"Who supports the families of black and minority ethnic children with life-limiting conditions?"

Wahida Shah Kent

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This work has not been submitted in substance for any other degree or award at this or any other university or place of learning, nor is being submitted concurrently in candidature for any degree or other award.

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This thesis is being submitted in partial fulfilment of the requirements for the degree of DSW.

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This thesis is the result of my own independent work/investigation, except where otherwise stated, and the thesis has not been edited by a third party beyond what is permitted by Cardiff University's Policy on the Use of Third Party Editors by Research Degree Students. Other sources are acknowledged by explicit references. The views expressed are my own.

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Acknowledgements

Abstract

This thesis is a study exploring the support systems of the families of Black and Minority Ethnic (BME) children with life-limiting conditions. Interviews were undertaken with twenty parent carers of BME children with life-limiting conditions, and ten practitioners working with the families of children with life-limiting conditions, in both Wales and England. The aim was to shed light on the lived experiences of this group of families, hitherto missing from the academic literature. This research has sought to address that gap, through interviews with parents BME children with life-limiting conditions. Interviews were also conducted with professionals working with families of children with life-limiting conditions. A mixed methods approach was adopted, which allowed for data from the Millennium Cohort Study, a nationally representative dataset, to also be utilised to look at the wider context of living with a disabled child.

The research explored if there was ethnic variance in terms of the experiences of this group of families in accessing support, and identify potential barriers to both informal and formal support. And also, to ascertain if professionals working with them perceived their needs and experiences to be different from white families. The interviews with professionals help to ascertain how professionals perceive working with BME families, and whether they see ethnicity as impacting on the needs and experiences of this group of families.

Findings from the research indicate that the families of BME children with life-limiting conditions face some similar challenges caring for their child and family, to those faced by white families. Religion and culture were not found to form a barrier to use of formal services. Those families

accessing formal support overall found it helpful, and formed strong relationships with practitioners. However, it is the way they and their needs are perceived by some providers of formal support services which demonstrate that they are perceived as being different. This was found to be one of the barriers to this group of families accessing formal support. Some assumptions and beliefs around the needs of BME families appeared to be based on 'racial' and ethnic stereotypes and anecdotal evidence, which the qualitative and quantitative and findings of this research challenge.

Recommendations from this research are for organisations working with BME families to ensure they are working in an anti-discriminatory manner by assessing the individual needs of that family. A shift away from what may be outdated 'racial' and ethnic stereotypes is needed.

Dedication

This thesis is dedicated to Yasmin Shah Kent and Murid Hussein Shah. The two people who taught me most about life, love, and loss.

Chapter 1 Introduction

1.1. <u>Why is this particular topic being researched?</u>

This thesis is about the families of black and minority ethnic (BME) children with life-limiting conditions (LLCs). It explored sources of support for the families – informal support, as well as formal support. The aim was to understand the experience of this group of families, hitherto missing from the academic literature, in order to ensure that the support they receive is appropriate, accessible, and effective. The contribution of formal support, in conjunction with informal support, could be very important in families of a child with an LLC.

In the case of BME families with children with LLCs, there is a dearth of direct research with this particular group of families (Brown, et al. 2013). There is, however, research to evidence low take up of palliative care and hospice services for adults (Evans, et al. 2011; Connolly, Sampson and Punadare, 2012; Firth, 2001; White, Haas, and Williams, 2012). In particular the voice of the parent carers of BME children with LLCs is missing from the academic discourse. This thesis has sought to address that gap, through interviews with twenty parents of BME children with LLCs, in order to explore their lived experience of being a parent carer, and to see if it is different from that of white families. Also, to look at their experience of access and engagement with both formal and informal sources of support, and to identify any barriers to engagement. The thesis also identifies what parents value as support.

Interviews are also conducted with ten professionals working in the provision of formal support services, in the social care, health and education sector, to ascertain their views of BME families, and any barriers they face working with this group, and to identify any needs they may have to ensure effective practice with this group of families. The thesis will conclude with summarising findings from five chapters of qualitative data (Chapters 5, 6, 7, and 8), and one chapter of quantitative data (Chapter 4). Potential sources of formal support include the following: health services, social work teams, special needs schools, religious and cultural institutions, and third sector services, with a particular focus on hospices.

The purpose of this study was to better understand the lived experiences, and supportive care needs of parents caring for a BME child with a diagnosis of an LLC. Is there ethnic variance in the experience of being a parent carer of a child with LLCs? Currently there is a dearth of research on this topic, particularly research that places the parent carers at the centre. The scholarly discourse on this topic is dominated by the views of academics and would benefit from the inclusion of the voice of BME families (Brown, et. al. 2013).

Interest in this topic came from practice experience of undertaking direct work and contact with such families over a period of thirteen years, when I worked for a third sector organisation. My role involved managing a service which employed a team of social care staff who undertook casework (in relation to social care,

health and education issues) with BME disabled children and children with LLCs, aged 0 – 25, and their parent carers. The research proposal resulted from numerous discussions with professionals working with this group who reported low or no take-up of formal support services.   Anecdotal evidence suggested that due to the availability of informal support systems, BME families may not wish to access formal support. This was reinforced by the views of professionals working with disabled children and children with LLCs and their families. A number of other explanations were provided by these professionals, some linked to cultural and religious beliefs and practices. However, all the theories put forward by these professionals were anecdotal and had not been based on the views and experiences of the families of this group of children. There appeared to be a need to test these assumptions by interviewing the parents of BME children with LLCs, to ensure that 'racial' and ethnic stereotypes were not forming a barrier to services and also a need to update knowledge regarding the experiences of this group of families.

1.2.   <u>What is the significance of the topic?</u>

BME groups are reported to have higher prevalence of children with LLCs (Fraser et al., 2012). Yet specialist services for the families of children with LLCs were reporting low take up of services from this group. The academic discourse shows BME groups as over-represented in terms of some services (Butt and Box, 1998) but under-represented in others (Greenwood, et al., 2015; Szczepura, 2005). In terms of their access to and take up of services, there is a gap in knowledge. This

research will help address this gap. Very little is known about the lived experience of this group, therefore the main aim of this study was to capture the dominant themes in the life experiences of parent carers. Understanding the needs of children with LLCs and their families has been highlighted as a global research priority (Downing, et al. 2015). This study will help to better understand the lived experiences and supportive care needs of parents caring for a BME child with a diagnosis of an LLC. It will also include relevant professionals, to explore their beliefs and experiences regarding BME children with LLCs and their families.

1.3. <u>Context of the research</u>

This study takes a mixed methods approach, albeit with more emphasis on qualitative research. The quantitative element involves analysis of nationally representative data from Wave 5 of the UK Millennium Cohort Study (MCS), to set the context for the study at a population level. Trying to find a suitable dataset which contained data regarding ethnicity and children with LLCs proved to be a challenge. As a result, data that pertains to children with long standing illnesses (LSIs) was used instead. This was the closest substitute that could be found. It should be noted that a quantitative element was a requirement from the funding body, Health and Care Research Wales. Chapter 4 focuses on the quantitative element, and provides a wider context of the lives of BME children with LSIs and their position in the general population.

The qualitative element involved semi-structured interviews with twenty parent carers of BME children with LLCs, and also ten professionals. This distinction is important, in that one may be the parent of a BME child; however, that does not automatically mean that the parent will also be from a BME group. Of the twenty parents interviewed in this study, all were in fact from BME groups. One parent from this group of families (the spouse of one of the participants) was not from a BME group, and they chose, for personal reasons, not to participate in the research. The participants came from both Wales and England. Most interviews were conducted in English, but some were done in Urdu, or Punjabi, as I am fluent in these languages.

Interest in this topic came from a range of social care, health and education agencies, as families of children with LLCs tend to access a broad range of services, and the boundaries between these sectors are often blurred, as taking a holistic multi-agency, multi-professional approach is considered good practice. It is also important to take a holistic view of families' experiences. In my practice experience, we worked closely with professionals across disciplines and agencies to ensure best outcomes for the families we worked with. Education and health were also focused on because they are universal services, and thus a useful way to include and involve marginalised groups.

1.4.   <u>Where is the research being conducted and why?</u>

The research was undertaken both in Wales and England. The PhD funding body required at least a partial focus on Wales, however, limiting the study to Wales-only proved to be a challenge.   There were risks associated with Wales-only research which included the fact that as this group of families are a minority within a minority, and it might be possible to identify certain families, even when anonymised. There was also the issue that the agency I worked for, and through whom I hoped to recruit parent carer participants, no longer existed by the time of data collection. Recruitment of parent carer participants became a challenge. By this point, I had also made contacts with organisations and professionals working in England, who were keen to participate in this research, as they also identified this gap in research, and felt findings would be relevant to them.

1.5.   <u>The research aims and objectives</u>

The aim of this research is to establish the supports networks of the families of BME children with LLCs. Does their support come from formal networks, or informal networks? What, if any, are the barriers to accessing formal or informal support?   Where are any weaknesses in their support systems, and who can address these, and how? What is the lived experience of being a parent carer of a BME child with LLCs? Is there ethnic variance, or is their experience shared by other parent carers of children with LLCs? Where there is ethnic variance, what does this look like, and how does it impact the family?

The aim was also to address the gap in research, and include the voice of the parent carers of BME children with LLCs. This is essentially the original contribution to knowledge that this study makes. The objectives of this research were essentially to explore the experiences of this group of families, and then to describe them in the context of their experiences of accessing formal and informal support.

1.6. __Conclusion__

The aim of this study was to fill a gap in the academic discourse, by including the voice and views of this specific group of families. The process of undertaking the research and the challenges encountered helped understand why there is such a dearth of research into this issue. The sensitivities around 'race' research, coupled with the need for a sensitive approach when using language and terminology to access and explore the experiences of this group of children and their families, proved a mental, and psychological, as well as practical challenge, in ways that I was unable to anticipate.

The results from this study, it is hoped, will help give clearer direction for social care, health, and education professionals working with this group, on where to focus future efforts in better meeting the supportive care needs of parent carers

of BME children with LLCs. It provides insights into their lived experiences and sheds light on the support needs, and available resources in both formal and informal networks. It also provides insights into the experiences and beliefs of professionals working with BME families, and help identify any particular challenges or needs they identify. It will identify ways in which organisations wanting to effectively engage with BME families could improve or build their capacity. Examples of good practice adopted by professionals and organisations are also highlighted.

Chapter 2 Literature review

2.1. Introduction

It is recognised that disabled people can face oppression and discrimination in a society which marginalises those who are different. There is evidence that families living with an impairment face social exclusion, inadequate services and stigmatising attitudes (Home, 2002). In the case of BME disabled groups, there potentially is an additional layer of vulnerability due to additional barriers (Brown, et al. 2013; Funk, et al. 2010; Bywaters, et al. 2003; Dilworth-Anderson, et al. 2002).

The experiences of BME parent carers are unlikely to be unique; nor generic. Inevitably there will be shared experiences of being a parent carer of a disabled child (or child with LLCs) irrespective of ethnicity. Families caring for a disabled child may require additional support in order to manage their situation and the wide-ranging responsibilities and complexities they encounter in their role as parent carers. This chapter will review literature on the topic of parent carers of disabled children (a broader group than my qualitative sample). It will provide a general overview of some of the issues faced by this group of families, and highlight ethnic differences where they arise. Due to the complexity of caring for a disabled child, or child with LLCs, there are a wide range of issues, agencies, and professionals likely to be involved in the care and support of the child and their family.

2.1.1. Literature review search strategy

In order to explore the academic research and discourse on the topic of BME disabled children and children with LLCs, a search of relevant literature was undertaken. Due to the paucity of research in this area, I was unable to narrowly focus only on parent carers of BME children with LLCs; the literature would have been almost non-existent. I therefore had to broaden the search criteria such as the inclusion of literature regarding disabled children, and research with parent carers, irrespective of ethnicity. The rationale for this is that some aspects of care giving are going to be shared with other parents, irrespective of 'race' or ethnicity. The topic of disabled children and children with LLCs crosses disciplines such as social work, health, and education, and therefore it was important to ensure I searched on databases relevant to these disciplines across the social sciences. As there was little literature specifically focusing on the topic of BME children with LLCs, I used a strategy of citation tracing, whereby I identified key texts and sources and then used the references/bibliographies of these texts to lead to other sources. Undertaking a search for relevant literature was not a one stage process. An initial search was undertaken at the start of the PhD. The literature review was then revisited in light of emergent findings. Some of the themes which came through the interviews, for example the theme regarding diagnosis, were unexpected and therefore there was a need to look at the literature on this topic, as often happens with qualitative research.

Due to the dynamic nature of language and terminology it was important to use a range of key search terms which encompassed a broad range of relevant language and terminology. For example, to address the 'race' and ethnicity element, key words used as search terms included: black and minority ethnic, BME, BAME, black, ethnicity, 'race', ethnic minorities, minority ethnic, anti-racist practice, anti-oppressive practice, anti-discriminatory practice, critical race theory, and intersectionality. In terms of finding literature on children with LLCs, key words searched for included: life-limiting conditions, life-threatening conditions, disabled children, children with complex needs, palliative care, hospice care, children, young people, end of life care, and parent carers. The parameters regarding dates were placed from 1950 to the present. Reasons for the 1950s start date included the fact that significant numbers of immigrants from former British colonies began to arrive in the UK, which is where my own study is located, during the 1950s, 1960s, and 1970s (Small and Solomos, 2006). Also, Britain's first Race Relations Act was passed in 1965, outlawing racial discrimination (Thomas, 2000), which most likely would have impacted on the way services were delivered or expected to be delivered.

Key literature was identified using the Cardiff University web-based library search facility, as well as that of the University of South Wales. The Cardiff University LibrarySearch provided access to journal articles as well as books. Some grey literature was also included in this thesis, as a result of additional web searches. I met with school librarians to identify relevant databases, and to set

alerts for new publications. Relevant databases included ASSIA (Applied Social Sciences Index and Abstracts). This was a particularly useful database as it provided references and summaries of articles covering: social services, social work, sociology, education, and health. The Cumulative Index to Nursing & Allied Health Literature (CINAHL) was also used, as this provided coverage of virtually all English-language nursing and allied health publications along with the publications of the American Nurses Association and the National League for Nursing. Other databases included PubMed, Scopus, WileyOnline, and Web of Science.

I also utilised the web-based academic search engine Google Scholar and set alerts in relation to the key search terms. Google Scholar is a free academic web search engine that indexes scholarly literature across a wide array of disciplines, document types and languages (Ortega, 2014). Martin-Martin, et al. (2017) consider Google Scholar to be acceptable and a credible alternative to traditional academic databases. As well as the above, I followed relevant academics on Twitter, who tweeted links to research articles on the topics. The majority of literature cited is from the UK or USA. Ideally, I would have preferred to have used studies based in the UK, because of the UK's unique social context. However, there were insufficient studies to completely limit this to the UK, so I also had to consider studies from other countries. It needs to be acknowledged, however, that there are challenges to finding cross-national research on 'race' and ethnicity issues that genuinely provide opportunities for comparison (Aspinall, 2007). Ethnic identity, ethnic classification systems, the groupings that compose each system and the implications of assignment to one or another

ethnic category are place, time- and context-specific (Ford and Harawa, 2010). The rationale was that publications would be in the English language; also, the UK and USA have contributed a significant proportion to 'race' research. They apply similar concepts and terms relating to ethnicity and 'race' (Aspinall, 2007). Preference was given to the most relevant publications (based on some of the aforementioned criteria). No study was automatically excluded on the basis of where it was geographically located. Instead it was critiqued to see what value each study could add to this research, in terms of comparing similar issues and associated experiences. Once relevant papers were identified, a scholarly critique and review was undertaken of the retrieved literature. Reviews can be an important and valuable contribution to a study, as well as providing the reader with context and relevant evidence (Kable, Pich, and Maslin-Prothero, 2012). As I am essentially conducting a qualitative study, exploring the experiences of parent carers, I was more drawn to and interested in looking at qualitative studies.

2.1.2. Chapter overview

I will start by discussing the highly specialised language, terminology, and labels used in relation to children with LLCs, in order to clarify meanings. An overview of some demographics in relation to ethnicity, languages spoken, and religion, prevalence of disability and LLCs will also be presented. This will be followed by identifying some of the issues faced by parent carers of disabled children – what is the parental experience of caring, and are there ethnic variances? This will help highlight issues pertinent to this group and help to identify the type of support

families may benefit from. Theories that underpin and inform the study are also referred to; the two main theories being anti-racism and Bronfenbrenner's (1979) ecological systems theory. Anti-racism will include reference to 'race' and disability discrimination, microaggressions, ethnic and 'racial' stereotyping, critical race theory, and intersectionality. I will refer to anti-racist social work practice. I also briefly refer to the medical and social models of disability. This study takes an approach aligned to the social model of disability.

The inclusion of education was considered relevant as disabled children spend a significant amount of time in special schools, often accessing a range of additional services at school such as speech therapy, physiotherapy, occupational therapy, drop-in sessions with paediatricians, amongst others. Their parent carers also can access a range of additional services and support from staff based in special schools. They can be a one-stop hub of support, and work very closely with families. They are a universal service, and therefore may be more likely to encounter parent carers who may otherwise be 'hard to reach'. This thesis draws attention to the fact that parent carers of children with LLCs may face many of the same issues. It is not the intention of this thesis to exclude or minimise the experiences of any group, nor to deny that identities are plural and fluid. However, there are likely to be some variations in their experiences, for a range of different reasons. Families with a disabled child from BME groups are more likely than comparable white families to experience considerable inequality, discrimination and disadvantage relating to work, education, housing, transport and social services (Broomfield and Dodd, 2004; Hatton et al, 2004).

On initial searches of the literature, it transpired that the range of potential topics to explore was wide ranging. Addressing all these issues was beyond the scope of this study. Focus has been narrowed to those topics which relate closely to the issue of support systems for disabled children and children with LLCs and their families. Any future research could focus on elements not included here.

2.2. <u>Language and terminology</u>

As researchers we have a responsibility to ensure we clearly define and describe our study population and the terms we use in relation to them (Bhopal and Donaldson, 1998). This has proven to be a challenge both in relation to disability (Bishop, 2017), as well as 'race' and ethnicity (Smithson, Ralphs, and Williams, 2013). In order to discuss issues pertaining to the families of BME children with LLCs, it is important to clarify and contextualise the language and terminology applied. The use of terminology that is precisely defined and acceptable to those being described is encouraged (Aspinall and Jacobson, 2007). There can be frequent use of highly specialised jargon and complex terms with more than one interpretation attached, often without definition. The terms and labels I will be clarifying are in relation to 'race' and ethnicity; the different terms in relation to children with LLCs; and the language around palliative care. However, establishing universally acceptable labels and terminology is a challenge, as terms are constantly evolving and developing.

2.2.1. 'Race' and ethnicity

When referring to Britain's ethnically diverse populations a number of different terms are used, often interchangeably and inconsistently (Thoburn et al. 2005). These labels include: 'Black Asian and Minority Ethnic (BAME) groups' (Calzani, et al. 2013), 'minority ethnic groups' (Kelly & Kelly, 2013; Evans, et al. 2011, 'ethnic minority groups', and 'minority groups' (Worth, 2009). The term 'race' is usually placed within inverted commas by social scientists. This is to highlight the fact that 'race' is a socially constructed concept, which is not based on any biologically valid distinctions between the genetic make-up of differently identified 'races' (Dominelli, 2018; Machery and Faucher, 2005).

Defining terms relating to 'race' and ethnicity is problematic, and the challenges are compounded by the pace of social change (Bhopal, 2004). For the purposes of this research, BME (black and minority ethnic) will be defined as: any group other than white British. This definition could in theory include white (non-British) Europeans, but in fact this has not proven relevant, as all parent carers interviewed in my study are people of colour. The term 'race' will be presented in quotes to signify the fact that this is a socially constructed concept. BME does not imply this is a homogenous group as there will be diversity within it (Phillimore, 2011).

2.2.2. Language of disability

Several terms are used when referring to children who are diagnosed with conditions which may result in their lives being shortened. These include: "life-limiting conditions" (Noyes, 2013; Huang, 2010), "life-limiting illnesses" (Sale, 2009), "children suffering from life-limiting diseases" (Junger, et al. 2010), "life-threatened or life-limited child" (Brown, et al., 2013), and "terminally ill patients" (Proot, et al., 2004). This can result in confusion. For example, often the term 'life-threatening' is used interchangeably with the term 'life-limiting conditions', even though they do not have the same meaning (Noyes, et al., 2013). 'Terminal illnesses' is also a term used when referring to children with LLCs. This is also the case in relation to children diagnosed with cancer. The Welsh Government's policy in relation to end of life care for adults and children, *Palliative and End of Life Care Delivery Plan* (2017) uses the term 'life-limiting condition'. The UK's leading children's palliative care charity Together for Short Lives, uses the term 'life-limiting condition' when referring to seriously ill children, as do many of the children's hospices in Wales and England. For the purposes of this research, the term life-limiting condition (LLC) will be adopted. The term life-limiting condition is defined as: "Diseases with no reasonable hope of cure that will ultimately be fatal" (Fraser, et al. 2012, p.923). In relation to children, this term encompasses both non-malignant and malignant conditions (Noyes, et al. 2013).

2.2.3. Palliative care and end of life care

Other terms which frequently emerge in relation to children with LLCs are end of life care and palliative care. These are often used interchangeably, but are distinct terms and have different meanings. According to Gaffin, Hill, and Penso (1996, p.51):

"*Palliative care is the active total care of patients whose disease no longer responds to curative treatment. It focuses on controlling pain and other symptoms and is concerned with the quality of life remaining, integrating the psychological and spiritual aspects of care and offering support to families during the patient's illness and into their bereavement*", Gaffin, Hill, and Penso (1996, p.51).

With children, it is often difficult to establish when it is the end of life, therefore palliative care services can be accessed over a long term, rather than just the short term, as is the case with adults. The caring role for some parents can span many years and involve a heavy commitment (Pelentov, et al. 2016). Due to the uncertainty surrounding a child's illness trajectory, palliative care is often combined with treatments which are cure oriented (Noyes, et al., 2013). Palliative care services can be provided by multi-disciplinary teams based in children's hospices. Referral to a children's hospice for palliative care services tend to generally be through GPs and hospital consultants (Gaffin, Hill, and Penso, 1996). According to Norman and Fraser (2014):

"*Children's palliative care is concerned with the treatment of children with 'life-limiting' or 'life-threatening' conditions and aims to maintain and improve quality of life in the weeks, months and years before death not just in the dying stages*" Norman and Fraser (2014, p.4).

2.3. Demographics in relation to BME populations of Wales and England, and prevalence of Disability and LLCs amongst children

In order to explore the support and service needs of this population, and to set context, the next section will look at demographic information regarding BME groups in England and Wales, as well as numbers of disabled children and children with LLCs. This general picture is important to note as the demographic context to the more specific minority (BME) within a minority (children with LLCs), which is the focus of my study. I will start by looking at BME groups in general as part of the population in Wales and England, and then look at demographics in relation to children and their impairments and explore ethnic variance. Data from the Census (2011) and Office of National Statistics (2013) will be presented, to establish the presence of BME groups, languages spoken, and religious beliefs. Knowledge of demographic profiles of this population may assist in planning future service provision.

2.3.1. Ethnicity (Wales and England)

According to the Office for National Statistics (2013), the total population of England and Wales was 56.1 million, and 86.0% of the population was white. England and Wales have become more ethnically diverse with rising numbers of people identifying with BME groups in 2011. Despite the White ethnic group decreasing in size, it is still the ethnic group that the majority of people identify with. London was found to be the most ethnically diverse area, while Wales was the least diverse. The following are the most common ethnicities in Wales: White

(93.2%), Indian or British Indian (0.6%), Polish (0.5%), Irish (0.5%), Chinese (0.5%), African (0.4%), Pakistani or British Pakistani (0.4%), White and Black Caribbean (0.4%), Bangladeshi, or British Bangladeshi (0.3%), Arab (0.3%), Other Western European (0.3%), White and Asian (0.3%), European Mixed (0.2%), Other White (0.2%), Filipino (0.2%), All other ethnicities (1.6%). The focus on Wales is due to the research funders having a particular interest in Welsh services. Initially I planned to recruit participants from Wales, before expanding to England as well. The most common ethnicities, in England (slightly different from Wales) are (in order of size): White British (largest group), Indian, Pakistani, African Caribbean, Irish, Polish, and Bangladeshi (smallest group).

2.3.2. Languages spoken

Data on languages and the locations and age groups of speakers are of interest to local authorities and service providers. Evidence on language diversity can provide an indication of community language skills, which can be of wider interest to economic planning. Lack of English language skills may also prove to be a barrier to accessing formal support services. Up-to-date and accurate information about languages spoken may also assist services to plan and budget for the use of interpreters in the appropriate languages and dialects.

In terms of languages spoken, over 9 in 10 people in England and Wales reported English (English or Welsh in Wales) as their main language in March 2011 (Office for National Statistics, 2013). Of those with a main language other than English

or Welsh (three per cent, 84,000), 77 per cent (65,000) could speak English or Welsh very well or well (Office for National Statistics, 2013). Of the many languages other than English, the largest by far is Polish, listed as the main language by 13% of the 4.2 million people who reported a non-English language. The second and third largest non-English main languages are Punjabi and Urdu at 6.6% and 6.5% respectively.

2.3.3. Religion

In terms of religion, despite falling numbers, Christianity remains the largest religion in England and Wales in 2011. Muslims are the next biggest religious group and have grown in the last decade. Meanwhile the proportion of the population who reported they have no religion has now reached a quarter of the population (Office for National Statistics, 2012). The main religions of England and Wales were found to be Christianity (59%) of the population, followed by Muslims (5%). The proportion of people who reported that they did not have a religion reached a quarter of the population. Religion is an important topic to include as religious beliefs may influence the needs and context of caregiving, with an impact on service uptake (Giunta, et al. 2004). It has also been cited as a potential barrier to service usage by BME groups (Bywaters, et al. 2003). This study used semi-structured interviews, undertaken between 1999 and 2001, specifically with 19 Pakistani and Bangladeshi families with a disabled child. The focus appeared to be on Muslim families alone. We also know from survey data that religion tends to be more significant in the lives of BME people than white people (Crockett and Voas, 2006). However, this survey measured religiosity in

relation to attendance at places of worship, rather than exploring religious beliefs of BME families in relation to care-giving roles.

2.3.4. Prevalence of disability / LLCs amongst children

Robust data on the prevalence of childhood disability and the circumstances and characteristics of disabled children is fundamental to understanding the relationship between impairment and social disadvantage. It is also essential for developing public policy which aims to reduce the prevalence of childhood disability and providing appropriate support services.   However, there are challenges to finding reliable data on disabled children, for a number of reasons. Blackburn, Spencer, and Read (2010) refer to theoretical, philosophical and technical issues. The multi-dimensional, dynamic, and contested nature of disability are also said to contribute to the difficulties of establishing accurate prevalence rates (Bajekal, et al. 2004). In a study undertaken by Blackburn, Spencer and Read (2010), using survey data, they found that 7.3% of UK children were disabled. In their study, data were generated from secondary analysis of the Family Resources Survey, a national UK cross-sectional survey, (2004/5) which had data on 16,012 children aged 0-18 years. Blackburn, Spencer and Read (2010) advocate for further research to establish accurate prevalence estimates of childhood disability among different BME ethnic groups.

There are few data available to estimate numbers of children with LLCs. However, it appears that numbers of children with LLCs are growing (Fraser, et al. 2014). This study undertook secondary analysis of the English Hospital Episode Statistics dataset (2009/20), in relation to 92,129 individual patients, limited to England only. It includes individuals aged 0–40 years with LLCs, also incorporating data from an older age group than the focus of my study. Worldwide statistics indicate that approximately 63 out of 100,000 children will require palliative care at the end of life (Adistie, et al. 2019). Each year, approximately 300,000 children are diagnosed with hemato-oncological diseases worldwide (WHO, 2018). In the UK, statistics for 2014-16 show that there are around 1,900 new cancer cases in children every year; approximately 5 every day (Cancer Research UK). The growing numbers could be due to a number of factors including advances in health care, resulting in improved survival rates amongst children (Burns, et al. 2010).   Mooney-Doyle, Keim-Malpass, and Lindley (2019) estimate that in the United States, over 40,000 children die annually, the majority of who have LLCs. However, ethnicity data and differences between ethnic groups were not addressed in this study.

In terms of learning disabilities, according to Mencap (2018), there are approximately 351,000 children aged 0-17 with a learning disability in the UK. Ethnicity data is lacking.

<u>Ethnic variations</u>

Several datasets were explored, to establish ethnic variance in terms of prevalence of disability and LLCs. However, there were issues trying to obtain the data required in terms of both ethnicity and disability. I looked to Understanding Society, and the Health Survey for England, but was unable to obtain the necessary information. The explanation provided by the Office for National Statistics for the lack of such data was issues regarding 'small numbers'. A further UK dataset considered was the Millennium Cohort Study. This dataset contains data regarding children, ethnicity, and long-standing illnesses, but not LLCs. It is for this reason that Chapter 4 focuses on children with long-standing illnesses, rather than children with LLCs. This issue is discussed further in Chapter 4.

Blackburn, Spencer, and Read (2010), in their study, used the Family Resources Survey and found that there was ethnic variance in terms of child disability. They found that the group with the highest prevalence of childhood disability was the 'Mixed Parentage' category (9.5%), White UK/Other was the next group with the highest prevalence rates (7.6%), followed by Black or Black British (7.1%), Pakistani and Bangladeshi (5.1%), Other ethnic group (4.4%), and Indian (2.7%). Fraser et al. (2012) found that BME groups had higher rates of prevalence of LLCs amongst children. The highest prevalence was found to be in the South Asian category (48 per 10,000, compared to 27 per 10,000 in the white population). The black category had 42 per 10,000, and Chinese, mixed, and 'other' had 31 per 10,000. Their study made links between prevalence and

deprived areas; they found that the highest prevalence was in the most deprived

areas, and the lowest in the second least deprived areas. The differences below

were statistically significant. The Fraser, et al. (2012) study referred to the

importance of planning for the excess prevalence amongst BME groups, in

particular in areas of deprivation. This study focused on 175 286 children (0–19

years) with LLCs, identified within the English Hospital Episode Statistics dataset

(2000/2001–2009/2010). Although it contains ethnicity data, it is limited England.

Ethnicity	Prevalence (per 10,000)
White	27
South Asian	48
Black	42
Chinese, 'mixed', 'other'	31

Table 2.1. Ethnicity and prevalence of LLCs

 In terms of ethnicity and health inequalities, large scale surveys like the Health

Survey for England show that BME groups as a whole are more likely to report ill

health, and that ill health among BME groups starts at a younger age then in

white groups (Parliamentary Office of Science and Technology, 2007). Emerson

(2012) undertook a cross-sectional study involving multilevel multivariate

analyses of data extracted from educational records on household disadvantage,

local area deprivation, ethnicity and identified intellectual and developmental

disability in a sample of English children aged 7-15 years (n=5.18 million). They found that minority ethnic status was, in general, associated with lower rates of identification of intellectual and developmental disabilities. Exceptions to this general pattern included higher rates of identification of less severe forms of intellectual disability among Gypsy/Romany and Traveller children of Irish heritage, and higher rates of identification of more severe forms of intellectual disability among Pakistani and Bangladeshi children. This study focused on a group different from my study (children with learning disabilities), whereas my study focuses on children with LLCs. It also is England specific, and looked at a narrow ages group of children aged 7-15 years only. A Public Health England (2016) report, based on pupil-level data collected via the school census, found the identification of Special Educational Needs associated with learning disabilities differed considerably between ethnic groups, with identification rates 25% or more above the national average recorded among the following ethnic groups: Gypsy Traveller, Pakistani, Bangladeshi, 'other' Asian, black Caribbean, black African, 'other' black, and 'other' 'mixed' heritage. It is worth noting that BME families, in comparison to white families, are less likely to report their child's impairment (Contact a Family, 2006). This could result in underestimates of numbers of BME disabled children. However, figures regarding numbers of BME children with LLCs may be more reliable as they are more likely to be accessing a range of universal services linked to their child's condition (e.g. medical and paediatric services). This lack of ethnicity, and child disability data appears to be a limitation of the literature.

Section Conclusion

What the above data show us is that the BME population of England and Wales is growing. There is diversity in terms of ethnicity, religious beliefs and languages spoken. There is also evidence of growing numbers of children with LLCs; and more children with LLCs from BME groups (Fraser, et al. 2012). Calls have been made for further research to establish accurate prevalence estimates of childhood disability and LLCs among different BME groups (Blackburn, Spencer, and Read, 2010; Fraser, et al. 2012). These factors will have implications for commissioners and providers of social care, health, and education services, including hospices. Hospitals that care for children with LLCs should consider clinical and training programmes focused on this increasing proportion of their population (Burns, et al. 2010).

2.4. <u>Parental caring experience</u>

The following section will address issues for all parents of disabled children and children with LLCs, and in places highlight those particular to BME parents.

2.4.1. Issues faced by parent carers

There have been significant developments in policy and practice for disabled children and their families. Despite this, many disabled children and their families continue to experience discrimination, poverty and social exclusion (Russell,

2003). Families caring for disabled children face particular challenges and demands compared to those caring for children without impairments (Isa, et al. 2016). To access services, they may encounter barriers, irrespective of ethnic group. These could include attitudinal barriers such as not wanting to involve outsiders or not seeing the need for services and practical barriers such as low awareness of services and service availability (Greenwood, et al. 2015). Midson and Carter (2010) conducted a survey of 28 parents whose child had died in a children's tertiary treatment centre (Great Ormand Street Hospital), and found that issues that parents (irrespective of ethnicity) were concerned about included lack of a place for privacy, or to be alone. Recurrent themes regarding the experience of being a parent carer include social isolation (Pelentsov, 2016; Whiting, 2012), negative impact on parental health and well-being, including a negative impact on parents' relationship (Da Silva, Jacob, and Nascimento, 2010; Contact a Family, 2004), work and financial issues and concerns (Cadell, et al. 2014), poor quality experiences of accessing services (Yannamani, et al. 2009; Sardi, et al. 2008). On-going stress and worry have been reported as a predominant experience for some parent carers (Buckloh et al. 2008). The caregiving experience involves a complex web of biological, physical and psychosocial aspects. Barriers common to all groups should not be underestimated and a better understanding of the relationship between perceived barriers to accessing services and dissatisfaction with services is needed before the experiences of all carers can be improved (Rifshana, et al. 2017). Issues specific to BME groups include language barriers and concerns about services' cultural or religious appropriateness. Studies investigating satisfaction with services reported a mixture of satisfaction and dissatisfaction.

A review of the academic discourse highlights some of the issues faced by families of disabled children. These include (but are not limited to) the following topics below.

2.4.1.1. Impact of caring on parental physical and mental health

It is important to note that although the literature regarding parent carers focuses on the negative aspects of caring, there is a small and emerging body of literature examining positive outcomes for parent carers (Kearney and Griffin, 2001; Stainton and Besser, 1998). However, it is worth noting that the Kearney and Griffin's (2001) study, involved qualitative in-depth interviews with six parents of children with developmental disabilities. The experiences may be different for parents of children with LLCs. Despite additional caring demands on this group of parents, it is worth noting the perspective of the social model of disability, which would argue that it is not so much the caring per se which is the issue, but the fact that as a society we are not equipped to meet the requirements of disabled people, which cause and contribute to the challenges faced by disabled groups (Milner and Kelly, 2009).

Over time, the meaning of disability has been understood in a variety of ways. The way in which disability is understood is important because the language people use to describe disabled individuals can influence their expectations and interactions with them (Haegele and Hodge, 2016). The medical and social models have been the two prominent models of disability discourse. According to

Oliver (2013, p.1024), the social model of disability, "argued that we were not disabled by our impairments but by the disabling barriers we faced in society". The medical model views disability as a medical phenomenon that results in limited functioning that is seen as deficient (Fitzgerald, 2005; Mitra, 2006; Palmer & Harley, 2012). Disability is defined, according to the social model as "a social construct that is imposed on top of impairments by society; a difference"; and according to the medical model as "an individual or medical phenomenon that results from impairments in body functions or structures; a deficiency or abnormality" (Haegele and Hodge, 2016, p. 194).

Which model is adopted is relevant, as interventions for disabled people are influenced by the approach taken. From a disability rights perspective, social model approaches are progressive, and medical model approaches are considered reactionary (Shakespeare, 2006). A growing number of scholars in Disability Studies have begun to critique the social model of disability. One critique of the social model is that it fails to address impairment as an observable attribute of an individual that is an essential aspect of their lived experience (Palmer & Harley, 2012). It has also been suggested that the social model ignores the intersectionality of different forms of oppression (Fitzgerald, 2005). The use of the social model of disability, to guide both research theory and practice, is advocated to equalise research power relationships, and involve and empower disabled people (Bricher, 2000). For the purposes of this study, I will be using the social model of disability, informed by the critiques of its usage, as mentioned above.

Parent carers of disabled children are considered at greater risk of poor health (Vonneilich, Ludecke, and Kofahl, 2016). Caregiving demands contributed directly to both the psychological and the physical health of the caregivers (Raina, et al., 2005). The study undertaken by Raina et al. (2005) included data on demographic variables and caregivers' physical and psychological health. They used standardised, self-completed parent questionnaires, as well as face-to-face home interviews with 468 carers of children with cerebral palsy. Ethnicity data are not provided in relation to participants. Parents of children with chronic illness have reported decreased psychological and physical quality of life, relative to parents of children without such illness, which may be associated with the extent of complexity involved in the caregiving role (Fairfax, et al. 2019). The Fairfax, et al. (2019) research was a systematic review of the association between coping strategies and quality of life among caregivers of disabled children and children with chronic illnesses. The review was based on 11 studies, addressing 5 diseases and a total of 2155 caregivers.

2.4.1.2. Impact on immediate family relationships

The pressures and stresses of caring for a disabled child can impact on relationships with other members of the family (Reichman, et al. 2008). The symbiotic nature of family life means that what impacts on one member of the family will also impact on others (Brown and Warr, 2007). Being the sibling of a disabled child can impact negatively on the psychosocial health of non-disabled

siblings (Hartling, et al. 2014). However, there are also positive aspects of caring for siblings (see Chapter 4). Parents can worry about the siblings, expressing feelings of guilt (Pelentsov, et al. 2016). Children and families living with rare disease often experience significant health, psychosocial, and economic burdens (Zurynski, et al. 2017). The Zurynski, et al. (2017) study collected Australian survey data in relation to 462 children living with rare diseases, aged 19 years and under.

2.4.1.3. Social isolation and insufficient support

Disabled children and their families face a high risk of social exclusion if they do not receive appropriate multi-agency support (Russell, 2003). As discussed above, caring responsibilities can impact on the health of parent carers; parent carers' health has been shown to improve as a result of support or respite, particularly during periods of high stress (Cantwell, Muldoon, and Gallagher, 2014). Without support from essential services, parents may feel they have little control over their situation, leading to feelings of loss of control, hopelessness or despondency (van den Borne et al. 1999). The van den Borne, et al. (1999) Dutch study was with parents of children aged 0-12 years with either Prader-Willi syndrome or Angelman syndrome, neither of which are LLCs. This was a cross-sectional study that utilised a self-report questionnaire with a total of 56 families.

2.4.1.4. Financial challenges

Disability and poverty have a complex and interdependent relationship. It is commonly understood that disabled people are more likely to be poor and that

poverty may contribute to sustaining disability (Trani and Loeb, 2012). Families of disabled children can incur considerable additional expenditure on heating, housing, clothing, equipment, and other items. In the UK, disabled children experience higher levels of poverty and personal and social disadvantage than other children (Blackburn, Spencer, and Read, 2010). Families of disabled children face greater financial burdens than families who have non-disabled children (Xiong et al. 2011). Providing the basic necessities can be costly and place financial pressure on parents (Isa, et al. 2016). As well as providing financial benefits, work can also provide additional advantages such as social support (Li, Shaffer, and Bagger, 2015). Parents caring for a child with an LLC have fewer opportunities to work; despite the availability of disability benefits, the complexity of the system can result in challenges in accessing these (Brown and Warr, 2007). Gupta, Featherstone, and White (2019) draw attention to changes in the welfare benefits system resulting in greater challenges for families of disabled children. Fraser, et al. (2012) found in their study that the highest rates of prevalence of children with LLCs were amongst those living in the most deprived areas of England.

2.4.1.5. Delays in identification and diagnosis

Research shows that the manner in which parents are informed about their child's diagnosis affects both the way in which they adjust to the situation and the well-being of their child (Brown and Warr, 2007). This process has the potential to take on added complexity when one or both parents does not speak English. Rapid diagnosis and treatment of cancers is a UK government priority. However, the

process of arriving at a diagnosis of childhood cancer has been neglected in comparison with the attention given to cancers in adults (Dixon-Woods, et al. 2001). Parents of children living with rare chronic and complex diseases have called for better education, resourcing of health professionals to prevent avoidable diagnostic delays, and to facilitate access to early interventions and treatments.

Breaking bad news is a difficult challenge for all – both for those giving the news, and those receiving it (Bartolo, 2002). Boyd (2002, p. 14), a study of mothers of children with autism, refers to the moment of diagnosis as "A crisis event", which a family never forgets. Access to psychological support and genetic counselling should be available to all parents receiving a life-changing diagnosis for their child (Zurynski, et al. 2017). Haimi, et al. (2011) believe that delayed diagnosis may affect survival rates, and that the education and awareness of medical staff needs improving in order to prevent such delays.

2.4.2. Service usage amongst carers of disabled children and ethnic variance

Evidence suggests that carers from all sections of the community, and particularly carers from BME groups, often fail to access care services (Funk, et al. 2010; Brodaty et al. 2005; Dunlop, et al. 2002). There could be many reasons for this, such as potentially services not being needed by some families and barriers to accessing services, but it could also be a sign of service dissatisfaction

(Chadwick, et al. 2013). Potential barriers, for BME families, were identified at three levels: patient level, provider level, and system level (Scheppers, et al. 2006). The study by Scheppers, et al. (2006), undertook a literature review of 54 articles published between 1990 to 2003, aiming to identify potential barriers and factors which may restrict BME patients from using health services. The research did not differentiate between adults and children, and focused on generic health services rather than support services for parent carers of disabled children or children with LLCs. One explanation for poor engagement with formal support services is that people may lack knowledge of services available to them (Funk, et al., 2010). The implication is that services are hard to reach. BME groups experience some of the same barriers as white (majority ethnic) groups. However, they are more likely to experience issues regarding both ill health and poverty (Modood, et al.1997). Language differences and cultural appropriateness of services may influence service uptake (Williams and Johnson, 2010). Poverty and inequality (Ahmad and Atkin, 1996), and racism (Katbamna, et al. 2004) may add to their disadvantage. Ethnic disparity and difference in terms of service usage can affect a number of areas. BME families, in comparison to white families, are less likely to access services and disability benefits (Contact a Family, 2006).

