful of it and where possible draw on the benefits that it could offer people as they move to support them. The professional interviewees recognise that people spend time in this sector to work through their experiences and they may receive support from family and friends. The approach taken is not to challenge this process because some people may need it as part of their journey; instead, they meet them at the point they are at, to offer support. This approach is guided by the principles of providing a non-judgemental, safe space.

6.2.2 Role of the Professional Sector

People with a CMD in this study spent a fixed amount of time in the Professional Sector. They engaged with health services once they were unable to manage their illness in the Popular Sector. For individuals that engaged because they recognised needing mental health services or were referred following other medical investigations, they did so for the period until their therapy sessions were completed – between 5 and 12 weeks. The expectation from the Professional Sector was they would provide a 'fix' for the symptoms experienced. As Kleinman et al., (1978) noted, the biomedical view of clinical reality held by health professionals is that treatment provided is based on a 'fix' rather than psychosocial (Kleinman, Eisenberg and Good, 1978). It could therefore be argued that over time, patients have developed an understanding of how the Professional Sector functions and what to expect if they engage services based on their health problem. This understanding revolves around the fact that health professionals attempt to construct a biomedical model of their disease from descriptions of events and episodes presented by the individual that is ill. Based on this construction, the professional is then able to offer a diagnosis and recommend a treatment plan based on their clinical knowledge (Patel, Arocha and Kushniruk, 2002). The expected outcome is their problem will be fixed once the treatment is taken up. Whether it addresses the actual root or cause of the problem was not a factor in their expectations, just that symptoms are alleviated. The other role played by the Professional Sector that some interviewees did not expect to be part of the support received, was the exploration of previous difficult experiences or feelings that may not have been dealt with and could be linked to their CMD. An understanding of the role previous difficult experiences or feelings may play was reached through these therapeutic interactions.

Another interesting aspect of people with a CMD's expectation and subsequently the package of treatment they received, was the emphasis placed on not being prescribed medication. Receiving therapy alone was perhaps viewed as signalling that their condition was not severe enough to require taking medication. This speaks to the time-limited engagement that people with a CMD that accessed therapy services took. Once their therapy sessions were complete, they did not feel a need to have any further sessions. The strategies and insight they learnt through the sessions were felt to be sufficient to enable them to manage their mental wellbeing going forward. This information was disclosed during the interviews without being prompted. A meta-analysis carried out by McHugh et al., (2013) showed there was a three-fold preference for psychological treatment over pharmacological treatment amongst patients for depression and anxiety disorders (McHugh *et al.*, 2013). This contrasts with the findings in the study by Rabiee and Smith (2014) examining the experiences of accessing services amongst African and Caribbean service users and carers, where some participants found accessing medication to manage at least one of their symptoms (e.g. insomnia) helpful (Rabiee and Smith, 2014).

Family/friend interviewees' time spent accessing services from the Professional Sector was over a longer period of time. This was due to the person they were supporting not being keen to fully engage with the recommended treatment or felt they did not require mental health support. When they managed to get them to engage, the pattern was not as smooth as they expected or hoped for. Interviewees also expected that the Professional Sector would provide a 'fix' for the symptoms and change in behaviour being experienced by the person they were supporting. They expected services to take an intensive treatment approach, where a combination of therapy and medication is offered. In this group, there was a strong emphasis on the importance of medication adherence and less of an emphasis on engagement in therapy. Where adherence was felt to be patchy, this was a challenge that interviewees found difficult to manage. The Professional Sector was expected to utilise a range of strategies to improve adherence such as constant monitoring or assignment of a case worker, that will interact with them and the individual on a frequent basis. The emphasis on medication adherence suggests these participants viewed it as a fast and effective means of providing a remedy particularly where the behaviour of the individual they were supporting was seen as erratic and difficult to manage. Petrie and Weinman (2012) noted that adherence problems are due to a mismatch between the patient's model of the illness and the form of treatment recommended, which means the treatment does not make sense to the patient (Petrie and Weinman, 2012). This again is in line with some interviewees' feedback about how the individual they were supporting, did not believe they had a mental health disorder and did not belong in the facilities they visited for care. This suggests there was also a difference between the person with a CMD's model of illness and that of the people supporting them. This difference may only pertain to this instance rather than their overall beliefs. Additionally, interviewees providing support had reached the point of recognising the need to reach out to mental health services whereas it could be concluded the individual with a CMD was still going through the stages of making sense of their experience.

In addition to anticipating the Professional Sector will provide a 'fix', family/friend interviewees were also of the expectation they will be actively involved in the care planning and ongoing management process. This is particularly due to them establishing contact with the services, navigating complex care pathways and then assuming the role of providing support to the individual. This was however not the experience of most interviewees. Where they were able to be involved or at least a member of the close network supporting the individual, it was due to their insistence and being proactive to maintain communication and a relationship with professionals in the sector. The lack of involvement of family/friends in care planning and support is consistent with findings from other studies. Participants understood that due to confidentiality and regulations on sharing care information, there is a limitation to how much could be shared however, it was felt that they were side-lined by services. Research suggests that family involvement is not routinely implemented in mental health services and this was highlighted in the study by Rabiee and Smith (2014), where carers were interviewed about their experiences of interacting with services on behalf of the person they were supporting (Rabiee and Smith, 2014). Families feel they are marginalised and distanced from the planning process, therefore, feel isolated, uninformed and their role in providing support is unrecognised. It is felt that confidentiality is used as a means of not sharing information (Eassom *et al.*, 2014; Rabiee and Smith, 2014). Again participants in the study by Memon et al., (2016) highlighted the reluctance of healthcare professionals to engage with the friends and relatives of service users when they attempt to access mental health services on behalf of the individual affected (Memon *et al.*, 2016). Additionally, as noted in Section 1.11, about 53% of respondents to the Community Mental Health Survey indicated hospital services definitely involved their family member or someone close to them, as much as they would have liked and 18% noted 'no, not as much as I would like' (Nuffield Trust, 2020).

People's confidence or trust in the Professional Sector is thought to be undermined if their experience of services is not positive (Layland, 2018). Interviewees that saw multiple specialists as they sought to investigate their perceived physiological symptoms, as well as family/friends that continued to push for better engagement and adherence to treatment, reported parts of their experience as being negative. There was dissatisfaction about the 'ping pong' experience they had, bouncing from one service to another as they sought some form of intervention or diagnosis. The symptoms were not recognised as being linked to a CMD by health professionals until after they had gone through a series of tests.

For some family/friend interviewees, they had to readjust their narrative about the symptoms and changes in behaviour of the person they support because their explanatory model of the illness differed to that of the professionals. The threshold that needed to be met before the illness was deemed at a level for professionals to actively engage was felt to be too high by those supporting the person with a CMD and therefore, steps had to be taken to meet it. This meant drawing on other parts of the system (the criminal system), to reach that threshold. Again Kleinman et al., (1978) highlighted the different explanatory models of illness held by different people depending on the domain of the healthcare system they sit in (Kleinman, Eisenberg and Good, 1978). Despite the trust issues some interviewees have with the 'system' as a whole especially the criminal justice system as well as healthcare services, and the access difficulties encountered, they still continued to seek help from this Sector and believed it offered the best options to reach the outcome they hoped for. There is an acceptance of the Western biomedical model and support the Professional Sector can therefore provide for mental health disorders. Involving the police was a last resort despite fears of what will be recorded in the individual's file and any future implications it may have.

Race, inequality and in particular the relationship between Black people and the criminal justice system is not discussed very broadly in some sectors. Difficult and tense conversations about race and discriminations experienced by Black people in the USA in the summer of 2020 had a ripple effect and led to similar difficult, more open conversations to be held in the UK (The King's Fund, 2020). The conversations resulted in the House of Lords and House of Commons jointly producing a report calling on the UK Government to set out a comprehensive race equality strategy and implement long-standing recommendations (House of Lords/House of Commons, 2020). As outlined in the introductory sections of this thesis, Black people are overrepresented in mental health care and reports have indicated similar statistics in the criminal justice system (Bhui *et al.*, 2003; House of Lords/House of Commons, 2020). The report by the House of Lords and House of Commons also indicated that over 60% of Black people in the UK do not believe their health is as equally protected by the NHS in comparison to White people. Additionally, 85% of Black people do not feel confident they would be treated the same as a White person by the police (House of Lords/House of Commons, 2020). In the study by Rabiee and Smith (2014), some service users and carers also shared their concerns and experiences of racism, with a number of them noting that it is part of their everyday encounters, both from service providers and more widely (Rabiee and Smith, 2014). These feelings, perceptions and experiences have fragmented trust in the system therefore there is hesitancy in accessing mental health care particularly through the emergency route, if it means the police will be involved. However as mentioned above, there is an acceptance of the role Western medicine and support the

Professional Sector can provide for mental health disorders. Coupled with this acceptance of the Sector's role, was the urgent need for support that interviewees had which was a much more important factor in the decision making process.