Low service use by BME groups continues to be part of the academic discourse (Greenwood, et al., 2015; Szczepura, 2005). Reference is made to the under-representation of BME groups in relation to the supportive elements of social care services; however, there is an over-representation of some BME groups in statutory and 'controlling' aspects of social care such as BME children in the care

system (Butt and Box, 1998). The literature highlights certain ethnic and 'racial' stereotypes and beliefs held by professionals regarding the needs of BME service users in relation to formal services which include the belief of greater availability of informal support for this group (Atkin and Rollings, 1996, Chevannes, 2002, Bhui, et al., 2012). Low service use by BME families is often attributed to cultural and religious barriers (Bywaters, et al. 2003; Giunta et al.2004; Ahmed and Rees-Jones 2008).

Brodaty et al. (2005) identified four main reasons for low take-up of formal support from their literature review, which developed a typography of the experiences of caregivers of people with dementia (irrespective of ethnicity). These were: services not perceived as needed (carers felt that they already had adequate support); reluctance to use services (caring was viewed as their role or duty); service characteristics (carers may want to use services but cannot because of factors such as cost or low availability); and lack of information about services. Yeandle et al. (2007) reported that in the UK, BME carers were more likely to say that they were not aware of services, that services were insensitive to their needs and that their use of services was restricted by lack of information, cost, and lack of flexibility. This study collected data from a questionnaire survey of carers (n=1,909) in England, Scotland and Wales and interviews with a sub-sample of 134 carers.

However, it is important to note that not all families who may be entitled to formal support services will necessarily want them, and some may choose not to engage

(Chand and Thoburn, 2005). Due to the additional barriers faced by the families of severely disabled children, children with LLCs, BME disabled children, and BME children with LLCs, it is likely that these families may experience even greater barriers to accessing formal services. Current models of service provision in social care, health and education need to review their approaches to take account of diverse groups in society and to meet their needs adequately (Phillimore, 2011).

Section conclusion

Generally speaking, families want good quality services for themselves and their children (Yannamani, et al. 2009). However, inevitably there will be some variance in terms of needs. Information regarding available services should be given to all families, irrespective of ethnicity, to ensure that all families have a choice of whether or not to engage with formal services. Ethnic stereotypes and assumptions should be avoided to ensure equity of access to formal support services. Families who are caring for disabled children are found to 'do well' where there is high social support and low financial hardship (McConnell, Savage, and Breitkreuz, 2014).

2.5. <u>Theories underpinning the research</u>

Within the field of social work, it has long been a convention for 'borrowing' knowledge from disciplines such as sociology, psychology, philosophy, and criminology, amongst others. In order to develop an appropriate intervention strategy for a particular client / service user, it is important to consider the individual in relation to a larger social context (Friedman and Allen, 2011). Application of theory helps us understand and contest ideas, to help solve problems. It can offer practice frameworks that organise ideas and research to provide guidance regarding complex situations. Theory also assists us in being accountable, because we can justify what we do.

The two main theories I will refer to below are Bronfenbrenner's ecological systems theory and anti-racism. These theories are appropriate to this study due to the fact that the two main themes of the study are about working with BME families and also looking at family support systems. Application of these theories may assist professionals undertaking assessments, mapping informal sources of support, and formulating strategies for intervention, when working with the families of BME children with LLCs.

2.5.1. Anti-racism

The debate on 'race' and 'racism' has a substantial history in social work (Dutt, in Cull and Roche, 2001). Issues discussed and debated include the following:

human rights, equality of opportunity, anti-discriminatory practice, empowerment, identity, diversity, and difference. Anti-racism and anti-racist social work are integral within the general concepts of anti-discriminatory and anti-oppressive practice in Britain (Coxshall, 2020). There is potential to strengthen anti-racism in social work practice, education and research, by making links to critical race theory (CRT). CRT emerged in the 1970s, in America. It was a response from writers such as Derrick Bell, Alan Freeman, and Richard Delgado, to the growing belief that new theories and strategies were needed to address subtle forms of racism that were emerging (Delgado and Stefanic, 2001). Proponents of CRT believe that it is a relevant theoretical framework for the field of social work (Daftary, 2018). CRT is seen as different from other theoretical frameworks in that not only does it advocate for the inclusion of marginalised voices, but it requires that action be taken to address issues of injustice exposed by research (Daftary, 2018). CRT includes an activist element which means in addition to trying to understand racism and its impact on society, it also includes strategies for addressing these issues (Delgado and Stefanic, 2001). Chapter 9 of this thesis includes implications for practice, incorporating specific recommendations for social work. Integrating elements of CRT to social work practice, research and education, provides an opportunity to reinforce the profession's commitment to social justice (Kolivoski, et al., 2014).

The rationale for utilising the term 'anti-racism' in this thesis, rather than a stronger focus on CRT alone, is simply that anti-racism is a more familiar term in my own field of social work. CRT is less well known and has been applied primarily to teaching, rather than being commonly used as a framework for

research studies (Daftary, 2018). Although seen as compatible with social work education, due to its emphasis on intersectionality, CRT has been criticised for not providing recommendations on how this issue could be specifically addressed in practice (Constance-Huggins, 2012). CRT is emerging as a framework for research and teaching, but is not yet a common framework for social work research (Daftary, 2018). Although it aligns with social work values, it has not been fully accepted by social work researchers, practitioners, or educators (Kolivoski, et al., 2014).

This section will focus on two aspects of anti-racist practice: intersectionality and micro-aggressions. Both CRT and anti-racism will be referred to in relation to these concepts. Intersectionality explores the interplay between overlapping and conflicting identities (Delgado and Stefanic, 2001). The rationale for the focus on micro-aggressions is because discrimination has evolved, influenced by a number of factors including changes in legislation and social policy, can manifest itself in a manner which is not situated in the historic view of overt racism. It can be much more subtle and covert, which the concept of micro-aggressions acknowledges. Greenland, et al. (2018) refer to the presence of two types of discrimination – hard vs, soft. 'Soft' discrimination is described as "Ignorance, inexperience, or an honest mistake" (Greenland, et al. 2018, p.547). Despite initiatives to address racism, and the progress made in this area, racism still manifests in aspects of modern life (Lilienfeld, 2017). Discrimination has evolved somewhat and can take much more subtle and complex forms. The justification for focusing on intersectionality is due to the fact that the families this research focuses on are at risk of discrimination on the basis of 'race' and disability.

2.5.1.1. Disadvantage and discrimination experienced by BME groups

Race and Disability discrimination

It has been argued that 'racial' and disability discrimination and inequality are issues of social justice and can undermine the quality of service to some groups in society (Walby and Armstrong, 2012). Social justice, equality and inclusion are complex and inter-linked concepts (Riddell, 2009). The presence of racism within social care institutions, structures and systems has significant implications and cannot be ignored. In line with CRT's commitment to social justice (Daftary, 2018), professionals working in health and social care settings are well positioned to address racism and its effects, due to their commitment to social justice (Kolivoski, et al., 2014). Despite a general consensus that discrimination is wrong, there are differences in opinion regarding what is or is not discrimination (Greenland, et al. 2018). In public services, open expressions of racism have largely disappeared in the UK, being replaced by what is referred to as 'covert racism', a concept associated with institutional racism (Holdaway and O'Neill, 2007). However, the political climate around Brexit has been seen as a means of almost legitimising overt expressions of racism. For example, Wilson (2016) believes that a negative Leave campaign that was fought largely on issues of immigration has seemingly given racism and anti-immigrant sentiment legitimacy. This is reinforced by Dominelli (2018) who states that dominant discourses in pre- and post-Brexit Britain have scapegoated 'immigrants'. However, for the purposes of this study, the context of racism being considered is primarily in public and third sector services. Advancing racial equality requires understanding

and awareness of the relationship between 'race', racism, and power (Kolivoski, et al., 2014).

The Equality Act 2010 refers to four types of discrimination: direct discrimination, indirect discrimination, harassment, and victimisation (Equality Act, 2010). There are nine protected characteristics. These include 'race' and disability (Equalities and Human Rights Commission). According to the Equality Act 2010, 'race' discrimination is when you are treated differently because of your 'race', in relation to a range of situations which include in the workplace, when coming into contact with public bodies like your local council or government departments, and when accessing public services. The Equality Act also covers disability discrimination, defined as situations where someone is treated less well or put at a disadvantage for a reason that relates to their disability, in one of the situations covered by the Equality Act. The treatment could be a one-off action, the application of a rule or policy or the existence of physical or communication barriers that make accessing something difficult or impossible. The discrimination does not have to be intentional to be unlawful. The Equality Act 2010 refers to six main types of disability discrimination: direct discrimination, indirect discrimination, failure to make reasonable adjustments, discrimination arising from disability harassment, and victimisation. Few researchers have examined the effects of the intersection of issues of 'race', culture, language, and disability (Blantchett, Klingner, and Harry, 2009).

Berman and Paradies (2010, p.216) discuss the complexity of what may or not be considered racism: "racism does not necessarily depend on ideological premises, does not have to involve prejudice or promote capitalist interests, and can be perpetrated by individuals from ethnoracial groups with limited social power". Modood, et al. (1997) note, "racism normally makes a linkage between a difference in physical appearance and a (perceived) difference in group attitudes and behaviour" (1997, p. 38). Dominelli (2002) speaks of the manner in which a dominant group can exclude minority groups through a process of 'othering'; where discussions are based on a binary approach, e.g. white/black, male/female, and where one group is perceived as being superior to the other, leading to practices which disadvantage certain groups in society. 'Othering' can have a negative impact on service delivery for diverse groups and exclude them and their needs.

Micro-aggressions

In Britain, it is against the law to discriminate against someone on the basis of their 'race'. However, how racism manifests itself in society has shifted. Micro-aggressions are one such example, and are typically defined as subtle snubs, slights, and insults directed toward minorities, as well as to women and other historically stigmatised groups, that implicitly communicate or at least engender hostility (Sue, et al. 2007; Trani and Loeb, 2010). Pierce (1970) coined the term microaggressions to refer to subtle insults and indignities that can collectively create a hostile atmosphere for minority individuals. Compared with overtly prejudicial comments and acts, they are commonly understood to reflect less

direct, although no less harmful, forms of racial bias (Lilienfeld, 2017). According to Kolivoski, et al. (2014), institutional racism is a form of covert racism, resulting in 'racial' disparities in terms of access to and experiences of formal support services. Microaggressions are one of the themes from CRT. CRT is an approach that offers a radical lens through which to make sense of, deconstruct and challenge racial inequality in society. It emerged through the discipline of Law, in the 1980s from American Law schools. However, accounts of its beginnings are multiple and contested (Delgado, et al. 2009). CRT is often cited alongside disability studies (Asch, 2017; Watts and Erevelles, 2004; Goodley, 2013; Zion and Blantchett, 2011; Annamma, Connor and Ferri 2013), and is considered to be a methodological and theoretical concept that can assist researchers exploring issues of 'race' (Howard, et al. 2016). Nakaoka and Ortiz (2018) believe that CRT can be used by social work educators to support the process of deconstructing systems which perpetuate microaggressions. However, Cabrera (2018, p. 209) believes that CRT was never meant to be a theoretical framework, but instead "a theorizing counterspace for scholars of color to challenge and transform racial oppression". Though social work recognises racism and racial inequalities and the need to address such issues, the profession has not fully incorporated CRT (Kolivoski, et al., 2014). According to Abrams and Moio (2009), there are few examples in existing literature, of CRT's application to social work theory or pedagogy.

<u>Ethnic and 'racial' stereotypes</u>

Nelson (2002, p. 667) states that "Bias, stereotyping, prejudice, and clinical uncertainty on the part of health care providers may contribute to racial and ethnic disparities in health care". Constance-Huggins (2012) believes that the assumptions and stereotypes held by practitioners related to 'race' can form barriers to accessing formal services. Numerous reports have identified the serious problems of under-representation of, and discrimination against, minority ethnic groups in the British NHS (Iganski and Mason, 2002). A growing number of scholars contend that in contemporary Western culture, prejudice often manifests in subtler forms than it did decades ago (Lilienfeld, 2017). From this perspective, prejudice has not genuinely declined—it has merely become more indirect and insidious. Furthermore, these processes are understood to be interconnected with other social divisions such as gender and class (Byrne 2006). Below I will discuss further the issue of complexity in terms of the concept of intersectionality.

<u>Intersectionality</u>

This term intersectionality was coined by Crenshaw (1989). There are various forms of social stratification, such as class, 'race', sexual orientation, age, religion, creed, disability and gender. Intersectionality acknowledges that social categories or identities (for example 'race', sexual orientation, class, gender, et al.) are not separate elements, but in fact are interconnected and mutually reinforcing components (Daftary, 2018). It is also one of the tenets of CRT, and holds the belief that a focus mainly on 'race' can obscure other forms of oppression (Abrams and Moio, 2009). CRT recognises the intersectionality of

different forms of oppression, and although focusing on 'race' it does not disregard these other elements (Constance-Huggins, 2012). In the field of social work, proponents of intersectionality believe that unless service providers take intersectionality into account, they will be of less use for various segments of the population, such as those reporting domestic violence or disabled victims of abuse (Fazil, et al. 2004). There is much complexity within this concept, and our understanding of the intersection of disability with 'race' and ethnicity in health care is still very limited (Horner-Johnson, Fujiura, Goode, 2014). Further research is needed to bridge the gap between research on 'racial' and ethnic health disparities and research on disability-related health disparities. Adding up the disadvantages, as in the notion of double or triple disadvantage, does not fully account for the intersection (Walby, 2007). According to Dominelli (2018), it is necessary to address racism, before promoting anti-oppressive practice. Critical Race Theory is considered an appropriate theory for promoting anti-racist social work, and as a tool for promoting intersectionality (Coxshall, 2020).

2.5.2. Ecological systems theory

With roots in von Bertalanffy's (1973) systems theory and Bronfenbrenner's (1979) ecological environment, the ecological systems perspective provides a framework that permits users to draw on theories from different disciplines to analyse human interactions within a social environment (Friedman and Allen, 2011). The ecosystems framework is relevant to social work because it helps to envision a better fit between people who use services and their environments by offering the potential for exploring (and thus improving) the quality of connections

across different ecological systems. Germain (1991) was instrumental in adapting these two theoretical models to an ecological systems perspective with specific applicability to social work. She strongly advocated looking at the biopsychosocial development of individuals and families within cultural, historical, communal, and societal contexts. This perspective requires us to look at all events in a person's life. Bronfenbrenner's ecological systems theory views individuals as influencing and being influenced by (both directly and indirectly) a series of interconnected social systems (Graves and Sheldon, 2017). Critics of this theory felt that the ecosystems perspective failed to address structural injustices, which resulted in it incorporating recognition of power imbalances and diversity issues (Healy, 2005).

Bronfenbrenner's ecological systems theory proposed a model for individuals interacting within nested and interdependent systems: the microsystem, mesosystem, exosystem, and the macrosystem (Deacon and Macdonald, 2017). The microsystem is the individual's immediate environment and it includes their family (immediate and extended), classmates, work colleagues, friends and neighbours, leisure, religious and other social groups. The mesosystem is the interactions and relationships between the different elements of the microsystem. The exosystem refers to elements of the individual's context which directly affect them, including interactions with social services, health and medical services, public transport, and other organisations such as school and work environments which are likely to have an impact on them (e.g. parent losing a job, mother dealing with the loss of her own parent, a challenging Ofsted inspection at school, all of which will affect elements of the child's microsystem and thus indirectly the

child). The macrosystem is the wider societal context which has an impact on the child's microsystem and determines the cultural and socio-economic context in which the child develops and is influenced by (Howe, 2011; Martin, 2010). This framework is a useful tool for practitioners to utilise when assessing a family's support system. They could evaluate the strengths and weaknesses of each system and address these by putting in place relevant support services to build the capacity of families. To ensure the mesosystem is strong and functioning well, it may not be enough for an individual (or family) to have informal support from friends or family; their interactions and relationships with formal services are also important. The different layers of these systems do not operate independently or in isolation (Piel, et al. 2016).

It could, however, be said that the ecosystems model takes a Eurocentric approach, making assumptions regarding the systems and values of different groups in society, and the availability of support from different institutions. For example, religious organisations and what they offer and how they interact with their community will vary across religions and within and between nations. This thesis will conclude by applying this model to the families of BME children with LLCs to see how different their systems are (placing the child and immediate family at the centre) and how their networks map on to these circles. The quantitative findings from Chapter 4 will provide a useful comparison in terms of ethnic variance. This approach can be useful to understanding the experiences and support systems of the families of BME children with LLCs.
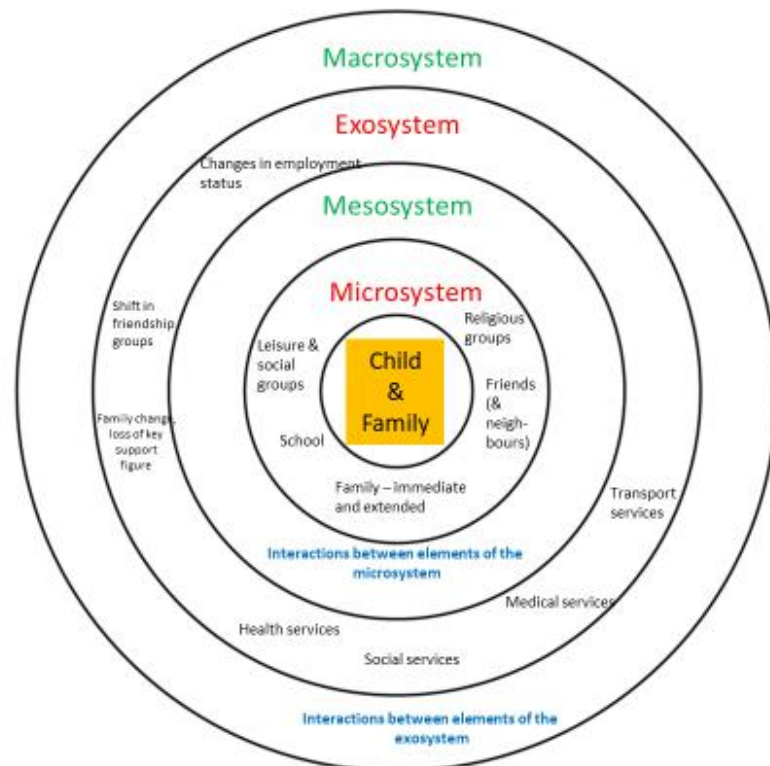
Figure 1 Ecological systems

Social workers utilise theoretical frameworks to enhance their understanding of an individual's personal resources and social capital, which the ecosystems perspective can provide. Understanding how families cultivate social support across multiple levels offers implications for practice and policy when considering how best to retain and support families who care for vulnerable children (Piel, et al. 2016). The ecosystems perspective does not dictate which tools to use but relies on the creativity of each worker to assess fully the dynamics of person-in-environment interaction. Tools such as a culturagram can support a practitioner to assess the individual's systems, including addressing issues of diversity. Paat (2013, p. 954) believes that "understanding the ecology of immigrant families can

help strengthen social work service delivery", as he believes such families' encounters with various ecological systems is likely to be shaped by their cultural differences and the diversity of family settings. They are likely to have different systems and support, and it should not be assumed that their systems will be the same as the majority ethnic groups in society.   Inevitably, there may be ethnic variance, and sensitivity to this will enhance social work practice and ensure we test our assumptions and do not rely on ethnic and racial stereotypes. Informal support is essential in providing practical and emotional support. Formal support (for example financial support), which may come through social care, health and education, will be critical.

Assessment is a core part of social work. Theories can provide explanations of the person-in-environment configuration, and help explain why the problem / issue is occurring and where the most efficient intervention should take place. Theoretical thinking will influence an assessment (Coulshed and Orme, 2006). The range of knowledge used by professionals to support the assessment should include n awareness of a range of relevant theories, such as the ecological systems theory, to explore the individual's support systems. The use of a culturagram can help a practitioner to understand, assess, and plan an intervention with a family who may have different cultural beliefs and values, and support systems (Jani and Okundaye, 2014).

The use of theory supports practitioners to make informed choices regarding the methods of interventions with families. The theories discussed above, would help

practitioners in social care, health and education to work effectively with the families of BME children with LLCs. For example, in terms of the ecosystems theory, the child and parents could be placed in the centre, and their networks of support explored through this context. In order to ensure the inclusion of diverse needs of a family, culturagrams could be utilised by professionals to support them in their assessment work.

2.6.   Chapter conclusion

This chapter sought to explore the wider context for disabled children and children with LLCs, and their families. It then narrowed its focus to issues pertinent to families with disabled children or children with LLCs, to address ethnic variance. Language and terminology were discussed, in relation to labels applied to this group of families. In order to explore their position in society, demographic information in relation to 'race', ethnicity, religion, and language use are also included, as well as drawing attention to the paucity of data regarding ethnicity and disability. The relative lack of ethnicity and child disability data appears to be a limitation of the literature.

A review of the literature demonstrates that some aspects of the experience of caring for a disabled child or child with LLCs are shared by parent carers, irrespective of ethnicity. The range of issues experienced by such families are complex and wide-ranging. In the case of BME families, some families may face

additional issues (language and literacy issues, racism, immigration issues), and barriers when trying to access services, based on 'racial' stereotypes and discrimination which could be linked to issues of intersectionality and micro-aggressions.

Theory in the form of anti-racism, and ecological systems theory are concepts which can help professionals to explore the support needs and available networks of support for ethnically diverse families, and tools to explore issues of anti-oppressive practice and lead to evidence based practice. These concepts allow for reflection and checking our 'racial' and ethnic assumptions and beliefs, in relation to individual families, to avoid generalisations or making assumptions regarding the experiences and resources of this group of families, who may experience a high level of social isolation and exclusion.

Chapter 3 Methodology

3.1. Introduction

The aim of chapter three is to describe the methods adopted to undertake this study. It also refers to the methods of analysis, and the profile of the research participants. The study is about the support systems of the parent carers of BME children with LLCs. The approach adopted was a mixed methods design that incorporated qualitative and quantitative approaches. Different methods and approaches can support researchers to ask contrasting and distinctive questions about the social world, and to conceptualise what they are researching, and what would 'count' as knowledge or evidence about it, in different ways (Mason, 2006). The quantitative element played a lesser role, in this thesis, and involved analysing data from Wave 5 of the Millennium Cohort Study.   The qualitative element involved interviews with the parent carers of BME children with LLCs (and professionals in the field). There is a dearth of research focusing on the views and experiences of BME children with LLCs, and calls have been made for the inclusion of the vice of this group in research (Brown, et al, 2013; Fraser, et al, 2012). Thus, the participation of parents of BME children with LLCs is central to this thesis.

3.2. Research question

The methodology was adopted to attend to the central research question:

"Who supports the families of Black and Minority Ethnic children with Life-Limiting Conditions?"

There were two sub questions: what support (from both formal and informal sources) is available to the families of BME children with LLCs? What support do parent carers of BME children with LLCs value, and are there any barriers to accessing this support?   Through qualitative interviews with ten professionals, the thesis sought to explore the views, experiences, and beliefs of the providers of formal services to BME children with LLCs.   Qualitative interviews were undertaken with twenty parent carers of BME children with LLCs. To frame the study with a population-level description, the research findings begin with secondary analysis of a nationally representative quantitative data set, the Millennium Cohort Study (MCS).

3.3. Research design

The research design adopted was a mixed methods approach. Although the study was mixed methods, the qualitative findings are to the fore and make up most of the empirical chapters. It is not mixed 50-50. There is one quantitative chapter and four qualitative chapters. There are a number of types of methods

mixing. Of the six strategies outlined by Mason (2006), the approach adopted here is closest to the first strategy she describes, of mixing methods for a close-up illustration of a bigger picture, or for background, with the latter option being more relevant for my primarily qualitative study. The rationale for using mixed methods was for the purposes of triangulation, which is the combination of two or more methodological approaches, used to study the same phenomenon (Hussein, 2009). Studying the same area of research interest, applying different methods, helps to test the validity and reliability of findings (Reif, et al., 2010). Additionally, mixed methods can contribute to improving the accuracy of findings and provide a fuller picture (Denscombe, 2014).

In this study, the qualitative element provided in-depth data on the views of parent carers of BME children with LLCs as well as professionals working with families of children with LLCs. This study is primarily focused on this method. Chapters 5 – 8 are qualitative. The quantitative element provided information regarding a much larger and more representative group of children (13,000, approx.). The quantitative research provided a broader contextual picture of a wide range of topics that are relevant to the families of BME disabled children, as well as a comparison with white children.

This mixed methods study was also cross-sectional, as there were two participant groups in the qualitative interviews: parent carers of BME children with LLCs, and professionals working with this group of families. Cross sectional studies are a common method of research in the social sciences, where participants are

investigated at a single point in time or during a brief time period (Mukherji and Albon, 2018). Although the quantitative dataset is longitudinal, I am using it in a cross-sectional manner by analysing data from one wave only.

3.3.1. Philosophical position

In terms of adopting a philosophical position, the quantitative element of this study would traditionally be considered as reflecting a positivist approach, and the qualitative element would be aligned with an interpretive position. Positivist and interpretivist research paradigms consider social phenomena through two different lenses (Cohen, Manion, and Morrison, 2003). An interpretivist approach involves trying to understand the meaning people attach to topics relevant to them. In this situation, the researcher is viewed as the main instrument in the study (Punch and Oancea, 2014). The positivist approach is focused on objective measurement and causality.

For the purposes of this research, a critical realist approach was adopted, which could be seen as drawing on aspects of both these epistemological traditions. Critical realism is defined as:

> "A philosophical approach that combines an ontological belief in the existence of a reality independent of those that observe it. With an epistemological approach that reality is only accessible through the perception of people, and is therefore necessarily affected by their interpretations" (Becker, et al., 2012, p.394).

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It is a philosophical approach associated with Roy Bhaskar (1989) to describe an interface between the natural and social worlds. Critical realism captures a variety of stances, but its key ideas sit between positivism and interpretivism.

Critical realists believe that social science can contribute to debates over how life should be lived as well as how it is lived (Archer, et al., 2016). Practitioners adopting the critical realism approach aim to identify structural inequalities, in order address them (Price and Martin, 2018). However, a realist stance denies that we can have certain knowledge of the world, and instead accepts the possibility of alternative valid accounts of any phenomena (Maxwell, 2012). This philosophy fits in well with the mixed methods approach adopted in this thesis, as well as the topic of inequalities addressed by this thesis. It also links well with the fact that as a researcher I am aware of what I bring to the research process, my personal experience of being a parent, a social worker, and a member of the BME group. Although I plan to be objective and professional in my approach, it is inevitable that these characteristics will impact and influence the research process. This issue is further discussed in section 8, below.

3.4. Quantitative research

There were several reasons for the inclusion of quantitative data in this study. The quantitative data helped to set the context for the more in-depth qualitative research, by looking at the wider population of ill children and aspects of their social support, comparing BME children with white children, and doing this from a nationally representative sample of children.

Quantitative research is a methodological approach that has gained pace in the health and social care sector, and can increase the comprehensiveness of findings as a whole (Chow, Quine, Li, 2010). The quantitative data from the MCS provided a larger sample size (13,000) that is representative of the whole population, as participants were randomly selected, in contrast to the participants in the qualitative element, who were in touch with specific services and had volunteered to take part. The data from the MCS has the potential to provide information that can explore health outcomes and inequalities affecting particular groups in society (Connelly and Platt, 2014).

The qualitative element primarily focused on the experiences of the parent carers, whereas the quantitative element focused much more on the child and their experiences. For example, data were looked at in relation to their social and recreational activities.

Utilising data from the MCS provided the opportunity to not only compare differences between BME children and white children, but also between children with long-standing illnesses, and those without. It is possible to look at what differences there are between groups, and if it is the child's ethnicity or their disability which has a greater impact in highlighting differences. With the research being focused on a sensitive area, and on a group who are a minority within a minority group (BME, then LLCs), access to this group proved challenging in terms of recruiting interview participants (20 parent carers) for the qualitative element; however, the MCS is a representative study of the whole population, with a much larger sample size (approximately 13,000 children). There is also the advantage of the MCS asking a greater number of questions, covering a wide range of topics (some of which relate to the themes in the qualitative chapters) which I would not be able to do due to resource and time limitations.

The potential for analysis of administrative data in Wales was initially explored, and due to the small proportion of BME individuals in the population (4.4%, Census 2011) it was difficult to anonymise health service or social care administrative data in relation to this group. Instead, an anonymised and publicly available dataset was used. The MCS contains information regarding children, their ethnic group, religion, and health status. This is a longitudinal study and contains extensive and detailed information about the child (CM-cohort member) and the child's family members (parents, grandparents and siblings), including family background. It provides a unique and valuable resource for the analysis of health outcomes and health inequalities and is an observational, multi-

disciplinary cohort study that was set up to follow the lives of children born in 2000. There have been five main sweeps of data collection. Participants were identified and recruited using child benefit records. A key advantage of this dataset was that efforts were made to ensure inclusion of 'hard to reach' populations such as those from socially disadvantaged backgrounds and BME groups (Connelly and Platt, 2014). For the purposes of this study, only data in Wave 5 (2012) was explored, therefore the study was applied cross-sectionally. The age of children in Wave 5 is eleven years.

The MCS has very detailed information on the ethnicity of the child and both parents, as well as religion. Although it has data containing 6 and 8 category ethnicity details, many of the ethnic categories had a low cell count, therefore these categories were collapsed to create a new variable – BME. A range of areas were explored in relation to formal and informal support systems, as well as general information regarding the child and their social interactions.   As this is a group about whom very little is known, the intention was to broadly describe this population and create a picture of their norms. There was a focus on the topic of education and how the family interact with these services. This was primarily because disabled children (and for the purposes of this thesis, children with long-standing illnesses – the acronym LSIs is used from now on) spend a great deal of time in school not only in term-time, but also during holidays, for example accessing summer schemes which are inclusive and meet their needs. Parents often utilise a range of support services through schools. The children in special schools receive a range of health-related services based at the schools, including speech therapy, occupational therapy, as well as clinics where they are

seen by nurses and paediatricians. Special schools can provide a wide range of support services for families, beyond educational support for the child.

This thesis used the MCS to draw comparisons between BME children with LSIs and white children with LSIs, as well as BME children without LSIs and white children without LSIs. Due to the challenges of finding a dataset that contained both ethnicity and information concerning children with life-limiting conditions, the decision was made to instead look at children in the context of long-standing illnesses. In the absence of a dataset containing information on both LLCs and ethnicity, LSIs is an alternative that provides a reasonable comparison. Although there are limitations to using this broader category, this was the best available option. The quantitative element of this thesis provided a wider context of BME children with LSIs and their position in the general population.

The quantitative element played a lesser, yet important contribution, by helping to describe a group (the families of BME children with LSIs). The data from the MCS helped in part to answer the question: "Who supports the families of BME children with LLCs?" by considering a nationally representative sample and a comparison between BME and white children with LSIs.

A possible alternative data set which was considered in place of the MCS was the Avon Longitudinal Study of Parents and Children (ALSPAC) study. However, the proportion of BME families in that study was much lower than the MCS, with a similar sample size for the whole study. The National Child Development Study

(1958 birth cohort) was also considered. The rationale for not using that dataset was due to it potentially being outdated. Cohort members may be too old to have children aged 18 years or under in recent decades, whereas the MCS is made up of parents of children born around the millennium (2000).

3.5. Qualitative research

There are four later chapters (5, 6, 7, 8) focusing on the findings from semi-structured interviews with parent carers of BME children with LLCs (20), and professionals working in social care, health, and education (10). Chapters 5 – 7 are based primarily on the parent carer interviews and chapter 8 is based on interviews with professionals working with the families of children with LLCs.

Qualitative research is a useful tool for trying to 'de-mystify' unknown (or little known groups) as it provides comprehensive narratives of their experience (Barbour, 2014). Qualitative approaches are best suited to describing lived experience and interviews help to achieve this by allowing for the collection of detailed information, flexibility and freedom to explore and address unexpected themes. As I was researching a sensitive topic with parent carers, I was keen to build rapport and gain their confidence. I was able to design the interview schedule so that the start of the interview was about learning about the child and the other family members and help participants relax. I felt it was an empowering approach because they were also able to ask me questions about my family life

and practice experience, and where my interest in the topic came from. It provided an opportunity for the participants to tell a story, and for me, the researcher, to listen actively and respond accordingly.

Data for the qualitative element was obtained through interviews. This technique aimed to explore the subjective experiences of participants, in their own words (Becker, et al., 2012). The interviews were a useful approach for identifying the feelings and motives of participants, and for eliciting reasons and explanations (Silverman, 1993). Semi-structured interview schedules were devised and used to gather data from the participants. There were two types of interview schedules, relevant to the two different groups of participants. The use of semi-structured interviews allowed the researcher some latitude to ask additional questions, when it was felt further probing was necessary. The flexibility offered by this semi-structured interview approach allows the researcher to probe meanings and interpretations and not impose their own views (Becker, et al, 2012). The nature of semi-structured interviews enabled flexibility for participants to discuss topics and issues which were pertinent to them and generated rich data, providing insights into the lived experience of families of BME children with LLCs. It also provided information regarding the second group of participants (the professionals) and how they perceived their role, and their perceptions of working with the families of BME children with LLCs. The language used provided powerful insights.

The principal aim of the qualitative element was to investigate the support systems available and utilised by BME families of children with LLCs, as well as identifying any barriers to accessing both formal and informal support. The interviews with staff in social care, health and education were conducted to explore the views, knowledge and capacity of the providers of formal support services to provide services or work alongside the families of BME children with LLCs. Please see section 5.1 for additional information regarding participants.

The aim was to gain an understanding of the lived experience of being the parent carer of a BME child with LLCs. The focus was on support systems (formal and informal). Formal support included access, experience of, and availability of social care, health and education services. Informal support considered the availability and experience of support provided by family, friends, neighbours, and religious organisations. These related to themes from the literature review and were some of the topics covered by the MCS.

The interviews with professionals provided data regarding their views and beliefs regarding the support needs of BME children with LLCs and their families. It explored their perception of what they saw were the different needs of BME families and to identify any barriers to accessing both formal and informal support. It was an opportunity to test if some of the stereotypes noted in the academic literature regarding BME families were held by those working with BME children with LLCs and their families.

From existing research, we know that BME families are under-users of formal services (Dilworth-Anderson, et al. 2002; Dunlop, et al. 2002; Elkan, et al. 2007). However, we do not know the reasons behind this. There is speculation that BME families may have greater access to informal support, such as larger informal networks of family and friends (Guinta et al. 2004; Chow et al. 2010). There is also speculation that religion and culture may be a barrier to accessing formal support (Funk et al. 2010; Ahmed and Rees-Jones, 2008). These assumptions and beliefs were tested in this research; with both BME parent carers, and professionals who work in social care, health, and education settings. This thesis aimed to identify interventions (formal and informal) which parent carers of BME children with LLCs find to be positive and helpful in meeting their needs, as well as bringing to light any barriers to accessing both formal and informal support. Areas explored through interviews with parent carers and professionals related to the support that families have access to; what they find helpful; barriers to accessing informal and formal support, amongst other areas. There is a dearth of knowledge around the nature and usefulness of informal support (often referred to as 'community' support), as well as its limitations, which this study aimed to address through the use of these interviews.

3.5.1. Participants - sampling technique

Interview participants were initially to come from or be resident in Wales, given that the research funder had a clear interest in the implications of research for Welsh services. However, this proved to be a challenge for two reasons. The first issue was that due to the small numbers of parent carers of BME children

with LLCs, recruiting from Wales alone could have led to the parent carer participants being easily recognised and anonymity would not be guaranteed. In Wales, only 4.4% of the population are from BME groups (Census, 2011). This is a specialised sector where numbers are small and people can be easily identified, even from a broad description. Several professionals working with this group of families felt this would discourage participants from being involved. Widening the group to include participants from both England and Wales was one way of ensuring anonymity for participants. Another approach was to not name any towns or cities.   All gatekeepers were asked to approach potential participants individually rather than in a group setting. Snowballing as a sampling technique was avoided. A strategy for recruiting parent participants could have been to ask them to refer other parents they may know in a similar situation, but this was avoided. In terms of pseudonyms, I ensured out of respect for their religious and cultural background that each child was given a pseudonym which tallied with their religion and culture. But the names were specifically very different from their real names. None of the parents are named in any way in the study, but instead referred to as the child's mother or father. Although some agencies and professionals who participated requested that they or their agency be acknowledged for contributing to the study, they were told this was not possible as it could compromise, in particular, the anonymity of the parent participants. Steps were taken to ensure confidentiality of participants, but the risk could not be wholly removed. Children with LLCs have a very different trajectory, compared to adults with LLCs, and can be accessing formal support through health and social care for many years. This could contribute to the risk of identifying participants.

The second issue was that when I initially proposed this research, I had good links with a third sector organisation that worked closely with this group of families. However, at the time of data generation, this resource was no longer available. When I discussed my research with colleagues in England, they expressed an interest and were keen to be involved, and support recruitment of participants. The professionals were also recruited from both England and Wales.

The approach to recruiting both sets of participants was through purposive (or non-probability) sampling, whereby participants are recruited in a targeted and deliberate manner (Punch and Oancea, 2014). In purposive sampling, researchers select participants to be included in the sample to meet their specific needs (Cohen, et al, 2003). Due to the nature of the research, it was imperative that participants who met certain criteria were specifically targeted (see inclusion and exclusion criteria below – section 5.2).

The research was with a minority group, within a minority (BME; parent carers of children with LLCs), and in relation to a sensitive topic. This recruitment strategy helped to engage with participants relevant to the research question. Non-probability sampling is typical of research where an interpretivist approach is adopted. This approach is known to involve a smaller sample size (in comparison to quantitative research), where data collected are much more detailed (Oliver, 2008). The main source of parent participants was organisations working with or likely to come into contact with this group. There were seven organisations in

total. Six organisations were Welsh, and four English. Professionals were recruited through children's hospices, hospitals, and special schools. Four professionals were from Wales and six from England. Their professional backgrounds were varied, and the sample included social workers, teachers, and health professionals. There was also diversity in terms of ethnicity. Of the ten professionals interviewed, three were from BME groups. This focused approach helped target participants who could provide the appropriate information needed to meet the research objectives (Mukherji and Albon, 2015). All participants were been given pseudonyms.

In terms of the socio-economic profile of the parent carer participants, the majority were well-educated, middle class individuals. It has been observed that the socio-economic position can be a determinant of participation in research, with participation rates lower in households with a lower socio-economic profile (Demarest, et al. 2012). Future research could address this issue by utilising specific strategies targeting the participation of lower socio-economic groups.

Please see below participant details:

	PARENTS INTERVIEWED (20)					
Pseudonym of Child	**Age of child**	**Mother / Father interviewed**	**Ethnicity**	**Language interviewed in**	**Religion**	**Resident in England or Wales**
Aisha	17	Mother	Indian	English	Muslim	England
Farhan	6	Mother and Father	Pakistani	English (mother) Urdu (father)	Muslim	England
Hanif	5	Father	Bangladeshi	English	Muslim	Wales
Dana	9	Mother	Pakistani	English	Muslim	England
Rishi	6	Mother	Indian	English	Sikh	Wales
Iona	8	Mother	African	English	Christian	Wales
Abbas	16	Mother and Father	Pakistani	Urdu (father) and Punjabi (mother)	Muslim	England
Zidane	7	Mother and Father	Indian	English and Urdu (both parents used a mixture of both languages)	Muslim	England
Eshan	8	Mother	Indian	Urdu / Hindi	Sikh	England
Nadir	5	Mother and Father	Pakistani	English	Muslim	England
Chand	18	Mother	Indian	English	Sikh	England
Adnan	18	Father	Pakistani	English	Muslim	England
Rehana	13	Mother	Pakistani	English	Muslim	Wales
Ruby	16	Mother and Father	Indian	English	Hindu	England
Fiaz	12	Mother	Arab	English	Muslim	Wales

PROFESSIONALS INTERVIEWED (10)				
Pseudonym	Type of organisation	England / Wales	Social care, health, education professional?	Ethnicity
1. Angela	Hospice (Charity)	England	Social worker	African-Caribbean
2. Maria	NHS	Wales	Nurse	White
3. Teresa	Hospice (Charity)	Wales	Social worker	White
4. Karen	Hospice (Charity)	Wales	Nurse	White
5. Nadine	School	Wales	Teacher	White
6. Radha	Hospice (Charity)	England	Social worker	Indian
7. Hema	Hospice (Charity)	England	Social worker	Indian
8. Rosie	Health	Wales	Nurse	White
9. Mary	Health	Wales	Social care	White
10. Anna	Hospice (Charity)	England	Nurse	White

3.5.2. Inclusion and exclusion criteria

3.5.2.1. Professional participants

Those included were social care, health, and education professionals who worked with families of children with LLCs or were likely to come into contact with them. They had to be working in England or Wales. The practitioner was required to be aged eighteen years or over. Exclusion criteria for professionals included practitioners who did not work with children with LLCs, and were working in areas other than England and Wales, and those under the age of eighteen.

3.5.2.2. Parent carer participants

Inclusion criteria for recruiting parent carers was that the participant was the parent of a BME child with an LLC; the child needed to be aged 0 – 18 years and be resident in England or Wales; and the participant was aged eighteen years or over. Exclusion criteria for parent carers was participants under the age of eighteen years; the participant's child being over the age of nineteen years; the participant not having a BME child with an LLC; and the participant residing outside Wales or England.

3.5.3. Data Generation

A separate semi-structured qualitative interview schedule was devised for each of the two groups of participants (see above and Appendix A). Twenty-eight interviews were conducted face to face; two interviews were conducted via the telephone. The two telephone interviews were with professionals. All interviews

were voice recorded and transcribed verbatim. Five interviews with parent carers were conducted in Urdu and Punjabi by me, and transcribed into English.

Participants were given the option to choose the location of the interviews - either their home or the offices of the organisation that referred them. Most of the interviews took place in the homes of the parent carers. All interviews with the professional participants took place at the offices of the organisation they worked for, other than two, which were telephone interviews.

3.6. Framework of Analysis

3.6.1. Qualitative data analysis

In terms of analysing qualitative research, there is no one universally adopted or accepted method for analysis (Johnson and Christensen, 2012). The approach adopted in this study was thematic analysis. Thematic analysis is the one of the most common approaches to qualitative data analysis, where recurrent themes are used as a basis for coding the data (Braun and Clarke, 2014).   In order to analyse the data, it is important to become familiar with the data (Denscombe, 2010). Transcribing interview recordings and reading through transcripts several times helped identify broad themes. I used N-vivo to facilitate coding, and to check the frequency of themes, as well as the quality of the data relating to those themes. Despite adopting an approach in line with the norms of qualitative data

analysis, it is important to acknowledge that it is inevitable that this process would be influenced to some extent by my personal experiences and values (Fontana and Frey, 2000). Listening to the recordings a number of times, and reading and re-reading the transcripts was one way of familiarising myself with the themes in the data. However, due to the nature of the interviews with parent carers, this was challenging as at times I found it very upsetting (in particular listening to the recordings and hearing parent carers cry). This topic is discussed further in section 8.