From the perspectives of the professional participants in this study, their role within this Sector is as a provider of a broad service that meets different needs in the populations they serve. This includes running therapy sessions and provision of support to enable service users to tackle other aspects of their lives which are likely impacting on their wellbeing, such as their employment or financial status. All the professional interviewees cited examples of the type of additional supportive services they deliver and how they continue to assess where the needs lie in the communities they are based in, to try and meet these needs. This holistic approach to service delivery sets the community organisations in this thesis apart from mental health services delivered in hospital trusts. As outlined in Section 1.11, feedback from the Community Mental Health Survey showed that respondents received much less support for their non-physical health needs such as help finding work (Nuffield Trust, 2020). Based on these survey results that have been implemented over a number of years, it could be concluded that there is less emphasis on providing the wrap-around activities that will help people maintain their wellbeing in services run by hospital trusts. This is likely one of the gaps identified and being addressed by some community organisations.

6.2.3 Role of the Folk Sector

Data from the interviews with people with a CMD and family/friends found that they did not increase their use of the Folk Sector as might have been expected when going through periods of difficulty. For those that practice their religion, they continued to do so through attending their religious activities as far as they could and doing their prayers. In some cases, they prayed even more. They used the sector by continuing to maintain the routines and practices they have established. The Folk Sector is complex and takes a different form depending on the context, traditions and cultures of the country or region. In some regions and cultures, due to the close relationship between traditional medicine and religious practices, traditional healers are also religious leaders in their communities and often use a combination of both teachings when providing care and treatment to people (Mokgobi, 2014). As noted in the study by Tuffour (2020), participants recovering from SMI have a strong reliance on their religion in addition to drawing on traditional African worldviews (Tuffour, 2020). This supports the findings of this study that dependence on faith to maintain wellbeing is an important aspect of the strategies used by Black Africans with experience of mental illness.

The role of the sector during the period where people tried to 'make sense' of their experiences through to when they sought treatment, was to enable them to draw strength from their faith, in order to continue coping. As previously mentioned, interviewees did not request for specific support from leaders or others in this sector as they believed the advice would be to continue praying and their experiences would not be understood. This was particularly relevant to faith leaders. There was also a conscious attempt during the period of active engagement with the Professional Sector, to reduce interactions with people within their social network that belong to the same faith community. The combination of being advised to pray and the fear of being judged as not having a strong faith or perhaps having sinned, is stigmatising and threatens their standing in the community. This is as described in the definition of social stigma earlier in Section 5 and has been found in other studies looking at the strategies Black women relied on when dealing with CMDs (Lamb *et al.*, 2012; Adams *et al.*, 2014). With the faith community also being part of participants' social network, it was important to them to maintain a good standing and be seen as engaging in activities as usual. The decision to selectively seek support also speaks to how illness or life challenges are viewed as being private (Kovandžić *et al.*, 2011) as has been found in other studies and discussed in Section 6.2.1.

Interviewees from the Professional Sector strongly recognise the role the Folk Sector plays in people's health seeking behaviours and engagement in treatment. They noted the tension some people feel as they attempt to decide where to seek help – the Professional Sector or the Folk Sector. Their decision making process can be influenced by family members and friends based on their own beliefs of the outcomes they think will be achieved through engaging the Folk Sector. This again aligns with the Kleinman model of the healthcare system; the importance of the beliefs of family and friends in seeking help. According to Peprah et al., (2018), the Folk Sector is believed to offer a holistic treatment and healing to individuals (Peprah *et al.*, 2018). Professionals in this study adopted a therapeutic model of care/intervention, where the beliefs of service users are not challenged. If using the Folk Sector together with the Professional Sector is what people with a CMD or their carers feel will provide them the best care, this is neither encouraged nor discouraged. It is also recognised that sometimes, people may go through periods of relying on both sectors particularly when there is a breakdown in family relationships.

The faith leader interviewed also recognised the role of the Professional Sector and was very much of the view that all three sectors are needed, in order for people to receive a holistic package of support. Based on the teachings of Islam (the religion practiced by the faith leader interviewed), people experiencing symptoms that may be physical or psychological, should make every attempt to seek the best possible care. If care is better provided through the Professional Sector, that should be the course of action taken. If they exhaust all options through these routes and their symptoms still persist or worsen, then they can also seek help from the Folk Sector. This was a surprising finding as almost all informal conversations that the researcher had over several years with faith leaders of different backgrounds and traditional healers, have centred on the view that mental illnesses are caused by jinns therefore, treatments should be guided by religious teachings and traditional practices. Where the cause is felt may not be linked to jinns is where there is evidence of substance misuse. The approach taken by the faith leader in this thesis is to encourage people to seek help from the Professional Sector first (essentially signposting), which is a different approach to what the researcher perceived would be the faith leader's practice based on knowledge of other leaders' views. There is a recognition however, that not all diseases can be treated using

Western medical practices as their causes are of a spiritual nature. In such cases, treatment should be sought from the Folk Sector, from someone that has the appropriate knowledge, to be able to treat the condition. Other research studies carried out in different parts of the world, note that similar approaches are taken by traditional healers and faith leaders when supporting people (Peprah *et al.*, 2018). The faith leader's explanatory model of illness and beliefs is largely guided by religious teachings.

6.3 Experience: From treatment to maintaining mental wellbeing

The fourth research question seeks to understand what people do (or not) to maintain their ongoing mental wellbeing. In this section, a number of key themes drawn from the Findings section will be discussed, relating to the steps people take to maintain their wellbeing once they have, or have not, received treatment. Discussions will again be framed around the Kleinman et al., (1978) model of the healthcare system and explanatory model of illness.

6.3.1 Role of the Popular Sector

Recovery in the area of mental illness has been described as: 'a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness' (Slade, 2010, p. 2).

These elements can be seen in the strategies for wellbeing maintenance utilised by the interviewees in this research. Once people completed their treatment and had 'recovered', they managed their wellbeing using two approaches – coping strategies mainly learnt through their interaction with the Professional Sector and ensuring they maintained a strong connection to their close family and friends as well as wider social networks. They take a proactive approach to implementing these coping strategies. Strategies ranged from the use of meditation, through to positive thinking and prayers and awareness of their triggers, which provides a source of strength and resilience. These are all well documented approaches used by the Professional Sector in therapeutic sessions, to ensure people are able to go on to maintain their wellbeing (Slade, 2010). With an estimated 70% to 90% of illnesses managed in the Popular Sector (Kleinman, 1978), employing these strategies therefore plays an important role in providing ongoing maintenance of wellbeing. As outlined in Section 5.7.2 (Support network), people that take a proactive, problem-focused approach to how they cope with difficult experiences are thought to be more flexible towards unexpected changes and have the ability to seek social support when the need arises (Holubova *et al.*, 2018).

Reliance on a strong support network within the Popular Sector is an important factor. As mentioned in the Findings section, Black Africans often replicate some of the social networks they held in their home countries when they emigrate e.g. by joining associations or hometown groups as it is often called. Three interviewees with a CMD noted that the hometown groups or associations are an important network in their lives as it gives them an opportunity to stay connected to people. These networks provide an avenue for engaging in a range of social activities as well as sometimes voluntary services which are deemed to be meaningful. It helps people that have emigrated to integrate in a new country and culture (Blumenstock, Chi and Tan, 2019).

From the perspective of family/friend interviewees, maintaining wellbeing through leaning on the Popular Sector is very much focused on being aware of the individual’s triggers, ensuring the support network communicate and work together to ensure adherence to medication and any further treatment. It also involves ensuring they can act swiftly if there are any signs of the individual needing further intervention from the Professional Sector.

6.3.2 Role of the Professional Sector

The professionals interviewed for this study viewed their role in helping individuals maintain their ongoing wellbeing as having four approaches that people can engage with depending on their needs. The first being provision of advice that is important to people’s wellbeing such as on employment and finances. The second being the provision of social inclusion events that offer people the opportunity to interact with others as well as engage in meaningful activities. The third is the delivery of services that continue to meet the needs of communities. This includes assessing any gaps that might exist within their services and the wider mental health field, to ascertain where needs might be going unmet and attempt to meet these through setting up specialist provision. The fourth and perhaps most important was always keeping their door open and holding a space if needed for those that go through periods where they disengage with their service. All of these are underpinned by continuing to take a non-judgemental, non-pathologising and confidential approach to delivery of services.

Once people with a CMD completed their therapy sessions, they did not think they required use of the Professional Sector again and none of them had done so up to the time they were interviewed. The coping strategies adopted were felt to be effective and therefore negated the need to return. On the other hand, family/friend interviewees’ expectations of the Professional Sector in helping to maintain ongoing wellbeing is that it will be a long-term relationship. This is so that adherence to treatment could be closely monitored and if further intervention is required, it could be easily accessed. It should be noted that for the family/friend participants, they had been providing support to the individual with a mental disorder over some time and as previously mentioned, providing unpaid care is known to be challenging (Parliament UK, 2018). Participants were therefore keen to reach a point where the individual’s mental disorder is ‘well managed’, they are happy and engage in ‘normal’ life activities.

6.3.3 Role of the Folk Sector

Similarly, to the professionals interviewed, the faith leader viewed the Folk Sector in helping individuals maintain their ongoing wellbeing as having two functions. The first being providing spiritual guidance and advice based on teachings of their religion and secondly, leaving the door open for people that may need to re-engage in the future. Reliance on the Folk Sector is in an indirect manner because many of the relationships maintained in the Popular Sector are formed through interactions with the Folk Sector e.g. informal religious networks where social activities are delivered.

6.4 Reflections on interviewees' overall experiences

As previously mentioned, people's experiences of accessing help and how they maintain their health is tied to where and how help is sought. This section provides a summary of the researcher's other reflections not covered above, based on some of the key elements that stood out in interviews with participants.

6.4.1 Navigating the healthcare system and promotion of early help seeking

It is well documented in studies referenced in Section 1 that care pathways can be very complex and confusing for people to navigate (Bhui *et al.*, 2003; Keynejad, 2008; Anthony, 2015; Memon *et al.*, 2016), which some participants in this study reported. Different population groups particularly migrants, utilise health services differently and this is sometimes influenced by a lack of awareness of how services are delivered (Memon *et al.*, 2016). Decisions on how and when to access services is also influenced by their knowledge of the healthcare system in their home country, they therefore use that as a guide to navigate UK services (Lamb *et al.*, 2012). Streamlining these complex pathways to make services more accessible, efficient and able to offer a better experience to patients and their families, is one of the main triggers for frequent system-wide changes to healthcare services (NHS, 2019a). Raising awareness across different sections of the population will therefore need to be nuanced to take into consideration some of these factors, that are creating access barriers for some groups.

Alongside work to streamline delivery of services and improve access, there has been lots of investment in educating the public on utilising services depending on their need. O'Cathain et al., (2008) noted that messages about how the healthcare system should be accessed and used by the public can often be confusing, particularly if people are unfamiliar with services (cited in Turner *et al.*, 2013). There have been national campaigns over several years discouraging people from accessing emergency services unless they have an urgent and serious need for it, in a bid to ease pressure on services (North East Ambulance Service NHS Trust, no date; Turner *et al.*, 2013). There have also been national and regional messages about the importance of cancelling GP appointments in enough time if not needed so they can be allocated to other individuals, as unused slots cost the NHS money (NHS England, 2019b). Additionally, only one health issue should be discussed with the GP in the 10mins appointment slot given (Baird *et al.*, 2016). Long waiting times for GP and some hospital appointments has been a long-standing issue that has lately been covered widely by the media and has been the subject of public and political debate since the 1990s (The Health Foundation, 2019). Messages about the importance of self-management are usually championed and targeted programmes ran for example, 6 week self-management workshops for individuals with diabetes, to give them the tools to proactively manage their condition (Khunti *et al.*, 2012). All these messages aimed at shaping public behaviour on how services are accessed and utilised are normally delivered in a strong tone. It can be surmised that they have gone some distance in achieving the intended outcomes although, may have also had unintended outcomes such as patients not seeking help early (based on how this is defined by health services) as they do not for instance, wish to waste the time of GPs and other health services (Cromme *et al.*, 2016).

Disseminating strong messages to guide behaviour on how healthcare services should be accessed alongside those encouraging people to seek help early, which do not usually take a strong tone, may be conflicting and confusing for the public and have an unintended consequence of deterring early presentation. This may have been a factor in participants' experiences however, the study did not focus on capturing details of how broad health navigation and promotion messages played into the decision-making process for interviewees. This is a potential area for future research.

Challenges of navigating the healthcare system apply to participants in this study. Some of these challenges are also experienced by other communities and groups as found in the meta-synthesis carried out by Lamb et al., (2012) and studies cited earlier in the introduction section, examining experiences of accessing mental health care across different hard to reach groups (Weich *et al.*, 2004; Keynejad, 2008; Lamb *et al.*, 2012; Rabiee and Smith, 2014; Anthony, 2015; Memon *et al.*, 2016). Again, messages need to be more nuanced and properly coordinated, to ensure it strikes a balance between encouraging early help seeking and the appropriate use of services, in order to address some of the known access barriers.

6.4.2 Coping and resilience

Where this research has found that the experience of Black Africans with a CMD in the UK does differ from the majority population, is, as mentioned in Findings section, that there is a belief amongst Black communities that they are meant to be resilient and be able to deal with different adversities (Lamb *et al.*, 2012). This belief along with religious teachings about people experiencing different hurdles and their faith providing them strength, is felt to build resilience within individuals, enabling them to cope with many challenges. Some of the resilience observed in Black Africans particularly those that migrated to the UK, could be as a result of the belief they can deal with many challenges, due to the sometimes difficult path taken to settle in the country (Lamb *et al.*, 2012). The meta-synthesis carried out by Lamb et al., (2012), drew out an important theme from across groups in the studies included which showed that there is a source of pride, self-esteem and a sense of belonging derived from

Black women's ability to cope with hardships. This links into a propensity to rely on self-management as a first option in preference to treatment from formal services as findings in this thesis has highlighted. The meta-analysis by Lamb et al., (2012) also showed there was a feeling of deep cultural connection to 'being strong' which is tied to people's community and understanding of experiencing longstanding difficulties which go back as far as slavery (Lamb *et al.*, 2012). Similarly in the study by Memon et al., (2016), participants noted how cultural background and identity defined acceptable responses to mental health issues and the appropriate coping mechanisms, which focused on individual resilience (Memon *et al.*, 2016).

For some participants in this thesis, during the period when they were trying to 'make sense' of their experiences, they partly attributed their situation to a challenge they would eventually overcome. There was also a belief that their resilience and faith would enable them to cope. The expectation that they needed to show their strength and maintain normal activities was also of importance. For those that went on to engage in therapy, part of their coping strategy is a reliance on positive thinking which includes drawing on the knowledge that whatever future challenges they experience, they have the resilience to overcome it.

6.4.3 The different explanatory models of illness

Kleinman et al., (1978) suggested that illness is shaped by people's culture in terms of how they perceive it. Their experiences and coping mechanisms are all based on their explanations of sickness and the social positions they hold in their systems. Individuals in each of the Sectors hold a different explanatory model of disease and illness due to their cultural beliefs (Kleinman, Eisenberg and Good, 1978). The findings in this thesis show differences in perceptions between the four categories of interviewees on the approach to treatment and maintaining wellbeing. These are explored and reflected on further in this section.

Prior to seeking mental health support, people with a CMD viewed their symptoms as either challenges they were going through that will get resolved or physiological symptoms that required investigation from relevant medical specialists. Whilst these challenges represent periods of higher than normal levels of stress, only one interviewee used the word 'stress' to describe their experience. This again suggests that interviewees did not attribute the challenges they were experiencing to their mental wellbeing. The point at which people with a CMD decided to seek professional help was driven by their own assessment. In the case of family/friend interviewees, they played a significant role in the decision for support to be sought. It could be argued that the people they were supporting had not concluded they needed help. This speaks to the ongoing debate within service delivery about how the public could be encouraged and their awareness of symptoms improved, to enable them to present to healthcare earlier for support. It is expected that if people seek help earlier, they are likely to have better experience at the least and potentially better outcomes however, there is limited research on this focusing on non-psychotic mental health disorders (Richards *et al.*, 2019). Based on findings from this thesis, it is evident that the definition of early presentation is open to interpretation. Mental health services view this definition as seeking help between onset of symptoms within a defined period based on relative average time taken by most patients to seek treatment (Richards *et al.*, 2019). From the perspectives of interviewees with a CMD, help should be sought after a period of trying to self-manage unless the cause is thought to be physiological. From the perspective of family/friends, help should be sought when there is an obvious change in a person's wellbeing which will be evident through their change in behaviour. From the perspectives of the professionals and faith leader, help should be sought when the individual with a CMD feels ready to.