3.6.2. Quantitative analysis

As stated earlier, the quantitative element of this thesis plays a lesser role, compared to the qualitative component. However, it provided some useful comparisons for the qualitative chapters. The Statistical Package for the Social Sciences (SPSS) was used to analyse the quantitative data, and cross-tabulations produced. Cross tabulations are a widely applicable method of studying the relationship between variables, allowing for the use of chi-square tests to measure significance (Punch and Oancea, 2014). Further details can be found in Chapter 4, which focuses on the quantitative element of this research. The data from the MCS Wave 5 were split into two categories (BME and white), in order for us to see the differences between these two groups. I was unable to look at more fine-grained ethnic group categories because the numbers of disabled children in each group would have been too small. It was also determined that differences would additionally be explored in terms of those children with LSIs, and those without. The results of the cross-tabulations were

entered into tables that provided comparisons of numbers and percentages of children in each category (BME children, BME children with LSIs, white children, and white children with LSIs). This provided information that indicated whether the differences between categories were due to the LSI, or ethnicity. Chi-square results were also produced to establish whether any differences between ethnic groups were statistically significant, or not, in terms of children with LSIs.

3.7. Ethics and Consent

Consideration of ethics is important at every stage of the research process. As there was a chance that participants may be recruited through NHS sites, an application for ethnical approval was made to the NHS Ethics Committee. This was a lengthy and bureaucratic process which was concerned with ensuring that the best interests of the participants were kept at the forefront of the research process. It was deemed necessary to ensure that participants who did not speak English (or for whom English was their second language) were in no way disadvantaged by the use of highly specialised medical jargon, and that the parent carers were not asked any questions which may cause them undue emotional upset and distress. It was also important to ensure the participants provided informed consent.

Both sets of interview schedules and the Participant Information Sheets (see Appendix B and C) were examined by the NHS Ethics Committee to ensure the language was accessible, and there was no element of bias. In order to address

the issue of informed consent, and to ensure parent carers' emotional and mental health and well-being were taken into consideration, a number of measures were put in place. The first was in relation to consent. It was decided that two-stage consent would be obtained from the parent carer participants. The first stage involved professionals identifying relevant families, providing a brief over-view of the research, and offering parents written information in their chosen language (Participant Information Sheet and interview schedule). Participants were then asked for permission to share their contact details with me. At this stage it was made clear to the parents that they were not consenting to take part in the research, but agreeing to be contacted by me, at which point they could ask further questions about what participating would involve, and to then make an informed decision about whether they would participate or not. The most common question from parent carers was: 'How will this research improve my child's health, or the services they receive?' Some parents chose to participate despite no immediate or direct benefit to them or their child; others chose not to. Another frequently asked question was whether I planned to interview their child with the LLC. Once they understood that I did not plan to interview their children, they were more likely to agree to participate.

A further rationale for the two-stage consent was that some parents may have had language, literacy or confidence issues. Many of the medicalised concepts and jargon used in relation to this area of research are difficult to translate or put into words in some minority ethnic languages; there are not easy to find equivalent terms. Therefore, verbal communication helped to overcome some of these barriers, and allowed me to answer parents' questions without any

constraints, and to their satisfaction, depending on the individual participant's needs. Every effort was made to ensure clear and simple language was used in my communication with families. I appreciated this process as it meant that the parent carers were made informed decisions about their involvement.   The second stage was obtaining consent from the parent carers after they had had the opportunity to ask their questions. This was consent to participate in the research.   Written consent was obtained from all participants. For those participants who were unable to read English (but did not request the forms to be translated) the documentation was sent to the referrer in advance of the interviews, for them to share with the participants. This provided them with the opportunity to have them interpreted or translated independent of the researcher. At interview, they were given the opportunity to ask any questions they may have, before starting the process. Approximately thirty parents were approached to participate, of which twenty agreed to participate.

An additional requirement from the NHS Ethics committee was to obtain consent from the parent carers to contact their GP and inform the GP that the parent carers had participated in this research. This was due to a concern for the well-being and emotional and mental health of the parent carers. Several parent carers were unhappy about this. They felt that they had the capacity to decide whether or not to participate in the research, and that the Ethics committee's decision was disrespecting their ability to make decisions for themselves. Parent carers were reluctant to provide this information, as they were worried that I may then have access to their medical records. This was a reasonable concern.   I reassured them that they were not consenting to me accessing this information.

They felt this element was patronising. This created some tension at the start of the interview process.

Concern for the well-being of the parent carers is understandable, when undertaking research on an emotionally sensitive topic. Weaver, et al (2019) refer to the tension of undertaking such research, and impact on those involved in the process; in their study they found benefits were more heavily emphasised by patients and family members, whereas burdens were more prominently emphasised by researchers and clinicians. However, ethically it is important to give people a choice of whether or not they wish to engage in the process. Carrol (2018) refers to the need for inclusive research on emotionally sensitive areas. There is a need to balance protecting participants, but also acknowledge that they have a right to choose to participate. This was an interesting ethical dilemma.

Several parents interviewed became upset at some stage of the interviews. They were offered the opportunity to end the interview or take a temporary break. They all chose to complete the interviews, and stated that they valued the opportunity to discuss issues regarding their child and how as a family they had been affected by their child's LLC. They stated they did not often get a chance to do so and gave positive feedback about how they felt the process was handled sensitively. The process was also challenging for me, as a researcher. I was keen to leave them in a positive mental state, so my final question was always about their wishes and feelings for their child's future. This had the desired effect of making the parents smile and look at the positive aspects of their child's life. I would also

ask if they wished for me to meet their child, or to show me a photo. The rationale for this was based on my practice experience with parents of children with LLCs, who would state that they felt that their child being labelled as having an LLC meant that people often did not value the child in the same way. I noticed that the parent carers always appreciated this. I approached the question sensitively. No parent took offence or refused to allow this.

For thirteen years I managed an advice, advocacy and support service for BME disabled children and children with LLCs. I drew on this experience and utilised some of the tools and techniques I used in my practice with families, to ensure the participants' emotional needs were met with a high level of sensitivity. Precautions were taken to ensure sensitivity around the language and terms used when discussing children with their parents. Every effort was made to discuss issues in a sensitive manner. I ensured no interviews were conducted in the presence of any children.

All participants were made aware of their right to confidentiality, anonymity, and to withdraw from the study, before interviews commenced, and at certain intervals during interviews when a parent appeared to be upset. It was also considered vital to make participants aware of the limitations of the research, as to levels of influence it would have on practice and on policy makers, in the immediacy and in the future. It was important to be as open and transparent as possible, and manage expectations. This was a topic parent participants asked about. In terms

of the quantitative data, as the MCS is an existing anonymised dataset, this did not require ethical approval.

In terms of the ethics of interviewing the professionals, there were a number of issues which emerged that I refer to later in this chapter. These were in relation to juggling my different identities, and gauging how they saw me – as a social work professional, researcher, or a member of the BME group. The first few minutes of meeting professionals involved assessing their perception of me. This inevitably would impact on the data generated. The professionals also had more than one identity, for example as parents, belonging to a white or BME group, professional identity. I remember one South Asian participant joking that I was not 'proper Asian'. This unsettled me despite not being the first time I had heard this. By the end of the process she gave me positive feedback about the way I related to the parent carer participants, and my use of Urdu. After I had finished conducting the interviews, she took me to her favourite South Asian restaurant for snacks. I felt that was her way of showing me that I was accepted or had past some sort of test. It is very difficult to describe and explain how complex this process was.

3.8. Writing the thesis 'reflexivity', emotion work

The notion of reflexivity is important in relation to qualitative research. Rather than a fixed self, engaged in research, Lincoln and Guba (2000) argue that the self is fluid in the research setting and is also created in the process of the

research. Reflexivity, they argue, can be linked to a process of coming to know oneself better within a research project.

The process of undertaking research in an emotionally sensitive area meant there were risks to both researcher and participants' emotional well-being. As discussed earlier in section 7, to protect parent carer participants, the NHS ethics committee put in place certain conditions, such as informing the parent carer participants' GP about their involvement in the research. No safeguards were put in place regarding the researcher. However, I had access to my supervisors who were aware of the nature of this research and they ensured they were available, if needed. Nevertheless, the research process was characterised by a number of ethical dilemmas and negotiating the qualitative fieldwork process was both an intellectual, practical and emotional challenge (see Loughran and Mannay, 2008).

The impact of emotion on social researchers has been noted by many authors (e.g. Grinyer, 2004; Johnson and Clarke, 2003; Carter and Delamont, 1996). The proximity of the researcher to what could be considered a distressing research topic can mean that there will be an emotional cost in such studies (Fincham, Scourfield, and Langer, 2008). Some of these authors suggest that emotion can be harnessed creatively as part of the interpretive process.

A decision was made to exclude participants who had experienced bereavement. However, the risk of making a decision based on protectionist reasoning is that

researchers then exclude the participation of some groups from research, based on concerns for their vulnerability (Carroll and Mesman, 2018). As researchers, emotional reflexivity is necessary to ensure inclusive research and this inclusiveness necessitates an engagement with, rather than an avoidance of painful experiences (Carroll and Mesman, 2018).

Despite the decision not to interview bereaved parents and the efforts to ensure this sampling frame, two parents I interviewed mentioned during the interview that they had previously lost a child. This was unexpected, and I had to reflect in action (Schon, 1991). Those parents were offered the chance to withdraw from the interview or take a break. Nevertheless, both parents chose to continue, making this decision to contribute to the research for themselves where other bereaved parents had been excluded by my initial protocol. This example raised questions about who decides what ethical practice means and the ways in which participants can become excluded from this process in attempts to follow established guidelines that position the researcher and institution as the expert.

In relation to this research, a further point of reflection was my awareness, as stated above, of having several identities, which could impact on the research process. The impact could be positive or negative. In social work this is referred to as 'use of self' (Trevithick, 2018). The use of self in social work practice is the combining of knowledge, values, and skills gained in social work education with aspects of one's personal self, including personality traits, belief systems, life experiences, and cultural heritage (Dewane, 2006).

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The identities are as a researcher, a parent (researching other parents), a social worker, and as a member of the BME group. These attributes positioned me as an insider, outsider and transient insider in the field (Morriss, 2016; Palmer, 2018), and engendered both advantages and limitations. For example, advantages included the fact that having a South Asian name acted to negotiate some barriers to participation by some BME participants. The majority of parent carer participants recruited for the study were of South Asian ethnicity. Furthermore, some of the families spoke little or no English, and were only able to speak Urdu and Punjabi, languages which I speak. This meant gatekeepers based in organisations, referring parent participants, did not have to exclude families who did not speak English.

Being a social worker may also have been an advantage when accessing the professional participants working in social care. Additionally, due to my practice experience, I was able to understand the medicalised language and terminology the parents often used when discussing their child's condition and care needs. However, as a result, some assumed I must share their experience so they would ask if I also had a child with an LLC. This form of questioning was very uncomfortable for me. At no point did I have any intention to lie to the participants, but I was afraid that they would see me as an outsider and may be guarded during the interviews, or even refuse to participate. In response, I explained that I had some understanding of their experience due to my professional experience only.

The participants were happy with this explanation and, despite my concerns, it did not result in creating a barrier to participation.

It is important to acknowledge how our identity, attitudes, and beliefs can impact on the research process. For example, how we interpret data is inevitably influenced by personal experiences and values (Guba and Lincoln, 2005). These elements cannot be eliminated from the research process but need acknowledgement and guarding against.

Factors that made me part of the parent group were: my ethnicity, my ability to speak some South Asian languages, being a parent, my knowledge of the health and social care system they were navigating, and my understanding of the medical conditions of their children, and the highly specialised language and jargon they used. What made me an 'outsider' with parents included: not being the parent of a child with LLCs, all my experience being professional, rather than personal, and the fact that I was a social worker.

With professionals, it was similar but different. They appeared to not notice my ethnicity. Interviews with some of the professionals could be challenging when they referred to BME families as 'they' and 'them' and if they made strong statements based on assumptions or racial stereotypes. In this way, it seemed that I was viewed as part of an 'in' group through my standing as a previous professional in social work, and my ethnicity appeared to have no impact in terms of forming a barrier in that professional participants were open about their views

and beliefs regarding BME families. There were regular micro-aggressions, sometimes before or after the interviews, which I needed to guard against. I did not want to allow my reactions to influence or negatively impact on the research process. It was important that I did not allow my body language to betray these feelings or to react in a way that participants would notice (see Lisiak and Krzyzowski, 2018).

Rather than attempting to engage with my study under the guise of an 'objective' researcher, exploring these facets of my identity and positionality, relationally, enabled me to be reflective and reflexive both in the field and in the analysis of the qualitative data. It is hoped that this has produced a more nuanced analysis of the data, which will be presented in the following chapters.

3.9. Conclusion

This chapter restated the research question that this study aimed to address, and outlined how the methods selected were chosen specifically to attend to these research questions. It described the quantitative and qualitative methodology adopted to explore the issue of support systems of the families of BME children with LLCs. A mixed methods approach was adopted, with emphasis largely on the qualitative element. The quantitative element focused on the experiences of children with LSIs, as this process drew attention to the paucity of existing

quantitative data in relation to children with LLCs, as well as ethnicity data. The qualitative interviews were conducted with twenty parent carers and ten professionals working in social care, health and education. Interviewees were from Wales and England, and all interviews were carried out either in English, Urdu, or Punjabi. The challenges of obtaining ethical approval were also discussed. The rationale for extra vigilance was due to the topics being addressed considered as emotionally sensitive. The parent carer participants were also a potentially vulnerable group (due to possible language barriers, and the risk of causing upset by asking questions about their child) and measures were adopted to mitigate this risk. There were many challenges to this process, which made me realise why this may be an under-researched area. Many lessons were learned as a result of going through the process of applying for NHS ethical approval and trying to access participants (the parent carers in particular). However, these efforts resulted in rich data, providing insights into an area that little is known about. It allowed me to engage with parent carers of BME children with LLCs and to include their voice in the academic discourse, which was hitherto lacking. The findings generated from the collection, production and analysis of this data will be presented in the following chapters.

Chapter 4 The wider context of living with a disabled child (quantitative element)

4.1. Introduction

This chapter sets the context for the qualitative research by looking at what a nationally representative study, the UK Millennium Cohort Study (MCS), can reveal about BME children with LLCs and their families. It will review quantitative data, which links to some of the themes from the qualitative chapters, and provide a narrative. It will address some of the themes and issues that emerge in the qualitative chapters, in addressing the following research question:

> *"Who supports the families of black and minority ethnic children with life-limiting conditions?"*

The quantitative chapter provides a wider context relating to the families of BME children with LLCs, as well as those without; and indicates where there are ethnic variances between categories, and explores the availability and accessibility of different types of support. Caring for a disabled child can place additional demands and pressures on some families (Boyd, 2002), and therefore it is important to assess and address these needs. There are 26 tables, which cover a range of areas, all relating to an aspect of the research question. Data from the MCS, Wave 5, will help explore the following question: is there ethnic disparity

between groups of children and their families (with or without LSIs) in relation to the availability and uptake of informal and formal support and services? Due to limitations regarding the coverage of MCS data, the focus will be mainly on educational settings, and the informal social context of the families. These areas link with the themes in the qualitative chapters (chapters 5-8). The chapter will start by explaining the aim of the quantitative element of this study, and the challenge of identifying a large dataset that includes both ethnicity data and data on children with LLCs. Two main areas will be explored: educational settings and interactions with formal and informal support, including social networks and family support, that is available to the child who is the focus of the study (referred to as cohort member (CM)) and their family. Education is a focus for several reasons; for example, disabled children and children with LLCs spend a large amount of time in school and can access a range of additional health services at these settings. Special schools can be a source of support for the parent carers, who may access a variety of support services through the school such as financial support, or peer support through groups facilitated by the school. Some of the themes that the qualitative findings chapters focus on, such as support from health and social care services, were not covered by MCS questions so do not feature in this chapter.

The aim of this chapter is to ascertain whether ethnicity plays a part in the experiences of BME children with LSIs. Do children with LSIs and their families have different experiences when it comes to education, socialising, and access to informal and formal support? Essentially, the focus is on children with LSIs, however, reference will be made to children without LSIs, when this is noteworthy,

and provides a useful comparison. According to the literature, families with a disabled child from BME groups are more likely than comparable white families to experience considerable inequality, discrimination and disadvantage relating to work, education, housing, transport and social services (Broomfield and Dodd, 2004). The data here allowed us to look at any ethnic variance in relation to some (but not all) of these topics.

4.1.1. Aim of quantitative research

The aim of this chapter is to paint a picture of the wider group of BME children with LSIs and their support systems (formal and informal), and social activities, interactions, and even behaviours. This data provides a comparison point for the qualitative data, which focusses on a more specific group of children (BME children with LLCs). There are several reasons for exploring quantitative data alongside the qualitative data. Fraser, et al. (2012) found that BME groups had higher rates of prevalence of LLCs amongst children; in contrast with reports of low take-up of formal support services from BME groups (Greenwood, et al. 2015; Szczepura, 2005). Low rates of engagement with formal services has been attributed to greater availability and accessibility of informal support networks amongst BME groups (Ahmad, et al. 2000). The data from Wave 5 can help to explore this disjuncture. The exploration of the quantitative data also provides an extra layer of information regarding the patterns of service use and engagement with formal and informal networks between different groups of families, and

children, irrespective of ethnicity and disability. It is an opportunity to explore the wider context of the position occupied by different groups of children and their families in society.

4.1.2. Ethnicity data on children with life-limiting conditions

This research process has drawn attention to the limited availability of ethnicity data, as well as data in relation to children with LLCs (Aspinall and Jacobsen, 2007; Fraser, et al., 2012). There could be a number of reasons for the paucity of such data, however, ethnicity data would be invaluable, were they to be routinely collected. One reason for the limited availability of ethnicity data could be the fact that ethnicity and 'race' are sensitive issues and a specialist subject, using concepts and language that may not be easy for researchers to apply. Researchers may not feel confident or competent to undertake this task. Kai, et al. (2007) found that despite receiving training in cultural competency, health professionals experienced uncertainty when working with ethnically diverse groups, leading to hesitancy and inertia; this could reasonably be extended to researchers. They may also not be aware that these data are needed, or the added value of ethnicity data. Details of some datasets which contain ethnicity data that could be used for health and social science research are provided by Mathur, et al (2013), who suggest that the situation is improving. Husnain-Wynia and Baker (2006) refer to the challenge of small sample sizes, resulting in the application of such data being limited to only broad ethnic and racial groups. This makes assumptions regarding homogeneity of BME groups. Focussing mainly on clinical trials, Hussain-Gambles, et al, (2004) give the following reasons why BME

groups are under-represented in research: costs (those for interpreters), participants' lack of ability to speak or understand English (a common exclusion criteria), prejudice or negative stereotypical views of such groups ('hard to reach', assumption that they will need greater help in understanding nature of research), mistrust on the part of BME communities or previous negative/racist experiences, as well as cultural and linguistic barriers. These are just some of the reasons that could be contributing to this phenomenon.

There is a noteworthy difference when comparing the participants of the qualitative interviews (undertaken with parents of children with LLCs) with the quantitative data, which relate to children who have long standing illnesses (LSIs). Although the focus of this thesis is on children with LLCs, the challenge of trying to obtain quantitative data which provided information on both ethnicity and LLCs proved difficult. Thus, the category of LLCs is substituted with that of children with LSIs, as this was the nearest comparator. This process has also drawn attention to the limited availability of quantitative data on children with LLCs, in particular in the Welsh context. At no point is it inferred that the experiences and needs of these two distinct groups (LSIs and LLCs) will be the same, or can be conflated. Despite efforts to identify a data set that contains such information regarding children with LLCs, this was unfeasible, and the data has been unobtainable. Datasets I explored, and which did not yield this information, included the following: Understanding Society, Health Survey for England, and the Family Resources Survey.   It was a requirement from the funder of my PhD that this research would include a quantitative element, due to

the need in UK social care research for capacity building in quantitative research methods.

4.1.3. Analysis of Wave 5 of the Millennium Cohort Study

There are opportunities but also challenges in terms of the dataset utilised. All of this is about families with ill children; hence the data on a wider group from the MCS are still pertinent to the qualitative study on the more specific group of children with LLCs. The children in Wave 5 of the MCS were approximately eleven years old. The thesis takes a binary approach of comparing two ethnic categories (BME and white). The rationale for not separating out the various BME groups is that it would have made the categories too small and any findings possibly meaningless. However, the BME groups are not homogenous and there will be differences amongst groups.

Where the crosstabs in this chapter are presented as statistically significant (chi-square tests at 0.05 level), this significance relates to differences between BME children with LSIs and white children with LSIs. It is worthy of mention that some of the actual numbers of children are relatively small; particularly concerning the BME group.

4.2. Education

The presentation of findings begins with results relating to education. There are also tables which contain data that provide an overview of general issues such as which categories of children enjoy school more, moving on to the additional support provided by teaching assistants, mode of travel to school, use of breakfast clubs, as well as questions relating to special needs statementing. Comparisons are made between BME and white children, and children with LSIs and children without LSIs.

4.2.1. Inclusion of data relating to education

As mentioned earlier, the rationale for including data on educational settings is due to the crucial role special schools play in the lives of disabled children and children with LLCs and LSIs. Schools often provide a much more holistic and specialist service to disabled children and their families. This can include a range of services as well as access to holiday play schemes, a source of support for parent carers. They can have a good understanding of the specific needs of a child due to the nature of daily contact. According to Spann, et al., (2003, p. 231) "A majority of parents (75%) noted that they also brainstormed with school personnel to solve problems or issues that arose at either home or school". Special schools often run support groups for parents, where they can obtain peer support, as well as receiving important information about formal services available to them, any changes in legislation or social policy impacting on them,

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and advice regarding parenting issues. Parents often speak about the benefits and value of peer support – both from receiving and providing this (Shilling, et al., 2013). Dedicated SEN staff (Special Education Needs Co-ordinators - SENCOs) also signpost families to relevant services such as hospices, as well as providing links to charitable grants for specialist equipment and financial support for essential equipment. Special needs schools also offer parents opportunities to enhance their skills, such as through ESOL (English for Speakers of Other Languages) classes, providing free transport to attend these classes, coffee mornings, and opportunities to meet other parents for exchange of information, and peer support.

A further rationale for including education in the secondary data analysis of the MCS is the fact that children spend so much time in school that this influences their lives in a substantial way – be this positive or negative. We may be able to identify the unmet needs of some groups of children, which could then be met through a range of services. Arguably, this can be related to extended family structure and involvement, which is perceived as more common amongst BME families (Katbamna, et al. 2004; Goodwin, et al. 1997).

4.2.2. General background/scene-setting

The first table presented (Table 1) looks at whether the child enjoys school. This question was considered important to include because a child's emotional health is just as important as their physical health (Greenberg, et al. 2001). Children also spend a lot of time in educational settings so whether they enjoy the

experience or not is worthy of inclusion. This section takes a broad approach to education, focusing less on academic achievement and more on the child and their interactions in education settings with a number of players – be they family or professionals.

Table 1 (below) gauges the level of enjoyment a child experiences at school. It would appear that a higher proportion of BME children with LSIs ('always') enjoy school compared to white children with LSIs (57% and 40%, respectively). In terms of the results, the difference between BME and white children with LSIs is statistically significant (P<0.05).

Table 1 - Whether Child enjoys school (P<0.001)*							
	White				BME		
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Always	605	40.0	4627	51.0	117	56.5	1401	74.0
Usually	674	44.5	3772	41.5	57	27.5	401	21.2
Sometimes	194	12.8	618	6.8	30	14.5	83	4.4
Never	40	2.6	62	0.7	3	1.4	8	0.4
Total	1513	99.9	9079	100	207	99.9	1893	100

*Table 1*All the chi-square results, throughout this chapter, refer to the differences between BME children with LSIs and white children with LSIs, unless otherwise stated.*

Whether a child is absent from school or not can have a considerable impact on parent carers of disabled children or those with LSIs. Connections are made between academic success and school attendance (Gottfried, 2010). Frequent absenteeism can affect parents in several ways including having a negative impact on their ability to work, thus potentially placing an extra onus on parent carers. This could result in loss of earnings; it is difficult to arrange childcare if a child has complex support needs. This could add extra mental stress and worry for parents, in addition to the challenge to their finances. Asked if the child had been off school this year (Table 2), 8% of white children with LSIs answered yes, compared to 11% of the BME group with LSIs, indicating that there is a higher incidence of absenteeism amongst the BME category. Here there is no statistical significance (P>0.05). However, this absence from school could negatively impact on the educational attainment of BME children, as well as having adverse effects on the child's emotional health and well-being; those who attend special schools can receive a number of health checks and other related services in school (such as access to a paediatrician, physiotherapy, occupational therapy, speech therapy).

Table 2 - During this school year, has Child ever been off school? (P=0.068)							
	White				BME		
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Yes	113	7.5	257	2.8	23	11.1	73	3.9
No	1402	92.5	8824	97.2	184	88.9	1821	96.2
Total	1515	100	9081	100	207	100	1894	100

The question relating to suspension from school (Table 3 below) was considered relevant for inclusion because certain BME groups of children have been shown to have higher rates of suspension from schools. Research conducted by Bhattacharyya, et al (2003, p. 3) found that, "Black Caribbean pupils are around three times more likely than white pupils to be permanently excluded from school". Disproportionate discipline, such as suspension from school, has also been linked to the underachievement of BME students (Gregory, et al., 2010). When asked if the child has been suspended from school for at least one day, 3% of the white group with LSIs said yes, compared to 2% of the BME group with LSIs. The results in Table 3, for children with LSIs are not statistically significant ($P>0.05$).

Table 3 - Has Child been (temporarily) suspended from school for at least a day? (P=0.271)							
	White				BME		
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Yes	51	3.4	127	1.4	4	1.9	27	1.4
No	1464	96.6	8954	98.6	203	98.1	1867	98.6
Total	1515	100	9081	100	207	100	1894	100

The next two tables (Table 4 and 5, below) provide data relating to whether or not the parent carers have been informed that their child has special needs, and whether the child has a statement of special educational needs. Having a statement of special needs can be helpful to families for accessing further formal support services. It can also be an indication of the severity of a child's condition, as the greater the special needs the more likely the child will be to have a

statement. Research undertaken by Marchant, et al., (2006) found that when comparing numbers of statements issued to white children with those for Asian children, a lower proportion of Asian children had a statement. This could negatively affect their ability to access formal support from a range of statutory and voluntary organisations, disadvantaging BME families.

The results in Table 4 yield similar results for children with LSIs, irrespective of ethnicity: 32% BME vs. 31% white. Table 5 reveals that a greater proportion of BME children with LSIs have a statement of educational need, compared to white children with LSIs: 75% BME vs 56% white. Table 4 is not statistically significant (P>0.05), but the results for Table 5 are statistically significant (P<0.05).   This is a noteworthy difference, and important because having a statement can be an advantage to the child and their family. This challenges the findings of research undertaken by Marchant et al (2006), although that research focused only on one ethnic category (Asian). According to Bhattacharyya, et al (2003, p. 3), referring to a broader range of ethnic groups, "Proportionately more Black, Pakistani and Bangladeshi pupils are recorded as having special educational needs compared to White, Chinese and Indian pupils", indicating that 'race' and ethnicity may be a factor impacting on the statementing process. A higher proportion of BME students being statemented could be an indication of BME children having disabilities that are more serious. However, concerns have also been expressed by some about the over-representation and labelling of a greater proportion of BME children and whether it is justified or a case of 'conveniently' labelling, when faced with a child whose first language is not English (Ali, et al., 2010).

Table 4 - Has Child's school told you Child has special needs? (P=0.802)								
	White				BME			
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Yes	470	31.0	743	8.2	66	31.9	97	5.1
No	1045	69.0	8336	91.8	141	68.1	1797	94.9
Total	1515	100	9081	100	207	100	1894	100

Table 5 – Does Child have a statement of Special Needs (P=0.013)								
	White				BME			
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Yes	265	56.4	253	34.3	49	75.4	34	35.4
No	185	39.4	461	62.5	15	23.1	57	59.4
Child currently being assessed	20	4.4	24	3.3	1	1.5	5	5.2
Total	470	100.2	738	100.1	65	100	96	100

Table 6 looks at whether the child has a bedroom of their own, and if there is ethnic variance. A larger proportion of white children have a bedroom of their own, compared to BME children. Of those children with LSIs, 75% of white children have their own bedroom, compared to 50% of BME children. To speculate, the larger proportion of BME children sharing a bedroom could be for a range of reasons, including cultural norms and traditions, an indication of inadequate housing, or possibly larger family sizes. The negative impact of not having your own bedroom is that there is less privacy for a child, or somewhere to study without interruptions.

Table 6 - **Does CM have a Bedroom of their own? (P<0.001)**								
	White				**BME**			
	With LSIs		**Without LSIs**		**With LSIs**		**Without LSIs**	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Own bedroom	1132	**74.7**	6944	**77.3**	103	**50.2**	905	**48.4**
Shared bedroom	383	**25.3**	2040	**22.7**	102	**49.8**	966	**51.6**
Total	1515	100	8984	100	205	100	1871	100

Grandparents can play an important role in supporting families, especially in relation to providing childcare for working parents (Mitchell, 2008). They can also be a source of informal and social support for families. When asked how often the child sees their grandparents (See Table 7), the data reveal that there is very little difference, across all categories, in the proportions of children seeing their grandparents every day. There is no difference between children with LSIs, irrespective of ethnicity. A statistic worth drawing attention to is that a higher proportion of BME children, compared with their white counterparts, stated that they did not see their grandparents at all or less than once a week. It would appear that 8% of BME children with LSIs (compared to 3% of white children with LSIs) do not see their grandparents at all. This challenges some of the assumptions made in academic and practitioner discourse regarding BME families, multi-generational households, and the greater availability of intergenerational support and intergenerational households and support systems (Katbamna, et al. 2004). This discrepancy could be explained by things like the parents being first generation immigrants, stringent immigration laws, or could just be a result of the changing demographics in society. Another explanation could be minority ethnic groups assimilating with the majority culture and adopting values where there is less contact with family members outside the immediate family. Alternatively, only one parent may have family in the UK and the other may have come over for marriage, and have no family in this country, thus immediately reducing this source by half. However, not every family will have close bonds between parents and grandparents and other dynamics within a family can affect the relationship (Mirfin, Veitch and Bray, 1997).

Table 7 - How often CM sees Grandparents (P<0.001)							
	White				BME			
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Every day or almost every day	309	20.3	1683	18.5	42	20.3	317	16.7
Several times a week	249	16.4	1656	18.2	24	11.6	169	8.9
Once or twice a week	429	28.2	2724	30.0	51	24.6	459	24.2
Once or twice a month	246	16.2	1464	16.1	20	9.7	204	10.7
Less often than once a month	210	13.8	1212	13.3	38	18.4	350	18.4
Not at all	39	2.6	191	2.1	16	7.7	228	12.0
Total	1482	97.5	8930	98.2	191	92.3	1727	90.2

Tables 1 -7 (above) provide some general information and help explore whether ethnicity impacts on different groups of children, and it would appear that sometimes it does and other times it does not.

4.2.3. Support for child in school (formal and informal sources)

This section will look at the support that the child receives at school – either from a teacher/teaching assistant (formal support), or a family member (informal support). The focus here is on the child at school. As can be seen from Table 8 (below), in regard to formal support, a higher proportion of white children with LSIs receive support, compared to BME children with LSIs. Whether they have an LSI or not, white children appear to have greater access to the support of a teacher or assistant in class. It could be said that white children have an

advantage over BME children, across both categories (with or without LSIs), as they are more likely to receive help in school from school staff. This could impact negatively on the attainment of BME children. The results in Table 8 are not statistically significant (P>0.05). However, it is noteworthy for purposes of future studies and the context of equitable service provision.

Table 8 - Whether Child gets help at school - Child gets individual support in class from teacher, asst (A) (P=0.181)								
	White				BME			
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Yes	487	32.1	908	10.0	57	27.5	130	6.9
No	1028	67.9	8173	90.0	150	72.5	1764	93.1
Total	1515	100	9081	100	207	100	1894	100

Table 9 looks at family (informal) support in class. This involves two elements (family and school) of the ecological (micro) system interacting. A positive relationship between parents and school would result in a strong mesosystem. In the case of children with LSIs, the proportions are low. In this context, 2% of BME children and 1% of white children with LSIs receive individual support from a family member. Input from family in a formal educational setting seems minimal for all children. Most 11-year olds begin to assert their independence at this age; they may not want parental input at secondary school. Overall, both ethnic groups get little formal or informal individual support in class. Ethnic variance is negligible. The results in Table 9 are not significant (P>0.05).

Table 9 - Child gets help at school - Child gets individual support in class from a family member (A) (P=0.181)								
	White				BME			
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Yes	19	1.3	31	0.3	5	2.4	7	0.4
No	1496	98.7	9050	99.7	202	97.6	1887	99.6
Total	1515	100	9081	100	207	100	1894	100

Table 10 focuses on the social and emotional skills and well-being of the child, in the context of a school setting. Children can experience a wide range of social and emotional difficulties which manifest themselves in a number of forms. These may include becoming withdrawn or isolated, as well as displaying challenging, disruptive or distressing behaviour. This is important to gauge, as it can have an impact on a child's mental health and well-being. The figures in Table 10 draw attention to the fact that small proportions of children (irrespective of ethnicity, and whether or not they have an LSI) receive this type of support. There is no ethnic variance between the two categories of children with LSIs. The results for children with LSIs, in Table 10 are not statistically significant (P=0.967). Overall, it would highlight the need for this type of support for all children in school. The proportions of children receiving this support are low. This could be due to resource limitations. It could also be a case of low take up of this type of support from children in school, due to fear of stigma from their peers (Gronholm, et al. 2018).

Table 10 - Child gets help at school Counselling, emotional support, social skills (A) (P=0.967)								
	White				BME			
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Yes	7	0.5	17	0.2	1	0.5	3	0.2
No	1508	99.5	9064	99.8	206	99.5	1891	99.8
Total	1515	100	9081	100	207	100	1894	100

4.2.4. Child's mode of travel to school

How children travel to school was felt to be relevant for inclusion, as modes of travel can have an impact on a child's health and well-being, and socialising with friends. This can also impact on parents; transporting a child to school by car can place an additional burden on parents in terms of their time (Gershuny, 1993) and may deprive children of the opportunity for regular exercise (Armstrong, 1993). Active modes of travel to school, such as cycling and walking, "significantly increased the odds for being fit" (Voss and Sandercock, 2010, p.286). Hillman et al. (1990) also surmise that reductions in children's opportunities for independent travel may have hidden costs to the children themselves in terms of damage to their social, emotional and cognitive development. According to Timperio, et al. (2006, p. 45), "Among children, physical activity is associated with improved cardiovascular risk factors, enhanced bone health, and psychosocial well-being".

There are a number of factors which can lead a disabled child having to travel further to school than children attending mainstream schools. The option to walk to school may be unavailable to these children and their parents. Local authorities often provide disabled children with free transport, in the form of a shared taxi or a minibus, as these schools can be much further to travel to. The data in Table 11 indicate that there is ethnic disparity in terms of modes of travel to school. It would appear that a greater proportion of BME children (with and without LSIs) travel to school via public transport. There is very little difference between children with LSIs and those without. However, ethnicity does appear to have an impact. Of those children with LSIs, 2% of white children travel to school using public transport, compared to 6% of BME children with LSIs – thus three times as many from the BME category. The difference between ethnic categories for those children using local authority provision shows a noteworthy disparity between categories for those with LSIs: 11% BME vs. 6% white. The results relating to children with LSIs, in Table 11, are significant (P<0.05). Due to the limited nature of this quantitative analysis, we can only speculate about why there may be such a discrepancy, such as perhaps greater severity of disabilities amongst the BME category. In terms of travel by car, a lower percentage of BME children with or without LSIs are driven to school by car. This challenges general assumptions about transport to school and the impact of ethnicity, and expectations that a greater percentage of BME children would be transported to school by parents or other family members. It would also infer that BME parents are not fearful of community or family judgement or stigma when accessing formal support, such as local authority transport, as this is quite a visible service. In terms of the ecological system of a family, this would affect two elements of the

exosystem – transport, and employment status. A reliable method of transportation could have a positive impact on a parent carers capacity to take up employment.

In terms of travelling to school by bicycle, lower proportions of BME children (with or without LSIs) cycle to school. As can be seen from Table 10 (below) a very small percentage of children (irrespective of ethnicity, or with or without LSIs) cycle to school. It could be speculated that cycling may not be a norm or popular amongst BME families. In their US study, Larsen, et al. (2009) found that more than 62% of students either walked or cycled to school, whereas the results from the MCS would indicate that UK children use this mode of travel less frequently. Although the difference between the Larsen, et al (2009) study and the MCS is not large, it is still noteworthy.

There is very little difference between groups in terms of walking to school, irrespective of ethnicity (or LSIs), although overall the largest category walking to school is BME children *without* LSIs. This confirms research undertaken by Owen, et al. (2012) that ethnicity is not a factor in terms of travel to school. However, as can be seen in the table below, there are ethnic variances in several modes of travel.

Table 11 - Transport to school (P<0.001)							
	White				BME		
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Public transport	34	2.2	247	2.7	12	5.8	100	5.3
School or local authority bus	86	5.7	431	4.7	22	10.6	22	1.2
Car or other vehicle	670	44.2	3748	41.3	77	37.2	726	38.3
Bicycle	34	2.2	208	2.3	2	1.0	23	1.2
Walking	678	44.8	4384	48.3	90	43.5	1021	53.9
Other	13	0.9	63	0.7	4	1.9	2	0.1
Total	1515	100	9081	100	207	100	1894	100

4.2.5. Childcare: formal support

As stated earlier, at the age of eleven (the age of the children in wave 5 of the MCS), when children move to high school, children in the UK tend to become more independent and parents rely less on formal childcare. However, in the case of children with LSIs, this may not be the case. The availability of formal childcare also decreases for this age range. For example, although primary schools often have breakfast clubs and afterschool clubs attached to them, this facility tends not to be available in state secondary schools. In the case of BME families, assumptions may be made regarding greater access to informal childcare support, and thus less use of formal childcare services. This topic is worth exploring, as after-school clubs can have a multitude of positive benefits for attendees in terms of their academic, social, and personal achievements (Durlak and Weissberg, 2007).

Tables 12 and 13, below, relate to the use of after-school and breakfast clubs – formal childcare and sources of support for parent carers, to enable them to either have respite, or to be able to work. Table 12 indicates that there is no difference in terms of ethnicity in proportions of children without LSIs accessing breakfast club, demonstrating that ethnicity may not be a relevant factor here. A slightly higher proportion of white children with LSIs access breakfast club, compared to BME children with LSIs. The results for Table 12 and 13 are not significant (Table 12, $P>0.05$; Table 13, $P>0.05$). The largest group using breakfast clubs is white children with LSIs, which may be unexpected, as it could be anticipated that children with LSIs may experience greater barriers to accessing such a service. The lack of significance differences between ethnic groups might suggest that there is not greater availability of informal childcare in BME families, as the families choose to access this formal service instead of relying on friends or kinship care.

In contrast to the data relating to breakfast clubs, a larger proportion of children, in general, attend afterschool clubs. The largest proportion accessing this service are BME children without LSIs (32%). This again may challenge conventional thinking (and racial and ethnic stereotypes) in regard to the availability and accessibility of informal, kinship care and support amongst BME groups (Beresford, 2008). This would indicate that after school clubs are equally accessible to those with or without LSIs; that disability is not a factor impeding

access to this service. It would appear that BME families are not playing a greater role in providing childcare.

In terms of children with LSIs, a slightly larger proportion of white children attend afterschool clubs, compared to BME children with LSIs (12% BME vs. 15% white). In a US study, Blau and Currie (2006) found that demographic factors such as ethnicity can influence use of formal child care services, stating that black mothers were less likely (compared to white non-Hispanic mothers) to utilise formal child care and more likely to use care from family members and less likely to use care outside of the family. The findings here show that this does not appear to be the case in the UK, and are a reminder that BME groups are not homogenous.

Table 12 - Whether Child attends Breakfast Club (P=0.165)							
	White				BME		
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Yes	231	15.2	1251	13.8	24	11.6	257	13.6
No	1284	84.8	7830	86.2	183	88.4	1637	86.4
Total	1515	100	9081	100	207	100	1894	100

Table 13 - Whether Child attends After School Club (P=0.374)							
	White				BME		
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Yes	478	31.6	2687	29.6	59	28.5	613	32.4
No	1037	68.4	6393	70.4	148	71.5	1281	67.6
Total	1515	100	9080	100	207	100	1894	100

4.2.6. Family support/engagement with school

This section will look at parental involvement with schools in the context of attending parents' evening. It is worth looking at whether there is ethnic variance in terms of parental engagement with schools, as in the case of disabled children, they can be an important source of support for parent carers. The results in Table 14 indicate that similar proportions of parents of BME children with LSIs attended parents' evening, compared to parents of white children with LSIs. A slightly higher percentage (1.7%) of BME parents with LSI children attend, but the results in Table 14 are not statistically significant (P>0.05). Specifically focussing on Pakistani and Bangladeshi parents, Crozier and Davis (2007, p. 296) found in their study that "It was clear from the parents that they were not very, and in some cases not at all, involved in their children's schools and knew little about the education system or what their children were doing in school". The implication is that BME parents are less engaged with their child's school. However, the authors go on to clarify that this is not due to a lack of interest on the part of these parents, but mostly due to the lack of schools applying proactive strategies to engage with them. Harris and Goodall (2008, p.277), reinforce these findings about schools being 'hard to reach' and state that, "powerful social and economic factors still prevent many parents from fully participating in schooling". Due to possible language and literacy barriers, and perhaps low confidence, fear of prejudice and racism, it may have been expected that fewer BME parents attended parents' evening compared to the British white group. However, this is not reflected in the figures from the MCS.

Table 14 - Who has been to Parents' Evening - Respondent (parent) (P=0.459)							
	White				BME		
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Yes	1229	89.5	7316	88.2	177	91.2	1599	87.7
No	144	10.5	982	11.8	17	8.8	224	12.3
Total	1373	100	8298	100	194	100	1823	100

4.3. Social networks and family support

This section will focus on informal networks - the family's social networks, and the support from extended family members, as well as friends and neighbours. It will explore the social support networks of families to highlight differences between those who have LSIs and those who do not. This type of support can be wide-ranging and include practical support (such as childcare), financial support, as well as emotional psychosocial support, which may help ameliorate stress during a crisis. Sources of support include grandparents, siblings (and other relatives), as well as friends and neighbours. Research has shown that even perceptions of social support can contribute to good mental health (Lakey and Orehek, 2011).

Katbamna, et al. (2004), in their study with South Asian families, challenged assumptions around extended family support; they found that South Asian carers did not have a greater resource of informal support from friends and families.

They found BME groups faced greater barriers to informal social networks, as their caring role restricted their capacity to build friendships and thus social networks of support.

The precarious nature of informal support would suggest that it might not be an adequate substitute for formal support services (White and Hastings, 2004). The two are not interchangeable. Informal support is precarious in that it could suddenly and unexpectedly become unavailable for a wide range of reasons. For example, people may experience their own personal issues and have crises to deal with. There is also the matter of the impact of informal care provision on family dynamics, and long-term relationships, and the tension this could create within a family. A family may feel indebted to others. Katbamna, et al. (2004) found that a barrier to accessing informal support from family members was the fear of obligation. Having to rely on family support may put a strain on family relationships.

4.3.1. Childcare and informal networks

This section will explore informal support networks and the availability of childcare. Does having an LSI have an impact? Potential sources of support are grandparents, friends and neighbours, and older siblings and other relatives. Data are provided regarding differences in childcare available in the week, compared to that on weekends. Informal childcare during weekdays would be a financial advantage for the parent carers (potentially free childcare), and could help them to take up paid employment, which could have a positive impact on the parent carers and the family in a number of ways. At weekends, it could be a

valuable source of respite for parent carers, irrespective of whether they work or not, as caring responsibilities can isolate carers and have a negative impact on their mental health and well-being (Andrén and Elmståhl, 2008). The significance of work for parent carers is discussed further, from qualitative findings, in Chapter 5.

4.3.1.1 Grandparents and informal childcare

Support from grandparents can take a variety of forms, and can include financial, emotional, and practical support. It is useful to address this topic, as despite the presence of a good deal of literature regarding the contribution made by grandparents, and grand-parenting for non-disabled children, there is a paucity of research on grandparents providing support for families of disabled children (Mitchell, 2008). Table 15 (below) presents results regarding childcare provided by grandparents, during weekdays. It appears that white children, irrespective of whether they have an LSI or not, have greater access to childcare from grandparents (during weekdays) than BME children. Of those with LSIs, 27% white and 19% BME are looked after by grandparents during term-time weekdays. The results in Table 15 are statistically significant, in relation to children with LSIs ($P<0.05$). This would indicate a greater need for formal support services for BME children with LSIs, to provide childcare and respite for the families of BME children with LSIs. To speculate, the BME group of children's parents will include first generation immigrants who do not have parents resident in the UK. This indicates less grandparent input and support for BME children and their families.

There is a notable difference between the two BME categories in terms of grandparent support during term-time weekdays. Fewer BME children without LSIs receive this support from grandparents, compared to BME children with LSIs (19% with LSIs vs. 16% without LSIs). In the white group, this difference is less marked: those with LSIs: 27%, and those without LSIs: 28%). Whether it is weekdays or weekends, makes little difference. An explanation may be that the BME children have a greater severity of disability, which grandparents did not feel they could manage. There could also be a possibility that grandparents may not have the knowledge and experience of the British system (as well as language and literacy barriers) for them to feel confident to provide such care, as well as the parents of these children having less confidence in their ability to provide care. There may be generational differences in child rearing practices and culture in the extended family. Anecdotal evidence and experience show that some BME children brought up in the UK do not necessarily speak the language their grandparents speak (from their country of origin), creating a possible layer of difference and a potential barrier.

Table 15 - Who looks after the child term-time *weekdays* – Grandparents (P=0.013)								
	White				BME			
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Yes	409	26.9	2558	28.1	39	18.8	312	16.4
No	1112	73.1	6536	71.9	168	81.2	1586	83.6
Total	1521	100	9094	100	207	100	1898	100

The same question was asked in Table 16 (below) but this time in relation to childcare provision, during weekends. A slightly lower proportion of grandparents provide such support for BME children with LSIs, compared to the white group of children with LSIs (20% white vs. 18% BME). The results for Table 16 are not statistically significant (P>0.05).   This reinforces the findings from Table 15 (above) that BME families have less access to practical support in the form of childcare, from grandparents. The difference is small, but worth noting.   This has important implications in terms of highlighting the increased need for respite from formal services such as hospices that BME families with LSIs may have. This issue will be further explored and expanded on in Chapter 6.

Table 16 - Who looks after the child Term-time *weekends* – Grandparents (P=0.706)							
	White				BME		
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Yes	296	19.5	1638	18.0	38	18.4	233	12.3
No	1225	80.5	7456	82.0	169	81.6	1665	87.7
Total	1521	100	9094	100	207	100	1898	100

4.3.1.2. Friends and Neighbours, and Childcare

Tables 17 and 18 (below) provide data on input from friends and neighbours in the context of providing childcare. Table 17 relates to weekdays, and Table 18 to weekends. The results for neither Table 17 nor Table 18 are significant (Table 17, P>0.05; Table 18, P>0.05).   BME children with LSIs are the category who are least likely to receive support from friends and neighbours. It could be speculated that the parent carers of BME children with LSIs face the greatest challenge to taking up paid employment or having access to weekday respite

through friends and relatives.   It would appear that overall, BME families, in comparison to white families, do not have greater access to friends and neighbours who provide childcare. The notion of BME communities supporting each other is challenged.   Therefore, it cannot be assumed that BME families have a strong source of community support.   This ethnic stereotype is open to challenge. Grandparents appear to provide greater access to childcare for BME children without LSIs, whereas friends and neighbours are a greater source of support for those BME children who have LSIs.

Whether friends and neighbours look after the child during term-time weekends (Table18), there is no ethnic variance between those children with LSIs (2% BME vs. 2% white). White children receive the same amount of support from friends and neighbours, irrespective of whether they have an LSI or not, whereas with the BME group, friends and neighbours are more likely to provide support for a child with an LSI than one without.

Table 17 - Who looks after the child term-time *weekdays* – Friends/Neighbours (P=0.593)							
	White				**BME**			
	With LSIs		**Without LSIs**		**With LSIs**		**Without LSIs**	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Yes	75	4.9	454	5.0	12	5.8	61	3.2
No	1446	95.1	8640	95.0	195	94.2	1837	96.8
Total	1521	100	9094	100	207	100	1898	100

Table 18 - Who looks after the child Term-time *weekends* -Friends, neighbours (P=0.425)							
	White				BME		
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Yes	25	1.6	148	1.6	5	2.4	27	1.4
No	1496	98.4	8946	98.4	202	97.6	1871	98.6
Total	1521	100	9094	100	207	100	1898	100

4.3.1.3. Older Siblings and 'Other' relatives, and Childcare

The next set of tables provide data on the availability of childcare from older siblings at weekends (Table 19), and other relatives during weekdays (Table 20), and at weekends (Table 21). It can be seen from Table 19 that a greater number of BME children (irrespective of whether they have an LSI or not) receive care from an older sibling, at weekends. For those with LSIs, 11% of BME children with LSIs receive care from older siblings at weekends, compared to 6% of white children with LSIs. There could be numerous reasons for this variation. It could be speculated that BME groups may have larger nuclear families. Alternatively, that BME siblings are more willing, due to cultural expectations, to provide this type of support for a younger sibling. Findings from a European study of BME young carers (Care2Work, 2017) showed that this group of young people face a number of challenges, including language and migration barriers as well as access to employment and support. However, it is important not to generalise about BME groups per se, as the category 'BME' is not homogenous, and there will be cultural diversity amongst this group. In some cultures (such as South Asian groups), it may be an expectation that siblings provide such support. This has implications for policy in terms of young carers from BME groups and

services engaging with them, and providing support and respite for them, as they may not identify as carers and consider this a normal part of their role in the family as older siblings. The results for Table 19 are not statistically significant (P>0.05).

Research undertaken by Dearden and Becker (2004) compared white and BME young carers, to see if there was ethnic variance in the amount of hours they spent undertaking caring responsibilities. They found there was no ethnic difference. The results from Table 19 challenge the findings of that research. Caring responsibilities could have a negative impact on the social life of the BME older siblings, as well as on their educational outcomes, and mental health and well-being.

Table 19 - **Who looks after the child Term-time weekends - Older brother, sisters (P<0.001)**							
	White				**BME**		
	With LSIs		**Without LSIs**		**With LSIs**		**Without LSIs**	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Yes	90	5.9	505	5.6	23	11.1	161	8.5
No	1431	94.1	8589	94.4	184	88.9	1737	91.5
Total	1521	100	9094	100	207	100	1898	100

Tables 20 and 21 (below) explore whether this childcare is available from other relatives. The results for Table 20 are not significant (P>0.05). However, they are significant for Table 21 (P<0.000). The proportions for all categories are low. It would appear that this type of support is a less available resource. According to these results, more BME children, irrespective of whether or not they have an LSI, receive childcare during term-time weekdays from other relatives,

in comparison to white children. There is no notable difference between the categories in terms of whether or not a child has or has not an LSI; however, ethnicity does appear to have an impact. Table 21 shows that these findings are replicated in the data for the weekends as well. These findings reinforce some of the ethnic stereotypes regarding BME extended families.

Table 20 - Who looks after the child term-time *weekdays* – Other Relatives (P=0.270)								
	White				BME			
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Yes	88	5.8	432	4.8	16	7.7	156	8.2
No	1433	94.2	8662	95.2	191	92.3	1742	91.8
Total	1521	100	9094	100	207	100	1898	100

Table 21 - Who looks after the child Term-time *weekends* Other Relatives (P=0.326)								
	White				BME			
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Yes	59	3.9	251	2.8	11	5.3	108	5.7
No	1462	96.1	8843	97.2	196	94.7	1790	94.3
Total	1521	100	9094	100	207	100	1898	100

The next section looks at the frequency of the child (cohort member) looking after elderly, sick, and disabled family members. The aim is to try to establish some pattern and norms around family support from the responses to this question. It

will also provide an indication of the numbers of young carers in the two ethnic categories and any differences. Caring responsibilities can negatively impact on a child's ability to socialise, as well as affecting their mental and emotional well-being (Aldridge and Becker, 1999). It may also affect their educational achievements and thus this information would be of interest and relevance to educational settings. Research, policy and practice regarding the needs of children with caring responsibilities and their families advocate for the need for interventions and support that are based on whole family approaches (Aldridge, 2018). Social work and social care organisations may be in a position to support young carers. From the data in Table 22, it appears that irrespective of whether or not they have an LSI, a slightly larger proportion of BME children have regular caring responsibilities. The difference between ethnic categories in relation to children with LSIs is not statistically significant (Table 22, P>0.05). 4% of white children with LSIs care on a daily basis for either elderly, sick or disabled family members, compared to 6% of BME children with LSIs. This difference could be explained by a number of possibilities, such as BME groups having more of a tradition of caring for family members. However, the risk here is that we could be resorting to ethnic stereotypes. Another possible explanation for the increased frequency of caring for relatives amongst the BME group could be due to larger families, and greater prevalence of certain disabilities and conditions amongst BME groups. Or BME groups may face greater barriers to accessing services.

The findings in relation to caring responsibilities of BME children have implications for carers organisations and for schools in terms of how they can support such children. There are also implications for social policy and

awareness amongst carers' organisations of the potential support needs of BME young carers.

Table 22-How often does CM look after Elderly, Sick and Disabled Family Members? (P=0.307)							
	White				BME		
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Every day or almost every day	58	3.8	272	3.0	12	5.8	100	5.3
More than once a week	105	6.9	537	5.9	20	9.7	150	7.9
More than once a month	101	6.6	526	5.8	11	5.3	146	7.7
Not at all	1257	82.6	7758	85.3	164	79.2	1501	79.1
Total	1521	99.9	9093	100	207	100	1897	100

4.4. Leisure / Social activities

This section looks at the child's engagement with social, leisure and religious institutions. It will cover access to and take up of service from a diverse range of formal institutions such as libraries, as well as religious institutions. Disabled children are said to experience higher levels of social exclusion, due to lack of disability friendly services (Morris, 2001). Children with physical disabilities are particularly considered to be at risk of social exclusion from commonplace social activities (Law, et al. 2006). There is widespread awareness and acknowledgement of the negative psychological impact of social exclusion (Kurzban and Leary, 2001), and therefore it is considered to be relevant to look at these areas. Through social activities, families often form networks of support and create social capital. If families are unable to access such opportunities, then this may form a barrier to informal support. Children tend to socialise and have friends who live local to them (school friends). In the case of disabled children or children with LLCs, they often attend special schools, which may be outside their locality. This may isolate them from peers during school holidays.

This section hopes to establish what local networks this group of children and their families may have access to and are engaged with. The relevance of some of these institutions, libraries, for example, may have altered since data were originally collected in 2012, and become of lesser importance since, with some public libraries closing in a climate of austerity (Goulding, 2013). However, engagement with religious and cultural organisations is particularly relevant, as

in Western society, these institutions can be a source of support for families (financial, practical, social, and emotional support), and assumptions can be made regarding these institutions being a substitute for formal services in the case of BME families. This issue is discussed in detail in Chapter 6, and in particular, barriers families may face.

Table 23 (below) asks the child how often they visit the library. In the past, libraries tended to play a much more significant role in the lives of children and their families in the UK, compared to the present, where technological advances mean society has access to virtual libraries without leaving the home. However, they can still be a useful resource in terms of a quiet place to study, and somewhere for families to visit together, and for children to socialise. Research undertaken by the Department for Digital, Culture, Media and Sport in England (Taking Part Survey, 2018), found a lower percentage of people from all ethnic groups used public libraries in 2015/16 compared with 2005/06. The largest drop in library use between 2005/06 and 2015/16 was among white people (from 47% to 32%) and people from the Other ethnic group (from 55% to 40%). In all 3 years, people from the Black and Asian groups were significantly more likely to use public libraries than white groups. However, these data relate to people aged 16 and over, whereas the participants in Wave 5 of the MCS are children under the age of 16.

The data in Table 23 (below) show that BME children (regardless of whether or not they have an LSI) were overall more likely than white children to use libraries.

White children with LSIs are the category who visit libraries least frequently. The results in Table 23 are not statistically significant (Table 23, P>0.05). The higher proportion of BME children attending libraries in the MCS could be due to limited resources at home, or the need to find somewhere quiet to undertake schoolwork.

As can be seen from Table 24, BME children (irrespective of whether they have an LSI) are less likely than white children to have a quiet area where they can work from. This could be a factor that contributes to a higher proportion of BME children visiting libraries; at this age, children usually move from primary to secondary school, where the importance and volume of homework tends to increase. Cultural factors may also be contributing to ethnic disparities such as some BME groups encouraging educational attainment amongst their children, cultural norms of visiting libraries, and there may be fewer places for children to visit without fear of experiencing discrimination or direct racism. The results in Table 24 are statistically significant (P<0.05).

Table 23 - How Often Does child Visit Library (P=0.162)							
	White				BME		
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Once a week (or less)	119	7.9	740	8.2	25	12.1	390	20.5
Several times a year	655	43.0	4011	44.1	96	46.6	803	42.3
Once a year/Never	747	49.1	4338	47.7	85	41.3	705	37.1
Total	1521	100	9089	100	206	100	1898	99.9

Table 24 - Quiet area where CM is able to do Homework (P=0.022)							
	White				BME		
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Yes	1446	95.4	8654	96.3	186	91.6	1749	93.5
No	70	4.6	330	3.7	17	8.4	122	6.5
Total	1516	100	8984	100	203	100	1871	100

The next table (Table 25) provides data on the child's contact with religious organisations. In the UK and Christian context, churches can provide a range of support services for families who attend and are part of their congregation, including access to childcare facilities such as playgroups, and financial and pastoral support, which cannot be assumed in the case of other religious groups. Religious organisations may also provide access to opportunities to socialise with peers, which is important in the case of disabled children, who can face barriers to social and leisure opportunities, impacting negatively on their well-being (Murray, 2002; Beresford and Clarke, 2009). It is worth noting that children with LSIs in this study may or may not have physical disabilities, which could impact their ability to access this resource. Physically disabled children may experience greater barriers to accessing such services. Even attending such a service once a week could have a positive impact on the psychological well-being of a child, especially one who has LSIs, to be able to connect and socialise with others and to leave the home for a purpose other than attending school or medical appointments.

The rationale for exploring this topic is based on several factors, including the possibility that isolated BME families may seek social support from people who

share their culture and language through religious institutions. They may be a source of emotional and practical support. There is also the ethnic stereotype of BME groups socialising and accessing support through such institutions, and them potentially being able to provide support services. They may be perceived as a substitute for formal services.

As can be seen in Table 25, ethnicity plays a part in terms of engagement with religious institutions. Overall BME children have higher levels of engagement with religious services than white children do. Table 25 and Table 26 (below) reinforce findings from research undertaken by Scourfield, et al. (2013). The figures that stand out are regarding the daily contact a large percentage of BME children have with religious institutions – 19% of those without LSIs, and 22% with LSIs. In contrast, less than 1% of white children (with or without LSIs) engage with religious services on a daily basis. Twice as many BME children (with or without LSIs) attend religious services on a weekly basis. The results in Table 25 are statistically significant (P<0.05). There are a number of significant factors to consider, regarding these findings. To speculate, BME children may have to prioritise these commitments over attending alternative events, which may be run for young carers, disabled children, or children in general. This could be a barrier to them attending afterschool activities and accessing resources such as Homework clubs, and other sports and recreational activities. The BME children may have less time to focus on their school studies and homework, and therefore may need extra help and support. Services hoping to reach this group of children (BME children) may wish to consider offering services in a different way – e.g. offering homework clubs and other sports activities that usually run

after school, at the weekend for those children who due to religious commitments cannot access them during the weekdays. Formal support services tend to refer to BME groups as being 'hard to reach'; this data would indicate that such groups can be targeted through religious institutions, as well as a good place to publicise the availability of formal support services amongst this group.

Table 25 - **How often child attend Religious Services (P<0.001)**							
	White				**BME**		
	With LSIs		**Without LSIs**		**With LSIs**		**Without LSIs**	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Every day or almost every day	8	0.5	45	0.5	40	19.3	407	21.5
More than once a week	222	14.6	1442	15.8	63	30.5	724	38.2
More than once a month	266	17.5	1745	19.2	33	15.9	272	14.4
Once a year or never	1024	67.4	5858	77.4	71	34.3	494	26.1
Total	1520	100	9090	99.9	207	100	1897	100.2

Table 26 gives data on frequency of interactions between a child and their friends, outside of school. Children form strong friendships with peers in and out of school. These relationships can contribute to their social and emotional well-being. Chu, Saucier and Hafner (2010) found positive links between social support and well-being for children. Friendships are an important aspect of childhood. It has been documented that disabled children experience high levels of social isolation and stigma (Weiserbs and Gottlieb, 2000). It is worth noting that due to technological developments such as online gaming, and access to various social media platforms, children may interact and socialise in different ways. They may not leave the home (or their room), but still manage to build and maintain friendships and social media. In today's technologically advanced era, we appreciate that

many relationships are conducted 'virtually' through the medium of social media and other IT equipment such as smart phones and computers. Socialising can take place with individuals and groups through such technology, whilst remaining at home. These technological advances also have potential to impact positively on disabled children in terms of reducing isolation and increasing their options for socialising and communicating with others. The results for children with LSIs are statistically significant ($P<0.05$).

Table 26 reveals that BME children see their friends less often than white children. Twenty-seven percent of white children with LSIs have daily contact with their friends outside of school, compared with 19% of BME children with LSIs. In the case of children without LSIs the ethnic variance is: 29% white vs 13% BME. The number of children who never spend time with friends outside of school would indicate that children with LSIs face a greater barrier to socialising. Twenty percent of BME children with LSIs never see friends outside of school. It would appear that ethnicity and having an LSI are both factors that affect a child's interactions with their peers. Fear of racism and of disability discrimination could be a further barrier. It could be said that ethnicity has a greater impact on contributing to social isolation, in comparison to having an LSI.

There are two issues to consider here: firstly, the barriers which BME children could be facing, and what factors contribute to these (e.g. racism, fear of racism, disability discrimination, stigma, etc.) and secondly, the impact this could have on these children and their well-being. These are issues for professionals working

in educational and social care settings to be aware of when working with these groups of children who share certain characteristics (disability, ethnicity/race). It could be that parents are fearful of discrimination and racist behaviour or have had previous negative experiences and therefore prevent the children from leaving the home. For the BME children religious places may also be playgrounds with their friends. Disability may also be a contributory factor, forming a barrier.

Table 26 - How often the child spends time with friends outside School (P<0.001)								
	White				BME			
	With LSIs		Without LSIs		With LSIs		Without LSIs	
	N	%	N	%	N	%	N	%
Every day or almost every day	414	27.2	2652	29.2	39	18.8	240	12.6
More than once a week	776	51	5227	57.4	86	41.5	914	48.1
Once a month or less	225	14.8	1060	11.6	40	19.3	477	25.1
Not at all	106	7.0	155	1.7	42	20.3	267	14.1
Total	1521	100	9094	99.9	207	99.9	1898	99.9

4.5. Conclusion

The aim of this chapter was to ascertain whether ethnicity or having an LSI plays a part in the experiences of children and their families. This has been carried out through exploring data (26 Tables) from the MCS, Wave 5, focussing on four categories of children: BME children with LSIs, white children with LSIs, BME children without LSIs, white children without LSIs. These children are approximately aged 11 years. Emphasis was primarily on educational settings, and the contributions family and social networks make to support these children

and their families in a range of ways, including providing childcare as a source of support for the parents. These are some of the elements of a child or family's ecological system, and this chapter offers insights into the strengths and weaknesses of some aspects of these systems for the different families. Are some groups of children disadvantaged because of these characteristics? It also provides a comparison for the qualitative data in chapters 5-8.

Key findings

In terms of school, BME children are more likely to enjoy school compared to their white peers. They are also more likely to miss school, compared to their white peers – across both categories (those with LSIs and those without). This may be an indication of greater severity of LSIs amongst BME children. Of those children with LSIs, a greater number of BME children will have an SEN statement, a possible advantage in terms of accessing formal support services. White children are more likely to get support from staff in class, irrespective of whether or not they have an LSI. In terms of usage of childcare such as breakfast clubs and afterschool clubs, there was no ethnic variance in terms of breakfast club usage. However, the largest group of children accessing afterschool clubs are BME children without LSIs, followed by white children with LSIs. This poses the question: are afterschool clubs addressing issues of diversity and ensuring these are accessible to children with LSIs? Breakfast clubs and afterschool clubs would be considered part of the exosystem, and could impact positively or negatively on a parent's ability to work, and may have an impact on the child in terms of finances as well as parental well-being. There are challenges to the belief that BME families may have greater access to informal childcare support through friends and family.

In terms of family and community support, it would appear that some widely held beliefs are challenged. Friends and extended family would be part of the microsystem, which does not appear to be strong for BME families. White children see grandparents more frequently than BME children do. A higher proportion of BME children do not see their grandparents at all. A higher number of grandparents provide childcare for white children (in weekdays), corroborating the data from Table 7 regarding BME children having less frequent contact with grandparents. This is also the case at weekends. White children and their families have an advantage here – the children have input and contact with grandparents, and the parents potentially have support and respite from grandparents. BME children, compared to white children do not have a greater access to support from friends and neighbours, challenging the notion of BME communities supporting each other. However, in terms of 'other relatives' BME families have an advantage in that they are more likely to receive childcare from this source during weekdays and weekends, reinforcing the notion of extended BME families. There is potential to explore this in future research.

It appears that BME children, irrespective of whether or not they have an LSI, are more likely to have caring responsibilities in terms of elderly, sick or disabled family members. Moreover, BME children are more likely to travel to school using public transport, whereas more white children are likely to be driven to school by car. BME children are less likely to have a bedroom of their own, compared to their white peers. BME children are less likely to have a quiet area to work from

at home, which may help to explain the statistic of a much higher number of BME children attending libraries, compared to white children. In addition, a high proportion of BME children who frequently visit religious services, compared to white children. It would appear that BME children have less contact with friends outside of school. BME children with an LSI are particularly disadvantaged and have less frequent contact with peers compared to BME children who do not have LSIs.

The findings could shed light on the lived experience of BME children with LSIs, an under-researched area. It may help influence policy and practice in health and social care and provide answers to some of the challenges faced by service-providers in reaching BME groups. For example, BME groups are often referred to as 'hard to reach'; this data reveals that a large number of BME children (hence by proxy their parent carers) attend religious institutions on a daily basis. This would make them accessible to agencies trying to share information about their services, or who wish to consult or involve those regarding unmet needs and how the service could work with them. There is also the high number of BME children who attend libraries weekly, as another location where these children (and their families) could be found.

This chapter has highlighted the paucity of ethnicity data, as well as data on children with LLCs. Discrimination can routinely and successfully only be challenged if organisations are able to demonstrate this in the analysis of their ethnically coded datasets. Accurate ethnicity data would enable experts to

assess inequalities in health and access to services and help to ensure resources are targeted appropriately. Due to the nature of the MCS data, we can only speculate regarding some of the findings, and it would be useful to explore meaning behind some of these through future qualitative interviews with MCS participants. The qualitative element of this thesis may help to illuminate some of these issues and also explore areas not explored by the MCS.

Chapter 5 Having a child with a life-limiting condition

5.1. Introduction

Much has been written on the topic of the caring experience of parents of children who are disabled, including that of BME parents (Ahmad, 2000, Golfenshtein et al., 2016, Croot et al., 2012, Koshti-Richman, 2009, Beresford, 1994). However, there is a dearth of direct research undertaken with BME parents of children with LLCs specifically, to provide insights into their lived experiences. Calls have been made regarding the importance of the inclusion of the voice of this group (Brown et al, 2013); and in particular for academic discourse to shift from anecdotal evidence to one that includes first-hand knowledge of the experiences of such families, and most importantly, contributions from this group (Calzani et al, 2013).

This chapter addresses this gap and provides insight into the experiences, views, thoughts and feelings, of the parent carers of BME children with LLCs, on the following topics: receiving the diagnosis for their child, the impact of caring on the physical and mental health of parent carers, access to work and employment, and the role of religion. A sub-theme was the impact pf being a parent carer on other members of the family, such as the siblings. There is more focus on the topic of diagnosis, in comparison to the other topics, as this was a theme which the parents discussed in detail, and it appeared to impact on them significantly and permeate several aspects of their lives, many years after the event. The

experience of receiving a diagnosis is an event which parent carers never forget (Boyd, 2002). How this is handled can impact on parent carers' coping abilities (Brown and Warr, 2007). The rationale for looking at these particular areas was that they directly impact on the parents' ability to cope with the challenges they face in this role, and relate to potential sources of support, and to identify the support needs of families. For example, a good experience with diagnosis will give parents hope and reassurance and help them cope better (Boyd, 2002). Religion and cultural practices can help parents and children to cope with a diagnosis that they can do nothing to change, and can be a source of psychosocial support, as well as a means of sense-making. Employment can provide a welcome distraction from the role of being a carer, as well as providing financial security and stability, and opportunities for socialising. Being a parent carer will inevitably impact on family relationships (siblings in particular), as well as the physical and mental health of the parent carers. Being a carer can negatively impact on your ability to work, as well as reduce access to social and recreational activities, both of which could negatively affect emotional health and well-being (Vonnielich, Ludeke, and Kofahl, 2016). The aim is to present the 'lived experience' of this group. Some of the findings from the interviews are true for all parents of LLCs, and not necessarily distinctive to BME families. These topics also relate to themes from the literature in Chapter 2.

5.2. Diagnosis

"Our life completely, on that day, completely altered, in every which way

imaginable" – Chand's mother

When interviewing the parents of children with LLCs from BME groups, I found that they saw the interview as an opportunity to tell their story. It transpired through interviews that they rarely had the opportunity to discuss their experience of caring for a child with an LLC, citing social isolation as the main reason. Additional reasons they gave for not discussing this issue with others included fear of upsetting family and friends, general lack of interest and understanding by others, and the highly specialised and medicalised language and terminology (a potential barrier to communication).

Parent participants would wish to start their story at the beginning, and this was usually the moment of diagnosis. Their recollection of this event continued to impact them, and was lucid, despite some recounting the experience from thirteen years ago, or even longer. Parents provided a rich description of the manner in which diagnosis was conveyed, the language used by medical professionals, their feelings at the time of diagnosis, and the physical space and location where they were first told their child had a serious condition. The language was full of emotion and several parents cried when recollecting that moment. Of the twenty parents interviewed, twelve parents cried (eleven were mothers and one a father). This was perhaps a surprising outcome, considering these parents had never met me before, and we had little time to establish rapport or a relationship before this highly sensitive topic was discussed. It highlights the

strengths of their feelings on the issue, and the lasting impact of that moment. The data yield some important insights into their experiences, as well as examples of how to improve practice, and some invaluable insights into the specific needs and experiences of this group of parents. For example, the fact that one parent may not speak English is relevant here, as in such cases who delivers the news to the non-English speaking parent? Is an interpreter utilised or is the English-speaking spouse expected to deliver this message? What if only one parent is currently available and the other is temporarily out of the country? Ethnicity, culture, and language barriers can create further complexity for BME parents (Ahmad and Atkin, 1996; Katbamna, et al. 2004; Williams and Johnson, 2010). Parents spoke about their experience and elaborated on the moment that they discovered their child had a life-limiting condition. As a researcher, several challenges were posed in conducting this research with parents, a process which could be considered to be 'emotion work'. 'Emotion work' is defined as "the work involved in managing feelings in both self and others" (Hochschild, 1983, p.27), the impact on me being that I would often question whether I should be persistent in asking questions on certain topics, for fear of upsetting the parents. Seeing parents upset impacted on me and I had to put on a very strong act of remaining emotionally detached, but supportive. A more detailed discussion on this topic is in Chapter 3.

The process of breaking bad news is a challenge for those in the medical profession (Parker and Johnston, 2008), and done badly it can have a lasting negative impact on both those delivering the news, and those receiving it (Bartolo, 2002). The moment of diagnosis is described by Boyd (2002, p.14) as "a crisis

event", and one she believes that a family never forgets. Parker and Johnston (2008) found that the moment of disclosure of the diagnosis was remembered vividly by 77% of parents of children diagnosed with cancer. My experience of conducting interviews with families would reinforce this.

5.2.1. Emotional response to receiving the diagnosis

This section looks at the experience of receiving the news of their child's condition, rather than living with the diagnosis. Parents do not always receive this information from medical professionals. Other sources of diagnosis may lack the training and sensitivity required to deliver such an important message. For example, Abbas was a 16-year-old young person whose parents are from a small village in Pakistan. Neither parent spoke English, so their interview was conducted in Urdu and Punjabi. When asked about how they discovered their child had Duchenne's muscular dystrophy, this is how the parents told their story:

> *"When he [Abbas] went to school, and was about 3 years old, the school contacted us and said that your son is unable to walk properly, and has some sort of illness and you need to take him to the doctors. The doctors then checked him and said that he has an illness that will not get better; there is no cure…"* Abbas' father*.*

Both parents felt satisfied with the way they were eventually given the diagnosis by medical professionals. However, it was difficult to draw out more information from this family (the interview only lasted about 30 minutes, compared to the average length of time being approximately 1 hour 30 minutes). They felt there

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was no point in asking questions or complaining, as if it will not change the outcome for their son. Abbas's parents gave very brief responses.

Snamen, et al (2017) believe current training offered to medical professionals, combined with poor self confidence in their own communication skills, contribute to the difficulties encountered by all parties. Some of the parents interviewed spoke of how this was an extremely difficult experience for them and that nothing anyone could have done would have made the situation any easier; others suggested ways in which the experience could be improved or done better, as well as referring to aspects of the experience that they found most beneficial. Parents used highly emotive language to describe their experience of receiving the diagnosis. Rehana's mother spoke of the moment she was given her daughter's diagnosis. Many years later when recalling the incident, she was in tears:

> *"But, yeah, my world fell apart when they told me that [sobs]. It was hard. Three days and nights just crying, and I asked myself what I could do to make her better, or… make this into a dream that… that didn't happen, you know?"* [Sobs], Rehana's mother.

Adnan's father spoke of the moment their child was diagnosed, at the age of one, after 3 weeks of being in hospital and undergoing numerous tests. It was a hospital consultant who broke the news to them (both husband and wife were present). The father spoke about the emotions felt by both parents, when they were first told:

"I mean it was just like… as if your world has turned over, you know…
[hesitates, tearful] Sorry". Adnan's father.

Both these sets of parents used language demonstrating the impact of this moment on them – both using the word 'world' to indicate how all-encompassing the diagnosis was for them.

A number of criticisms were made by parents regarding the manner in which the diagnosis was delivered, and the physical environment, which they felt further compounded their experience of receiving bad news. Referring to the context of diagnosing childhood cancer, Haimi, et al. (2011) refer to the complexity of this situation and the need for a delayed diagnosis in order to explore alternative diagnoses. Eiser, et al. (1994) refer to parents' views on this topic and that they often recalled feelings of shock at diagnosis, the need for information, and appreciated that this was a difficult process for all parties concerned. In my interviews, parents identified issues which contributed to a negative experience for them. These included: language and terminology used, location of disclosure, who was present or absent (e.g. husband not being there, and too many other staff such as trainee doctors being present).   Parents also identified what contributed to a positive experience: presence of (female) staff to support and comfort a mother while the medical practitioner was disclosing the diagnosis; providing an interpreter; reassurance of continued support from the medical team; as well as sign-posting to a number of sources of formal support, and hope

for the future were some of the ways in which parents felt the doctors made the experience more positive.

Rishi's mother felt she had a particularly negative experience in receiving her son's diagnosis of microcephaly. She was unhappy that the medical professionals did not pick up her son's condition immediately after birth, and unhappy about the way in which she was given the diagnosis. She described the difficulties she experienced getting staff to initially accept that there was a need to check Rishi. This participant believed there were several warning signs which were ignored. For example, the pre-birth scan showed some abnormalities, the child did not cry at birth, there were physical signs such as a small forehead, the child could not feed and constantly cried. When Rishi's mother eventually got staff to take action, a nurse took the baby to a Registrar on another floor in the hospital to have him checked. It was the nurse who returned to give her the news, not the doctor. She was alone and would have preferred the doctor to have spoken to her, so that she could ask questions to get a better understanding of the likely impact of the diagnosis on the baby and the family, and also to have been told with her husband being present. She was particularly upset about the fact that she was given the news in the absence of her husband, as this then meant that she was left to break the news to her husband, which she found difficult. She felt that as she had not spoken to the Registrar herself, she was unable to answer his many questions, adding to the tension of an already difficult and stressful situation:

"I was a bit terrified, you know, 'why are they taking the baby, and the doctor not coming to me?' But I agreed. They said they have found a little problem, his brain looks a little small too, and they're going to have to investigate a little more. And… That's all I was told. In a ward on my own. They just left me with him and went. I feel really, really angry and annoyed", Rishi's mother.

What was interesting is that the interviewee spoke in the current context – she clearly still appeared to be angry. Ptacek and Eberhardt (1996) refer to the need for practitioners to identify relevant people who are able to provide support for the person about to receive bad news, and to ensure they are present at the time of diagnosis, as the presence of such a person gives the recipient of bad news the sense of not being isolated in this situation, and having the support of others. Coffey (2006) talks about parents expressing feelings of isolation and fear around the time of diagnosis. Rishi's mother suggested ways in which the process could have been better managed:

"The Registrar could have come and made her way down for a start. I was worried, and I was terrified. I didn't have reassurance from anybody. Having to break that news to my husband… it was terrifying… He was like, 'How do you know?'" Rishi's mother.

This feeling of isolation was echoed by Aliyah's mother. She was given the news by a consultant over the phone on a Sunday afternoon. She did not feel this was the best approach; despite a follow up meeting being arranged for the next day:

"I tell you, out of everything, what the worst thing was, is… when Dr H did the test, he actually rang with the results… I mean, when I think back on it now, it was very stressful for me, because I didn't have my husband there", Aliyah's mother.

She described how she had to break the news to her husband:

"*I think the worst thing for me was not to be able to tell my husband until I actually got there [South Africa]. I told him face-to-face. He had a complete breakdown. It was just… a complete, complete breakdown. And that's why I say that it was me that was left with… just having to deal with everything, because… It was pretty bad. He had to be taken to another hospital in South Africa – he was put on antidepressants, which he still has until today*", Aliyah's mother.

5.2.2. Language and terminology

Adnan's father spoke of how difficult it was in the early stages of diagnosis to understand the information they were given by professionals. He felt the medicalised language used by professionals created an additional barrier to effective communication. Adnan's parents were both British Asian and had an excellent command of English. Despite this, they struggled with the medical jargon, as would most parents, irrespective of ethnicity:

"What I didn't really like was the terminology – the English – that they actually came out with. It's the medical field, where they use the big, big words, like… he's got 'encephalitis' and so… 'what is encephalitis? I've never heard of encephalitis before!' [laughs wryly]. It's just frightening!"
Adnan's father.

Farhan's mother spoke of a negative experience with a doctor when her son was first diagnosed with his condition. This was a particularly fraught situation, as the child was a five-month-old baby who had acquired a brain injury. She recalled the doctor told her, "if he survives, he's going to be a cabbage", which she found extremely difficult, "I was going crazy… I had to walk out of those rooms so many times because of the words they were using". It was not the message they were conveying that she had issues with, but the actual words they used. She spoke of a different doctor who took over her son's care, and how the language he used, and his approach inspired trust in her; she would follow any advice he gave her regarding what course of treatment to follow for her son. Farhan's father was abroad when their son was born (a commander in a foreign navy), and arrived in the UK immediately after hearing about the incident. He was also unhappy with the previous doctor, who gave him his son's prognosis as soon as he arrived at the hospital:

"I went to the ICU (Intensive Care Unit) and he [Farhan] was there and he was struggling…And the doctor briefed me about EVERYTHING on the very first day. I had travelled all that way, taking a nine-hour flight, and I was shocked and everything". Farhan's father.

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This couple were in extreme emotional turmoil because of the circumstances around the baby's acquired brain injury; this process further exasperated an extremely challenging situation. Both parents were being asked to make the decision to switch off their baby's oxygen. Greater sensitivity was required from the medical team at this time.

At initial diagnosis, it is common for individuals to not understand the medical practitioners when they are informed of the diagnosis, potential treatment, and other relevant information (Gabrijel, et al, 2008). There is much information to absorb, and they can be in a state of shock (Eiser, et al. 1994), and so will inevitably struggle to absorb all information provided. Harrison and Walling (2010) recommend that practitioners ensure that the information they provide to parents is devoid of jargon and euphemisms, accurate, and that this is also provided in written form to take with them. This is in order that parents can read the information at a later date and time, which may be more appropriate. In the case of BME parents, written information may be particularly helpful where one or both parents are not fluent or confident speakers of English. This allows them the option to seek support from family or other members of their social support system to translate the information. Friedrichsen and Milberg (2006) refer to the primacy and recency effect, where patients (or in this case, parents), are likely to only remember the information they were given at the start and end of such a meeting; emotional turmoil can be a barrier to effective communication between the doctor and parents. This concept of not fully absorbing the information given is demonstrated in the case of Nadir and the occasion when his parents were

given the diagnosis of his condition. Nadir, a boy aged 5, was diagnosed with a life-limiting condition. His parents were told that he could expect to live until the age of five. Nadir's mother started the interview by saying, "I was told this illness does not have a happy ending". She described the experience of receiving the diagnosis:

"I said, 'We won't tell anyone just yet' and he [neurologist] goes 'Oh, no – you have to tell people – it's really serious!' I goes 'You said he's got epilepsy', and he goes 'No, it's more serious than that; he's also got this; this, this' and I thought 'Huh? I didn't hear that' you know, because I thought… and then it was like 'Oh my God!'". Nadir's mother.

Nadir's mother heard the epilepsy diagnosis but did not hear the second part of the diagnosis. Her strength of feeling and fear was palpable from the language used above, reflecting the overwhelming emotion she experienced as the reality and enormity of the situation dawned on her. Other parents also evidenced the strength of emotions on such occasions, which impacted on their ability to remain focussed at this critical time. Rishi's mother used strong and emotive language to reflect the strength of her feelings at the time of diagnosis, and also some years later: 'terrified', 'terrifying', 'angry'. Adnan's father used language such as 'frightening' when referring in particular to the language used by medical professionals at initial diagnosis. Zurynski, et al. (2017) recommend access to psychological support for parents in this situation. In their study, almost 50% of parent carers were offered psychological support, a significant number supported by social workers.

5.2.3 Ideas for improving practice

Parents spoke of practical ideas which could contribute to improving the experience. Asked if the experience could be improved, Adnan's father responded:

"I think… what they could have done is… taken you into a room, seated you down – away from Adnan. Because thinking back, now, when a child is sick, they don't want people overpowering them, especially these new, new faces, you know? They just want their mum and dad at the bedside, instead of having a herd of people overlooking you and asking you all these questions!" Adnan's father.

Hanif's father also felt there were ways in which the diagnosis could have been done better. Essentially, he was happy with the efforts the medical professionals made to explain the diagnosis and the prognosis for their son. It was a practical issue that he highlighted which may be noteworthy:

"Because the consultation rooms are on other clinics, when we walked out – me and my wife – and we were all emotional [they had been crying]*, and obviously seeing other people around… kind of… it was kind of – what would you say – a little bit embarrassing. We were obviously in tears in front of other people, and stuff",* Hanif's father.

Adnan's father felt that an aspect of the process he struggled with was when the consultant visited their son at his bedside. He [consultant] would arrive with a large group of other doctors which was challenging for them. He particularly felt this was the case for his wife:

> "*She always mentioned 'Well why do they have to all walk in, you know, 5 and 6 at a time?' It's quite daunting*", Adnan's father*.*

The importance of training future medical staff or obtaining the opinion of other practitioners is understandable, but it is worth noting the impact on parent carers and considering alternative ways to manage this in the initial stages. It does not appear that the family were forewarned or given an explanation or the rationale for the presence of others – which may have helped. As they were a Muslim couple, I explored religious or cultural reasons being the basis for this discomfort, but he felt that was not the case. He also expressed his dissatisfaction with the fact that they were given the diagnosis of their child's condition by the bedside of the child, in his presence, which added to the distress of the parents:

> "*Everything was done at the bedside, where Adnan was. Because then you're looking at your son – you're looking after him – and then you've got to answer questions, you've got to talk to the doctors, which I thought was… wasn't really fair, you know. It's not that Adnan doesn't understand. I mean… ok, he's a year old, but it's the sense that he's got fright as well*", Adnan's father.

Ptacek and Eberhard (1996) refer to some of the qualities that were valued by parents when receiving a diagnosis, which included clear and comprehensive information, and an approach which demonstrated compassion, care and empathy. However, there is a need to be mindful of not providing too much information, as that can be overwhelming, potentially causing parents unnecessary stress, worry and anxiety (Pelentsov, et al. 2016). Ruby's mother spoke of being extremely upset at the time of diagnosis, but felt that the manner in which it was done helped her to cope better. She explained how the consultant broke the news to the parents gently, ensured there was a female member of staff present to comfort her, and provided reassurance that the family would get all the support that they needed from him and other specialist services:

"He did help a LOT, to give us comfort, but it still wasn't good to hear this news", Ruby's mother.