Interviewees with a CMD opted for short-term engagement with mental health services. Once therapy sessions were completed, they felt able to continue coping on their own. Self-management was important to them and they relied on their coping strategies learnt, resilience, family and friends, social network and faith, to deal with any other challenges that they experience. It could be concluded that they have an awareness of their own ability to maintain their mental wellbeing using all these tools. With family/friend interviewees, their perspective is that engagement of mental health services should be long-term. This would provide them the reassurance that the person they are supporting is receiving the care they need. It could be concluded that they did not feel able to assess whether the person they support will be able to cope on their own. This is partly because they got involved once the symptoms of the person got difficult for them to manage on their own, so are not aware of prior coping strategies that may have been used.

As noted in Section 6.2.2, family/friend interviewees' experience of navigating the healthcare system to access the right service for the individuals they were supporting was difficult. What was highlighted is the different parts of the public system that may need to be drawn on to access care. Kleinman et al., (1978) noted the different explanatory models of illness held by people depending on the domain of the healthcare system they sit in (Kleinman, Eisenberg and Good, 1978). Reaching the threshold to receive care may sometimes require engaging the criminal justice system and exaggerating symptoms the person is experiencing. Where family/friends are unable to deal with the symptoms the person they are supporting is experiencing, the only solution they felt was available is to ensure their descriptions meet the requirements of the Professional Sector to access services they felt was needed. People in the criminal justice system have an overview of how to manage incidents where it is suspected an individual may have a mental health problem. Their training on how to manage such incidents is guided by parameters set by the Professional Sector (healthcare services) (Puntis *et al.*, 2018). It could be concluded that this influences the explanatory model of illness of people in the criminal justice system that respond to such incidents and the steps they may take to ensure people needing mental health support are able to access it.

6.4.4 The beauty of hindsight

Hindsight, according to the Cambridge Dictionary is 'the ability to understand an event or situation only after it has happened'. What was consistent during the process of carrying out this research and interviewing participants was the insight into their mental health they gained through reflecting on their experiences. People with a CMD and family/friend interviewees have a much clearer awareness and understanding of the symptoms they experienced with hindsight. For one participant, it was through taking part in this research and the conversation during the interview, that the realisation of having a CMD was reached. This was because CMDs such as anxiety are not recognised as a mental health disorder by some people. Some individuals identify with mental illness labels whereas others do not. Labels are used for a vast number of reasons ranging from helping people to understand their illness, through to professionals being able to offer appropriate support as well as getting it onto the health agenda. The use of labels can make it difficult for some individuals to conceptualise their illness. Perhaps one of the most profound impacts it has is on stigma. There has been an ongoing debate amongst scholars about the use of labels and specifically the extent to which mental health is over-treated and over-medicalised. The debate has garnered more interest due to some scholars indicating that over-treatment and over-medicalisation has arisen as a result of the pharmaceutical industry expanding the boundaries of 'illness' and creation of more diagnostic categories, that lead to a rise in development of medication to address these 'illnesses' (Barbour *et al.*, 2013).

Whilst participants had their hindsight moments, so did I. At the beginning of this study, I thought that I would find interviewees have a heavy reliance on the Folk Sector for support, similar to practices in many African countries. This was particularly my expectation of people that emigrated to the UK as adults. Whilst the Folk Sector is important in the healthcare system, perhaps people change how they seek help once they move to a Western setting, where access and availability of medical services is more readily available. I am aware of people in my personal network that have used the Folk Sector to find a resolution to different difficulties in their lives, including health issues. In some cases, they sought support from faith leaders and traditional healers practicing in their home countries. It is based on this anecdotal information that I presumed use of the Folk Sector will be much more proactive and direct.

Interviewees may well have reached out for support from traditional healers here in the UK or their home countries but chose not to disclose it when interviewed. Based on my observations over many years, seeking the services of traditional healers is also a private matter for some people and one that they may not wish to discuss openly. However, participants may have also chosen not to use these services as they did not associate their difficulties with traditional medicine. My conclusion upon reflection is that participants did not access services from traditional healers. This is because of how vocal they were about limiting interactions with people and reluctance to disclose their experiences with faith leaders, due to for instance the fear of being seen as not having a strong faith. Additionally, based on my knowledge of practice in The Gambia and noted in the research paper by Mokgobi et al., (2014), there is some overlap in traditional healing practices and religious practices (Mokgobi, 2014). Some faith leaders also practice traditional healing, therefore have a dual role in their communities. Where this is the case, people with a CMD that do not wish to confide in their faith leader, will not do so with a traditional healer as it is the same person. Based on the interview with the faith leader, some people do engage the Folk Sector more actively when they need mental health support. This may be people less likely to take part in research or other approaches need to be used to recruit them. As the participants in this study are largely young (aged 18 to 44 years) and have been living in the UK for a number of years, their help seeking behaviours may have shifted.

6.5 Reflections on the theoretical framework

As detailed in Section 3, Kleinman’s explanatory model of illness has been critiqued and this relates mainly to its perceived limited breadth and insufficiency in capturing the role culture plays in illness and disease. Kleinman’s view of the model has changed over time, moving away from a structuralist position to focus more on narratives of experiences of illness (cited in Weiss, 2001). As noted in Section 3, the model continues to be widely used by clinical practitioners and cross-cultural psychiatric researchers (Kokanovic *et al.*, 2008), however, anthropologists have moved towards a more organic and nuanced concept of culture (Scheper-Hughes, 1990). Although these critiques were not initially considered when linking the two Kleinman models, nonetheless, the framework was valuable for analysing data from the interviews because to understand the experiences of participants in this study, it is necessary to have an appreciation for the role culture plays. Also for understanding participants’ experiences, it is important to take account of the role and influence of their religious beliefs, practices and networks.

Bonney (2004) proposed that “culture may be thought of as a causal agent that affects the evolutionary process by uniquely human means. Whereas with religions, to a greater or lesser extent, there is a process of revelation and a concept of the "faithful" who receive the message of revelation, culture permits "the self-conscious evaluation of possibilities in the light of a system of values that reflect prevailing ideas about what human life ought to be" (Bonney, 2004, p.31). There are many overlaps between culture and religion however, the relationship that participants in this study have with their faith, religious teachings and religious networks, point to some really important distinctions between the two. This is most evident as detailed in Section 6.2.1, where participants made a conscious decision to limit the information they share with their family/friends and wider network including religious leaders, as a result of the cultural belief that managing an illness is a private matter. This is in contrast to their own perceptions about religious leaders often being a source of support when people experience difficulties.

Kleinman’s explanatory model of illness does not explore the differences between culture and religion, particularly as it pertains to different communities and contexts. It also does not delve into how the polarity/dichotomy of culture and religion may shape people’s experiences, their explanations of illness and how they manage their wellbeing. Whilst the boundaries between culture and religion remains fluid, a key finding of this study suggests that it is vital to explore where some of the distinctions may lie as it pertains to some communities, as this underpins the decisions they make about accessing help and managing their wellbeing. The analysis derived from the findings in this study suggests that a more nuanced approach needs to be taken to understand the relationship between culture and religion, and the different factors that may impact on how people draw on both to manage their wellbeing. This is a distinct contribution of this study to Kleinman's explanatory model of illness and the body of work that has been contributed by other researchers, since the theory was developed. The concepts of culture and religion are important to explore further in future research, to continue refining the application of Kleinman's explanatory model of illness particularly in clinical practice, where it is most utilised.

7. Conclusion

This research aimed to contribute towards providing a more holistic picture of the pathways to care amongst Black Africans with a CMD living in the UK, with a particular focus on treatment and ongoing maintenance, to help inform strategies, service planning and delivery. With research literature and service level data indicating that Black Africans have some of the lowest levels of engagement relative to their population in some mental health pathways and they are over-represented in others, improving outcomes for this population therefore required carrying out a focused piece of work specifically exploring factors that may contribute to the lower uptake rates seen, in order to begin shifting this pattern. Studies cited in Sections 1 and 6 demonstrate the breadth of work that has been carried out to understand the mental health experiences of Black Africans and other BAME groups. The main focus of these studies has been on understanding barriers to accessing services and in the case of the study by Tuffour (2020), the role of religion in recovery. This thesis builds on that body of work, by taking a very focused look at the overall experiences of Black Africans in the UK with a CMD, instead of the broader BAME umbrella. Additionally, this study details participants' full journey and experience of managing their CMD, whereas other studies about Black Africans recruited participants with SMI or examined one part of their journey/pathway, therefore distinguishing this thesis from other work that has been carried out. This study also contributes to work on the overlaps between culture and religion and highlights the importance of recognising the distinctions, as they influence how people manage their wellbeing.

The qualitative in-depth interviews elicited data on individuals' experiences which is unique to them, and although this led to a range of experiences, as detailed in the Findings section, there are also common threads. Black Africans are motivated to engage in mental health services and once they do, if not at the point of crisis, they are able to maintain this engagement and go on to have positive experiences. The tools and insight gained from their therapeutic experiences go on to be applied to their life and they draw on them consistently to maintain their wellbeing. As would be expected, accessing services at the point of crisis can be a difficult experience for some individuals therefore sustaining engagement can be difficult. Based on the views and experiences of interviewees in this study, it suggests that Black Africans have a preference for relying largely on the Popular Sector particularly their own personal resilience, as they work to manage their mental wellbeing. This is intricately linked to their cultural and religious beliefs about the benefits that the Popular and sometimes Folk Sectors offer, in supporting them to get through difficult times. Reflecting on Kleinman et al.'s, (1978) suggestion that illness is shaped by people's culture in that their experiences and coping mechanisms are all based on their explanations of sickness and the social positions they hold in their community; it puts the journey of interviewees in this study into perspective. Their perceptions of when the Professional Sector should be engaged is shaped by these beliefs. Help should be sought when people are no longer able to cope on their own or with the support of their network. As culturally illness and life challenges are regarded as being a private matter that should be handled sensitively and discreetly, this again shapes when people make a decision to seek help from the Professional Sector (Memon *et al.*, 2016). It could be concluded that reliance on the Popular and Folk sectors may be to a much greater degree when compared to other populations such as White British, which would help to explain the lower access rates seen in some services, however, further research is needed to understand if this is a contributory factor.

For people who access services through crisis routes, the difficulties of navigating a complex healthcare system was highlighted. This is consistent with other research that has been carried out and highlighted in this thesis (Bhui *et al.*, 2003; Fearon *et al.*, 2005; Anthony, 2015). What was perhaps not clear in some of this research is how these difficulties ultimately lead to actions being taken to ensure help is accessed. It has been noted that some people's pathway into mental health services involves interaction with the criminal and justice system (Bhui *et al.*, 2014; Memon *et al.*, 2016). Through the experiences of interviewees in this study, it is evident how this can be the case for many. Where family members or friends contact ambulance services who then attend with the police, this is undoubtedly captured in service level data. In instances where the individual is deemed to not need mental health care when services attend due to the thresholds that need to be met, families and friends feel they have no other options but to exaggerate descriptions or symptoms and behaviour, to access the care needed. Whilst this may not be the situation in many cases, it sheds a light on some steps that perhaps family and friends have to take in order to access services which is not captured in reports.

It is important to promote early help seeking to potentially improve people's experiences and outcomes. It should however be noted that the term 'early' in the context of seeking help is subjective. People seek help in different ways. What might be termed as late help seeking by health professionals may be considered as early or timely for some people based on their explanatory models of illness, how they perceive health should be managed and from where and how they seek help. This is aligned with Gross and McMullen's, suggestion (1983, as cited in Nagai, 2015) that people seek help to solve their problems therefore an awareness of subjective needs has implications on decisions of whether or not to seek help. It is one of the most important factors that influences help-seeking (Nagai, 2015).

As discussed in previous sections, study participants recognised there was a need to raise awareness of CMD amongst Black African communities, to improve mental health literacy and encourage people to seek help from the Professional Sector when needed, in a timely fashion. This is consistent with the recommendations made by Keynejad (2008) in the study carried out in Redbridge to understand barriers to help seeking amongst BAME populations (Keynejad, 2008). There is also an appetite for some changes to be made to service delivery to maximise treatment options, experiences and outcomes. Family members and friends providing support to someone with a CMD are keen to be involved in care planning and be kept informed of progress. Better integration of services to make them easier to navigate and maximise on the opportunities it presents is important. Sustaining investment in these services is equally vital.

Drawing on the findings of this study, it is imperative to make some recommendations that could be taken into consideration when commissioners and providers design and deliver services. Most of the recommendations have been highlighted in national and local policies and strategies, however, there still remains a significant gap in achieving the ambitions set.

i. **Recommendation 1 – Awareness raising to improve mental health literacy and challenge stigma**
National campaigns aiming to raise awareness of mental illness have been running for several years. Adopting and personalising the resources and messages to align with people's world views is key if they are to engage with it. There are nuances that need to be acknowledged between different population groups therefore, tailoring messages accordingly is important, to get people to engage. A grassroots approach to disseminating these messages will be key and this could be achieved through working with religious networks, key influencers in the popular sector and community groups/associations formed and led by Black Africans. An element of awareness raising will need to include creating a safe space where people could have an open dialogue, to start addressing the silence that surrounds mental illness. Awareness raising efforts should consider how messages are crafted to ensure they complement others promoting help seeking.

ii. **Recommendation 2 – Broader adoption of non-pathologising approaches to care**
Some individuals identify with mental health labels whereas others do not. The broader adoption of non-pathologising approaches to the way mental health services are delivered may provide a step change in improving early access. Examples of approaches taken by some community organisations delivering mental health services offer a great insight.

iii. **Recommendation 3 – Improve trust between Black communities and the 'system'**
The trust between Black communities and the wider system is frayed particularly the criminal and justice system, where they are over-represented. For people to proactively access healthcare services, it is paramount that trust between different parts of the 'system' is improved but particularly the criminal and justice system. This will provide reassurance that people from Black communities will not face discrimination or have a poorer experience of healthcare services. There are a number of community organisations and statutory services that are working to address such issues but there still remains a vast amount of work to be done.

iv. **Recommendation 4 – Greater range of accessible and local services**
Models of accessible and local services similar to the one set up in Birmingham and Solihull, have the potential to ensure more sections of the communities they serve opt to engage (Birmingham and Solihull CCG, 2017). Whilst this is an ambition in the MHFYFV and the NHS Long Term Plan, all efforts should be made to ensure it is realised. Integrated Care Systems that are forming across the country will have greater

opportunities to take a place-based and person-centred approach to how services are designed and delivered.

v. **Recommendation 5 – Truly integrated commissioning models**

The provision of funded mental health services largely sits in the Professional Sector. Considering 70% to 90% of illnesses are dealt with in the Popular Sector, there is a need to truly consider how integrated commissioning models should look and how much more needs to be done, for it to reflect the actual ‘healthcare system’. Involving other parts of the healthcare system could go some way to simplify care pathways. It has been argued for instance, that there are both strong economic and moral imperatives to create meaningful contribution and collaboration between families and health professionals (Eassom *et al.*, 2014).

vi. **Recommendation 6 – Specialist services**

One size fits all approaches to service delivery can often widen health inequalities. There is a need to continue assessing the needs of local populations and developing services that meet them. Services geared towards engaging Black Africans could draw on research and learning carried out in African settings, to gain a better insight and understanding of cultures, beliefs and practices. Again, Integrated Care Systems present an opportunity to examine these longstanding issues more closely to develop services that better meet the needs of diverse communities.

vii. **Recommendation 7 – Increased investment**

The burden of mental illness continues to grow. It has a negative impact on the wellbeing of people and the economy of the country. In previous years, investment in mental health services did not quite match needs of the population. With mental health being on the agenda, it needs to be maintained as a priority. Investment in services and broader support including those recommended in this study, should also grow at a rate that will meet the needs of the population.

With the COVID-19 pandemic highlighting the poorer health outcomes that people from BAME communities experience, it should provide the impetus for greater and more creative investment in making sustained improvements for this population. A light has also been shone on how the pandemic has impacted people’s mental wellbeing. The government spending review in November 2020 indicated there will be continued growth in investment at least in the short term on health services. There remains a question on the level of investment that can be dedicated to mental health services as the country recovers economically from the pandemic. It is vital however that there is continued spending in this area to have any chances of not further exacerbating health inequalities and not stalling the progress that has been made over the last number of years.

Future research

Research focusing on the mental health experiences of Black Africans in the UK is still limited. There are many differences between ethnic minority groups under the BAME umbrella and steps should be taken to drill down further to gain a better understanding of these. One area of interest that has been highlighted through carrying out this research is the extent to which early presentation may influence the outcomes of people with a CMD, specifically, Black Africans. Another area that has been emphasised is the importance of gaining a better understanding of the events that lead to Black people presenting to services via crisis routes. Developing further insight to the decisions taken to access care via this route may enable the development of more informed strategies, to help address this important issue.

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APPENDIX 1 – Commissioning of mental health services

Role of bodies with commissioning responsibilities

NHS England

NHSE has the remit of commissioning specialised mental health services and it forms one of its six National Programmes of Care (NPoC). The role of the NPoC is to provide leadership and oversight of the development and delivery of a work programme in line with national ambitions (NHS England, no date). The Mental Health NPoC includes a board and clinical reference groups leading on specialised mental health, adult secure services, child and adolescent mental health services and perinatal mental health.