Eshan's mother also spoke positively about the process of being told her son had a serious renal condition, a few weeks after he was born. Of course, it was distressing news, but how it was managed helped her accept the diagnosis. She spoke of how she valued that the consultant spoke to her openly and honestly, creating a bond of trust, and told her, *"He's alive today, don't know about tomorrow"* and encouraged her to be positive and enjoy the time she had with her son. She also stated that she valued their use of a professional interpreter to help her understand the information provided. Chand's mother spoke about the moment when their son was diagnosed with a serious heart condition. She had taken Chand (at the age of 4 months) to the GP as there were feeding issues and

he had diarrhoea. She spoke of how the GP noticed something unusual and told them to immediately take him to the local hospital. After conducting tests, she recalled the doctor stating:

"'We think there's a problem with his heart, and we need to transfer you to [nearest children's hospital]'. I said, 'OK'. I said to my husband, I said, 'Right go and get the car then' [laughs wryly], and he [doctor] said, 'No, no, we'll come with you' and I was like 'Oh, ok… Ok, this is really nice…' And then…Down the ward came this incubator, and I was thinking 'Oh wow! Some child's really poorly' and she said, 'We're going to put Chand in this' so I was like 'Oh my God!' I didn't realise how ill he was. I was like, 'Oh my God! It was quite traumatic, really, yeah". Chand's mother.

Their son had heart surgery immediately. That night they took him into theatre at 9.30p.m. and the parents were allowed to see him the following morning at about 10.00a.m. (twelve hours later) in the intensive care unit.

"And yeah, that was it. So yeah, within 24 hours, he'd had major heart surgery… It was life-changing". Chand's mother.

When asked if the way news was broken to them could have been improved, Chand's mother stated:

"There's no easy way to break bad news, really, and I think they just needed to tell us the information quickly – and get consent as quickly as

possible. So, under the circumstances, it was the best they could have done". Chand's mother.

Dana's mother was angry about how she discovered her new-born daughter had a serious condition. Her son (now deceased) had been born with this same condition; both children were born with cataracts, a symptom of the condition. She informed staff at the hospital about the cataracts straight after her daughter had been born and raised concerns but was told "she's fine". Having previously lost a child to the same condition, this mother was alert to her daughter having some of the same symptoms so when she found the hospital staff were not taking her concerns seriously, she went home and found all the contact details of the specialist medical teams who had cared for her son and contacted them directly. At this point the isolation must have been overwhelming for her, especially as she also had to break the news to her husband. However, the mother spoke about her daughter's condition being rare and that it was unreasonable to expect medics to know about these rare conditions and to be able to identify them immediately. This reinforces the literature on the topic of diagnosing rare diseases (Pelentsov, et al. 2016; Muir, 2016). The mother here experienced a high level of mental health issues and spoke about having recently had a serious mental health episode which she referred to as a 'nervous breakdown'.

There was an interesting dimension to the diagnosis issue where the parents of Abbas (sixteen-year-old with Duchenne muscular dystrophy, and full capacity) – unprompted - discussed his awareness of his condition:

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"Our son knows what illness he has. Someone told him in school that when he will be 18 years old, he will pass away… Not live. He will not live… He was so, so, so upset… And asked me if this was true. I said no, that is not the case. We will leave it all to God, and what is His will is what will happen". Abbas' mother.

To conclude, it appears that this is an area fraught with potential pitfalls for all involved. Medical professionals appear to receive some form of training relating to communication of sensitive information, and research has provided guidance for practitioners on some of the actions and interventions that are valued by patients and their representatives, and what to avoid, but this does not necessarily translate into practice. Claramita, et al. (2019) suggest that by using a partnership-oriented and culturally sensitive communication approach, doctors can improve their communication skills with their patients leading to optimum health outcomes. The negative impact of a poor diagnosis experience can be seen to have a lasting negative impact on the mental and emotional well-being of parents, and a good experience helps parents to cope better with their situation.

The next areas I focus on are: impact of caring for a child with an LLC on parental health and well-being, impact on the non-disabled siblings (from parental perspective as no interviews were conducted with children), work and the availability and accessibility of this as a source of informal support, and how religion is mentioned by parents as a coping strategy and source of comfort and hope. These topics relate to sources of support, parental coping (and adjustment to their child's condition and illness trajectory) as well as providing insights into

the experience of being a parent carer. What we know is that caring for a child with a disability or LLC can impact negatively on family dynamics in several ways, leading to disruption within the family and high levels of stress for the parent carers (Floyd and Gallagher, 1997; Pelentov, et al. 2016; Whiting, 2012; Isa, et al. 2016). Therefore, trying to get a better understanding of the family experiences gives practitioners vital insights in terms of how to support families, and may lead to improved outcomes for such families.

There are many challenges faced by the parents of children with life-limiting illnesses. In the case of BME parents these challenges and pressures can be further exasperated by additional issues (Williams and Johnson, 2010). These additional issues may be language and literacy barriers, immigration issues resulting in fewer available support services and resources (including access for formal support services and informal support systems), racism, and current negative discriminatory experiences, lack of knowledge of their rights and entitlements, and the pressures of navigating an unfamiliar statutory system which is complex and continuously evolving (Funk, et al. 2010; Katbamna, et al. 2004; Ahmad and Atkin, 1996).

5.3. Experience of caring and impact on family well-being

Parent carers of disabled children (or children with complex health issues) are known to be susceptible to poor health (Vonneilich, Ludecke, and Kofahl, 2016; Raina, et al., 2005; Fairfax, et al., 2019; Pelentsov, et al. 2016; Whiting, 2012).

This section will look to identify support needs of the family, which could be addressed through both formal and informal support. These issues are not specific to BME families, however, it may be worth highlighting that they also impact on this group of families.

5.3.1. Impact of caring on parental health

I noticed during interviews the frequent and casual manner in which the interviewees mentioned mental health issues. Glidden and Schoolcraft (2003) discuss the high prevalence of depression amongst mothers of disabled children, due to the stress of caring responsibilities. Aliyah's mother spoke of both her and her husband having nervous breakdowns. Dana's mother also mentioned she had experienced a nervous breakdown. Farhan's mother described her mental health issues; she had the full support of her husband, parents, and four siblings (who all lived locally):

> "*I've been on depression tablets. People around me – my husband even – they said don't take them, but I knew at that time… I was finding it difficult – especially when I'm alone and he's [husband] not here – I find it REALLY difficult because you've got no one to talk to. You don't share what you're going through*", Farhan's mother.

Many of the parents experienced acute worry and fear that the next episode of their child's illness could have unspeakable consequences, making them very vulnerable. Chand's mother articulated this state of worry and anxiety thus: "We're faced with death, almost on a daily basis". Parents spent much time

focussing on the needs of others and did not appear to pay due regard to their own health and well-being. "You forget yourself" said Dana's mother, who felt she ignored her own needs for so long that she did not realise how bad things had become until she had a nervous breakdown. Parenting a child with an LLC has been shown to have profound physical and psychological health implications for parents (Vonneilich, Ludecke, and Kofahl, 2016; Whiting, 2012) including their relationship with each other (Da Silva, Jacob, and Nascimento, 2010). However, Pelentsov, et al. (2016) found in their study with parent carers of a chronically sick child, that some parent carers felt that their experience of caring had a positive impact on their relationship, bringing them closer and strengthening them as a couple. However, the majority of parents found their experiences to be negative, which is also reflected by the participants of my study. Direct questions were not put to participants about their marital relationships, but this issue was mentioned by some. This topic is something which could be explored further as part of a future study.

Some parent participants had significant additional responsibilities of providing physical care for their child. Several mentioned acquiring back problems from the effort of carrying their growing child. Cantwell, Muldoon, and Gallagher (2014) undertook research looking at the impact of caring on the physical health of parent carers, and found parents of disabled children were at greater risk of poor physical health. The complexity of the issues faced by some parents was highlighted by the case of Eshan, a young boy who was diagnosed with a serious renal condition at birth. Both parents struggled with their son's diagnosis. The father was diagnosed with depression and was unable to support his wife, who

donated a kidney to her son (the father was diabetic so could not be considered as a donor, and Eshan's condition was so serious that they could not wait for a donor to come forward). The mother of Eshan was then diagnosed with cancer. This was too much for the father to come to terms with and the couple separated. Eshan's mother also found the situation overwhelming, "It's really hard to look after my son *and* husband, otherwise I'd go mad". This participant was a young woman who came to the UK when she got married, and had her son soon after arriving in the UK with little time to adjust to her surroundings, her new family, build social capital, or learn English. She had no family in the UK, and had to make some difficult decisions, and deal with a whole range of complex issues relating to her son's health, as well as her own. Rishi's mother spoke of back issues she developed from manual handling of Rishi.

Nadir's mother was experiencing a high level of stress at the time of the interview and discussed the impact on her mental health:

> *"I'm not right in the head, or something's not right. I started feeling really scared, like I was having panic attacks and stuff. I need to deal with this; I have to be fine for my kids. But I do worry about myself sometimes."*
> Nadir's mother.

She mentioned how difficult it was for her to access formal support, despite approaching services on a number of occasions, and informal support was unsuitable as family members were unable to care for Nadir due to his high level of needs. There was tension between her and her husband and their relationship

was clearly under pressure as they both aired grievances and resentments towards each other during the interview. Nadir's mother expressed a great deal of anger and frustration, which is a theme which comes up in the literature (Da Silva, et al., 2010).

5.3.2. Impact on siblings

Parents spoke about worrying for their non-disabled children and juggling the needs of all family members – a stressor which could have a negative impact on their emotional and psychological well-being. This reinforces the literature on the topic (Pelentsov, 2016). Several parents expressed concerns for the siblings of the child with an LLC. This reinforced what the literature on the topic states. Reichman, et al (2008, p. 679) refer to "the ripple effects of child disability on the family", suggesting that this experience cannot be gone through in isolation; it inevitably will and does impact on other family members. Concerns expressed by parent participants particularly focused on the following areas: the negative impact on their relationship with their well child/ren, the challenge of trying to maintain a 'normal' family life, and concern for the emotional and psychological well-being of the non-disabled child/ren. Of the fifteen families interviewed, 2 families did not have any additional children. The remaining had at least one other child. These 13 families all raised concerns for the siblings of the child with an LLC. Due to the interdependence of family life, it is inevitable that there will be some impact on the non-disabled siblings (Brown and Warr, 2007; Hartling, et al., 2010). Several parents discussed the challenge they faced trying to have a 'normal' family life. Hanif's father spoke about his efforts to do 'normal' family

activities with *all* his children, arranging collective sibling activities. However, due to Hanif's condition this was a challenge which led to disappointment for his siblings. This had a negative impact on Hanif's older sibling, who had previously enjoyed a very close relationship with Hanif. This sibling missed his brother and playmate and found it very difficult to understand what was happening. Rishi's mother spoke of her children asking questions such as, "will he [Rishi] ever be able to play football with me in the garden?" She found it difficult to be direct and wanted to tell them, "He's got a damaged brain. He's never gonna be able to do that".

Aliyah's mother spoke about the lack of time she spent with her younger daughter (who was now fifteen), and the negative psychological impact on this child. She expressed feelings of guilt, and felt that she had prioritised caring for Aliyah over responding to the needs of Aliyah's younger sibling, which had impacted negatively on their relationship. She expressed regret for not utilising practical support to address Aliyah's needs, allowing her to focus more on her younger daughter's needs. She felt that in retrospect, others could have easily met Aliyah's care needs, but only she (as her mother) could have met the emotional needs of her younger daughter. But this was a tension many of the parents faced – to care for the child with an LLC or the non-disabled sibling – a very difficult decision, and one that they did not always necessarily have a choice in, irrespective of how this may appear to the non-disabled siblings. This is not unusual and comes up regularly in the literature on this topic (Zurynski, et al., 2017; Stoneman and Rivers, 2004).

Poor mental health outcomes are not only prevalent amongst the parents of children with life-limiting conditions, but can also impact on the siblings (Reichman, et al, 2008). Farhan's parents spoke of the impact on their younger (4-year-old) child (who had major thalassemia): Farhan's mother: "it's affected her a lot". Father: "A lot…". Her mother said, "It's affected her so much; she's come out with 'I don't want Farhan to die'". The family requested and received play therapy from their local children's hospice, to address the needs of the sibling. They also decided to have another child, believing this would help their daughter. Chand's younger brother would ask, "Is Chand going to die?" and "Does he have pain?" This provided insight into the kind of worry that some siblings were carrying. This reinforces the fear that the family unit experience, and as noted by Collinson and Bleakly (2009, p.108), "The impending death of a child within a family shakes that group to its core, affecting all those associated". Rishi's mother spoke of her concerns for her non-disabled ten-year-old son, as he would often offer to sit next to Rishi whilst his mother cooked, to ensure he did not choke (his condition meant this was a risk). This was quite a responsibility for a ten-year-old to want to take on. Special occasions such as birthdays and religious festivals tended to feature cultural food, which was particularly difficult for this family as Rishi was unable to eat food. The siblings found it difficult to enjoy the food while he could not; they felt guilt. Rishi's mother discussed how she had to carefully manage the situation when the siblings wanted to share food with Rishi. Parents mentioned concerns about siblings accompanying their parents to hospital appointments and over-hearing discussions with medical professionals about their sibling's health, which could be confusing, upsetting, and frightening for them. Having a sibling who is disabled or has a chronic illness

is associated with a negative impact on the psychosocial health of non-disabled siblings (Hartling, et al., 2010). Parents in contact with formal services asked for support for the non-disabled siblings, and encouraged them to participate in services such as play therapy, counselling, and attending sibling social activities offered by children's hospices.

Despite efforts parents made to meet the needs of *all* their children and to address the emotional and practical needs of non-disabled children, inevitably there were issues of competing needs, and feelings of guilt on the part of parents. A number of themes came through the interviews: sibling fears for the child with an LLC; the non-disabled sibling feeling that they were competing with their sibling for the attention of their parents; the non-disabled children being unable to engage in activities which they would enjoy because of the additional needs of the child with an LLC. Chand's mother spoke about the fact that Chand's younger sibling was unable to participate in some activities due to Chand's condition. For example, the non-disabled sibling wished to go for family bike rides, but because of Chand's heart condition, he was unable to participate, so no one went for bike rides. This sibling also wished to catch a train to London, but the family had to drive instead, as Chand was unable to walk far. This may seem a minor issue but repeatedly being told no appeared to take a toll on this child, and his resentment levels were high. Other concerns for the siblings were in relation to the health of the sibling with an LLC; the non-disabled sibling feeling that the child with an LLC was the recipient of preferential treatment, was more loved by the parents, and in particular their needs took priority. Dana's mother stated that she felt her other children had missed out on many things, because of

the care needs of Dana. In order to address this, she made an effort to access some form of respite so that she could focus on her other two daughters. She would order pizza, and they would cuddle on the sofa, watching a film, "It's just nice to sit down and not worry about Dana". Fiaz's mother spoke of the impact on her other children, and how the family had become socially isolated. She explored creative ways to address this issue so that the children were able to socialise with other children, "It becomes the norm; we learn how to cope with it". The symbiotic nature of family life will inevitably mean that what impacts on one member of the family will also affect others in the family (Brown and Warr, 2007).

Non-disabled siblings would highlight how the child with the LLC received preferential treatment, or their needs took priority. This came up a number of times in interviews. It could be expressing anger over something as simple as being asked to fetch their own socks from upstairs (whereas the child with an LLC will get help), to watching their mother feeding the child with an LLC, but not feeding them. They felt the parents (mothers in particular) spent more time with the child with an LLC than with them. Rehana's mother recalled an incident where her 5-year-old non-disabled child stated, "If I was like how Rehana is, maybe you'd look after me more". Her two non-disabled children (aged 5 and 11), felt that their mother loved Rehana more than them and expressed this in anger. Ruby's mother stated how her son resented her feeding Ruby but not him (she attempted to feed both at the same time, but found this impossible so had to stop). He learned to accept this and would say, "It's ok, you feed my sister. I'll sit next to you". Ruby's mother wept at the guilt she felt. Her son was now 18 years old and she had accessed support for him through his school. She felt he

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had adjusted remarkably well, and managed his worries. Aliyah's mother spoke about the negative impact of being a carer on Aliyah's younger sister (who was now 15). She felt that the younger sibling's needs had taken second place whilst the family gave priority to Aliyah's needs. For example, she stated that they did not take her away on trips in the school holidays to give her a proper break, they took her to all of Aliyah's appointments (which can be up to 2 or 3 appointments a day), and Aliyah's mother particularly regretted sending the younger sibling to be with family members while she focused on Aliyah's needs during periods of crisis. She meant to protect her from what was happening, but realised that it resulted in her feeling excluded. Adnan's father highlighted another way in which having a sibling with LLCs can impact negatively on family members. He spoke of how Adnan did not sleep well at night, and could be very noisy, which negatively impacted on the ability of the other children in the home to sleep. This would have an adverse impact on their health and well-being. As a result, he sought to pre-empt any negative impact on them by remaining alert to Adnan's needs and addressing these on a number of occasions in the night. It meant he did not get to sleep properly, but he did not want to risk the other children's sleep being disturbed. These are some of the stresses and dilemmas parents faced.

Parents spoke about the overwhelming needs of the child with an LLC and the fact that there were regular crises which meant they had to give this child's needs priority. Parents felt they had no choice but to prioritise the needs of the child with an LLC, due to few, if any, options for respite. In terms of informal support, the needs of the child with LLCs were often too complex and specialist for other informal carers to meet. And formal services were not readily available. The

parents felt they had no other option as they were the only ones who could address these needs. This comes up in the literature where the parents assume the role of expert (Pelentsov, et al. 2016). The needs of the non-disabled siblings were considered much more straight-forward, additionally they had the ability to communicate their needs, so informal carers were much more receptive and confident in looking after that child. These were tough choices for the parents, and Zidane's father summed it up as: "You have to split yourself".

Although this section has focused on some of the negative aspects of having a child with an LLC and the impact this can have on immediate family, Price and McNeilly (2009) mention that there are also positive aspects to this role, something which is echoed by several of the parents interviewed. Cadell, et al. (2015) state that although the circumstances are undisputedly stressful, for some parents benefits can co-occur along with the negative outcomes. Even through tears, parent carers' eyes would always light up when asked questions about their child which did not focus on the child's disability or condition. Rishi's mother spoke of how pivotal his presence was in the family and that they would not be without him. She referred to his siblings acknowledging the positive experiences they have had due to Rishi. For example, the family were invited to the premier of a movie they were big fans of and the siblings were thrilled saying "this is all because of you, Rishi. All because of you". Emerson and Giallo (2014) identify some of the positive impacts on siblings, such as an increased level of self-control, and being more understanding and tolerant of others.

5.4. Employment / Work

"My job is to look after my child" – Nadir's mother

Despite perceptions that work can place an additional burden on carers, it can also provide advantages Li, Shaffer, and Bagger (2015). Work can function as a source of psychosocial support, providing access to practical and emotional support from colleagues. Thus, an additional layer of informal support, potentially contributing to psychological well-being. However, several studies have found a negative correlation between caring for a disabled child and being in paid employment (Hatzmann, et al. 2013); Hill, et al. 2008). Unemployment is also negatively associated with well-being (Artazcoz et al., 2004). Of course, mental and physical health issues are also connected to their ability to seek and retain employment. Having an interesting job can reduce parental stress (Warfield, 2005). The interviews with parents revealed challenges to accessing employment, and how this affected their well-being. Experiences varied. Some parents saw work as a way of trying to retain a sense of normality in the family. Chand's mother said:

> *"When you're trying to maintain a sense of normality – and we have to have a normal life – I have to work; my husband has to work".* Chand's mother.

Adnan's father spoke of advice provided by his son's consultant. He was told that the care needs of his son would be demanding, and that he should not leave

all caring responsibilities to his wife, and should consider leaving his job to become a carer for his son:

> "To keep the family intact, I was told to leave work and sort of help her out. I don't actually think it's actually fair, you know, for one parent to have to take the overall burden", Adnan's father.

He adopted the role of prime carer. Adnan's mother worked full time as a social worker. He recalled his previous working life fondly [he ran his own business], highlighting some of the social aspects of work that he particularly missed:

> "I'd love to go out to work, and be out there with other people and chatting away, and being out with the lads and, you know… being out for a meal here and there, go and play football or something like that", Adnan's father.

Despite this, he was quick to state that he enjoyed the role of being a carer, something which he felt others failed to understand or appreciate. This expression of positive feelings around parenting a child with LLCs, is consistent with research findings from parents of disabled children (Scorgie & Sobsey, 2000; Hastings & Taunt, 2002; Jess and Hastings, 2017; Ylvén et al. 2006).

Issues identified and barriers to employment included: lack of childcare for their child, relatives being unable to provide informal childcare because of the level of specialist care needed, frequency of hospital appointments, and frequent hospital admissions. Chand's mother spoke of how she used to work full time as a

psychiatric nurse, but now worked part-time because of her caring responsibilities; she stated that she used annual leave to cover his hospital appointments, instead of using her leave to have a break or holiday with her family. Hanif's father spoke about the lengths he went to in order to try to retain his job. Eventually he had to accept the inevitable (despite his employer trying to accommodate his needs by providing flexible hours) and resigned from his job to become a full-time carer. He found it impossible to juggle the demands of employment with his caring responsibilities. Nadir's mother described the decision-making process that some parents may go through, and some of the factors that impacted on her ability to work:

"After he got poorly I had to give my job up, because we don't know how long he's got, and I thought with my work I can always go back to it any time. But really, I did want to throw myself into work, but this was my priority." Nadir's mother.

This above quote highlights the importance of work as providing some form of respite or social support for parents. This parent spoke of how much she missed the social aspect of working:

"*I used to have a bit of a social life, and go out at Eid and things like that*…" Nadir's mother.

Nadir's mother also referred to her loss of financial independence, which she appeared to be struggling with, explaining how she had worked since the age of

13 and never had to ask anyone for money until now. She felt financially dependent on her husband, which appeared to be an area of tension between them.

Chand's mother spoke about the difficulties her husband had coming to terms with Chand's condition, and how work had been a useful outlet:

"*In order for my husband to cope, he throws himself into his work*", Chand's mother.

Parents spoke of the financial impact, impact on their social life, and also impact on their confidence. Nadir's mother stated:

"*I don't even know how to speak any more*", Nadir's mother.

This was echoed by Rishi's mother:

"*I can't even speak. It's like your brain doesn't work like it used to*", Rishi's mother.

Rishi's mother felt that the negative impact of caring on her physical health meant that she could no longer consider returning to work, something she expressed great sadness over. She felt that work would have made a positive contribution to her mental health and well-being.

Employers appeared to lack understanding of the issues faced by parent carers and were unwilling or unable to accommodate their needs, and provide a certain level of flexibility that was required. Eshan's father had to reduce his full-time job to part-time hours, because of the numerous medical appointments they needed to attend. Eshan's mother was unable to speak English at that time, and was struggling to cope with the diagnosis; her husband acted as interpreter. She also donated a kidney for her son, so needed her husband there to support her at these appointments. She spoke of their experience thus:

> *"His workplace – they're fed up. Hospital appointments are a full-time job, but people don't understand",* Eshan's mother.

Eshan's father stopped attending appointments for his son. Although not necessarily because of this, the couple soon separated.

Zidane's father had a more positive experience with his employer. He found him to be supportive when his new-born baby had to undergo a heart transplant. Initially he was allowed leave and given sick pay. After that he was asked to take unpaid leave, but he was grateful that his job was kept open for him to return to, once his son's condition had stabilised. Hatzmann, et al. (2013) noted that social workers can support families in this situation by facilitating access to appropriate childcare.

5.5. Religion as a coping mechanism; source of comfort and hope

This section will explore the role religion can play in terms of helping parents to cope with any challenges they face as a parent of a BME child with an LLC. It will not look at the potential support religious and cultural institutions may provide (that will be discussed in Chapter 7 – Formal Support), but instead how the religious and spiritual beliefs of parent carers may support their emotional and psychological well-being – sensemaking (why did this happen to me or to my child?), as well as giving hope. It has sometimes been assumed that religiously based explanations for, and attitudes to, having a disabled child have led to fatalistic attitudes and contribute to low uptake of formal support services, by BME families in the UK (Fazil, et al., 2004). The parent carers who participated in this research, however, did not express beliefs where they no longer wished to engage with medical services or sources of formal support. Each parent carer was explicitly asked if their religion prevented them from accessing help and support and all said it did not. Religious beliefs and spirituality are not a substitute for formal support services, or medical interventions.

The literature on this topic, in relation to parent carers, speaks of how some parent carers of disabled children can utilise religious and spiritual beliefs to help them to cope with their situation (Kelleher & Islam 1996; Atkin and Ahmad, 2000; Gallagher, et al., 2015). However, in the case of BME families there is a risk of racial stereotyping and assumptions, potentially conflating ethnicity and culture with religion, implying that these families find answers to most issues in relation to their child's impairment, in religion (Bywaters, et al., 2003). Religion can also

be used to justify low service usage for BME groups (Ahmed & Rees-Jones 2008). Beliefs relating to ethnic and racial stereotypes can pathologise BME families and their religious beliefs (Westbrook, et al., 2003). For example, cultural values and religious beliefs are believed to influence the context of caregiving in BME families, thus impacting on service uptake (Giunta et al. 2004). For a number of different reasons, including personal discomfort, professionals do not always assess the religious needs of patients and their families (Nash, Parkes, Hussain, 2015). In the UK, families embrace a wide range of religious beliefs, with or without commitments to religion (Brown, et al., 2013). It is risky / easy to assume that those who profess to a religion on a hospital form are in fact what they have stated, that is to say, for example, a practising and believing Muslim, Hindu, or Jew (Neuberger, 2004). However, it is important to clarify this with family members, as being religious is a fairly wide / broad spectrum. In my study, while religious beliefs did inform the ways in which some parents conceptualised their experience, their attitudes were complex and varied.

The idea that parents of disabled children or those with LLCs find prayer and their religious beliefs a useful source of support and comfort is well-known (Brown and Warr, 2007). Park (2005) believes that religion has the greatest impact in situations that no intervention can make any difference to (e.g. having a terminal illness), as is the case with the families here. No medical intervention can make a fundamental difference to these children's life expectancy, nor will reassurance be provided by medical professionals, whereas religion provides hope. Croot et al (2012) undertook a study with Pakistani parents living in the UK and noted that these parents found meaning and purpose from the notion that their child's

condition was from God.   Adnan's father spoke of the importance of being able to pray for his son, as it helped him cope better:

"I do read my Quran quite often. I find it quite comforting. Spiritually, yeah, I think it's… it's actually important in hospitals and hospices, to actually have those sort of facilities", Adnan's father.

He found comfort but did not state that his son's illness was due in any part to religion. Neither did he refuse to engage with formal support services. He was accessing a number of services. Aliyah's mother also spoke of her faith and the many occasions that religion helped her to cope with her daughter's condition. She particularly found it helpful to pray on those occasions when Aliyah would be admitted to hospital. She explained that Aliyah herself also sought comfort and reassurance through religion; she maintained contact with a Muslim Imam via text messaging. Rishi's family relied on prayer as a source of comfort. His siblings also used this to help them cope and give them hope: "*Mum I prayed for him [Rishi] today*" (quoting nine-year-old brother). Nadir's father was a parent who utilised religion as a form of sense-making. He spoke about how he felt that his son's condition could be considered to be a manifestation of a form of religious testing. He gave an example of how God judges you by the way you care for the sick and disabled: "*It is testing…*"   Rehana's mother spoke of the support and comfort she received through religion:

"Allah's there for everybody all the time, and he's saying, 'call me, and I'll be there for you' and I do call him, and he's there for me, and he listens to my prayers. That's all I need", Rehana's mother.

The parental perspectives of parents who have lost children may be different or more diverse. Dana's mother had lost a child to the same condition that Dana had. She spoke angrily in relation to religion and did not appear to seek any solace or explanations in religion. However, there may have been any number of other reasons for this stance, which I was unable to explore at that time. Park (2005) refers to the notion that having a strong belief system helps those facing adversity understand and make sense of the pain and suffering endured. There are examples of parents using religion to make sense of the situation they find themselves in. Nadir's father refers to the notion of a test:

"I believe in God and I believe in fate. I believe all good and bad comes from God, and I believe that you've actually… you're put in a situation where you're being 'tested'. And to overcome that, you know, you've got to be really, really… really strong", Nadir's father.

Abbas' parents stated how they would choose not to ask many questions regarding their son's condition, from medical professionals. They did not ask for information: *"We know enough. We leave it in the hands of Allah",* Abbas' mother. The parents also spoke of how they both prayed for their son.

5.6. Conclusion

This chapter shed light on a hitherto under-explored area of looking at the caring experiences of parents of BME children with LLCs. It examined some of the issues that are important to them in addressing the needs of their child and family. Parents spoke of the negative impact on their health and well-being, as well as the positive aspects of being a parent carer. They expressed their worries and concerns for other members of their family, with a particular focus on siblings. It focused on the parents' perspectives and highlights the interplay of being a carer and being a parent and trying to retain some sort of order in what could be seen as extraordinary circumstances. This was the primary reason I chose to place both the child (with an LLC) and immediate family in the centre of the family's ecological system (see Appendix E), as what happens to one member of a family can have a ripple effect on others. This may be more so than usual for this group of families, due to their social isolation and fear of stigma or 'racism'.   Emotional impact is discussed, as well as the practical impact, of having a child with an LLC. Lack of work and employment options, due to the demands of the caring role, add to financial pressures the family may face. The parent carers of disabled children or those with LLCs face huge challenges in their role as carers (Collinson & Bleakley, in Price and McNeilly, 2009).

This chapter has focussed on aspects of family life of BME children with LLCs and their families. Parent carers where interviewed and they spoke of their experiences of navigating their various roles and commitments, firstly to the child with LLC, who understandably tends to take priority, the siblings, and then

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themselves. It is through the lens of the parent carers, and understandably can focus on some negative aspects. Considering the themes and topics up for discussion, for example the experience of receiving the diagnosis, this is inevitable. Parent carers are challenged to navigate their way through a complex system, often facing practical and emotional issues. For example, when speaking of the challenges of retaining employment, this impacted on them in practical terms, but also psychologically and emotionally, affecting their identity. They spoke of the demands of caring on both their physical and mental health. This is understandable, to a certain extent, as they were still battling for their child – to access medical treatment, and other services. The challenges they face are on-going. I also only met with these parents once; had I met more times, they may have focused on different aspects. They were evidently grateful to have the opportunity to discuss their experiences, as they spoke of this being a rare opportunity, and as I am a social worker, they probably felt I would be able to cope with hearing about negative aspects of their lives, which they would most likely protect others from. It felt that they were able to speak to me without having to put on a front of being positive and grateful for their situation. This was one of those moments where I felt I was considered an 'insider' who due to my professional experience, would not be surprised or phased by the issues they raised. As I was in no way involved in the care of their child, they were unlikely to offend me or risk negative repercussions. However, it is as true a picture as possible that I aimed for, and the issues they raised help in identifying their needs and to explore ways in which such families can be better supported. There are other studies with parents where positive aspects of caring have been discussed by parent carers (Redmond and Richardson, 2003). It has also been stated that

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providing care helps create a stronger attachment between the care giver and cared for, benefitting both parties (Boerner, Schultz, and Horowitz, 2004).

This chapter reinforced the fact that the parent carers of BME children with LLCs face many challenges, worries and concerns which may be similar to those of parent carer of a white disabled child or child with LLC. Essentially theirs is a shared experience. The negative impact on physical and emotional health and well-being will be a shared experience across parent carers. As will be barriers to employment, and the financial implications. The concerns for the non-disabled siblings, and impact on their relationships may be common to parent carers, irrespective of ethnicity. However, there are certain issues which may be considered unique to BME families, and there is some ethnic variance. For example, the issues around diagnosis and language barriers are specific to this group. Rishi's mother having to break the news to Rishi's father, and her having to assume the role of expert to respond to his questions, whilst herself grappling with what was devastating news. Aliyah's mother speaking of having to travel to South Africa to break the news to her husband, and feeling alone and isolated when she herself received the news, and still struggling with the impact of that on herself but worrying about the rest of her family. In terms of religious beliefs, it would appear that BME families are disadvantaged by the belief that religion may be perceived by them as a panacea or an acceptable substitute for formal services. Religion is part of a family's microsystem, and a family's interactions with religion and religious institutions may influence their values, such as feeling a stronger sense of duty to family. However, practitioners would do well to check which needs (if at all) religion meets. Bronfenbrenner's ecological system refers

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to the influence religion has on a child and family, however, in the case of children with complex needs, this may not be a resource open to them. Parent carers may also face barriers. This was in no way evidenced by the data from interviews from parent carers. The academic discourse refers to religion as providing explanations for low service usage, however, the parents interviewed in this study made it clear that religion and culture did not form a barrier to service usage.

Chapter 6 Informal support

6.1. Introduction

The academic discourse in relation to carers of disabled children or children with LLCs refers to the challenges faced by parent carers in this role, and the resultant negative impact on their mental and physical health and well-being (Vonneilich, Ludecke, and Kofahl, 2016; Fairfax, et al., 2019). Factors identified as contributing to this included the high physical demands of caring, impacting on physical health, and the associated stress, worry and social isolation affecting mental health (Buckloh, et al., 2008; Wynter, et al., 2015). Informal support has been shown as one way in which to support carers, to mitigate against the negative impact (Felizardo, Ribeiro, and Amante, 2016, Gouin, et. al, 2016, Holt-Lunstad, et al. 2010, Boyd, 2002). Formal services are available to support families and address these issues, but some needs can remain unmet, and are perceived as being met through informal support systems. In the case of BME families, there are stereotypes and assumptions held regarding the greater availability of informal support networks (Atkin and Rollings, 1996; Chevannes, 2002; Bhui, et al., 2012). These may contribute to creating barriers to accessing formal support. As stated previously, while there is literature on the experiences of parent carers of disabled children and children with LLCs (Russell, 2003; Isa,

et al., 2016), there is a lack of research focusing on the informal support systems of the families of BME children with LLCs.

This chapter primarily focused on interviews conducted with parent carers of BME children with LLCs to explore their experiences of informal support, providing an insight into the views and experiences of these families. It also placed parent carers at the centre of the discussion, to test some of the theories and views espoused regarding greater availability of informal support for BME families. It is vital to ensure our professional perspectives are in line with the reality experienced by families – to ensure equitable service provision. For this reason, there is inclusion of the views of professionals regarding the accessibility and availability of informal support. It is important to explore current assumptions held by professionals. Findings from interviews serve as a reminder that cultural practices and norms are dynamic and constantly changing.

This chapter will start by defining what is meant by the concept of informal support and discuss potential sources of informal support. It will then explore the experience of BME parent carers of children with LLCs and their informal support systems, as well as discussing ethnic and racial stereotypes of BME families and their informal support networks. There is some evidence to suggest that use of informal support may differ amongst ethnic groups, with BME groups accessing a greater level of informal support than formal support (Giunta, et al. 2004; Chow, et al. 2010). The research tends to be anecdotal statements made by academics, not based on specific interviews with families, and may be in the

context of caring for adults, which would be very different from the needs of children with LLCs. Is it generalisable and applicable to this group? The research may also be from earlier times when multi-generational households were common, but there have since been changes in the way families function. For example, as more women take up paid employment opportunities, couples may have the financial means to choose to live independently and not live as part of an extended family. Cultural norms and practices can change and evolve over time. This chapter tests assumptions, and a counter narrative is provided by the parent carers. Parent carers views and experiences will be discussed to test these views throughout the chapter. There will then be a discussion regarding barriers and tensions in terms of accessing informal support, as well as shedding light on what parents find helpful, or would value from terms of informal support. For the purposes of this chapter, the focus in terms of informal carers will not be placed on the parent carers, as parents of children under eighteen years of age would be expected to provide care for their children. It will instead shed light on the wider network of informal support and care for parent carers and their immediate family, which may or may not be available. It will also highlight some of the invisible barriers to informal care.

6.2. What is informal support?

Informal support (sometimes referred to as social support) is defined as, "an interpersonal transaction of emotional, psychological, informational, instrumental or material assistance with support provided by members of the social network"

(Dunst, Trivette and Deal, 1994, cited in Felizardo, et al. 2016, p. 831). It is characterised by being a source of support mainly from family members, in an unpaid capacity (Heaton, 1999). The needs of families of children with LLCs are diverse and wide-ranging, and not all will necessarily be met by formal services. It is therefore appropriate to explore additional and alternative resources, which may come from informal networks of support. Some sources of informal support, such as peer support, may be accessed via formal services, thus the two can be inter-related.

The complexity of caring for a child with LLCs can place increased demands on a family. It is therefore important that parent carers are made aware of potential sources of both formal and informal support that may benefit them (Greef, Vansteenwegen and Gillard (2012). It has been suggested that informal support can help families with a disabled child cope better with stress (Gouin, Estrela, Barker, 2016). However, it cannot be assumed that just because a family has access to a social network that the network has the capacity to provide support; nor that the family should be under duress to accept this type of support. In the case of BME families there may be additional issues, forming barriers to the availability of informal support. Issues which may only be relevant to BME groups, particularly refugees and asylum seekers, and newly arrived migrant families, may relate to a lack of family and social networks due to lack of time and opportunities to establish such networks of support. Racism (or fear of racism), may also form barriers to establishing relationships. Harrison and Melville (2010) refer to the challenges of migration and how this can lead to social isolation, due to loss of family support, and social networks, and the challenges of adjusting to

a new culture and social system. Although BME families are perceived as having larger family support systems, the reality may be different.

Informal support can be a valuable source of psychosocial support for families experiencing challenges in their lives. The aim of informal support is to supplement support provided by formal services; to complement them. It is not considered a substitute for formal services. The parent carers interviewed in this study spoke about two different types of support – practical support (examples of this include financial support, childcare), and emotional support (the space to speak about how they are feeling and what issues they are currently grappling with). There is a gendered element to this support. For example, the majority of parents interviewed spoke of male members of their family providing financial support, and female members providing emotional and practical support. There were few, if any, examples of crossovers (one such is where Hanif's father speaks of his sister providing financial as well as practical support).

Academic discourse and definitions of informal carers in general tend to refer to immediate family members, as well as extended family, friends, and neighbours (Heaton, 1995). Chand's mother used the term 'significant family' to refer to her family support network; this included her and her husband's parents and siblings:

> *"They've shared that journey with me and Chand. They understand him better than the other people".* Chand's mother.

Rishi's mother was grateful for the emotional support of her family, who lived locally: "My sister. My older sister. My dad's always there. My brothers". In the case of BME families, it is often assumed that they have larger and stronger support networks, from whom to access help and support (Atkin and Rollings, 1996; Chevannes, 2002; Bhui, et al., 2012). However, even when people are part of a large family, it was found through parent interviews, that barriers could still exist to accessing such support. These barriers will be identified and discussed. There will also be a small amount of input from interviews with professionals, as these complement the narratives of the parent carers.

6.3. BME parents' lived experience of informal support (including stereotypes of BME families and their informal support systems)

This section contains contributions mainly from parent carers, but with some input from professionals working with them. They relate to 'racial' and ethnic stereotypes of BME groups and the availability and accessibility of informal support. Here some of the stereotypes regarding BME groups and families were challenged by parent carers, as well as by some of the professionals working with BME parents.

A perspective often shared about BME families by professionals in health and social care is that they have larger families, and by implication have a greater resource to access in terms of informal support. This was a stereotype that I heard

about during my practice experience, hence my exploring this through interviews. Interviews I conducted with professionals support this notion of community and family support for BME parent carers:

"A lot of the BME families have very large networks, they're very close to, or certainly spend a lot of time with their extended families and so on, much more than, you know, than a nuclear family which is much more typical of someone from a white background", Maria (a professional).

This was reiterated, in terms of religious affiliation, by Mary a professional interviewed, who believed that BME families were large and supported each other:

"In a Christian world, community isn't as close knit and tight. We do still try and support each other but I do think in BME communities they are closer", Mary (a professional).

Asked if BME groups and families formed closer networks and were more supportive of each other, in comparison to white communities, and 'look after their own', Adnan's father responded by saying, "It's a complete myth!"

Another assumption made of BME families is that larger families equate to greater capacity. This may be the case for BME families in general, but does not mean it will also be the case for families of BME children with LLCs. The needs of children with LLCs may be more complex and not easily met by informal carers.

There may be additional factors which can form a barrier to support for BME families, such as their families being dispersed across the globe. My data from interviews with BME parent carers highlights this as one way in which the experience of this group differs from that of white families. Grandparents can be a valuable source of support for families. However, there is limited research exploring the support grandparents provide for the families of disabled children (Mitchell, 2008). The data from the MCS (see Chapter 4 for further discussion), Table 15 provide findings regarding childcare provided by grandparents, during weekdays. It appears that white children, irrespective of whether they have an LSI or not, have greater access to childcare from grandparents (during *weekdays*) than BME children. Looking at data regarding grandparents providing childcare during *weekends*, a slightly lesser proportion of grandparents provide such support for BME children with LSIs, compared to the white group of children with LSIs (20% white vs. 18% BME). The MCS data also show that BME children with LSIs are the category who are least likely to receive support from friends and neighbours. It would appear that BME families, in comparison to white families, do not have greater access to friends and neighbours who provide childcare. The notion of BME communities supporting each other is challenged.

Therefore, it cannot be assumed that BME families have a strong source of community support. This ethnic stereotype is open to challenge. It is worth noting that there is variation within the BME group in MCS data, between those with LSIs and those without. Grandparents appear to provide greater access to childcare for BME children without LSIs, whereas friends and neighbours are a greater source of support for those BME children who have LSIs. There is ethnic

variance in terms of availability of childcare from older siblings. It can be seen (from Table 19 in Chapter 4) that a greater number of BME children (irrespective of whether they have an LSI or not) receive care from an older sibling, at weekends. However, according to the MCS, more BME children, irrespective of whether or not they have an LSI, receive childcare during term-time *weekdays* from 'other relatives', in comparison to white children. These findings are replicated in the data for the weekends as well. There is no notable difference between the categories in terms of whether or not a child has or has not an LSI; however, ethnicity does appear to have an impact. Some of these findings, from the MCS, reinforce some of the ethnic stereotypes regarding BME extended families whilst other MCS findings challenge some stereotypes about BME family support.