Integrated Care Systems

As of 1st April 2020, there are 135 CCGs in England, following a series of mergers over the years (NHS, 2020b). With the transformation of local healthcare systems into ICSs, local authorities will have an increased role in commissioning mental health services. As part of their mandate, public health teams have a role in promoting mental well-being and preventing poor mental health throughout the life course. Additionally, they have overview and scrutiny powers of mental health provision. Public health teams are therefore well placed to work with internal departments and providers, to commission services that meet the needs of populations including tackling inequalities such as those that exist in the access to mental health services particularly amongst BAME communities. Beyond this role, councils have a statutory role to provide social care to support people experiencing mental health problems (Local Government Association, 2018).

Each healthcare system adopts its own model to meet the needs of its population and to implement innovative approaches. CCGs and their local partners need to ensure people with multiple needs do not fall through service gaps (CentreForMentalHealth(forNHS), 2016).

APPENDIX 2 – Mental health services delivered

Funding

The MHFYFV called for mental health crisis teams to operate on a 24/7 basis and this was re-affirmed in the LTP. Just under half of crisis teams currently operate this model however, with this additional boost in funding, more services are expected to reach a level of providing round the clock support. A further £140 million will be provided from 2021 onwards to support this work. All these modifications are expected to improve patient experience and release resources by providing an alternative to A&E and inpatient admission (NHS England, 2020).

Services are delivered in a range of settings including specialist, hospital, primary and community care.

Secure services

Secure services are typically for people detained under the Mental Health Act who may pose a serious danger to the public (Duke et al., 2018). People entering low secure settings have either stepped down from high/medium secure care, been admitted directly from the community, adult inpatient services or from CAMHS as part of their transition to adult services. In some cases, they are transferred directly from prison or court or have been charged with an offence whilst in the community (NHS England, 2018).

Community mental health services

CMHTs operate under a model where people requiring support will have a certain level of severity of mental health need in order to access the service (NHS, 2019b). Service models do vary by area to meet local population needs. CMHTs are multidisciplinary teams that could consist of community nurses, doctors, occupational therapists, social workers, vocational and employment psychotherapists, specialist personality disorder workers, drama and art therapists (Hertfordshire Partnership University NHS Trust, no date).

As with other mental health services, the MHFYFV has ambitions to transform and modernise community services by developing new, integrated care models of primary care and community mental healthcare. The LTP reinforces this vision and has encouraged local systems to take a proactive approach to address racial disparities. Strengthening relationships with local community groups and voluntary sector organisations will play a key role in helping realise these ambitions.

Primary care and other community settings

Receiving mental healthcare in a GP practice or other primary care setting, in comparison to hospital or specialist settings can be less stigmatising for service users. It is also expected it will enable the achievement of shorter waiting times for treatment, a clear pathway to primary care services and be part of patients’ recovery plans (NHS England and Improvement, no date).

Non-commissioned mental health care support

Some religious organisations also work in close collaboration with secular voluntary organisations and in some cases, public sector organisations. Not only do they provide services to individuals with a mental health condition but also to their family and friends that may have a caring role (The Church of England, 2020).

APPENDIX 3 – Barriers, pathways and facilitators to accessing services

Barriers, pathways and facilitators to accessing mental health services amongst BAME groups

In the study carried out by Memon *et al.*, (2016) looking specifically at the perceived barriers to accessing mental health services amongst BAME groups living in Brighton and Hove City, there were key themes that emerged which the authors classified broadly as personal and environmental factors, and relationship between service user and provider. In addition to symptom recognition, stigma and cultural identity, social networks, waiting times, recognition and response to needs, culture, awareness of services, the following were also perceived as barriers by participants (Memon *et al.*, 2016).

Language

As some people within the BAME community, particularly recent immigrants speak little to no English, their inability to effectively communicate their needs to healthcare professionals prevented them accurately conveying their problems. As a consequence, individuals remain with their illness or might experience additional stress, not engage with healthcare services or receive unsuitable investigation and treatment.

Finances

The financial costs of complementary medicine or therapies was seen as a barrier to access due to most individuals being unable to afford these services. Informal community services are therefore used as a means to access some form of support. There is an additional financial impact for people in low income or insecure jobs taking time off from work to attend appointments may mean a loss of earnings.

Communication

Challenges with communication was not only attributed to language barriers but also to perceived inability of healthcare professionals to listen to the concerns and needs of patients. Healthcare providers are viewed as taking a generalised approach and do not listen to the individual needs of patients. A further challenge highlighted is the reluctance of healthcare professionals to engage with the friends and relatives of service users when they attempt to access mental health services on behalf of the individual affected.

APPENDIX 4 – Participant recruitment materials

People affected by mental illness

Take part in research

"Feeling happy is a part of mental wellbeing. But it's far from the whole."

Professor Stuart-Brown

Mental illness affects 1 in 4 of us. It is important for people affected by mental illness to access the right support and treatment. Some people affected by mental illness do not or are unable to access help early. Making sure high-quality services and the right support are accessible to everyone affected remains a high priority in England. To adapt services for people's needs and ensure support is in place, it is essential to get feedback from those affected by mental illness and understand how they maintain their wellbeing.

To take part in this research and share your views and experiences of mental illness, **contact Fanta Bojang on** fanta.bojang@lshtm.ac.uk. **We are especially keen to hear from people of black African backgrounds.**

This research project has been approved by the London School of Hygiene and Tropical Medicine.

Professionals in community organisations

Implementing the Mental Health Five Year Forward View has raised the profile of mental healthcare services in England. Mental illness affects 1 in 4 people. Accessing the right support and treatment early is key to recovery and ongoing mental wellbeing of affected individuals. Figures show that uptake of psychological therapies for common mental disorders by people from minority ethnic communities is relatively low especially amongst black Africans. To understand how services could be made more accessible to encourage early health seeking and engagement with services in this community, it is important to examine the key factors that drive engagement with psychological therapies. It is equally important to understand the forms of support provided and accessed via community organisations as they form an important part of maintaining wellbeing amongst people affected by mental illness. Professionals providing this support in the community are key to understanding how to meet the needs of individuals affected by mental illness.

To take part in this research and share your views and professional experience of providing mental wellbeing support, **contact Fanta Bojang on** fanta.bojang@lshtm.ac.uk. **We are especially keen to hear from professionals that have experience of providing support to people from black African communities.**

Faith Leaders

Mental illness affects 1 in 4 of us. It is important for people affected by mental illness to access the right support and treatment. Some people affected by mental illness do not or are unable to access help early. Making sure high-quality services are accessible to everyone affected remains a high priority in England. It is equally important to understand the forms of support provided and accessed in the community as they form an important part of maintaining wellbeing amongst people affected by mental illness. To adapt services and support for people's needs, it is essential to get feedback from those that provide emotional and spiritual support to people experiencing mental health illness.

To take part in this research and share your views and experience of providing support to people affected by mental illness, **contact Fanta Bojang on** fanta.bojang@lshtm.ac.uk. **We are especially keen to hear from Faith Leaders that have experience of providing support for people from black African communities.**

Traditional Healers

Mental illness affects 1 in 4 of us. It is important for people affected by mental illness to access the right support and treatment. Some people affected by mental illness do not or are unable to access help early. Making sure high-quality services are accessible to everyone affected remains a high priority in England. To adapt services for people's needs, it is essential to get feedback from those that provide care and support to people experiencing mental health illness.

To take part in this research and share your views and experience of providing support to people affected by mental illness, **contact Fanta Bojang on** fanta.bojang@lshtm.ac.uk. **We are especially keen to hear from Traditional Healers that have experience of providing care for people from black African communities.**

APPENDIX 5 – Interview Topic Guides

Introduction:

- Thank you for agreeing to take part in the study exploring the experiences of black Africans that have a CMD and may have received treatment or support in the community and how they maintain their ongoing wellbeing.
- This research is voluntary; you can stop at any time without any negative consequence. You do not need to give a reason.
- If you need to take a break, please say so.
- With your permission I will digitally record the interview
- Your interview will be attached to an ID number not your name.
- Everything you tell me will be confidential, however if you tell me something that suggests that you or someone else are at serious risk, I will have to tell someone. In this case we will inform you and pass the information on to someone who can help.
- All written/recorded information will be destroyed ten years after the study ends.
- All information will be stored securely on the LSHTM network.

People with experience of a CMD

Interview questions:

1. To begin, can you tell me a bit about yourself including where your family is originally from and how long you have lived in the UK?
2. When you were first approached why did you feel that it was important to take part in this research?
3. Have you received a diagnosis of a common mental disorder by a healthcare professional at some stage in your life? When was the diagnosis made?
4. If you have not been diagnosed by a healthcare professional, what are some of your experiences which led you to indicate/believe that you may have a CMD?
5. Can you tell me about your journey and experiences prior to receiving a diagnosis or recognising that you may have a CMD.
6. Has your CMD had any impact on your life? Can you give me an example of how it has impacted on your life?
7. When you were diagnosed or recognised you may have a CMD, did you take any steps to get better? If so what? If not, why not?
8. Did you seek professional treatment or support for your CMD? If so, what type of treatment or support?
9. If you sought treatment from a healthcare professional or support, what were your motivations for doing so?
10. How did you reach a decision about the type of treatment service or support to access?
11. Has this treatment aided your recovery or maintenance of your wellbeing? If so how (give and example). If not, can you describe why/how it has not?
12. What motivated you to continue (or not continue) your treatment?

13. Have you had/used/accessed any other treatments or support?
14. Have these additional interventions supported you in your recovery or helped you to maintain your wellbeing? Give an example of how it has supported you in your journey.
15. If you decided not to seek treatment or support, what were your reasons?
16. What impact if any has the decision not to seek treatment or support had on your experiences of recovering or maintaining your wellbeing?
17. What could motivate, support or enable you to access treatment?
18. What support from family, friends, peers have you received to help you access treatment and/or maintain your wellbeing?
19. Have your family or close friends been involved in your treatment or support planning? If so, please describe how, give an example
20. Do your family and friends play any role in your ongoing treatment?
21. Do your family or friends support you to maintain your mental wellbeing? If so, in what way have they supported you?
22. Did you access support from faith groups or traditional healers? What type of support did you access?
23. Did support from these groups or traditional healers help you in your treatment journey? Can you describe how?
24. Do you receive any support now from these groups or traditional healers? If so, what is the nature of the support?
25. At what stage do you think you are now at in your journey of maintaining your mental wellbeing?
26. What could have been different in your journey to support you in accessing help earlier?
27. What strategies/approaches do you use to maintain your mental wellbeing?
28. Are there any other services or types of support that you think will help you maintain your mental wellbeing?

Professionals providing support through community organisations

Interview questions:

1. To begin, can you tell me about your personal profile and experience?
2. What type of services do you currently provide?
3. When you were first approached why did you feel that it was important to take part in this research?
4. There is a variation in the uptake of mental health treatments. Data shows that uptake is lower in BME groups particularly black Africans. Are your services adapted in any way to meet the needs of the different populations?
5. Is there a variation in uptake of the services you provide amongst different population groups?
6. If there is variation, who typically engages in your services?
7. How can services you deliver be adapted to ensure black African ethnic groups engage more?
8. Do you have experience of providing support to black African people?

9. How do you adapt your personal approach to ensure engagement of the people you provide services to?
10. What are typically some of the experiences of the people using your service when they receive a CMD diagnosis or recognise they may have a CMD?
11. What usually motivates your service users to seek support? At what point in their journey do they seek support?
12. Are you familiar with the use of traditional healing by some people for mental health disorders?
13. Have any of your service users disclosed the use of traditional healers for treatment of their condition?
14. If they have, how did you work with them to identify/understand how it fits into their recovery?
15. In your experience, how do black African service users maintain their ongoing mental wellbeing?
16. How well do black African service users engage once they access your organisation's services?
17. What are some of the reasons cited by service users or families for lack of engagement in formal healthcare services in your experience?
18. Have any of your service users disclosed the use of faith leaders for treatment of their condition?
19. If they have, did you work with them to understand how it fits into their recovery?
20. What role do families and friends play in the treatment and recovery of your patients?
21. Are families and friends included in the support planning process?
22. Do your black African service users see their support plans through to completion?
23. What support is provided to service users once they complete their plan through your work, to help them maintain their wellbeing?
24. Is there any specific support put in place for black African service users after they complete their plan?
25. In your experience of providing care/support to people with a CMD, what needs to be done differently within the health and care system to encourage black African people to seek help early and maintain their mental wellbeing?

Traditional healers / Faith leaders

Interview questions

1. Tell me about your profile and experience.
2. What type of care or support do you provide to people that have a CMD?
3. How do your clients engage with your services?
4. Tell me about the profile of your clients. Gender, nature of illness, nationality, where they reside?
5. At what stage in their recovery / treatment / journey do your clients engage with you?
6. What are some of the reasons your clients give for accessing your services?
7. Do you think your services compliment Western medicine? In what way?

8. Do you signpost or have links with healthcare professionals as part of the support you provide? If yes, how do you work with them to provide care and support to people affected by CMD?
9. Do your clients disclose the use of Western medicine for their condition?
10. What proportion of your clients disclose use of Western medicine for their condition?
11. How do your clients maintain their ongoing wellbeing?
12. Are families / friends involved in your treatment planning?
13. What training / support do you think would be beneficial to you to help you provide better support to your clients?
14. In your experience of providing care/support to people with a CMD, what needs to be done differently within the healthcare system to encourage people to seek help early and maintain their mental wellbeing?

Family / friends of a person with a CMD

Interview questions

1. To begin, can you tell me a bit about yourself including where your family is originally from and how long you have lived in the UK?
2. Who within your family or social network that has a CMD did you provide support to?
3. When you were first approached why did you feel that it was important to take part in this research?
4. What was the journey and experience of your affected family member/friend prior to them getting a diagnosis of a CMD or recognising they may have a CMD?
5. If your affected family member/friend did not recognise they may have a CMD, what did you do in helping them with their recovery?
6. What experience has their journey had on their wider family / support network?
7. Did your affected family member/friend access treatment? Types of treatment?
8. What motivated them to seek treatment/support if they did?
9. How has the treatment/support impacted them and their wellbeing?
10. If he/she decided not to seek treatment/support, what do you think were their reasons?
11. What impact has this decision had on their journey, experiences and ongoing wellbeing?
12. How did you support your affected family member/friend?
13. Who else is involved in providing support to your affected family member/friend? How have they supported your affected family member/friend?
14. Were you included in the process of treatment/support planning for your family/friend?
15. How does your family/friend maintain their ongoing wellbeing?
16. What type of support would be beneficial for your family/friend to help them access help early? Support to maintain their ongoing mental wellbeing?

APPENDIX 6 – Participant Information Sheet

An investigation into Black Africans in the UK's experiences of treatment and support for common mental disorders and their strategies for maintaining their ongoing mental wellbeing

What is the purpose of the study?

Mental illness can have huge implications on the lives of affected individuals and their families. Much research has focused on psychotic disorders, late presentations to healthcare services and outcomes experienced by ethnic minorities particularly those from African communities. Adjustments to services have been made in an effort to make them more accessible to groups at most risk.

There is limited research available on the use of psychological therapies and informal treatment and support for common mental illnesses by ethnic minorities. It is important to understand the experiences of black Africans with a common mental illness, the support they access if any, outside of formal healthcare settings and the strategies they use to maintain their ongoing mental wellbeing. The aim of this research is to contribute towards providing a more holistic picture of the formal or informal care, treatment and support received by this ethnic group as well as how they maintain their ongoing wellbeing. This insight will help inform strategies, service planning and delivery to ensure they are diverse to the needs of a diverse population.

What does participating involve?

Your participation in this study is important to provide input on how services could be made more accessible, to encourage people from ethnic minority groups that need psychological support to engage.

Participation in this research is confidential (participants will only be identified by a study number, not by name) and it is entirely voluntary. If you agree to take part, you will be invited to participate in an interview to explore your views in more detail. If consent is given, the interview may be recorded. Your participation will not be shared with your healthcare providers, patients or any other individuals.

You can withdraw from the study at any time with no consequences and without having to give a reason. If you withdraw, any information you provide for the purposes of the study will be destroyed.

How will confidentiality be ensured?

Your medical information **will not** be collected for the purposes of this study, only accounts of your experiences, feelings and opinions. The transcripts of the interviews are available to the investigator only. Information obtained through the interviews will be used in aggregate form. Where transcripts are quoted, no reference will be made to your name and references will only be used following your approval. All transcripts will be kept by the investigator in a secured file on the London School of Hygiene and Tropical Medicine's IT system and can only be accessed by the investigator. Transcripts will be held for 10 years including the duration of the research study until the investigator has submitted the report and successfully passed all exams. The transcripts will not contain your name or any other personal data. Data will then be destroyed after 10 years.

Will the study be published?

The data collected during the study will be analysed and collated into a report for submission to examiners for the investigator's doctoral studies. A version of the report may also be published in academic journals to contribute to the growing knowledge in this very important topic area. Your name **will not** be included in the report or any other published information.