Katbamna, et al (2004), in their study with South Asian families, challenged assumptions around extended family support; they found that South Asian carers did not have a greater resource of informal support from friends and families. However, this is a complex issue and will depend on a number of factors, including whether families are first or second generation British. For example, in the case of Eshan's mother, she came to the UK from India when she got married; her parents lived in India and her sister in Canada. Her marriage broke down soon after her son's condition was diagnosed, and she found herself very isolated, with a little support from her in-laws. Not only did she not have a strong family network available to her locally, she had the additional pressure of travelling abroad to attend to family issues, with the added financial and practical pressures that brings. Parent carers made it clear that being part of a large family

did not automatically lead to greater support. Apart from the geographical distance, they faced similar issues that could be faced by white families caring for a child with an LLC. Dana's mother stated: "I have a big family, but we don't get on". Aliyah's mother, whose family was based in the UK but also in South Africa, felt unsupported:

"*We've got a very big family, but I think they do fail to understand the challenges we face as a family*", Aliyah's mother.

Hema, a BME professional, made an interesting point regarding assumptions that intergenerational households automatically guaranteed extra availability of informal support. She felt that it was quite the contrary; the antithesis being that actually there are more people to care for – elderly relatives, ill relatives, and their care needs to be attended to. Hema felt it led to more people interfering in something that they know very little about – adding to the stress of parent carers. Having to cook, clean and attend to the needs of a large group of people places a huge burden on carers. This is where the application of ecological systems theory, when undertaking assessments with BME families, can assist professionals to not succumb to the ecological fallacy and assume there is an intergenerational household without doing a proper assessment. Despite appearances, and greater numbers of people living in close proximity, there may not be the support expected:

"*Sometimes they end up looking after the whole family, as well as doing everything else! And then they do need respite – they do need something*

– you know… a key worker or a support system. And I think it's not just about Asian families or black families; it's about any family", Hema (a BME professional).

Teresa (a professional working with families of children with LLCs) makes a distinction between families of children with LLCs and families of non-disabled children in relation to the social isolation they can experience. She felt the former group of parents faced greater social isolation leading to poor networks of informal support:

> *"Given the sorts of families that we're talking about where, actually, their social isolation is huge because of the needs of their children, and the fact that they might not even be able to get to the community centres, I suspect that it's not much. You know, that their interaction isn't much",* Teresa (professional).

An unexpected issue that emerged was professionals identifying the stigma and isolation which BME families of children with LLCs face within their extended family and community – an additional barrier to informal support. This could be a barrier to accessing informal support, and contribute to social isolation. Negative experiences and stigmatising interactions have the potential to socially isolate families (Green, 2003). It is important to highlight these in order to challenge assumptions regarding BME communities and their support systems, and to provide a counter narrative to challenge ethnic stereotypes. Nadine, a professional working with families, stated how a BME family she had worked with

refused to accept local authority transport offered to their child to collect and return him from school (he was attending a special needs school). She stated this was because the parents did not want the neighbours and community to know their son had special needs and was attending this school. They feared the family would be socially excluded and isolated if members of their informal networks were to find out that he was disabled:

"Anybody can have a disabled child, but of course there is with religion and different beliefs, that they've done something wrong and it's a punishment. I think it could be cultural", Nadine (a professional)*.*

Angela, a BME professional, felt that although there is a perception that family and community provide support and assistance, family can often be more of a hindrance than help. This was reinforced by an incident Nadine recalled, whereby a parent carer had attended a meeting of BME mothers (a forum for peer support). Her brother-in-law arrived and demanded to see her:

"She went outside and hid behind a car from him and they [staff] went out and said, 'Is everything alright?' but he took her by the arm and took her back, in the car. I wonder what people are up against in their own culture", Nadine (a professional).

This was a very difficult situation for all concerned. Cultural and ethnic assumptions, beliefs, and fear of offending may all have played a role in the resultant inaction of staff. The fact that they did not intervene in what is quite a

fraught situation, could be due to what Dominelli (2018) refers to as 'othering', where ethnicity and religion formed a barrier to this mother receiving the same treatment and enforcing her legal rights, from the way in which the situation may have been approached had it been a white woman. Would staff have acted differently if this had been a white woman? There may have been a school policy in place in terms of addressing issues of an individual arriving on school premises and demonstrating hostility, threatening behaviour, and aggression towards staff and parents. However, this was not referred to or applied in this case. Could this be seen as an example of a micro-aggression? This is also a case where Crenshaw's (1991) theory of intersectionality comes into play. Had this been a white woman, would the brother-in-law have had so much power? There is no real evidence, but it can be speculated that staff resorted to 'racial' and ethnic stereotypes and gave the brother in law the power to have such influence over this woman – the stereotype being that in BME families, the extended family (and in particular men) have a right to interfere and exert such power and authority over women.

There is also a notion that BME families are more open and willing to involve extended family in decision-making regarding their child, therefore providing a layer of emotional/psychological support for parent carers. This was supported to a certain extent by some of the views expressed by parent carers who participated in this research. Rehana's mother had a very close relationship with her family and stated that she could discuss important issues with them:

"We [her and her brothers and father] do communicate in each and every way; but when it comes to these sort of decisions [about Farhana's treatment], they do guide me – they do make me understand the benefits of things. But, me being me, I don't like burdening anybody", Rehana's mother.

Rishi's mother made the point that it was difficult to involve extended family in decision-making, as they lacked the shared experience and the knowledge to help. She did, however, discuss matters with her brothers:

"I don't think they would be that much help because they've not experienced what we're going though and… I don't think they even know, what, you know, how it is to live with a disabled child. So it is my husband, and my brothers. My brothers help me a lot. I don't feel like I can go out and speak to my community, really." Rishi's mother.

Zidane's parents spoke of additional barriers to effective communication and involvement of extended family:

"My husband's sister in India and her husband is a doctor, and they have a doctors' group over there, and we were talking about our child and what we have to do next. So she speak with her husband, and they talking with other doctors. They don't understand about the child because nobody have child like this. In India they don't have these facilities, so they get confused, so we make the decisions. We have to", Zidane's mother.

Nadir's parents had family who lived locally (both parents were British born), and they consulted family to obtain their views and asked for their opinions, but ultimately as the parents it was they who made the final decision. They felt that they were the ones who had all the knowledge and information to make the right decision, as they knew their child best. The lack of shared experience made it difficult for others to advise, as stated earlier by Rishi's mother and Zidane's parents. The accessibility and availability of informal support from family and social networks varied across the families interviewed, and there were a range of factors which formed barriers to the availability of this support.

There is also an implication that BME families involve community and religious leaders in decision-making in relation to their child with an LLC. When asked if she involved religious leaders or sought their advice, Rehana's mother was emphatic that she would not involve them in decision-making in relation to Rehana and her treatment or care. However, Aliyah's mother spoke of the fact that religious leaders played a role in providing advice and reassurance for Aliyah.

6.4. Barriers identified to accessing support

During interviews with parent carers, it became clear that there were three ways in which informal networks could provide support for them. These were: financial support (for unexpected expenses such as a washing machine breaking down), practical support (childcare), and psychosocial support (visiting to reduce social isolation, and providing a sounding board during difficult times). It also emerged

that barriers to this support took two forms: practical barriers, and attitudinal barriers. There were two main practical barriers: lack of time, and lack of the knowledge, skills and confidence to provide support. In terms of attitudinal barriers, these were: parent carers not wanting to burden others and feeling (due to their reduced capacity) that they would not be able to reciprocate, inflexible approach of family members (which meant the family risked losing autonomy and agency to make decisions), and fear of rejection (asking for help, and then being refused help was something parents found particularly difficult).

6.4.1. Practical barriers

Lack of time

When parent carers were asked why they felt family were unable to support them, they gave a number of responses. Time was one such factor identified by several parents. Zidane's father stated:

> "*In this country the big thing is time… Everyone's working, busy…*" Zidane's father.

Adnan's father, when referring to the capacity of extended family to provide support, mentioned challenges to their limited capacity:

> "*I don't like asking them because they've got their own careers, you know. They work, and they've got their own children*", Adnan's father.

Iona's mother spoke of the fact that all her family were abroad, but her two brothers lived in the UK (both lived local to her). However, they were limited in their ability to help her. She stated:

> "*Because they have their families – they have their lives. Even if they want to do it, they can't do it because they have other stuff – job, and this and that – and their family as well*", Iona's mother.

There was a dichotomy whereby some BME families mention having large/extended families, but that did not equate with a greater resource in terms of support. They may be part of large families, but this did not automatically lead to extra help:

> "*I gotta lot of family; a lot of nieces and nephews, they're around my age and they're like friends and they would come around and it's not the same because everyone goes to work…*" Rishi's mother.

Ruby's mother spoke of how difficult it was for her when she first had Ruby, and the complexity of caring for her, and attending hospital appointments, without support. It was particularly difficult for her as she did not speak English and was newly arrived in the UK from India. She struggled to find support, even though she lived with her in-laws:

> "*The hospital appointments were every 2-3 months, and my husband couldn't take the time off. So sometimes, I have to book like the taxi/ambulance. I'm from India; I struggle with the language, I never went*

out by myself, and so that was like… And I have a son and have to think about him, while I take Ruby to hospital. Whenever he [husband] could take time off work he come with me. They [her in-laws] all used to go to work, so I couldn't ask anyone. They all need to go to work. I had to do everything", Ruby's mother*.*

Lack of confidence, capacity, or skills

Another barrier parent participants mentioned, in addition to lack of time, was that extended family lacked knowledge and awareness of their needs, and the knowledge, skills and confidence to provide the necessary practical support. Particularly where the child had complex support needs. They also mentioned elderly and ill family members, who themselves had caring needs, and thus were unable to help. For example, Chand's mother spoke of her parents wanting to help but being too elderly and infirm. Instead she found herself trying to care for them and running errands for them.

Lack of knowledge/understanding:

Parents highlighted the fact that members of their family did not always understand the reality of being a carer and their needs, as they did not have a shared experience:

"They [extended family] do fail to understand the challenges we face as a family", Aliyah's mother.

Parent carers generally felt that people outside the immediate family did not have an understanding of their circumstances, and that the complex medical terms and

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jargon formed an additional barrier to communication. The parent carers became fluent in using complex medical terminology, which was not necessarily accessible to others. The problem here is that people did not know what the family were going through and what type of help they needed. Parent carers would not speak about the issues they faced because they felt others would not understand, and they also did not wish to burden them, or others did not seem interested in learning or listening:

> *"You just know from their expression that 'you know what, I think this is going over their head a little bit', because they're not engaged. You know from their body language, they're just not engaged",* Aliyah's mother.

Dana's mother tried to share her experience with her family, and access psychosocial support from them. She had lost a child previously to the condition Dana was diagnosed with, and was struggling:

> *"I told my family [about Dana's diagnosis]. But my family are bloody useless, anyway. We don't talk. They're not interested*", Dana's mother.

Even where informal networks had the will to support parent carers, sometimes they lacked the skills or confidence to meet these needs. The condition of the child and the level of need would inevitably influence the availability of support from informal carers. Some feared doing more harm. For example, Iona's mother stated that her brothers did not feel they had the skills to care for Iona, due to the high level of physical care she required. She also stated that once Iona hit

puberty, her brothers did not feel comfortable providing personal care for her, adding gender as an additional potential barrier. She stated that culturally (the family were originally from Africa) they did not feel it was appropriate for men to provide personal care for a young woman. However, this may just be specific to this family. As a result, if her brothers cared for Iona, while she ran errands or socialised, she had to ensure she had fed and changed Iona before she left, and had to rush to return in time to address the needs for feeding and changing her daughter. She found this very stressful. This was an example of when informal support was an inadequate substitute for formal support. Farhan and Adnan both also had complex support needs which required professional carers. As did Ruby. The quote below further highlights this issue:

"There is no one, actually, that can take over Ruby because I don't think they can deal with epilepsy. They don't know how to feed Ruby. They don't know how to deal with fits… I don't think anyone will have that confidence to look after Ruby", Ruby's mother.

Ruby's father felt that family and friends could be taught how to provide care for a child, but that an additional barrier was possible fear of harming the child, or a general lack of interest or willingness to acquire these skills. He felt that the lack of skills on the part of informal carers created additional risks and placed further pressure on families:

"It's frightening for us. You don't want to leave your daughter if you're not confident with someone; that you don't know if they know how to deal with

your daughter. You can teach them, but they have to have that interest to come to me and ask. 'You teach me, then I'll learn'", Ruby's father.

The above experiences may not be distinctive to BME families. However, it is the perceptions which are different. Ethnicity is relevant in how others perceive BME families have access to informal support.

Aging/unwell family members.

Some family members were unable to provide help due to their own health care issues. Chand's mother described her family situation. She stated that her husband had developed renal failure and was unwell for a long time, resulting in him having a double kidney transplant. She found herself caring for a large number of family members, as well as Chand:

> *"My mother-in-law passed away from cancer, my father-in-law was diabetic – he passed away three months ago. My older brother passed away as well. So now my mum and dad, are needing help themselves, as they're in their 80s"*, Chand's mother.

It was a similar situation with Hanif's father, who mentioned his elderly mother; who was unable to help in any substantive manner, but would purchase gifts for the children, which they appreciated. Eshan's mother's family were all in India, but she spoke of her in-laws who were based in the UK who could not provide practical support, as they were "too old".

Distance/migration

Moving abroad can inevitably disrupt social and family support networks, with a risk of reduced availability and accessibility of support (Sime and Fox, 2015). Trying to build a new support system can take time, and this is doubly challenging when you have a disabled child or child with an LLC, due to reduced capacity to socialise. Not to mention language barriers. Ryan (2011) refers to assumptions in the academic discourse regarding the accessibility of family and friendship networks amongst migrant individuals and communities. In the case of BME families, migration patterns could contribute to a reduced network of family support. The experience of parent participants in this study varied. Several parents (Farhan's father, Rehana's father, Ruby's mother, Eshan's mother, Dana's father, Rishi's father) had come to the UK as a result of marriage, and therefore had limited family to support them. There were also parents who had no family on either side such as Zidane's parents who had come to the UK to work and had no other relatives living here, other than Zidane's uncle. This was also the case for Fiaz's parents, who had come to the UK to work and undertake postgraduate studies, and had no family in this country.

Rehana's father had no family in the UK, but her mother (who was born and brought up in the UK) had parents and siblings who all lived nearby and were able to help and support her. As a single parent, she valued support from her four brothers, sisters-in law, and her parents. Ruby's mother felt that the lack of support from her side of the family (who were all in India) was particularly amplified by the fact that her husband's family (who lived in the UK) did not support them. Some parent carers spoke of tensions and issues trying to

communicate with family members who were scattered around the globe, often adding complexity and risk of misunderstanding to an already fraught situation. For example, Zidane's mother spoke of when they were told that their baby would be born with a serious heart condition, and the couple had to decide whether to go ahead with the pregnancy or not, and to consider a number of options. They tried to speak with her husband's sisters who were living abroad. The sisters, who were both doctors, tried to give them advice regarding their unborn son. However, the differences in healthcare systems in India and the UK made the communication and sharing of advice and information such a challenge that Zidane's parents eventually decided not to consult the extended family. It proved more unhelpful than helpful, and added to their stress. Farhan's parents also spoke of similar issues where family members living in America and Scandinavia, who were medical professionals, would try to advise and guide the family regarding choices in relation to their son's condition and medical treatment. They also found it unhelpful, and distance a barrier to effective communication and support. These were some of the issues which could be said to mainly be applicable to BME families.

Very few of the couples interviewed had two sets of family in the UK. Adnan's parents were an example of a couple who both had family in the UK, but they did not mention them very much in the interview. Nadir's parents (a young British born couple), both had parents and siblings in the UK, as did Hanif's parents (his father was born and brought up in the UK and had family living local, and his mother was white British with family living local). Rehana's mother was born and brought up in the UK and had a strong local family support network. Chand's

parents both had family in the UK, but both his paternal grandparents had passed away.

A number of additional barriers were also identified by parent carers, in terms of accessing informal support. These will be discussed below. If a social worker had undertaken an assessment, based on the ecological systems theory, they would have found gaps and weaknesses in the informal support networks of these families. Working in an anti-racist manner, they could incorporate the use of culturagrams as a tool to help gather information relevant to the diverse needs of the BME parent carers.

A culturagram is a family assessment tool that provides a graphical representation of various aspects of an individual and family's culture (see Appendix G for an example). It was developed to help understand the cultural background of families, and to address the need for ethnic sensitive practice (Congress, 1994). The culturagram recognises that families are culturally diverse and social workers must be able to understand cultural differences between and within families. However, assessing a family only in terms of a specific cultural identity, may lead to overgeneralisations and stereotyping (Congress & Kung, 2013). The culturagram enables practitioners to understand different aspects of culture in terms of a specific family, avoiding generalisations based on ethnicity (Congress, 1994). It helps practitioners see differences amongst families who may have similarities in terms of 'race' and ethnicity, and reinforces that most ethnic groups in any country are heterogeneous (Chau and Yu, 2010). Congress (1994) and Torres (2006) warn of over-generalisation of racial or ethnic group

characteristics. Culture should not be perceived as a singular concept, but instead as incorporating "institutions, language, values, religious ideals, habits of thinking, artistic expressions, and patterns of social and interpersonal relationships" (Lum, 1992, p. 62). There are ten areas addressed by a culturagram, which include: length of time in the community, reasons for relocating, legal status, contact with cultural institutions, and health beliefs. The responses to these questions may help a practitioner gain valuable insights into the support networks and needs of a family, and could be a good starting point for exploring this area.

6.4.2. Attitudinal barriers

Fear of Burdening Others

Parent carers of children with LLCs, irrespective of ethnicity, are known to experience social isolation (Russell, 2003; Whiting, 2012). Inevitably there are overlaps with barriers faced by white parent carers. There are likely to be many similarities in experiences between the two groups. Ethnicity is but one aspect of the identity of these parent carers. Parent participants spoke of the isolation they experienced. They spoke of their fear of burdening others, which could lead to less contact with extended family and social networks. Their concern regarding limited opportunities for the family to socialise was something that is widely reported in the academic discourse in relation to families, irrespective of ethnicity (Whiting, 2012; Marchant, et al., 2006). This again draws attention to the shared experience of being a parent carer of a child with an LLC. Participants spoke of some of the strategies they adopted to mitigate against this issue:

"We don't demand and take a lot off one person; we just have little bits off everyone in the family. And I normally bribe them with food [laughs]. We might go and play a game of pool. And that will be enough for me to feel supported, in order to get through the next week. Because it's not the same person doing it repeatedly, they're not drained, and I've used different people. We use that as a very 'positive' 'memory-making', doing nice – good – stuff", Chand's mother.

Adnan's father spoke of his fear of placing a burden on others. He worried that if they (as a family unit) placed too much expectations on the extended family, then they may reject them, and they would become further isolated. Conversely, Hanif's father spoke of visits to his mother and sister, with his sons. He lived near his family and appreciated the socialising opportunities they provided for his non-disabled sons, taking some pressure off him and his wife. He stated how important this was to his sons. His mother-in-law provided care for Hanif, which allowed him and his wife to spend time focusing on the non-disabled children, whom he felt missed out on the amount of leisure opportunities he would like to access for them.

Loss of agency/control

Due possibly to a lack of shared experience, informal support networks did not appear to always understand the needs of such families. In order to access support, parents felt they had to accept the terms imposed by others. For example, Nadir's father spoke positively of the childcare offered by his sister to the family. Nadir's mother, however, did not value this offer. She wanted her sister-in-law to babysit Nadir at home, a familiar setting where he is happier, and where she [the mother] would be at hand if anything went wrong. Nadir's mother felt that by the time she made all the practical arrangements and driven to her sister-in-law's house, she was exhausted. No sooner did she drop Nadir off then she had to go back and collect him again. The effort versus reward was not worth it – practically and emotionally. Adnan's father felt the cost of accepting help was a loss of control and agency. He felt that asking for help from family resulted in having to make compromises and do things on their terms, which may not necessarily be in the best interest of the child or family. He gave an example of when Adnan was initially diagnosed, and referred to a specialist at a hospital in a city distant from where they lived. His extended family members made it clear that if they were to continue visiting him in hospital and supporting the parents, Adnan should be moved to a hospital closer to home. Adnan's father feared he would lose the care of a highly specialist team, which was not in the best interest of his son. He chose to keep Adnan where he was. This impacted negatively on their long-term relationship with their extended family. Many of the issues raised here may not be specific to BME families, however, it is useful to highlight them, to counter the narrative that BME families may have stronger relationships and may not face such challenges.

Fear of judgement/rejection

Several parents mentioned that they felt there were attitudinal barriers, which prevented their extended families from providing support. They had experienced people making inappropriate and stigmatising comments. For example, Ruby's parents were told by people at their temple that they must have done something awful in their previous life to have a disabled child. This resulted in them no longer attending religious events and contributed to their social isolation. Ruby's mother wept as she discussed this issue. Pity was another reaction parent carers wished to avoid. Abbas' parents stated that Abbas resented socialising with extended family as they would refer to him as "bechara" [poor boy] and pity him, which upset him. He refused to socialise or interact with those members of his extended family. As a result, all of his immediate family also severed contacts with that element of family. Fiaz's mother also spoke about pity, but in the context of people feeling sorry for her:

> *"We, as parents want support from the right people. We don't want sympathy. We have dignity"*, Fiaz's mother.

Parent carers spoke of the challenges and barriers they faced asking for help. These included a fear of rejection, and the negative impact this would have on their mental health and well-being:

> *"When I did get the courage to ask people, and I was getting let down, it was taking more of a toll on me, you know?"* Nadir's mother.

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Dana's mother felt people were not interested in providing her with emotional support:

"You can tell when someone is listening to you or not listening to you", Dana's mother.

This parent carer spoke of experiencing a mental health crisis as a result of caring for Dana, coupled with grieving for a child she had previously lost to the same condition. Ruby's parents spoke of how they gauged if someone wanted to help. There were tensions around accepting help:

"If we think they don't want to or are not interested in looking after her, then I am not going to ask. If they are interested in looking after Ruby, then you will see that", Ruby's mother.

Invisible barriers

During interviews with parent carers, a number of other issues were also identified which formed barriers to asking for and receiving informal support: several mentioned what could be referred to as the 'hidden costs' of requesting or accepting informal support. These are relevant as they form an invisible barrier to accessing such support. These tend to not be practical barriers, but attitudinal. They may be things that practitioners may not consider when assessing the availability of informal support for parent carers of BME children with LLCs. There was tension regarding the fact that parent carers may not be able to reciprocate,

therefore people did not want the burden of feeling indebted to others. Several parents felt that they struggled with the burden of not being able to 'return the favour' for those who supported them, despite no one demanding this from them.

An unexpected theme which emerged was the cost of asking for help between couples (the parents themselves). This related to financial dependence; loss of independence associated with one parent having to give up work to care for the child, and how this impacted on a number of aspects of a parent carers life. It also impacted negatively on the couple's relationship. For example, Nadir's mother spoke of how much her life had changed since her son's diagnosis, which resulted in her leaving work. She had lost contact with the friends she had made through work, and the associated social support, as well as her financial independence. This parent spoke of the loss of her previous identity and independence. She stated that although her husband was prepared to financially support the family, she lost her autonomy and right to make her own choices. She stated that she was unable to socialise with friends because she did not have her own money to use for such occasions:

> *"I had to give my job up. [Husband] said 'don't go to work, we'll be ok'. So, it wasn't like I could say 'Can you give me money; I'm going to that [socialising with her friends]. Because he'd basically say 'no' to me. And I felt like… you know… I didn't want to rely on him! Since 13 years old I've been working myself, and now all of a sudden… I've never been taking no money off my dad, and I now have to ask him [husband], and I just didn't feel comfortable",* Nadir's mother.

6.5. Support parent carers valued

What families find helpful and meaningful will vary. Support can take a variety of forms. Three types of needs, and associated support were identified by parent carers in this study: financial support, psychosocial / emotional support, and practical support.

6.5.1. Financial support

Financial support was one area where BME parent carers were able to request and receive support from informal support systems, such as extended family. This may be because providing financial assistance involved less complexity and challenges than providing support such as childcare. Being a parent carer of a disabled child can have a negative impact on income and finances (Blackburn, et al., 2010; Trani and Loeb, 2012). Asked who the family could rely on for financial support, Rishi's mother stated, "My dad. My brothers". Eshan's mother experienced financial difficulties when her husband became unemployed. Her brother-in-law provided financial support for her to purchase a house. None of her immediate family were in the UK. Examples parents gave of the way their family supported them included help to purchase a car or help to pay the mortgage. This tended to involve lending money to the family, on terms they could realistically repay:

> *"I have got family who help me in that kind of way, where if I can't buy something straight away, they're willing to borrow me [sic] the money to*

buy it so then I'll save up £100 or £50 a week, or so, and then pay them

back when I get the chance", Hanif's father.

Chand's mother spoke of her father lending her money to buy a car. During a further family crisis [Chand's father became ill and underwent a kidney transplant and could not work for several months] Chand's mother spoke of her husband's brother providing financial support by paying the mortgage. Dana's mother also stated that they turned to family during an emergency, "We borrow from his [husband's] brother".

6.5.2. Emotional support

Parent carers interviewed valued emotional and moral support provided by family and friends. They appreciated people taking an interest in their child's well-being. They identified a need for someone to listen to them and offer space to discuss their worries and concerns. Emotional, psychosocial support was highly valued by this group of parents, not just for themselves but also their other children. This came from several sources. Chand's mother spoke of how her parents could not help her practically, but they provided valuable emotional and spiritual support:

> *"A lot of my spiritual guidance and support comes from my parents – comes from my Dad – because I feel confident and comfortable enough with my Dad",* Chand's mother.

Eshan's mother valued the emotional support she received form her sister-in-law, who lived abroad. This highlighted how geographically dispersed the family

support systems of BME families can be. It was a similar situation for Ruby's mother. Although her family were in India, she was able to speak to her mother and receive emotional support from her. This was one of the advantages of technological advances such as smart phones. Fiaz's mother spoke of the emotional support and comfort she received from her family who were abroad:

"Emotionally they [her family] are very good. My dad in particular provided very good emotional support", Fiaz's mother.

Chand's mother mentioned an additional barrier and risk associated with seeking emotional support from family:

"How do I deal with my family's upset? Because my sister's very upset – my mum's very upset, and his [husband's] brother's very upset – but actually, I'm upset! And nobody is looking at me; I'm just worried about how everyone else is feeling", Chand's mother.

Another source of support identified by parent carers was peer support. Peer support was accessed through formal services. There is research to demonstrate the positive impact peer support can have for parents of disabled children (Bray, et al. 2017; Wynter, et al. 2015). Radha, a professional working for a hospice, spoke of the links between formal support and peer support:

"We can involve mums in the Mothers' group so that they get support", Radha.

Parent carers spoke of receiving emotional support from peers. Dana's mother spoke of experiencing social isolation. She stated that most of her friends were people who had a shared experience:

"My friends, I mean, most of my friends, they all have special needs children. We met through a support group, going back years now, from my son [she had a son with the same condition as Dana who died several years earlier]. So, we just stayed in contact, so… That's my support. If we do have a problem, we turn to each other, but we don't turn to each other too much because we know we all have our own issues. So, we try not to burden each other, really", Dana's mother*.*

Anna described the peer support group events that the organisation she worked for ran:

"The families all get together, um, usually it's within the hospice sometimes outside of the hospice and we're hoping to extend the outreach side of things in the next year or two. But it's groups of families that can come together and just be a family doing a joint activity but with other families who get it, who are in the same position. So, it can build relationships. I think it's the whole understanding, particularly the siblings and the parents", Anna.

Teresa, a professional working at a hospice explained that although the organisation she worked for did not offer peer support, it was something which

they noted families valued. She spoke of how she tried to create opportunities for mutual support:

> *"We've tried to always invite families in together, and you know, some of that's about 'careful matching'.   Where we have identified that there may be a mutually supportive relationship – we would try to invite those families in to stay at the same time, so that they can establish – or re-establish – that network",* Teresa, hospice staff*.*

This support was not only focused on parents but also on siblings and fathers. Adnan's father spoke of attending a father's group, arranged by the children's hospice he was in contact with. A study undertaken by Hartling, et al. (2014) found that chronic illness or disability in children can have an adverse effect on the psychosocial health of siblings. Rishi's mother mentioned the social events and activities that the hospice organised for siblings, which her children attended. Chand's mother spoke of her younger son attending a sibling group, which he really valued. However, she feared that once Chand would reach a certain age, he would no longer receive hospice support, and this would also mean the support for his younger sibling would end. It would have really benefitted the younger sibling to continue with this support. It is something which services may wish to consider. Parents stated that peer support helped them to feel less isolated:

> "*It helps to know I'm not the only one [laughs]. Makes me feel a bit normal*", Dana's mother.

A theme of loss featured throughout interviews with parent carers. For example, loss of job, former self, home they had, independence, choices, friendships, social life, hopes and dreams, which contributed to their needs for emotional support.

6.5.3. Practical support

Parents gave examples of occasions when they had received help, and the type of practical help and support they appreciated and valued from family and friends. One such example came from Zidane's mother who recounted the time when Zidane was critical in hospital, and she spent all her time by his bedside. Zidane's mother spoke of how grateful she was for her brother-in laws support:

> *"He came to the hospital, and he stay with my child whole night. So, we came home, and we take a rest"*, Zidane's mother.

This type of support, respite, was identified as a key need. Aliyah's mother stated that she would have valued the opportunity to ask family, "Can you take over Aliyah for a little bit?" Parents spoke of the challenge of ensuring they also made time for their other children, and the potential for negative impact on sibling emotional well-being, "'Cause they miss out on a lot" (Dana's mother). Respite for a short time would allow them to focus attention on the non-disabled siblings:

> *"My mother-in-law, she's been really supportive. She's always there; whenever we need to go out, she'll come down. She tends to stay home*

with Hanif while we take them [other children] out. But it is difficult, because
we want to take them all out, together, which we would prefer doing, but…
it's hard to do", Hanif's father.

The numerous hospital appointments led to challenges for parent carers in ensuring they were able to collect the siblings from school. This was a need for support they identified, where informal networks could assist. Rehana's mother, had a strong support network, and spoke of the many hospital admissions she had for Rehana (some planned, others unplanned) and the needs of her other children:

"So, one of my friends is very good; I just ring her and say, 'I'm in hospital.
Until I'm discharged with Rehana, could you please take her [younger
child]?' And she does. All I have to do is phone either one of my brothers
to pick up my kids. And my two sisters-in-law they look after them – take
them to school", Rehana's mother.

Childcare support was highly valued by parent carers – not only for the child with an LLC, but also for the non-disabled children. Due to frequent unplanned hospital admissions and appointments, there was often a need for someone to collect siblings from school. Parents also identified the need for childcare and opportunities to socialise (for siblings) during school holidays. Although Rehana's mother had a strong support network, this was not widely applicable, and there were variations within this group of parents, impacted by a number of

factors. Rehana's mother was British born and spoke English and had lived in the same city all her life. Her family were all based in the UK and lived locally.

Practical help such as someone cooking for the family was also appreciated, as it meant parents could spend time with their other children. Chand's mother stated how much she appreciated others cooking food so she could get a little respite or just spend time with her other son. Rishi's mother spoke of the challenge of trying to spend time with her other children and the limited availability of respite from formal services, and the inflexibility in terms of time/day that they can access this. She felt this was an area where she would really appreciate help from others. These needs are not specific to BME families.

6.6. Conclusion

Families are unique in terms of their makeup, values, and experiences. As a result, inevitably, their practical and emotional needs will vary. Ethnicity, culture, and religion are important aspects of a person's identity; however, this is only one aspect, and other elements of their social identity need to also be considered. It is important to balance addressing these needs with ensuring we do not resort to ethnic and 'racial' stereotypes, or assumptions when making judgements about families or groups in society. Otherwise we risk working oppressively by excluding certain groups from receipt of vital services, which they have equitable rights to. Racial and ethnic stereotypes may disadvantage certain groups in society and risk a violation of legislation such as the Equality Act 2010. Evidence

based practice requires engagement with facts. This can be done through the process of assessment, and the application of Bronfenbrenner's ecological systems theory can support this process. Even if informal support is available to a family, it is important that families feel empowered to choose whether or not they wish to accept this. Having the element of choice taken away from them may lead to additional stresses and pressures. For example, some parent carers participating in this research mentioned a fear of burdening members of their family, or being obligated – as this could affect their long-term relationships with them. Professionals can utilise a range of resources (such as training) to build their skills and confidence to undertake assessments with diverse groups, and to create space for them to speak about their challenges.

It would appear that a paucity of informal support is a feature common across ethnicities. Social isolation is a feature in both BME and white families. BME families have the same issues and tensions in families as white families do. However, their social isolation is further compounded by the fact that their social support system is spread across the world – or at least much further afield than that of the average family in the UK. It appears that there is a place for both informal and formal support, and one should not be seen as a substitute for the other (Mindel, Wright, and Starrett, 1986). Each family is unique and what one parent needs or values, will not necessarily be the same as another. For example, Nadir's parents spoke about the support family offered. His father was very grateful for the fact that the family were able to move in with his family and live in their home, an important source of financial help. However, Nadir's mother felt she would like a different form of support, and in fact resented giving up the

independence the family had of living in their own home, to have to live in her in-laws' house, on their terms.

Assessing each family's individual needs is key to ensuring we practice in an anti-oppressive manner. We need to ask and listen to what each family would find helpful, and to try to fit their support in around their needs – what would make a difference to the family? Anti-oppressive practice requires a flexible approach tailored to the needs of the family, which only the family themselves can adequately describe. The same principal should apply here as does for formal support – the element of choice is important, and parents need to feel they have agency and control over their affairs.

Chapter 7 Formal support

7.1. Introduction

The families of disabled children and children with LLCs can face extraordinary challenges and may therefore need additional support from external sources in the form of formal support services (Isa, et al. 2016; Mitchell, 2008). Formal support can come from a number of sources: statutory services such as social services, hospitals, and schools, as well as third sector and community services such as hospice care, and support through religious and cultural organisations. This chapter will focus on the range of formal support services which may be available to families and seek to identify any barriers that BME parents of children with LLCs may encounter, as well as looking at their experience of accessing such services. It will look at how BME families experience the provision of formal support services, needs parents identify for formal services, any barriers identified to accessing services, and ways in which these could be addressed.

Featherstone and Broadhurst (2003) raised the issue that despite there being availability of a range of services for parents and children, those who may need help from formal services do not always access these, thus identifying barriers to access. It is noteworthy that despite preconceptions amongst professionals, and

some academic contributions to this debate, the differences between BME and white groups are not as clear as might be expected. Parent carers of disabled children and children with LLCs have some common experiences and needs, irrespective of ethnicity, as noted in previous chapters. However, religious, ethnic and cultural variations may be one of a number of ways that their experiences and needs will vary. This is not a homogenous group, by any means. Despite some shared experiences and characteristics, there are also bound to be family-specific differences. Many of the issues faced by BME parents of children with LLCs will also be experienced by white parents of children with LLCs. To expect there to be vast differences between the experiences of the two groups is an example of 'othering' of a minority group, which can lead to negative pathologies of minority groups. What is of note, however, is how others perceive them and may treat them differently.

7.2. Formal support services

The type of support available from formal services can include the following: access to welfare benefits advice, housing adaptations, grants for specialist equipment such as wheelchairs, adapted equipment such as specialist computers/chairs/beds, as well as short breaks/respite, access to peer support groups, and counselling. A range of psychosocial support needs require addressing for the child, the parents, and the siblings. These services can support and guide families through the complex maze of health-related services and processes, as well as supporting them through transition, and helping the

families to better manage short term and long-term challenges, be they financial, emotional, or practical, leading to improved outcomes for the child and family. Wodehouse and McGill (2009) advocate for improvements in partnership working between professionals and families.

Featherstone and Broadhurst (2003) refer to the dangers of undertaking research into help-seeking behaviours when the focus is on the perspective and views of professionals alone. This research bridges that gap and ensures the inclusion of the vital voices and perspectives of parent carers. Chapter 8 will include the perspective of professionals in terms of how they view families of BME children with LLCs. All families trying to access formal services are potentially likely to experience struggles and challenges in accessing these, due to a range of reasons including the complex, and changing health and social care system, evolving language, terminology, and jargon, as well as the nature of policy and legislative changes impacting their rights and entitlements. There may be particular challenges faced by BME groups, for a number of reasons. Szczepura (2005) believes that BME families have poorer access to health-related services, and face greater barriers. There may be attitudinal barriers from professionals believing "they look after their own" (Katbamna, et al. 2004; Gaffin, Hill, and Penso, 1996, p.52). Families of children with LLCs are likely to access support through a range of sources in the social care, health and education sectors. Services across health, education and social care operate differently, and work collaboratively but also autonomously; "Health systems and health care institutions are among the most complex and interdependent entities known to society" (Kodner and Spreeuwenberg, 2002, p. 2). It is likely, therefore, that many

of the barriers or challenges to accessing services faced by BME families may be the same as those faced by white families. However, any differences in experiences will potentially be based on different religious, cultural, and language needs of some families. This is the prime reason for a specific focus on religious, cultural, language and dietary needs of BME families, in this chapter. This is one area where the needs and experiences of this group of families may be different. This may particularly be in the case of newly arrived or first-generation immigrants, refugees and asylum seekers, international students, and economic migrants. There are challenges to clearly defining what is meant by concepts such as culture (Cohen, 2009). These challenges, and how they impact on the delivery and receipt of services for BME families will be discussed further in Chapter 8 - 'Professionals' Experience of working with BME parent carers of children with LLCs'. Scheppers, et al (2006) refer to the notion that BME groups face barriers to take up of services which service providers may not be aware of.

Ethnicity and culture can be concepts challenging to define (Cohen, 2009), and address. This could be for several reasons, including fear of offending. In the interviews conducted with parent carers, they refer to religious and spiritual needs, as well as cultural needs. A number of personal characteristics may contribute to forming barriers to accessing services for BME groups, including the following: ethnicity, education, socio-economic status, language, and culture (Scheppers, et al. 2006). Barriers may also exist due to 'racial' stereotypes and beliefs professionals hold in relation to the needs of BME families. In my practice experience I noted the widely held belief amongst professionals in health and social care that BME families have greater availability and access to informal,

kinship, support systems. This was used to explain and justify low or no engagement of BME families with formal services. This research is an opportunity to ascertain whether these assumptions are valid or need challenging and updating. The data from interviews conducted for this thesis will help to provide a picture of the current situation, and may help move along that debate, due to these insights and contributions from parent carers. Both positive and negative experiences of accessing services, from the parental perspective, will be discussed.

7.2.1. Religious institutions

Whether religious and cultural organisations constitute a formal service is debatable. They are certainly very different from statutory services in that they have less bureaucracy than the NHS or social services. Some mosques, for example can be affiliated to a national or international structure (e.g. the Muslim Council of Wales, or the UK Islamic Mission). But other religious institutions may be standalone local organisations without any formal or legal status, run by local volunteers. It is important to explore provision by such agencies, as the academic discourse, and perceptions of some professionals working with BME families, refer to the notion of religious institutions providing an extra layer of support for BME parents, thus potentially addressing and meeting the needs of BME families which statutory services may not be meeting. There is also the belief that religion can be a barrier to accessing formal support (Bywaters, et al. 2003; Giunta et al. 2004; Ahmed & Rees-Jones 2008). This viewpoint is challenged by the findings of this research, where parents were directly asked if religion prohibited them

from seeking help and support and not one parent felt that religion prohibited them. Abbas' father stated:

"No, religion doesn't really prohibit us. He [Abbas] is entitled to his rights". Abbas' father.

Bywaters, et al (2003), refer to the fact that service providers use religion to justify low take-up of services from BME groups. Hanif's father explained that as a Muslim, his religion provided a flexible approach to observing and following religious procedures and guidelines, which were relaxed in exceptional circumstances such as those experienced by this group of families. Aliyah's and Dana's mothers also stated religion did not form a barrier to accessing services. Several parents were perplexed by the question itself. They were also asked if culture, or community were a barrier to accessing formal services, to which they also responded in the negative.

Some assumptions about the type of support that religious institutions may provide may possibly not be applicable to BME groups; they may essentially be Eurocentric perspectives held by professionals which do not apply to BME groups. Krause et al (2000) refer to emotional and spiritual support provided by those who work at churches, or are attendees, for members of their congregation who may be experiencing difficulties. This is reinforced by Coulthard and Fitzgerald (2007) who believe that as well as emotional support, organised

religion can also be a source of financial assistance for families. Potential types of support available through church type institutions include: financial support, nursery places, parent and toddler groups, opportunities for socialising, counselling, information regarding welfare rights, accompaniment to appointments, et al. It would appear from the interviews conducted that these are part of church traditions but not necessarily other religions. In fact, the parents interviewed identified several barriers to religious organisations – both practical and attitudinal. For example, Ruby's mother spoke of the stigma she experienced from some people who attended the Hindu temple she visited:

"Sometimes people say, 'because you did something wrong in your past life, that's why you got your daughter like that'", Ruby's mother.

Asked if she could expect help and support from the temple, her response was, "as far as I know, no". Parents interviewed discussed religion in the context of it providing comfort when coping with the emotional impact of having a child with an LLC (this could be considered spiritual needs). But they did not refer to support in the form of financial help, or any other practical help including peer support. Parents interviewed referred to stigma they experienced from some members of their religious group, which may have contributed to creating a barrier for them to interact and engage with religious institutions and groups. People were generally well-meaning, but the risk of hurtful comments was an additional issue for parents to consider, in addition to other challenges they were facing.

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There were also references to physical barriers to engaging with religious institutions, such as lack of disabled access. The parents of Abbas (a 16-year-old with Duchenne muscular dystrophy) mentioned that he could not attend religious events in the local mosque due to him being a wheelchair user, and the mosque lacked disability access. This potentially could have had a negative impact on him, as twice a year at Eid, members of his family attended mosque (which is a significant social, as well as religious, event), and he was unable to participate. The type of religious support from institutions BME parent carers refer to in interviews is primarily prayers and blessings, with a small element of emotional support. Attending religious events at mosques and temples and Gurdwaras also allows families to maintain some form of normality and less socially excluded. It would appear that these institutions are not in a position to offer practical support, or address the complex needs of such families.

7.2.2. Statutory services

GP surgeries

GPs are most likely to be the first service parents contact regarding their child's condition. It is an important source of support in the early stages and may influence the parents' help-seeking behaviour. It could affect the initiation of contact with other services for the family. Parents mentioned the significance of a good relationship and support from their GP. They placed a high value on having a GP who knew of their child's condition and would respond accordingly by giving them a prompt appointment (when needed in an emergency) rather than referring them to the generic appointment making system. When their child had

a cold or infection, they needed to be seen immediately otherwise the child could deteriorate rapidly, leading often to hospital admission. A few parents mentioned that their GP surgery had notes on their child's file which meant that receptionists would provide an appointment without asking too many questions; to not have to fight for an appointment, and have that level of understanding from a GP was seen as extremely helpful. Iona's mother explained how important it was for Iona to be seen as soon as she had some form of infection, and that her GP surgery were aware that Iona "is a special child", and so would see her immediately. Farhan's parents also spoke about how much they valued the support of their GP. Farhan's mother stated, "My GP is brilliant" and cited a number of ways he had supported the family: making home visits outside of surgery hours and writing letters of support for the family.