Ethical approval

This study has been approved by the London School of Hygiene and Tropical Medicine's Research Ethics Committee to protect the interests of any participants that may take part.

Thank you

Thank you for considering taking part in this study and for taking the time to read this information sheet, which is yours to keep. If you decide to take part in the study, you will also be provided a copy of your signed consent form.

Further questions

If you have any further questions or queries about the study, please do not hesitate to contact me at Fanta.bojang@lshtm.ac.uk.

APPENDIX 7 – Informed Consent Form

Study title: An investigation into Black Africans in the UK's experiences of treatment and support for common mental disorders and their strategies for maintaining their ongoing mental wellbeing

Consent form version and date: V0.3 24.11.2019

Investigator: Fanta Bojang

Please initial

I confirm that I have read and understood the information sheet dated 24th November 2019 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary, confidential and that I can stop the interview at any time without giving a reason and without my medical care or legal rights being affected.	
I understand that if I decide to stop the interview all data collected will be destroyed.	
I understand that recording the interview is optional. By ticking this box, I agree to have this interview recorded.	
I understand that any quotations used in writing up the study findings will be used anonymously and I consent to this.	
I understand that anonymous notes of my interview may be shared on an online data repository to advance research in this field	
Understanding all of the above information, I agree to take part in the study.	

Name of Participant (please print): ________________________________

Signed: ______________________________ Date: ____________________

Name of Investigator (please print): ________________________________

Signed: ______________________________ Date: ____________________

APPENDIX 8 – Data Management Plan

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

Data Management Plan
for Research Students

Author name	**Fanta Bojang**
Email	Fanta.bojang@lshtm.ac.uk
Project title	An investigation into black Africans in the UK's experiences of treatment for common mental disorders and their strategies for maintaining their ongoing mental wellbeing
Date of last edit	23rd May 2019
Supervisor	Dr Nicki Thorogood Dr Julian Eaton

Support

Information on writing a Data Management Plan can be found at
https://lshtm.sharepoint.com/Research/Research-data-management/
For advice and feedback on your Data Management Plan contact
researchdatamanagement@lshtm.ac.uk

1. What data or other resources will you be working with in your study?

List the resources - data, code, collection tools, etc. - you will use in your research. Relevant details to mention include: its content (e.g. themes/topics), type (e.g. interview, survey, spatial), source (collected by self or others), capture method (e.g. face-to-face interview) and volume (100 people interviewed).

Content

- People that received a diagnosis of common mental disorder (CMD) – an account of experiences of people who may or may not have received treatment. Details of how they maintain their ongoing mental wellbeing.
- Family members of people with a diagnosis of CMD – an account of their experiences of caring and supporting a family member that received a diagnosis of CMD who may or may not have received / is receiving treatment
- Mental healthcare practitioners
- Traditional healers and faith leaders

Type – one to one in-depth interviews with people that received a diagnosis of CMD, family members of people that received a diagnosis of CMD, mental healthcare practitioners, traditional healers and faith leaders with experience of providing support to people that received a CMD diagnosis; field notes.
Source – collected by me (researcher) and with the aid of an interpreter where the participant does not speak English or Wollof (local Senegalese and Gambian language).
Capture method – face to face in-depth interviews that will be recorded and transcribed. Interviews conducted in a language other than English will be translated prior to transcribing.
Volume – between 16 and 21 people will be interviewed.

2. What software/hardware tools and file formats/standards will you use?

Outline the software and hardware you will use during your research, as well as the file formats/encoding standards in which data will be held. E.g. Open Data Kit for collection, STATA and MS Access for analysis.

Data collection – Dictaphone to record interviews where consent has been given to do so; notebook for field notes
Transcription and analysis – NViVO

3. What data-related activities will be performed during your research?

List the actions you will perform on your resources from initial collection to archiving/deletion and approximate timescales when each will occur. This may be presented as an activity list, workflow diagram, or other form. E.g. trial draft survey in month 6, collect data in month 9-10, clean data in month 11.

Data collection (face to face interviews) – August 2019 to November 2019
Transcription and analysis of interviews – August 2019 to January 2020
Data analysis – August 2019 to January 2020

4. What quality checks will you perform to ensure data are fit for purpose?

Problems often occur which result in data being unsuitable for use. Review the activities listed above and consider the quality checks you could perform before, during and after each stage to ensure the correct data are captured and it remains accurate and complete throughout the analysis process. Visit http://ukdataservice.ac.uk/manage-data/format/quality.aspx for guidance.

Review interviews after they've been carried out to refine semi-structured questionnaire for subsequent interviews and ensure data required is being collected.
Check for interview transcription errors particularly for interviews that are translated from another language not spoken by the researcher.
Check quality of interview recordings to ensure it is audible.

5. Will any ethical or rights issues influence your data management approach? How will you address these?

E.g. participant consent must be obtained to enable data analysis and sharing; the licence of a 3rd party dataset should be checked and a data sharing agreement signed to enable use.

All participants will sign a consent form prior to taking part in the research. Participants can withdraw from the study at any point and data collected from the participant will be destroyed and not form part of the analysis or thesis report. This is clearly outlined in the participant information sheet and informed consent form.

6. What documentation is needed to understand your data?

Describe the information needed to enable your data's content and context in which it was obtained to be established. This may cover coding systems used for collected/missing variables and the audit trail of activities. Visit https://www.ukdataservice.ac.uk/manage-data/document for examples.

Research protocol
Interview topic guides
Field notes
Publications and presentations

7. Where will you store data during the project lifetime? (choose one or more)

Consult the LSHTM Data Storage Options document for guidance
https://lshtm.sharepoint.com/Services/IT-Services/Documents/LSHTM-data-storage-options.pdf

My desktop PC at home		My Laptop or tablet		Personal area on university network (e.g. drive H:)	√	University Shared Network drive accessible to all (I: drive)	
Server at collaborator institution		University-based project server		LSHTM Secure Data Server (for confidential data)		LSHTM Open Data Kit server	
For-cost cloud service (e.g. Amazon S3)		Free cloud service (e.g. Dropbox)		Portable storage (e.g.USB disk or memory stick)		LSHTM SharePoint	
Other							

8. What security measures will you apply to protect data? (choose one or more)

I will not collect any data considered personal, sensitive, or otherwise confidential		Store personal details in a separate secure location & link it via an identifier		Delete confidential details at earliest opportunity (e.g. via anonymisation)	√
Use digital storage systems that require a username/ password or other security feature in order to access files	√	Physical security (such as locked cabinet or room)		Protect portable devices using biometric, passwords, or other security features	
Encrypt data storage devices		Encrypt data during transfer		Avoid use of cloud services located outside EU	
Other:					

9. How will you organise and label data to make it easy to find and analyse?

E.g. By adopting a consistent approach to folder structures, filename/variable labelling, versions.

By having a consistent folder structure, file naming convention and version control.

10. What resources should be kept as evidence of your research?

Research data are often covered by requirements that state the time period it must be kept. For instance, the LSHTM retention schedule states that anonymised data must be kept for a minimum of 10 years following research completion. Review the resources listed in Q1 and identify those which need to be kept as evidence of your research and whether they can be shared with other researchers.

Interview transcripts – Yes, cannot be shared with other researchers

Interview recordings – No

Thematic analysis – Yes, cannot be shared with other researchers

Field notes – No

11. If resources can be made available, when is this likely to happen?

Identify the time period when resources listed above are likely to be made available (choose one).

During the project lifetime		On thesis submission		On publication of thesis	√
At the same time as research findings are published in an academic journal		A set time period after project end (e.g. 12 months). Please specify time period			
Other					

12. Where will these be stored after you've completed your thesis? (choose one or more)

I will look after the data myself		My supervisor will look after the resources	√	They will be looked after by the project team	

Submitted to the LSHTM digital repository		Held in a university project system		Held in a 3rd party data repository. (Specify which in Other field)	
Other:					

13. What actions will you perform to ensure your resources can be accessed and used in the long-term? (choose one or more)

Prepare a user guide that provides a high-level overview of data		Ensure codebooks and other documentation are accurate and made available alongside data		Use open formats to ensure data can be easily accessed, e.g. CSV	
Remove personal and confidential data	√	Adopt an appropriate licence that clearly states allowed/non-allowed uses		Apply appropriate domain standards for labelling data	
A description will be published in a digital repository and a DOI obtained					
Other:					

14. What are the primary data management challenges in your research?

As a part-time student, I work off-site majority of the time. A challenge would be ensuring that I am able to get access to the LSHTM network at all times.

15. How can LSHTM & others help you to better manage your data?