As the care and medical needs of such children are highly specialised, and most of the services they access are through hospitals, it is inevitable that GPs will not have the expertise to support them. Dana's mother stated that she felt she knew more about her child's condition than her GP did, and therefore had to provide in-depth knowledge and information to help her GP to understand the needs of her daughter.

Although GPs may be the first point of contact for families, the family will be referred to a paediatrician, or hospital-based consultant. They are in a position to direct the family to a host of relevant formal support services or provide relevant information. This may influence the family's ability to adapt to their situation.

Hospital Staff – nurses and consultants

Many of the children, once diagnosed, had little contact with their GP as they were regularly seen by specialist consultants at hospitals. As a result, they were unlikely to have in-depth knowledge about the child's illness, or knowledge of the family's situation. This is where the relationships the families have with hospital staff, specialist nurses, paediatricians, and consultants come into play and are seen as much more significant by the parents. Several parents spoke of the close bond they had with their consultants, with some providing access to their mobile phone numbers outside of working hours, and being willing to provide letters of support with any non-medical issues, which was highly appreciated by the families. This may be an indication that they felt the family were isolated and vulnerable and required this level of extra input. It appears to be above and beyond the role of a consultant.

When asked who had been the most helpful to the family, Abbas' parents stated this was the specialists at the hospital their son attended for regular check-ups. Abbas' father specifically referred to hospital-based doctors and nurses, and the help they had provided:

> "*They've helped us a lot. Sometimes we don't know how to claim things and they show us and help us. Anything we need for our home, they help us*", Abbas' parents.

The above quote demonstrated that the support they received from hospital-based staff went beyond the medical needs of Abbas and included the needs of the family. Aliyah's mother spoke of the high level of confidence she had in the care provided by hospital staff. In times of crisis she felt that the hospital staff were better able to cope with Aliyah than she was. Eshan's mother particularly valued the support of hospital staff at a time when she agreed to donate her kidney to her son (her family were not supportive of this decision). She was very isolated as she had just come to the UK and had very little time to build a network of support:

> "*They were positive and really helpful. They brought all the professionals to talk with me and I was able to ask questions and get answers*", Eshan's mother.

Ruby's mother spoke about the positive relationship she had with her daughter's consultant, and in particular spoke about the ways he ensured good communication:

> "*They always say, 'Mrs M ask if you don't understand. If you want to speak in Gujarati, you can speak in Gujarati', because certain doctors can speak in Gujarati*", Ruby's mother.

She appreciated the efforts they made to ensure she understood the information they provided, and she mentioned how they observed her non-verbal communication (such as looking confused when they used highly specialised medical language) and responded to this appropriately and sensitively. This sentiment was also echoed by Zidane's parents who spoke of the efforts hospital staff (specialist nurses and consultants) made to reassure the parents:

"*We went to [children's hospital]. They said when he is born they will transfer him to this ward. They showed us the operating theatre where he will be taken straight after birth, and the ICU where they will be keeping him. And we saw a couple of babies with heart problems. They explained everything*", Zidane's parents.

Parents appear to really value the efforts professionals go to in order to communicate effectively with them and to explain processes and procedures. This appreciation is not specific to their ethnicity, but something that any parent, irrespective of ethnicity, would value. There were examples of some extraordinary efforts made by health professionals to support the families. Farhan's mother spoke of how her son's consultant gave her his mobile phone number, and she was able to contact him if there was an emergency and her son was hospitalised. During a crisis, the consultant would immediately arrive at the hospital, providing reassurance for the family, as he knew their child better than anyone else. They found it comforting to see a familiar face in an emergency. The professionals

working in these settings appeared to have had a good understanding of how to reassure and support parents in challenging situations.

Social Work Support

Parents interviewed spoke of having infrequent contact with their social worker, if they had one. Very few parents had a social worker and several asked how they could access one. Abbas' parents spoke of the minimum contact they had with their social worker:

> *"He comes to see Abbas about once a year. In fact, I think it has*
>
> *been 2 years since he [Abbas] last saw him", Abbas' parents.*

The family knew they could contact the social worker and request a visit but felt that the help they needed was provided by their hospice key worker or staff based at the hospital. They did not approach him, unless it related to disability adaptations to the house. It would appear that due to the high level of engagement with health services, and the frequency of interactions with them, their needs were more readily met there. Farhan's mother did not like the fact that she had to chase her social worker when she required support. A more proactive approach would have been valued by the family. The main criticism of social workers centred around the lack of contact and regular communication. Social workers appeared to lack the specialist knowledge required to support families in this situation; whereas hospital and hospice staff, appeared to be more

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aware of their needs, and resources to help meet these. Quereshi, et al. (2000) in their research found that the BME families who were in receipt of social work services felt the service did not meet their needs. However, in this case it may have been less to do with ethnicity but more with the specialist nature of the needs of children with LLCs. Social workers may not be best equipped to address such complex and specialist needs. Chand's mother felt that social worker contact was minimal, and although she was aware that she could ask for help, she felt that she would just be referred to another service rather than getting the practical help she needed from the social work team, so did not approach them for help. She appeared to be exhausted by the effort required from her to access practical support:

> *"I think there needs to be more social workers; there needs to be*
> *more resources, just more time", Chand's mother.*

Adnan's father felt worn down by the effort of trying to access support through his social worker:

> *"Everything's a battle; to get a wheelchair is a fight", Adnan's*
> *father.*

He felt that social workers did not have a good understanding of the issues faced by parents of children with LLCs, and that in his experience, they did not get to

know the child sufficiently, therefore were unable to support them adequately. He felt that they should consult other professionals involved with the child, such as teachers and hospital consultants, who had more frequent contact and knew the child well. A closer multi-agency approach was suggested. This he felt would lead to improved relations through a person-centred approach. Iona's mother reinforced this view; she felt it was a struggle to get social workers to understand her daughter's needs, which formed a barrier to her seeking help from her social worker. Aliyah's mother spoke of two comparable experiences she had – one with a 'good' social work team and the other with a 'bad' social work team. The 'bad' she described as providing very little support for the child and family. The 'good' she described as follows:

"We didn't know how much a social worker could actually do to impact on our situation. She's even been in to see Aliyah in hospital. There were a lot of issues which are now slowly being dealt with", Aliyah's mother.

She felt that social workers should undertake more home visits to get to know the child and familiarise themselves with the family to create a relationship of trust. In contrast to what she referred to as "the one visit a year", she felt there should be at least four set visits per annum, just to keep up-to-date on changing circumstances. Aliyah's mother felt that leaving it to the parents to chase social workers for help was unfair as parents can be overwhelmed by their various caring responsibilities and could end up in a crisis situation, "It's hard to ask for

help sometimes". A risk associated with expecting parents to chase social workers was highlighted by Hanif's father who said that although he had a social worker for his son, he did not know where they were based, how to contact them, and what form of support he could expect, "All I know is just her name", Hanif's father. This family were experiencing many difficulties and appeared to be close to reaching crisis point.

Dana's mother lacked confidence in social workers; despite experiencing difficulties, resulting in a nervous breakdown, she would not seek help from them as she felt they would let her down and she would only be further disappointed. She spoke of poor experiences with previous social workers. Iona's mother could not be sure whether or not she currently had a social worker. She stated that she had one once, but that person left their post, stating that the new social worker would contact her, which did not happen. She spoke well of the previous social worker:

> *"I felt like she listened. Others just tell you what you need but this one asked me what I needed", Iona's mother.*

Social work teams are in a position to support families of children with LLCs to access support and respite from hospices. They are essentially gatekeepers in a position of power (due to the knowledge they hold, and their ability to make referrals to other services, which cannot necessarily be accessed directly without

social work support. It could be a potentially invaluable source of support. At least two parents (Adnan's father, and Aliyah's mother) had only learned about hospice support through their social workers. The issues raised by the parents here were not unique to BME parents. They also were not in relation to their 'race', ethnicity, nor connected to language or culturally distinct services.

Special Schools

Most parents interviewed had children who attended a special needs school. These schools provided a range of services to the child and the family, including access to community paediatricians, hydrotherapy pools, speech therapy, ESOL classes for the mothers, and opportunities for peer support. They also provided information regarding grants for disability equipment, and supported and facilitated access to respite. The holiday schemes they ran were also a highly valued source of respite. School is where children can spend the majority of their time outside of the home. It is also a universal service; all participants are likely to have access to, and experience of, this service.

Iona's mother felt that the school was her best source of support. She valued their input in giving her daughter opportunities for socialising and gave her a break from caring responsibilities so that she could address other issues in her life. Nadir's parents also spoke of how much their child enjoyed the social element of attending school: "he's always happy there" (Nadir's mother). The bond between the child and their key worker was seen as a very special relationship. Schools provided stability, normality, and routine for the family,

during difficult times when they were having to deal with some very challenging issues such as their child's deteriorating health and increased care needs. Rehana's mother felt that the school was the most valuable source of support she had:

> "*If I go to them and approach them for something, if they can't help me they go out of their way to explain or show me other routes*", Rehana's mother.

Parents appreciated communication from professionals where empathy was evident. They felt supported when professionals acknowledged the challenges they faced as parent carers; and when they were willing to go that extra step in terms of support.

However, some parents expressed dissatisfaction. Adnan's father was unhappy with his son's school. He felt that BME families are expected to accept a lower standard of service. He complained about his son's school and felt the school did not take his concerns seriously nor address them adequately. He gave an example of a situation where he noticed that Adnan was coming home after spending an entire day in school in the same pad he left home in, but soiled. He provided evidence but the school did not appear to respond, and his complaints went on for more than six months:

"It actually hurts, you know… I've had incidences where he's reeked of urine because they haven't changed him. Adnan excretes acid from his urine, so it burns him, and so he should be changed", Adnan's father.

This father felt professionals working in the school did not have first-hand experience of having a disabled child, which made it difficult for them to empathise:

"Have you ever lived with a child with severe needs like mine?", Adnan's father.

Aliyah's mother referred to the important role schools play in the lives of such families:

"If the school fails to meet the child's support needs it has a knock-on effect on everything", Aliyah's mother.

7.2.3. Hospice

Hospices provide support for families of children with LLCs. Although most hospices receive a contribution to their income from statutory/government sources, they gain the majority of their funding through fundraising and are therefore independent of the state and have registered charitable status (Gaffin,

et al, 1996). In order to ensure the provision of high-quality care from suitably qualified professionals, organisations and professionals providing such care in the UK are regulated. Hospices provide a range of services through professionals such as nurses, social workers, and therapists. These services include respite for the child and the family, sibling groups, counselling, social outings, and support to access grants for equipment. Farhan's mother spoke appreciatively of the support she received from the hospice:

> "*For me, they're my family. They are closer to me and I can talk to them about stuff you can't speak to your family about*", Farhan's mother.

Hospices were also an important source of peer support for some of the parents. Social isolation can be a big issue for this group of families (Whiting, 2012). A hospice worker interviewed (Teresa) mentioned that she worked with two BME mothers, separately, who both felt very isolated; she planned their stay at the hospice to coincide, in order to facilitate an introduction between them. This resulted in a long-term friendship between the two mothers, and a source of mutual support. Teresa also mentioned arranging open day visits for BME families to visit the hospice to coincide with stays times when other BME families would be accessing care. She hoped this would encourage the visiting family to feel more comfortable to arrange a stay. These were examples of positive strategies for engaging BME groups. Those who accessed hospice support spoke enthusiastically of the services received. Abbas' parents stated that they

appreciated his stays at hospice, "*We are able to get rest and have a break*", Abbas' mother.

However, Eshan's mother spoke of an incident when due to a family emergency in India, she had to leave her son with a hospice for a few days, as she had no other support. As a Sikh boy he had long hair which he wore according to religious and cultural traditions and expectations. However, the hospice did not investigate this aspect of his care and put the child's hair in a ponytail. On her return, on seeing this, Eshan's mother was upset.   Due to a number of reasons, including fear of losing the service, she did not complain. It clearly had affected her as some years later she recalled the incident. Whether this occurrence was a contributory factor or not, she then chose to have his hair cut short in order to avoid any future challenges for those who care for him. This was one of those incidents where ethnicity, religion, and culture had an impact on service usage. This was also the type of incident which is less likely to happen to white families, as their family are less likely to be spread so widely across the globe. Even where they are, a white family may have access to wider social support. Eshan's mother had only been in the UK for a few years and had not had the opportunity to develop strong support networks. It appeared that families valued a flexible approach; a holistic approach of supporting them which included their cultural and religious needs.

Farhan's mother had a close relationship with her son's physiotherapist (based at the hospice), who would support her when Farhan was rushed to hospital in

emergencies; and she also attended the scan appointment with her when she discovered she was pregnant. This mother felt the support was irreplaceable, as she felt that she could discuss issues with this worker that she could not with anyone else. This was a key message. Despite plenty of family around her, she still needed and valued the formal support offered to her.   Aliyah's mother appreciated the proactive approach of the BME worker at her local hospice:

"*If she's not heard from me she'll give me a call or drop me an email to say, 'I hope everything's ok'*", Aliyah's mother.

She spoke about how much she valued the peer support group which the hospice ran for BME mothers, "this has been fantastic". She spoke of how responsive the hospice had been to their needs. However, she did not mention cultural or religious needs. Dana's mother also spoke of the value she placed on the BME mothers' group and the sibling groups they ran which her children attended. She appreciated the social outings they arranged for parents and the mutual and peer support from other mothers. This is in line with the literature, which refers to the families of disabled children experiencing isolation, negatively to impacting on their well-being (Whiting, 2012; Mencap, 2006). Adnan's father valued what a hospice service offered, "hospices are lovely places". He referred to support they provided for siblings of Adnan:

"*They're due to attend a siblings group at [hospice] which the children love – they think it's fantastic*", Adnan's father.

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However, he expressed dissatisfaction with some aspects of the service. This included the amount of respite he could access. On the day of my visit to the family home, Adnan had been expected to go to hospice for a day of respite. However, two days before the visit the family received a letter cancelling the visit with no explanation for the cancellation, and no offer to rearrange or suggestions of alternative dates. He described how much he had been looking forward to having a short break (for a few hours) and that the disappointment of this being taken away (with no hope in the form of an alternative date) was overwhelming. He explained how much pressure he was under and how desperately he had been looking forward to that short break:

> "*And this is the first time he was going for respite after 6, 7 years*", Adnan's father.

In terms of preconceptions of what a hospice is, Dana's mother believed this was somewhere a child went at the end of their life. Aliyah's mother also described what she had envisaged a hospice to be:

> "*I thought it was just end of life care – totally end of life care. But the hospice are actually there for you all the time*", Aliyah's mother.

Chand's mother described how she imagined a hospice to be, prior to visiting one:

> *"I thought a hospice was a place where people went to live their last days. I thought it was somewhere where people would be sad, and unhappy and crying; it would all be 'doom and gloom'. But it's not like that at all. It's happy, it's positive, it's fine, it's making memories, it's giving confidence to do the things that you would never do", Chand's mother.*

Iona's mother stated she felt she could trust a hospice to look after her daughter because of the medical professionals who were based there. Adnan's father stated:

> *"I thought it was mainly medical support, you know, strictly medical and that you can't do much there; but no, it's a lovely place", Adnan's father.*

Two barriers to accessing hospice support were identified by Aliyah's mother. She stated that she was anxious about the location of the hospice (in a rural setting, quite a distance from where the family lived) as children with conditions like Aliyah's could deteriorate rapidly, and she feared if Aliyah became unwell, they would not get there in time:

"There have been a few deaths there, where parents have not been able to get there on time. And I think that's my fear… What if something happens to her and I'm not there. What if we were put into that sort of situation?" Aliyah's mother.

She also spoke about the psychological and mental aspect of accepting your child has a condition which means they need hospice support:

"I think there will be some point where I will be completely 'acceptable' of it [her daughter's condition, and the need for hospice], but I've not quite reached that yet", Aliyah's mother.

Rehana's mother also stated she had negative preconceptions:

"I know of [hospice]; I was petrified of what [hospice] is known for; to even know more or get involved in something like that", Rehana's mother.

But once she visited a hospice, she decided to accept their services:

> *"I decided to ignore the 'ifs and buts' and put my demons aside.*
>
> *Now I just think it's a resting home for the family", Rehana's*
>
> *mother.*

But she made it clear that she would not leave her daughter there alone ("that will never happen"). Rishi's mother, however, had no such concerns about leaving her son at the hospice, albeit only for a few hours, as she valued the opportunity to focus on her other children:

> *"We'll leave him and say, 'we'll be back in an hour' or 'back in 2*
>
> *or 3 hours'. We know that he's in safe hands", Rishi's mother.*

OVERVIEW OF FINDINGS SO FAR

As can be seen, most experiences the participants of this research had are most likely the same as those which white families would experience. However, there were exceptions, such as that of Eshan's experience. And there may be ethnicity related barriers which were not identified or spoken of by parents. It reinforced the point made earlier in the thesis that parents (irrespective of ethnicity) are likely to have many similar concerns and experiences. Ethnicity is but one aspect of the complex situations these families were addressing. Parents appear to value a flexible and adaptable service from professionals. A service that responds to their individual needs; a person-centred approach. A humane, person-centred,

and kind service is what they appreciated; one where the professionals took the time to get to know their child and treated them as an individual:

"*I've only had one really good social worker. She got to know Adnan really well. Others didn't even know he was tube-fed. It's just a matter of reading the files*", Adnan's father.

Parents did not wish to complain about formal support services; they were grateful for any help they received, and where they did raise an issue, they were able to suggest how practice could be improved. A number of factors may have contributed to this reluctance to highlight negative experiences such as fear of reprisals, a culture of low expectation or deferring to authority therefore not challenging it. Adnan's father refers to this notion that BME groups fear complaining about services and will accept a lower standard; he spoke of BME children he had seen in school and hospitals using wheel chairs that they had outgrown but the parents would not complain or request replacements. Parents may also have feared repercussions from services, despite being reassured of anonymity and confidentiality, as many were referred through formal support services.

7.3. The BME Parental experience and views on: (1) religious, cultural and dietary needs; and (2) language and communication

7.3.1. Religious, cultural and dietary needs

Parents were asked if they felt able to identify, discuss, and request specific religious and cultural services from providers of formal support services. Examples of such needs included religiously appropriate food, culturally appropriate and familiar foods, a prayer space, and religious artefacts and prayer books. All parents responded in the affirmative, and said they felt confident to ask for appropriate services. However, they stated that although they felt confident, they tended not to ask for these needs to be met, as they did not wish to inconvenience others or place an additional burden on service providers:

> "*They don't need to work around our culture or anything like that. We're not fussy like that. We're grateful that you're offering something, so we'll just take it. We don't make demands; we just appreciate if there is somebody there with a helping hand or offer a bit of support*", Nadir's mother.

Parents stated that they adapted to their surroundings. For example, if there were no facilities for ablutions, then they would make their own arrangements and take in their own equipment.

The issue of religiously and culturally appropriate food came up. Some parents stated that they lacked confidence in the ability of the service to meet their religious needs in relation to food, so they would take in their own food, as then they would know it was, for example, definitely halal. Adnan's father, a Muslim, stated that he did not expect or request halal food from service providers. He did not have confidence that the food they would provide would be halal:

"*I never ask. I normally take my own food. If we do eat there [hospice] I will ask for vegetarian food. I don't make a scene out of it*", Adnan's father.

Anna [hospice worker/participant] was aware of this issue:

"*A lot of our families who would eat halal food actually say they're vegetarian because they're not convinced it will be true halal food. Some bring their own food and microwave it. A lot of families said to me, 'I always eat salad when I come here, so I don't have a problem with it, it's just so that I know exactly what I'm eating'. So I think food is a really big issue*", Anna.

However, others such as Nadir's father spoke of how much they valued the efforts made by staff to accommodate their religious and dietary needs:

"*The man came all the way to [UK city] just to get the halal meat, and we'd said we were happy with vegetarian*", Nadir's father.

"*I can't fault anyone by saying that they were abusive towards us because of our religion and stuff, because they haven't been. They've been fine with it, so we haven't had any issues over that*", Hanif's father.

Abbas' parents were happy with the hospice service, and the fact that they provided Abbas with halal food. Aliyah's mother stated:

"*We've never ever felt, because of our culture or race or anything, anybody's treated us any differently*", Aliyah's mother.

An issue of concern for some families was the fact that professionals would see their names and make assumptions regarding their religious, cultural and dietary needs.

"*What does get to me is when people assume things – not in a horrible way, but they will hear a name that's not English, and assume you're Indian or Muslim, and you have to correct people. They will assume things, like every Indian is vegetarian, or that Chand won't eat pork or sausages – but he does*!" Chand's mother.

It is the complexity that professionals seem to struggle with, which led to resorting to ethnic and religious stereotypes. The fact that you can have diversity of beliefs in one family, or that South Asian groups are not homogenous, is something professionals may wish to consider.   There is a wide spectrum in terms of religious beliefs and practices, and people can be on different points of the same scale; even those in the same family. Professionals need to be wary of the pitfalls inherent in stereotyping BME families (Fazil, et al. 2004).   For example, Chand's mother (part of a Sikh family) was vegetarian, but her children were not. When asked how professionals could do things better, in an exasperated manner she stated:

> "*Just ask me! It's just basic respect. I'm not offended if you ask me; I'm offended if you assume things about me*", Chand's mother.

Hanif's father also mentioned the importance of staff not making assumptions about families and stated:

> "*Just because you have an Asian family it doesn't mean they'll want Asian food – they may not. They may want English, you know. They have Asian food at home – they may want a change*", Hanif's father.

He felt that services did not allow for any further choices or for the fact that people may also have other preferences other than religious and cultural – some agency in choosing their meals:

> "*The attitude of services is 'ok, we've got a Muslim or Sikh family coming, so let's do halal food, or let's do non-halal food' and when we get there it may be food we don't like. It's a shame because you have people making food that no one wants to eat. Instead they should ask the family in advance what they would like*", Hanif's father.

The need for halal food is not a cultural need – it is a religious need. It does not necessarily have to be in the form of a curry – although some may prefer this as it may be familiar food, for which they will know the main ingredients. This goes back to the issue of professionals conflating religion and culture, and making assumptions, and feeling they should have the answers, however, asking parents and giving them choices is empowering for the families, and they would not be offended by such questions.

Aliyah's mother recalled a positive experience and one that was not so positive. She spoke of an occasion when Aliyah was admitted to hospital during Ramadan; she (mother) requested a side room from the hospital so she could have some privacy to rest/nap during the day (as she was tired from fasting and getting up at pre-dawn to eat and close her fast, and had not initially been provided with this). She felt that the hospital staff did not understand her needs, and would

have been more receptive to her demands if they had asked her more questions to gain a better understanding of her issues; instead she felt that they saw her as demanding and unreasonable. However, she also stated that the hospital provided a women-only prayer room, which she was very grateful for. She mentioned that when formulating the Advanced Care Plan for Aisha the family ensured that her religious and spiritual needs were included:

"*It's surprising how understanding they actually are, because you'd think they wouldn't be*", Aliyah's mother.

Parents mentioned the availability of prayer rooms and how much they appreciated this, but they highlighted that they were often unable to take up this facility as they were reluctant to leave their child unattended (in hospital).

Rehana's mother spoke regarding the importance of religion and culture influencing a family's needs. She stated that although religion was important to her (an observing Muslim), it made allowances for the extraordinary situation families such as hers were dealing with. She observed religious and cultural practices but stated that as far as her daughter's needs were concerned, culture took second place at a time of crisis – the priority would be her daughter's health and well-being. She spoke about how Islam did not impose strict expectations on families in crisis. Most parents made it clear that they would not allow religion or culture to form a barrier to meeting the needs of their child. They referred to exceptions made in religion for disabled children, where religious rules and

expectations are relaxed because of the extraordinary circumstances. Some of the parents stated that they did not expect services to meet their specific needs, so would take in their own religious artefacts (such as a prayer book). They spoke of how they adapted to their specific situation, such as instead of requesting a specific space to pray, praying behind the child's bed (if they were in hospital). Although religion and culture are very important to some families, they do not take precedence over their child's medical needs. However, that is not to say that service providers should not be addressing these needs.

7.3.2. Language and communication needs

The language and communication needs of families whose first language is not English can be difficult to assess. Language barriers in health care have led to poor quality care (Rhodes & Nocon, 2003). Bischoff (2003) showed that people speaking minority languages and patients who do not share the language of the health professionals are at double risk of receiving less than optimum care because they are more exposed to health risks, with an additional risk posed by language barriers. Adnan's father spoke about how language can be a barrier for BME families to accessing appropriate services and knowing their rights and entitlements. He specifically referred to examples of South Asian families he had come across (in hospital and school) who lacked confidence to raise any issues with service providers, despite expressing dissatisfaction to him about the quality of service provided:

> *"I've spoken to other Asian families where they don't get much [in terms of services] because of the language barrier, which I think is really sad; that shouldn't be a barrier, but it is a barrier!"*,
> *Adnan's father.*

He felt South Asian people's cultural values prohibit them from challenging those in authority and cited a number of reasons for this, including not wanting to be seen as demanding, fear of losing the service, and feelings of shame and stigma associated with not being fluent speakers of English. This was demonstrated when interviewing the mother of Eshan. I asked what language she wanted to be interviewed in and she stated English. It soon became clear to me that she was struggling with English so I then conducted the interview in Punjabi (her first and main language). She was thrilled and relieved when she realised I could speak Punjabi and this helped build good rapport with her.

Zidane's parents spoke very little English (they had just arrived in the UK from India) when they received the diagnosis regarding their son. They were both happy with the way the hospital addressed their communication needs. They felt grateful that their consultant spoke Gujarati and explained everything in detail and answered all their questions. Abbas's parents both apologised for the fact that neither of them spoke English, and were aware that services would be willing to provide interpreters:

"We don't ask for an interpreter, and just muddle through.   We don't want to be a bother", Abbas' mother.

They had been living in the UK for over eighteen years so assumptions could be made that they would have some ability to speak or understand English, but they had always lived in an area where people mainly spoke the same South Asian language that they spoke, and they shopped in local South Asian businesses, so they managed to get by without English. People deploy a range of strategies to overcome such barriers, including getting their children to read letters and fill in forms, which can make it difficult for professionals to even realise that there may be issues with English.

Preferred form of communication

Abbas' parents stated that they preferred to be given important information in written form (English) as they were then able to get their (adult) sons to translate the information, and explain things to them. Ruby's mother arrived in the UK speaking no English and stated how when she had her daughter's diagnosis, she had to learn quickly, but it took her about 5 years. She still struggled with English and expressed a preference for communication to be in writing (in English), "that way if I don't understand then I can ask. I can go to the dictionary and look for it and see what it means". Parents preferred the opportunity to look at information in a relaxed environment at home, without the pressure to try and absorb everything in a short period of time; they valued being able to revisit the information.

Children and family members as interpreters

Abbas' parents mentioned that Abbas began interpreting for them at hospital appointments when he was about twelve years old. Using children as interpreters is considered inappropriate for a range of reasons, including the increased chance of errors occurring in interpreting information (Giordano, 2007), as well as the high risk of stress disorders affecting children if they had to translate emotionally tense matters (Hadziabdic, et al. 2010). During interpreting situations, when using children, the roles of the family are reversed and may cause conflict at home (Lehna,2005). Concerns are also raised regarding the use of wider family members as interpreters due to issues regarding accuracy and confidentiality (Hadziabdic, et al, 2010).

Eshan's mother stated that when she first attended hospital appointments with her son, the staff there expected her husband to interpret for her. This she struggled with as, amongst other things, their relationship was very strained at this point and they were close to separating, and she felt her husband was put under additional undue pressure. She felt that a professional interpreter would have been preferable, and so eventually requested one. Fiaz's mother spoke about the problems of using family members as interpreters:

> "They [family members] may not present your feelings, they may
> misinterpret things. Also, I may not be open with my answers

when I know someone else is listening. I think an independent

person would be a better representative", Fiaz's mother.

Iona's mother spoke a little English but was not confident with written information in English so would ask her brothers to translate information for her. She had a very close relationship with her brother and felt she could trust him to honestly translate and explain information to her. Rishi's mother expressed a lot of anger about the way she was expected (by hospital staff) to interpret information for her husband regarding her son's condition; she felt the fact that she was made to break the news of their son's condition to her husband was unacceptable and was avoidable stress in what was already a very challenging situation [their son had the condition microcephaly]. Many years later she was still very upset about this issue.

This issue will be further discussed in Chapter 8, from the perspective of professionals working with BME families, and their experiences of assessing and addressing communication needs.

7.4. Conclusion

All parents interviewed here were accessing some form of formal support, be it from a hospice, or a statutory body. These parents were therefore able to provide valuable insights into their experiences with services, and whether they were

willing and able to meet the needs of BME families. There were mixed experiences. Parents identified some issues and barriers in terms of language and communication needs not always being adequately assessed and met (there is a lack of consistency in terms of approaches adopted by different professionals), poor confidence of parents to challenge or demand more suitable services, coupled with a fear of offending service providers. Interviews with the parents also provided examples of ethnic and religious assumptions and stereotypes. Effective interactions between health, social services, and education (elements of the exosystem) could impact in a positive way on the macrosystem. For example, health professionals could refer families to hospice and hospital based social workers, who may be in a position to provide the type of holistic, family-focused support needed by families of children with LLCs. This could have a positive impact on the child with LLCs, parent carers, and siblings.

Families were asked if there were cultural or religious reasons for them not taking up formal support services; all stated there were no such barriers. Religion and culture was significant and of high priority to some, but there was diversity within groups in terms of practice. Practical support through religious and cultural organisations was not available. However, these institutions were able to address spiritual needs of parents and older children. The parents did not wish to complain about services, however, some frustrations came through. Parent participants were largely focused on positive outcomes for their child with a LLCs, and the family as a whole. They valued the input of the services they received, and in particular hospice support was highly valued for numerous reasons including the fact that it encompassed the entire family.

The research evidence refers to the fact that BME groups in the UK are, in comparison with white and majority groups, at increased risk of poorer health outcomes and a shorter life expectancy, and face greater challenges in accessing health-related services (Memon, et al 2016). The families of BME children with LLCs will be interacting with such services, and in order to ensure best outcomes for the children, it is important that any issues and barriers to access to these services are identified and addressed appropriately. The interviews with the parents here demonstrated that culture and religion are important aspects of their identity, however, there are also other characteristics which impact on their needs and experiences, such as social class, degree of religious beliefs, and overall the stresses and pressures of dealing with a number of different professionals and services, which do not necessarily work together to reduce some of the pressures placed on parent carers. For example, Adnan's father spoke of his frustration at the fact that his social worker did not work with his son's school; communication between the two would have required less input from him, and also would have helped the social worker get a better understanding of Adnan's needs and the caring responsibilities the parents faced. A social worker, equipped with the knowledge of the complex care required to look after Adnan would have looked into the issue of respite and helped the family to access hospice care (which they had not received for many years), and advocated on the behalf of the parents, reducing the need for the parents to expend energy on 'fighting' to get a service. The hospice would have had a greater understanding of the family's needs and looked at flexible and creative ways to support the family and access respite.

Chapter 8 Professionals' views and experiences of working with BME families

8.1. Introduction

This chapter explores the views and experiences of ten professionals, who worked with children with LLCs and their families, in Wales and England. It explores the following topics: the experience of working with BME families (including racial and ethnic stereotypes, stigma and blame, assessing diverse needs (religious and cultural needs, as well as language and communication needs), training for staff, BME staff, and examples of good practice. Interviewees came from a range of professional backgrounds: hospices, health service, social work, and schools. They included BME and white professionals (see Chapter 3 for further information regarding participants). Their responses provide a rounder picture of the dynamics and interactions between the two groups, and together help identify barriers to services from another perspective. Thus, where relevant, parents' perspectives are also presented. This process has highlighted that carers, irrespective of ethnicity, primarily have shared experiences and similar challenges (Greenwood, et al., 2015); thus, some of the issues which emerge may be applicable across all groups of parent carers and may help address the needs of carers in general.

8.2. Professionals' views and experiences of working with BME families

Professionals were asked about their perceptions of the needs and experiences of BME families of children with LLCs. They were also asked to identify barriers to uptake of services, and provide insights into the experiences of BME families who had engaged with their service. Two themes emerged from interviews with professionals, which did not feature in the parent carer interviews, but could be a barrier to accessing formal services. These were 'racial' and ethnic stereotypes of BME families, and the stigma and blame directed towards this groups of families. However, the chapter also has sections on assessing diverse needs, BME staff, and good practice in relation to diversity.

8.2.1. 'Racial'/ethnic stereotypes of BME families

The interviews provided insights into how practitioners perceived the needs of BME families of children with LLCs as being different from white families, and refer to culture, and religion as the rationale for low engagement with formal services. This draws attention to racial and ethnic stereotyping of BME service users, and the stigma and blame directed towards some BME parent carers, unique to this group of parents, and which may be an invisible barrier. Practitioners, in line with anti-racist practice, should avoid engaging with stereotypical views, which can alienate families and damage a potential partnership (Broomfield and Dodd, 2004). These 'racial' and ethnic stereotypes are explored in the context of how they affect the availability and accessibility of formal support for this group of parents.

Karen, for example, referred to several common ethnic/ 'racial' stereotypes of BME families (below). She explained:

> *"Well, for example, they [colleagues and service providers] say*
> *'Families from BME communities want to provide all the support*
> *themselves'. 'They have so many extended family that their*
> *needs are all met'. 'Mother would like some help but father won't*
> *allow it'. It would be absurd to make that assumption apply to all*
> *families – it can't possibly! It's all very anecdotal. It may be true*
> *for some families, but there's a tendency for stereotypes to be*
> *created and then for people to say, 'Oh well there's no point in*
> *referring them'. The fact that we and other hospices have had*
> *families in proves that's absolutely not right", Karen.*

Katbamna, et al. (2004) challenged assumptions regarding greater accessibility and availability of support for BME families from informal support networks such as family members. Research studies demonstrate that often despite having contact with extended families, this did not necessarily translate into practical support (Atkin and Ahmad, 2002; Chamba, et al., 1998), and that like most families, BME parent carers found interference from extended family could be a source of stress rather than help.

Despite the critical awareness of stereotyping shown above by Karen, other professional interviewees aired stereotypical views which they applied in their practice. For example, BME families were perceived by some participants as having greater access to informal support networks, in comparison to white families. This was used to justify low engagement with, and take up of formal services by BME families:

> *"They're a closer community and a closer network. A lot of them have larger families and they will depend on family more. Their faith leader, if they have one, will probably already know about their situation and support them. I do think in BME communities they are closer", Mary.*

Cultural norms, beliefs and expectations were referenced by one interviewee:

> *"I think coming to a hospice may not be the way that they [BME families] feel they should be meeting their children's needs, or their own needs because there is very much, going back to a sense of community, it's about being part of a community. I've worked with families from particular minority ethnic faiths, who feel that their child's disability is a gift and therefore they've been chosen to care for this precious gift and therefore to ask for help wouldn't be appropriate", Anna.*

Anna's practice experience was mostly from the 1970s and 1980s. She had not worked directly with families for many years, due to her move into management, yet strongly held on to this viewpoint. She had a nursing background and was in a position of power in her organisation, and able to influence practice, policies and processes. For her to base interventions with an entire group in society on anecdotal evidence, rather than taking an evidence-based approach, demonstrated the subtle and hidden ways in which BME service users can be excluded from equitable access to service provision. Croot et al (2012) undertook a study with Pakistani parents living in the UK and found that parents found meaning and purpose from the notion that their child's condition was from God. However, this did not mean that they would not accept formal support, or that this notion could be generalised and applied to ALL BME families. The parents interviewed for my research (see Chapter 7) did not express such views and did not feel their religious beliefs prevented them from accessing formal support. As noted in Chapter 7, when parents were asked if religion was a barrier or restricted their use of formal support, all stated that religion did not prevent them from accessing formal support. None corroborated this view. Abbas' parents stated that their religion (Islam) understands that Abbas is unable to support himself and needs help; therefore, it did not forbid access to formal support services or benefits. The majority of parents stated that religion allowed them to accept help, and that extended family did not judge them for accepting support. Aliyah's mother stated that her reluctance to accept services was due to her own personality rather than religious or cultural reasons.

I in no way wish to accuse these participants of 'racism'. None of them meant to deliberately exclude BME families from service use. Kai et al (2007) refer to the fact that professionals can unwittingly contribute to unequal access to formal support for BME families. Maria (another participant who worked for a hospice) also spoke of the greater availability of informal support networks for BME families, demonstrating that these stereotypes were embedded in their beliefs:

"A lot of the BME families have very large networks; they're very close to their extended families", Maria.

Interviews with parent carers of BME children with LLCs (Chapter 7) demonstrated that BME families had support needs and valued the support offered by formal services, irrespective of whether or not they had family support. Formal support can be a gateway to further services and sources of support, such as peer support, charitable grants for relevant disability equipment, and family holidays. The inclusion of discussion regarding informal support networks was considered relevant in this chapter, due to the high regard some professionals gave to this resource as being an adequate substitute for formal support.

Academic literature on support through informal networks (irrespective of ethnicity) refers to tensions around the precarity of informal support systems (Fazil, et al (2004). An unexpected crisis in the informal support network may result in that resource suddenly (and without notice) being withdrawn. Parent carers may fear placing a burden on friends and family or be afraid of being indebted to them, or being rejected, which could lead to tensions amongst

families. This is something which came through in the parent interviews as part of this study. Informal support from family and friends may not always be a suitable substitute for formal support. Especially where a child has complex support needs that only a trained professional would feel confident in addressing.

Changes in gender roles, across ethnicities, can also contribute to less availability of informal support – a role traditionally performed by women. The level of care required by some children may be highly specialist and as such informal carers may not be appropriate, or have the confidence to deliver this (Katbamna, et al 2004, Atkin and Ahmad, 2002, Chamba et al, 1998). Informal care and support may not be as readily available as is perceived by some practitioners, neither is it an appropriate substitute for formal support services. Anna was firm in her perception that, "Families support each other very well". However, she also stated that she feels some of the families do not have this support and are quite isolated:

"We've seen a number of families where things have been incredibly difficult, and the family have been almost ostracised or isolated", Anna.

This demonstrated how ethnic stereotypes are so strongly embedded in the minds and practice of some staff. Despite being challenged by evidence, they still held on to the original stereotypes. Anna stated:

"Some communities that I've worked with don't want support, whether that's a religious thing, whether that's a faith thing, or whatever that might be. I don't think it's about saying, 'I don't want your support because you're not from my community'. I think that's about saying, I think it is often faith, 'this is my responsibility and it's not your responsibility'", Anna.

Participants were asked whether they saw BME families and their needs as different from white families. Anna felt that the needs of BME families of children with LLCs were essentially the same as those of white families of children with LLCs, "to have their needs recognised; no different from any other family actually". This was reiterated by Angela, who also identified some of the challenges professionals may face:

"The issues are the same, in terms of what families want for their child", Angela.

Maria felt it was less about the needs of BME families being different, but more about the way they were perceived and treated by some professionals (and services) that was different. She felt that BME families were treated differently from white families and essentially their needs not addressed:

"*I think people are sometimes afraid of what they don't understand and so they shy away from it and pretend that it's not there*", Maria.

Some participants were willing to discuss the challenges they faced working with people who were different from them. Anna, for example stated:

"I guess on a personal level I can feel that I can more easily identify with a white British woman than I could with a South Asian woman because of my experience", Anna.

Professionals highlighted certain differences they encountered when working with BME families. These involved what they referred to as needing to be 'more thoughtful'; also that it was more time-consuming. This was in the context of using interpreters:

"I think with an interpreter it can perhaps make it feel more laboured and perhaps a bit more intense" Angela.

Overall, the majority of participants felt that there were no real differences in the needs of BME families, in comparison to white families. The difference appears to be the manner in which BME families were perceived by services.

8.2.2. Stigma and blame

A second theme which emerged through interviews with professionals, is that of blame and stigma towards BME parents of disabled children or children with LLCs. This came from both informal networks, and also formal networks such as

professionals working in health and social care. Due to the over-representation of certain genetic conditions amongst some BME groups, the topic of consanguinity can emerge during such discussions. BME parents can be 'blamed' for contributing to their child's disability or condition, in cases where they may be married to a cousin or close relative. It is believed that consanguinity can be a factor which can contribute to an increased risk of congenital abnormalities (Manchaiah, et al., 2011). This can particularly apply to South Asian Muslim populations, where such practices can be customary (Brown, et al., 2013). BME families are aware of the stigma and blame culture around the concept of consanguinity, and when questions are raised around family make-up, they tend to know the implications of this line of questioning. South Asian parents anticipate the implications of this question, and it can lead to families not engaging with formal services (Rhaghavan & Bollard, 2009). Dana's mother spoke of her daughter's condition as being a genetic condition which is prevalent in her husband's village in Pakistan and stated that her children would have the opportunity for genetic testing before they choose to start a family; she felt it was necessary to inform me that they were not likely to marry their cousins, despite me not broaching the topic. It implied knowledge and awareness on her part of the stigma faced by South Asian (particularly Muslim) families. A number of parents volunteered information during interviews to state that they were not related to their partner; they stated since this was not the case they could not understand why their child had an LLC. BME parents will be aware of this type of stigma, and consider the underlying message of such questioning, and will interpret it as placing blame on them for their child's disability. This is an onerous burden to place on a parent and may contribute to poor psychological well-being

and isolation. BME parents and carers see this as a personal issue which they are reluctant to share or discuss with others, due to risk of facing stigma, and the many layers of negative impact on them and their children, which can include poor marriage prospects of family members (Shaw and Hurst, 2009).

Marrying within extended family is an integral aspect of some cultures and impacts in particular on some ethnic groups such as South Asian Muslims, African Muslims, and Arab groups (Oniya, et al. 2019). These are cultural norms which form an integral part of their wider lives. The impact genetics have on disability is a highly specialised and complex area, which most providers of health and social care services will lack understanding of (Jacobs and Deatrick, 1999), therefore they may not be best placed to raise such issues. Such questions and approaches may form a barrier to effectively engaging with BME groups, due to the blame element, and also of stigmatising and 'othering' of groups who follow such practices. When asked what she considered to be some of the unique issues faced by BME families, Angela (a social worker based in a hospice) referred to the issue of consanguinity:

> *"There are slightly different issues in the Pakistani Muslim community in terms of some of the reasons why some of the children may have certain disabilities. When we're getting the referrals and we're asking those questions, you know, in terms of your family make up or whatever, you know, it does feature quite significantly"* Angela*.*

The above quote is worth highlighting for several reasons. Angela spoke of asking this question during assessments, however, it is difficult to imagine that a standard assessment form would contain such a question. Thus, a reasonable assumption could be made that this question was introduced by the staff member undertaking the assessment. This could be considered as being informed by prejudicial values which are rooted in a form of negative ethnic stereotyping, leading to the stigmatising of this group of parents for their choices in relation to marriage, and their cultural norms, and are specifically applied to BME groups. In Chapter 2 I referred to the subtle forms racism can take, and this could be an example of a microaggression. Microaggressions can contribute to low use of formal services (Hook, et al. 2016). Such questions could impact negatively on future working relationships, and on the process of forming trust, and non-judgemental relationships. This could be an invisible barrier to accessing support. Such questions are highly unlikely to be asked of a white family, and thus one less barrier they would experience to service provision.

Stigma, judgement, and prejudice can also come from sources of informal support. BME parents of a disabled child or child with LLCs may be exposed to stigma, judgement, and social exclusion from BME groups (Katbamna, et al., 2000). This is addressed from the parent carer perspective in Chapter 5. Anna, a nurse working in children's hospice setting, discussed the stigma from family members and their local community, experienced by BME parents of children with LLCs. She gave an example of a family who had lost their first 2 children, within a few weeks of birth, due to complex heart conditions. On discovering she was

pregnant for a third time; the mother feared the stigma and judgement she may experience from family members and others in her social networks:

"If everybody finds out that I'm pregnant and I have another child and it dies, people will think I'm a witch. As it stands I can't go home now because I come from a very small rural village and people are, sort of almost medieval in their views and I will be seen as a witch and actually my life is at risk if I go home".

Anna stated that prejudice and social exclusion towards families who have disabled children is not just limited to BME families and talked about examples of when people cross the road to avoid the family of a disabled child, irrespective of ethnicity. Although it may be countered that families of disabled children experience a level of stigma, blame, and prejudice, irrespective of ethnicity, these particular issues, and the level of fear of repercussions may be specific to certain BME groups and pose grave risks for individuals. Gary (2009) refers to the notion of double stigma. Alsabah and Vittrup (2017) draw attention to the negative stigma prevalent in some Arab countries, towards the parents of children with cognitive disabilities, placing additional pressures on parent carers and leading to negative outcomes for those children. As can be seen from the quote above from Anna, this mother feared for her life. In this situation, the third child was not born with the same condition. However, the birth of a child with an LLC is not always stigmatised or perceived as a 'punishment' by all religions, organisations or their representatives, and may be seen as part of that family's fate or written path (Hussein, 2010). It is a complex issue.

Nadine (a professional participant) considered the connection between stigma, culture, and religion:

> *"Anybody can have a disabled child but of course there is with religion and different beliefs that they've done something wrong and it's a punishment and… but I've been talking to lots of white mothers who have said 'what have I done wrong? I've done everything right why have I got this child?'"*, Nadine.

Anna specifically highlighted the blame culture within some BME groups and believed there is a gendered aspect which has a particularly negative impact on mothers:

> *"The superstitions of her community were such that she was blamed for what happened and we've seen a number of parents that are in the situation where it's seen to be often the women's fault",* Anna.

Radha also referred to the blame element that BME families experience. She spoke of the concept of karma and how this is applied to families – the belief that some action in their past life is the reason for their current predicament. Awareness raising and training amongst professionals working with this group drawing attention to the stigma, prejudices, and social exclusion BME families of children with LLCs may experience from within their social networks may aid their understanding of the challenges faced by such families. It challenges some of the

assumptions and stereotypes professionals have about the availability of support within BME groups, see for example earlier comment from Mary regarding community and family support. The levels of prejudice and reactions experienced by BME families and white families provide an interesting comparison. Prejudice and stigma in any form is unacceptable, however, it is one thing to be ignored and avoided, and quite another to fear for your life. This issue of stigma is quite complex and multi-layered and can contribute to social isolation and exclusion and is by no means an issue confined to BME parent carers.

8.3. Assessment of diverse needs

Capacity to attend to diverse religious and cultural needs is important for health and social care staff, in a diverse society. Undertaking assessments is an integral aspect of practice in health and social work. The availability of ethnically sensitive services relies on undertaking good quality assessments (O'Neale, 2000). Services that are sensitive and responsive to religious, language and communication needs can form an important aspect of inclusive service provision. Effective communication is necessary to establish good working relationships, and to ensure needs are adequately assessed, and misunderstanding does not occur. Inadequate assessment of language and communication needs can be an obstacle to BME groups accessing a service, as can using family members as interpreters (Gerrish, et al. 2005). These are important areas to address when services try to reduce or remove barriers to access for BME groups. Although BME families state they are confident in asking

for religiously and culturally appropriate services, whether these are met or not, and how confident staff feel in addressing these issues were explored. Interviews with the professionals provided insight and a useful evaluation and reflection on interactions.

8.3.1. Assessing and addressing religious and cultural needs

It is generally agreed amongst health and social care professionals that religious and spiritual needs are an integral and important aspect of the needs of an individual. In the case of children, these needs will be most likely gauged through their parent carers. Each family or group in society will have different needs, and it is important to acknowledge that there will be variations in terms of needs and beliefs, and therefore a one size fits all approach is inadequate. Providing appropriate care will require collaboration between the family and professionals.

Professionals interviewed spoke about challenges they faced in their practice, to address the diverse religious and cultural needs of families they worked with. Angela felt this could be due to a range of reasons, and in particular where staff lacked religious beliefs themselves:

> *"I think sometimes they question their own culture, and you know, I think*
>
> *those questions of culture, I think, sometimes politically they don't like it,*
>
> *it's uncomfortable for them. They don't want to talk about those sort of*

issues, you know, race, culture and 'I might upset somebody' and that sort of thing", Angela.

The above quote may have referred to lack of skills and confidence. It may also be referring to a fear of offending by using the wrong language/terminology, and not knowing or being able to explain the reason behind asking these questions – what the data will be used for. If staff knew what the data would be used for - to improve service provision – then they may be more confident asking such questions. Angela gave an example where the organisation undertook an audit of assessments undertaken with service users. This exercise highlighted significant deficits in terms of staff not collecting the information required regarding religious and cultural needs. The organisation had included these questions as an essential part of the assessment but there were issues regarding the level and depth of information some staff members had collected. Training was identified as one way to address this issue:

"Assessment is a key to our area of work, so people need to feel comfortable in saying 'this is the reason I need this evidence. I'm not just being nosey. This information will inform our decision in terms of what we can provide for you'", Angela.

Karen also spoke about gaps in information regarding the diverse religious and cultural needs of families when undertaking assessments. That organisation also found there were issues:

"We found that it wasn't completed anywhere near as often as we'd like, or as thoroughly as we'd like. It became apparent that [staff] - whilst they understood the importance of it all – they lacked the confidence to raise some of these issues", Karen.

In contrast, none of the parent carers interviewed felt questions regarding their ethnicity, religion or culture were offensive or invasive, or something they did not wish to address. In fact, not asking questions can lead to confusion and create a greater risk of offending service users:

"Sometimes assumptions are made. There are assumptions made that if you are Indian then you've perhaps got a religion that is probably either Sikh, Hindu or Muslim. That you're not Christian, when we know there are Indian Christians. Again, with African-Caribbean, there is sometimes an assumption that you can't be a Muslim. So, there's a lack of awareness that there are cross overs", Angela.

The above quote was corroborated by Chand's mother, in Chapter 7. Nadine also spoke of her fears when approaching families to assess their religious or cultural needs, despite being a highly experienced professional working in a school with a diverse range of ethnicities represented amongst both the children and staff:

"I don't feel confident. There's always the fear that you're going to offend. We avoid any tricky questions", Nadine.

Angela provided an example where a BME Christian family from Eritrea was wrongly assumed to be Ethiopian and Muslim, which caused offence to the family. They would have appreciated being asked rather than inaccurate assumptions made about them. Hema expressed concerns regarding staff not being able to undertake assessments, which addressed diverse religious and cultural needs:

"There are issues with our staff not wanting to ask questions about religion and ethnicity. They say, 'No, we don't want to ask, we're not comfortable with asking people's religion'. And it's more about them than the families", Hema.

Maria stated that although organisations assessed and held information regarding diverse religious and cultural needs, it was not necessarily acted upon in a meaningful way. She referred to a dominant organisational culture where staff felt it was important to treat all families the same:

"Although the information was collected, that was often not a consideration. There was very much a view of 'we treat everyone the same. And so we don't necessarily need to make any special provision'", Maria.

A colour-blind approach ignores differences based on culture, ethnicity, and 'race' (Stevens, et al, 2008). The thinking behind this approach is that, "potentially harmful or negative racial and ethnic stereotypes are not made salient, and therefore prejudice and discrimination are minimized and possibly eradicated" (Rosenthal and Levy, 2010, p.218). Critics of this approach believe this can result in ignoring important differences between groups, and structural and individual racism that is present in society and experienced by BME groups (Neville, et al, 2000). Maria illustrated the use of such an approach by staff at a hospice; she gave an example where at Christmas, all the children were given gifts and a Muslim child was given a cuddly pig, "It was absolutely dreadful and showed no thought had been given". Maria felt that collecting ethnicity, cultural, and religious data was pointless if the data was kept on the child's file, but the file was not reviewed prior to a visit, to accommodate the needs identified – a practice she regularly witnessed. She gave an example where a family identified the need for a quiet room for them to pray during the day, which was not offered to them when they visited the hospice, as their file was not reviewed.

Angela spoke about how she felt confident exploring the cultural and religious needs of BME families. She attributed this to her own strong ethnic identity, and Christian beliefs. She also referred to the fact that as a social worker she had acquired some of these skills through training. When asked why her colleagues may be struggling with such questions and issues she said:

> "*Well I would question their own foundation. If you're not grounded yourself, then it must generate something uncomfortable in you*", Angela.

She felt that training would benefit such members of staff – an opportunity for them to explore their own cultural and religious beliefs. She gave examples of staff stating, "I might offend. Or I might get it wrong". Angela had tried to explain to her colleagues that if she were to bring her child to the hospice, she would want them to ask her questions about her specific needs, rather than them making assumptions, or not attending to these needs at all. Rosie spoke of the challenge she faced when speaking to families about religious and spiritual needs:

> "*Not being religious myself, I think… I always feel a bit… out of my depth discussing religion. Whether it's Christianity or whatever*", Rosie.

She felt she would benefit from training, "Because you really worry that you might do something wrong" but had not been offered it, nor had she requested it.

8.3.2. Assessing and addressing diverse language and communication needs

BME families may have specific and different language and communication needs. Staff may need to engage and work with interpreters. This is an area

where the needs of BME families are likely to be different to white families. This is a generalisation, and there are exceptions such as Welsh speakers who may need an interpreter. Challenges for professionals working with parent carers who do not speak English include the cost of interpreters, as well as the extra time involved. Professionals stated that this can add a whole new dimension to the interaction with families. The majority of families I interviewed were fluent in English, however there were still parent carers who did not speak English, or their English was very basic. Some of these were couples where only one partner spoke English. Here the needs of the parent who did not speak English were at risk of going unnoticed or addressed inadequately, placing an additional burden and expectation on the parent who does speak English. This person then also has to undertake the role of interpreter, in what are often challenging circumstances. The expectation can be for the English-speaking parent to rapidly assimilate and communicate complex and jargon-laden medical information, in what may be a very emotionally charged situation. This leaves little time for either parent to ask questions. These needs were at risk of being neglected by professionals.

Radha (a bi-lingual hospice worker, and professionally trained interpreter) spoke of the importance of using trained professional interpreters, and the complexity involved in terms of providing interpretation:

"Day to day interpreting can be done by other members of staff

'do you want a cup of tea?' But any sort of medical consultations,

we have to have a professional interpreter involved. Because we

realise the complexities of not making sure we used trained interpreters. Things can go really badly", Radha.

Below is an example of exactly the kind of issue Radha refers to. Mary spoke of a situation where she worked with a Chinese family who lost a child. Despite several professionals being involved with the family, and all knowing that the family did not speak English, they did not offer this resource to the family. The family thus brought an informal interpreter (a friend of the family) to their meeting. Mary spoke of how the interpreter/friend of the family was unable to manage her emotions, whilst having to translate highly sensitive content between Mary and the newly bereaved parents:

"And the hardest thing is the interpreter broke into tears and cried all the way through it and uh it was just making the whole thing even harder than it already was. It's very isolating, when you don't speak the language and you know that people around you are talking about you and talking about your situation and you can't understand. It is very, very isolating", Mary.

This situation was avoidable as the family were known to the service for not speaking English; the relevant professionals were aware of the availability of professional interpreters. The family were not given the option to access a professional interpreter through them.

The communication needs of diverse families, facing such challenges need to be rigorously assessed and addressed, if meaningful relationships are to be formed. Also, to avoid further distress to those already facing emotional turmoil. Had the family made an informed choice to bring their own informal interpreter, then it would be very difficult for a practitioner to insist on using a professional interpreter. However, if the practitioner explained the sensitive nature of the discussion and the need to use language, terminology and jargon which may be difficult for someone who is not a professional interpreter to interpret, then families may be more inclined to accept the need for a professional interpreter. The family friend did not appear to have been aware of the nature of the discussions they agreed to interpret on. There are many risks and disadvantages to not utilising professional interpreters, including breach of confidentiality, the risk that the medical and disability language and jargon may not be easy for a lay person to interpret, therefore likelihood of misinformation. Obtaining informed consent could also be an issue.

There were also challenges for professionals utilising the services of an interpreter effectively, which could be addressed through training (Gerrish, et al 2004). Anna discussed her experiences of using untrained, informal interpreters and associated risks:

"I learnt very early on, you don't use relatives to interpret because people will either try and protect each other, or they make value judgements about whether

or not that person needs to know the information. So, we try very hard not to use relatives, and particularly not to use children. So, if we don't have our own staff that speak the language and there isn't an immediate family member like mum or dad that speaks English, then we would try and bring an interpreter in. We did have a family where mum spoke perfect English and dad didn't. Mum had protected him for a long time around the decision-making, and when the child came to the hospice we brought an interpreter in to speak to dad and she [mother] was really cross with us because we found out there was a lot of things he didn't know and he'd been excluded from", Anna.

The above quote demonstrated the norm of expecting one parent to interpret for another. The language is also telling in terms of 'trying' not to use relatives or children. Radha expressed concerns regarding professionals who expected one parent to interpret for the other. She felt that both parents had the right to the same information, at the same time. Radha gave examples of where a parent volunteered to interpret for the other, and where she found the parent was not disclosing all the information, or involving the other parent, as had been expected. Professionals assumed that if they were having a good conversation with one parent, then they will ensure the other parent received all the same information, but this was not always the case. She also urged caution where workers would assume that just because one member of the family spoke English, then they will cascade the information to other family members -she felt this was not always the case, so extended family members may know very little about the situation, and therefore be unable to provide any support. In terms of one parent interpreting for

another, Anna felt this was not a practice that should be followed by professionals:

"I think it's a huge burden to place on somebody. Parent A is getting the information before Parent B and they've got to assimilate that information and then relay it. They should hear that information together. So that everybody hears the same message", Anna.

She acknowledged that it is not always possible to use an interpreter, especially in an emergency situation, but felt it was unfair to expect one parent to relay sensitive information to another. Research shows that where families do not speak English, they are at risk of receiving a poorer quality of service, and poorer outcomes, compared to those who do speak English (Bischoff, et al, 2003).

In general, across the majority of organisations, there appeared to be no clear strategy for informing staff or families of access to and availability of professional interpreters. It often depended on the knowledge and awareness of the member of staff who encountered the family, and if and when they informed the family. There was no set process or procedure to ensure this information was communicated to a family at the first point of contact, or even before the initial assessment was undertaken. The decision was left to individual members of staff, and many of these had stated they have difficulties addressing such issues. The risk here is that families may not be getting this information in a timely manner. This could be another 'invisible' barrier to services. Radha made an

insightful point that hospices (as well as other services) do not always address and acknowledge the diversity of needs and provision – at the initial point of contact (e.g. leaflets and posters), therefore it causes families much anxiety in terms of accessing services and can prove to be an unexpected barrier as BME families assume this provision is lacking:

"*Coming here to an environment which might not be familiar to them; not knowing whether their dietary requirements or spiritual needs will be met, and whether the organisation even knows about these needs, and whether they'll be able to support them*…", Radha.

8.4. Training for staff

Catering to diverse needs requires a certain skill set. Professionals interviewed spoke about challenges, such as staff lacking the confidence to ask questions (at assessment) around religious and cultural needs. A suggestion for improving their practice, and increasing confidence, was to acquire training on diversity issues (e.g. Teresa, Rosie, Angela). This was a recurring theme which they felt would help address this deficit. Maria spoke of how she would value training on ethnic, cultural and religious diversity, as most of the knowledge she had on these issues she had acquired independently, and she felt formal training would help: "I would have felt a little better prepared". Recounting her negative experience regarding the family who did not speak English, Mary stated there were

advantages to acquiring such training, irrespective of the current ethnic make-up of service users:

"It might be that I use that skill rarely, but you can guarantee that one time when you really need that skill nobody else is gonna be around and you're gonna be on your own and you've gotto do it", Mary.

The majority of staff interviewed stated that they would like training on working with diverse groups and reasons they gave included: "I would feel better prepared" – Maria. Constraints mentioned were in relation to the cost of obtaining training, and some organisations felt their BME population was too small to justify this expenditure.   Where BME groups are either under-represented or not represented at all, this type of thinking can mean that BME service users are much more vulnerable and likely to experience a notably poor service (Scourfield, et al. 2002).

Anna spoke about the importance of diversity training for staff:

"*You understand people better by knowing a little bit more about their culture; about their community; knowing a bit more about their history; and kind of getting a feel for why people are the way they are; why does this family do this*?" Anna.

She stated further benefits of training for staff:

> "*It makes you think in a different way, because I think without the training you can make assumptions, whereas training helps you to see things differently*", Anna.

Chevannes (2002) found that diversity training helped staff to think differently when working with BME groups, and, to become more aware of the risks of ethnic stereotyping.

Radha spoke of the importance of training to help staff to challenge personal negative stereotypes they may have regarding certain groups in society. She was particularly concerned about staff she had witnessed making automatic assumptions that Muslim women experienced sexism and oppression from their husband and other male family members and that they were not able to express their views or needs. She gave examples of when she had to challenge colleagues on several times on such issues. She urged staff to not jump to conclusions and resort to negative stereotypes without checking the situation out more comprehensively, as this made matters even more difficult for BME families, and may make them reluctant to access a service. Rosie felt that diversity training should be mandatory for all staff.

Teresa felt diversity training gave her the confidence to feel that she could ask questions of a family, without offending them:

"*I know if I ask in a sensitive way, then I will find out the information I need to know to be able to provide the service that the family need. Training taught me not to be afraid, that I'm much more likely to cause offence by not asking, and getting it wrong, than I am to ask*", Teresa.

Cultural competence training is an organisational strategy designed to respond to the issue of health inequalities experienced by BME groups (Horvat, et al., 2014). However, there is evidence to suggest that diversity training is not the panacea that it is often perceived as (Kai, et al., 2007; Brach and Fraserirector, 2000). Renzaho, et al. (2013) raise concerns regarding a lack of available research to demonstrate the connection between cultural competency training, and improved outcomes for service users, despite increasing practitioner knowledge about working with culturally diverse service users. Most of the professionals interviewed stated that there was a deficiency of skills, knowledge and confidence among some staff in terms of addressing diversity issues and understanding the importance of assessing and addressing these diverse religious and cultural needs.

Most participants (8 out of 10) had not received training in their current work setting, and those who had received diversity training had acquired this many years earlier in other roles they had undertaken, reinforcing findings from research carried out by Chevannes (2002). Practitioners referred to 'limited amount of training', 'historical, many years ago', 'as part of my nursing training, many years ago', 'I'm self-taught'. Most participants had not been offered this training whilst in their current roles. There were also concerns from staff

regarding the frequency of training. Frequency of commissioning diversity training appeared to be random, often triggered by an incident, and staff felt this needed to be addressed more strategically, to meet the needs of new staff. Nadine spoke of the benefits of diversity training for staff:

"It gives people a better understanding of what families go through, and how they may be feeling. An insight into the stigma and issues they face in their own communities", Nadine*.*

Radha believed that although there were organisational policies and processes, as well as practical strategies in place to address diverse needs, lack of staff confidence meant that in practice these were not utilised in the way the organisation hoped and expected. There was a disconnect between policies and practice; management and frontline staff. She gave an example regarding the religious artefact cabinets that the organisation had, and how a member of staff was asked for the Islamic cabinet by a young person staying at the hospice. The member of staff wheeled it into the room and left it there. The young person did not open it or utilise it – they had no idea what was in it. Radha arrived and went through the cabinet and showed him [young person] what they could offer him to support him to pray. The original member of staff then, with the support of Radha, sat with this young person and, at his request, read passages from the Quran for him, and asked the young person to guide her in terms of what she could and could not do or touch. This was a powerful example of staff overcoming their fear and engaging in a positive way with the young person.

Radha felt benefits of training also included the fact that it broadens a person's perspective and experience – it shifts you from thinking what you would want, and what your anecdotal experience is, to actually looking at the bigger picture and a wider perspective. She felt it was important for staff to know how people feel when they are discriminated against, and accepting that people are different, "yes, things are different, but there are ways of dealing with these things". Those interviewed who undertook a strategic role and could affect this process in organisations, discussed the possibility of acquiring this training and the importance of it, but there was no clear strategy or plan for implementing training in the foreseeable future. Professionals interviewed were keen to have such training and felt that their practice would benefit from it, as would that of their colleagues, but significantly, none had asked for it.

8.5. The role and expectations of BME staff

Two of the organisations interviewed (out of six) employed BME staff, whose roles included an element of focussing on BME families and their needs. Expectations of these staff were to work closely with BME families, BME community groups and networks to fundraise and publicise their services, provide diversity training, provide interpreting, and to provide advice, support, and expertise to colleagues on diverse cultural and religious needs. Such strategies have their strengths and weaknesses. Ahmed (2012, p.5) refers to the risk of employing BME staff, "Becoming the race person means you are the one who is

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turned to when race turns up. The very fact of your existence can allow others not to turn up", allowing institutional racism to go unchecked. This was an issue Maria raised (see pages 282 and 283).

A positive aspect of having BME staff included the fact that such organisations may face fewer barriers to addressing 'race' and ethnicity issues. For example, Angela, a BME member of staff in a hospice, spoke of the challenges faced by some staff when addressing the religious and cultural needs of BME families:

> *"I know of one member of staff who says, 'I find it hard to talk about religion because it's somebody's personal stuff'. Being black myself makes it easy for me to ask questions like 'How does your religion and culture affect you in your daily life'. I have no problem talking about my culture, so I can't see why other people would", Angela.*

However, it is worth noting that this was not the case for all BME staff. Radha spoke of how despite being from a BME group, when she first had to assess diverse needs of families, she found it a challenge:

> "*It wasn't easy, but as you work along experienced colleagues and see how it's done, then you learn*", Radha.

There is something here about mentoring as a form of building skills and confidence – the importance of reinforcing training through practice. However,

BME staff also need training and support and direction in terms of these issues, especially as social issues are dynamic – terminology has changed, as have concepts in terms of discussions around 'race' and ethnicity. It is not to be assumed that being BME means that one automatically knows all the issues relating to this group.

Hema, a social work professional working with families, spoke about the many benefits of having an ethnically diverse workforce, and highlighted the advantage of having multi-lingual staff:

> *"If you employ an interpreter to work with a family, they are there*
>
> *for the one or two hours at most. If you have multi-lingual staff,*
>
> *they are there the whole time a family is there and can support*
>
> *the family much more effectively and get to know the family and*
>
> *their needs much better over a longer period of time. They can*
>
> *build a rapport with the families", Hema.*

On a number of occasions, senior staff spoke of nominating BME staff to deliver training on diversity issues (a minimum of three organisations). These BME colleagues were assumed to have the expertise to deliver this training. Maria spoke about how the hospice she worked at demonstrated their commitment to equality and diversity issues by appointing (volunteer) BME representatives from the staff team to an equalities committee. This was in addition to their substantial role. However, she mentioned risks associated with this included the fact that

when these members of staff were not on duty when a BME family were staying, then no one knew how best to support that family, and "things tend to go by the wayside". However, concerns were raised regarding this, particularly from some of the participants. They felt this should be a shared responsibility, organisation-wide, and felt the burden on BME staff was onerous.

BME staff expressed tension around delivering training on this issue to their colleagues, and they did not always feel they had the skills to deliver diversity training, nor the confidence. They expressed anxiety at the thought of delivering training on a sensitive topic to people they had close working relationships with. Staff who had not been explicitly recruited into their role for this purpose and with this role in mind, and not provided with the necessary training, found this a challenge. They had personal, cultural, and religious knowledge, and sometimes wider, but lacked the skills and confidence to deliver this to their peers, in the context of wider groups in society and their beliefs and diverse cultural practices. BME staff raised concerns regarding the expectation to deliver such training, giving a range of reasons, including the fact that they had not received 'Train the trainer' training, and they themselves wanted to take part in receiving diversity training and have the opportunity to ask questions of an external trainer. It can be risky to challenge your colleagues on such a sensitive topic. In fact, diversity training can cause discomfort per se, so it is a very sensitive issue and external trainers are a much safer option. Also, assumptions were made regarding the level of knowledge BME staff have on these issues, and the skills for delivering training, as additional support was not provided by any of the organisations (in the form of training) for the BME staff to provide this training.

Angela (a BME professional) spoke about being part of a staff diversity group and how she and other BME staff were pushing for a diverse workforce to represent their users, and to attract more diverse service users:

> *"One of the issues that I am pushing forward, as well as other BME staff, is trying to increase the number of nursing staff who are from certain ethnic groups, to represent our users. We've got a number of families coming from this demographic, surely we should try to represent that in our staffing",* Angela*.*

Anna (a senior manager at a hospice) felt that a possible barrier for BME families accessing hospice services was also around the ethnic diversity (or lack of it) of staff:

> "*I think one of the problems we have is, regardless of the fact that [hospice] is in a multicultural community, most of our staff are white British and female*", Anna.

She also felt that their publicity materials and publications did not contain images which represented ethnically diverse groups, "If you look at photos… There's not huge numbers of people that would represent you if you're not a white British person". When asked why she felt ethnic diversity and representation amongst

staff was important Anna responded, "how do you [white staff] not see them [BME service users] as different if they're not part of your life?" Professionals spoke about the multi-faceted gains for the organisation (as well as for service users), of having a diverse workforce. These included a number of benefits such as staff who spoke several different languages, families feeling accepted and welcome when seeing a diverse staff team, staff able to learn about different cultures and religions from colleagues, and visual representation of the diverse society we live in.

Anna made an interesting statement regarding the impact on BME service users of the presence of ethnically diverse staff:

> "*They [BME staff and service users] just understand each other better. I think it's about being safe*" Anna.

What Anna meant by safe is worth exploring. Did she mean BME service-users feel they are less likely to face racism from BME staff? It is unclear. This is an example of 'othering' of BME groups – staff and service-users, and assuming BME groups are homogenous with shared experiences. It also shifts the responsibility to address anti-discriminatory practice to BME staff, and the majority of organisations interviewed did not have BME staff. Participants felt it would be beneficial to have diverse staff, but the reasons for this varied. Some felt that having visual representation was reassuring for families and encouraged greater engagement with diverse ethnic groups. White staff felt they lacked the skills and confidence to work with BME groups, therefore they felt more

comfortable referring families to BME staff. Concerns were raised of the high expectation and burden placed on the BME staff, who were normally only allocated part-time roles which were time-limited, based on how successful they were in increasing engagement with diverse groups:

"*I'm putting a lot on these two new [BME staff members] who are only working four hours a week… I expect them to do everything*", Mary.

Staff also felt it was important to have an ethnically diverse workforce to represent society as a whole and stated that they felt uncomfortable about the fact that they lacked this type of representation, and the message this may be sending out to others. The risk associated with just having one or two staff members representing and addressing diverse needs is that when these individuals leave, they take their knowledge and expertise with them (Fernando, 2005). This is a strong argument for taking an organisation-wide approach, to ensure the retention of tacit and explicit knowledge, benefitting both staff and service users. Nadine stated one of the benefits of visual representation:

"*Our children see a reflection of their own communities. It's greater respect for everybody. And it's about looking outside your own customs, and your own faith, your own way of life. It does break those barriers*", Nadine.

Mbarushimana and Robbins (2015) found in their research with BME social workers, that they were noticing racist behaviour in white colleagues which they

[white colleagues] may not have been aware of. This raises the issue of unconscious bias. However, due to the reflective nature of social work practice, the lack of self-awareness is a concern.

8.6. Barriers identified to accessing services

It is well documented that BME disabled children and their families face barriers to accessing services (Raghavan and Waseem, 2007), however, identifying and removing/reducing such barriers can be a challenge. This can be for several reasons, including families being unwilling or fearful of being seen as criticising a service, and fear of a service or support being withdrawn. However, professionals are thus in a strong position to reflect some of the barriers they may have perceived and are likely to be more willing to reflect on their practice and to explore ways in which these barriers could be addressed. In this section, I will discuss some of the barriers identified from the perspective of professionals.

Angela referred to the notion of multiple layers of exclusion that were inter-related and could be onerous for BME families, such as the fact that written applications are required to access most services (automatically excluding those facing language and literacy challenges). She also spoke of the trend for online applications for benefits, and charitable funding, which some families may not have the necessary tools (such as a computer, printer and internet access), or the skills and confidence to complete.

Earlier in the chapter, religion and religious and cultural stereotypes of BME families was discussed as a means of justifying low service engagement with BME parent carers; thus identifying a potential barrier to accessing formal services. Immigration status may also be a barrier, and influence what services individuals and families can access. Immigration status can also be a barrier to some services. Refugees and asylum seekers are one such group who this may directly impact on. If a family does not have leave to remain then this can have a negative impact on what services and support they can access. For professionals, the complexity of ethnicity, disability, and immigration status (and associated rights, or lack of rights and entitlements) can be overwhelming and would require specialist knowledge to navigate the system. Nothing in the interviews conducted with professionals indicated training had been provided on the varying rights and entitlements of groups, based on their immigration status. Karen identified immigration status (and lack of recourse to public funds) as a barrier to services experienced by some BME families. She spoke of a family she worked with:

> *"They were on a student visa and had no recourse to public funds… The normal routes were all blocked. Oh God, it was awful"*, Karen.

Both parents were international students and had no recourse to public funds; they also lacked informal support of any type (as their family were all in India, and they had not had time to establish social networks of support from their locality).

This again, distinguishes the different ecological support systems some BME families may have, in comparison to white British families, and the complexity in terms of their formal and informal support systems.

Phillimore (2011) believes that there need to be changes to processes and policies to address the increasing and evolving needs of a diverse society:

> *"Models of welfare provision need to be rethought to take into account the new reality of super-diversity in a way that is affordable, politically acceptable and meets the needs of all"* (Phillimore, 2011, p.5).

Misperceptions and lack of awareness about services can together impact negatively on the experience of accessing and using formal support services (Wiles, 2003). Qureshi, et al (2000) found in their research that BME families lacked knowledge of what services were available to them. There are also power imbalances in terms of the relationship between a practitioner and carer (May, Ellis-Hill, and Payne, 2001), which means knowledge of services, how to access them, and deciding whether to refer a family to a service are very much in the control of a practitioner. Thus, the views and values of professionals are important to explore in relation to different groups in society, as they will affect their decision-making. Hema expressed concerns that professionals acted as gatekeepers, and therefore withheld information (and choice) about potential sources of support from BME parent carers. She felt that they made decisions based on assumptions founded on outdated ethnic stereotypes that believe BME

families have access to large informal support systems, and that culture and religion did not allow formal support. She felt that this was a significant barrier to BME parent carers accessing formal support:

"I think there should be a choice; I think the families need to make that decision rather than professionals. Because sometimes [BME] families don't know what's available", Hema.

Raghavan and Waseem (2007) found in their research with South Asian families, that lack of knowledge of services was a key barrier to formal support. The system is complex, and constantly changing, as is the language and terminology used; irrespective of ethnicity, all families of disabled children may struggle to know what their rights and entitlements are, what services are available, and how to access these. This will not be an issue that only impacts on BME families.

Location of services (such as a hospice) and transport to reach these was another barrier identified by some interviewees. Radha (a hospice worker) spoke of the fact that hospices are often outside of towns and cities and can be in rural areas where there are poor public transport links. This can particularly have an impact on some BME families, due to the size of the family group, stepping outside of a familiar geographical area, and the costs associated with paying for a taxi service:

"We've got a family that arrived from India, and they haven't got transport, and so it's a big barrier to have to pay for a taxi, especially as they will need two taxis for the family", Radha.

Gaffin, Hill and Penso (1996, p.S52) refer to the fact that hospices are often located in "white middle class areas". This could result in creating barriers in terms of transport and access to these locations, as well as the fact that BME families may not necessarily be familiar with these areas, or have the confidence in terms of 'belonging' and may perceive these areas as 'white spaces' where they are not welcome. A reasonable solution, and one which several interviewees suggested, could be for outreach work – hospice staff to go into communities and provide services in the home. There is evidence to suggest that care provided in the home, an environment familiar to the child and parent carers, can be an empowering experience for a family (Carter, et al., 2012). Several parents (Dana's mother, and Aliyah's mother) also expressed concerns regarding the location of hospices. They feared that the distance was a cause of concern for them, as they felt if the child became unwell during a stay, the parents may not get there in time for their child, as a child's condition can deteriorate rapidly. They gave examples of when this had happened to other families.

Where a hospice is located could adversely and disproportionately affect certain groups in society, in this case BME groups. Scott, Pearce and Goldblatt (2001) state that BME populations are concentrated in large urban centres; for example, forty-nine percent of the total BME population are said to reside in London. This

could suggest that locating hospices in rural areas may disproportionately negatively impact BME families.

8.7. Examples of good practice

In this chapter, various issues were identified in terms of potential barriers to engagement with BME families. Professionals also highlighted some of the challenges they faced when working with BME groups. These were explored with research participants, in order to help identify positive strategies for addressing. Asked what could be done to better support staff members who lacked confidence to assess and address diverse needs, this was the response from one participant:

"Well, we're going to be looking at more training, and addressing it, because we've just brought out a new assessment tool that we have to use, and you have to ask those questions, erm, and it has highlighted where the deficits are with individual workers. Because when they produced their [assessment] document, you can see how much depth people have gone in to, so it has flagged up a training issue. Assessment is key to our area of work, so… people need to feel comfortable in saying, 'this is the reason I need this evidence. I'm not just nosey. I'm not going to share that with the next-door neighbour, or whatever, these are the reasons, and this information will inform our decision in terms of what we can provide for you' sort of thing [regarding diverse needs]. So the training

needs to be around why we have to do this type of assessment and WHY

we need to bring this forward", Hema.

Angela spoke about a religious artefacts cupboard the hospice has, with objects to meet the diverse spiritual needs of families. Karen spoke about what the hospice did to ensure diverse spiritual and religious needs of their users are met: "We maintain a list of leaders of various faiths and groups, which we can call upon when needed". A BME hospice worker (Radha) spoke of a specific room they have created to meet the spiritual and religious needs of families using their services:

> *"In that room we have four cabinets – a Hinduism cabinet, an Islamic cabinet, a Christianity cabinet, and a spirituality cabinet. Each one contains objects of worship. We've also got religious music and religious books, available at different levels; so if a child wants to read a religious book they can. We have holy water, we have rosary beads, prayer mats. These cabinets are on wheels so they can be moved around the hospice to suit the family",* Radha*.*

The hospice also had 'end of life boxes', with artefacts relevant to a number of diverse religions.

It is also important to know that some parent carers may question their faith, as a result of their child's diagnosis, and may reject their religion and the support of faith leaders and groups (Hexem, et al. 2011). Radha spoke of how some of the

families who visited the hospice expressed anger at their predicament, and as a result their faith was not as strong as might be expected:

> "*They will say, 'Why is this happening? Why didn't my God look after me*?'*", Radha.

Teresa gave an example of good practice where she stated that the organisation had made links with a number of diverse religious leaders, as well as establishing good contacts with shops who sold religious and spiritual artefacts. They then advised the organisation how to handle these artefacts and how to appropriately store them.

8.8. Conclusion

This chapter sought to explore barriers to accessing formal support services, encountered by BME families, from the perspective of professionals working with this group. It also looked at whether professionals felt there were any challenges when working with BME families. There is a dearth of research exploring barriers to service provision faced by BME carers (Greenwood, et al., 2015), which this study helps to address. The overall impression is one of individuals highlighting a lack of skills, knowledge and confidence on the part of some professionals, leading to poor engagement. There is often a disconnect between strategy, policy, and staff undertaking the role with BME families, and assessments and rationale for collecting what may be considered sensitive data. Where BME

families are able to articulate their diverse religious and cultural needs – when provided with the opportunity in the form of holistic assessments – these needs may still not be addressed in practice, due to a number of factors including the notion of applying a 'colour blind' approach, and also fear of offending, on the part of the professionals working with them. There are also some examples of 'racial' and ethnic stereotyping, which may contribute to forming barriers for BME families accessing services. There is a need for social care, health, and education to work together to help identify the support needs of a vulnerable group of families. These agencies form part of a child and family's exosystem. By taking a multi-agency approach to identify and address support needs, they can help to strengthen a child and family's macrosystem.

Karen (Head of Care at a hospice) spoke of how important it was for the hospice to attract BME service-users, acknowledging some of their limitations in terms of meeting the diverse needs:

> *"I don't pretend that we know all about various customs and practices and so on, but we let the family guide us and teach us, and then we will bend over backwards and make the service fit them, not the other way around",* Karen.

This is a powerful statement and could contribute to reducing barriers to services by providing reassurance to all potential families. These are the types of messages they could use in their marketing and communications campaigns to effectively increase engagement with what is often referred to as a 'hard to reach'

group. Anna spoke of the need for services and professionals to be honest with themselves:

"*We do need to put more in to supporting BME families more effectively than we do the white families*", Anna.

This chapter identified several key areas which could be addressed in order to improve engagement with BME families. Most interviewees highlighted the value of training to help them and their colleagues, however, there appears to be no mechanism for identifying and accessing this. Very few of the organisations – only two out of six interviewed - had accessed ethnicity and religious diversity training. The majority of staff interviewed had not received diversity training in their current role, nor were there plans for them to receive this in the future, despite many highlighting this need, and able to articulate the benefits. Staff members are not raising these issues with their managers and asking for support, and may lack confidence to request this. There will be a need to identify and commit to resources (financial and otherwise) to support change and progress in this area.

Chapter 9 Conclusion

9.1. Introduction

The conclusion to this thesis will commence by referring back to the research question and methodological approach adopted by this study. I will then discuss key findings which emerged from the qualitative and quantitative data, and relate these to the literature, under five broad themes: social isolation, impact of caring on parental mental and physical health, the role of religion and culture, informal support and BME families, and formal support and BME families. The discussion will refer to elements of the framework provided by Bronfenbrenner's ecological systems theory and how ethnicity and 'race' impact on families will be highlighted where relevant, making reference to anti-racist theory informed by CRT. Implications for practice and policy, and recommendations will follow. I will then discuss limitations of this study, and suggestions for future research. As a reflexive researcher, I will briefly refer to the learning I acquired through the process of undertaking this research, before providing a conclusion.

9.2. Research question and methodological approach adopted

This thesis posed the question: "Who supports the families of black and minority ethnic children with life-limiting conditions?" There were two sub

questions: what support (from both formal and informal sources) is available to the families of BME children with LLCs? What support do parent carers of BME children with LLCs value, and are there any barriers to accessing this support? In Chapter 4, however, I also consider a wider population of disability, looking at data regarding children with long-standing illnesses.

By being aware of families that have weaker support systems and resources, health and social care professionals can identify appropriate sources of support to ensure better outcomes (Pelentsov, et al. 2016). This can also prevent families experiencing crisis, which can lead to much more costly interventions. There is a serious dearth of research with the parent carers of BME children with LLCs. Little is known about their experiences of caring for a life-limited child. Calls have been made for the inclusion of the voice of this group of parents in the academic discourse (Brown, et al. 2013; Calzani, et al. 2013). An important principle of Critical Race Theory refers to the importance of the inclusion of the voices and experiences of marginalised groups, which I believe this thesis helps to address. CRT seeks to empower marginalised perspectives, while considering issues of power, privilege, racism and other forms of oppression (Daftary, 2018). This study aimed to help address this gap in the literature. This is my unique contribution to knowledge, the inclusion of the voices of parent carers of BME children with LLCs in research on this topic. This thesis provides the inclusion of a new perspective (parent carers') on a previously studied topic.

The methodological approach adopted to help address the research question was a mixed methods approach. The quantitative element is limited to one chapter (Chapter 4), and the thesis takes a mainly qualitative approach (Chapters 5 – 8). As stated in Chapter 3, the quantitative element utilised data from Wave 5 of the Millennium Cohort Study and a wider category of disability, namely long-standing illnesses (LSIs), given the lack of population data on the narrower category of life-limiting conditions. The analysis considered the following four categories of children: white children with LSIs; BME children with LSIs; white children without LSIs, and BME children without LSIs. The focus was primarily on the children with LSIs, but this quantitative data set provided an opportunity for comparison between children with or without LSIs, as well as the opportunity to see if there were ethnic variance between categories. The survey data are representative of the UK population, to explore engagement of these groups with a range of support. However, the quantitative data did not provide an opportunity to explore positive experiences of accessing services, nor identify barriers to formal or informal support, which are addressed through qualitative interviews with twenty parent carers of BME children with LLCs and ten professionals working in organisations likely to encounter children with LLCs, in England and Wales. Through face-to-face qualitative interviews with parent carers, conducted in English, Urdu, and Punjabi, it was possible to place what could be referred to as a marginalised, minority group, in the centre of this research, and to contribute to the academic discourse. This action could be perceived as adopting an anti-oppressive approach. The qualitative element offered the opportunity for the lived experiences of this group to be shared in their own words. The qualitative and quantitative data collected and analysed generated five chapters of rich empirical

data, covering a broad range of topics, helping to address the gap in the literature regarding the families of BME children with LLCs, and helping to address the research questions.

The aim of this thesis was to explore the caring experience and support systems of the parent carers of BME children with LLCs. It was never my intention specifically to identify and expose incidents of institutional or individual racism. However, it was an opportunity to identify any ethnicity or 'race' related barriers which may impact on service usage – from the parent carers' and the professionals' perspective. Discrimination can take a variety of forms and is a subjective concept (Greenland, et al. 2018) and sometimes it is the subtle actions and inactions which can create barriers to engagement. There is, of course, overt racism, which individuals from BME groups may encounter in their day-to-day lives, separate from service usage, but which may still have an impact on their confidence to engage with and access formal services. The main aim of this study was to capture the dominant themes in the life experiences of parent carers of BME children with LLCs, some of which are highlighted below.

9.3. Findings

Whilst undertaking the literature review, several themes emerged, which I will discuss below, and relate to my research findings. I will utilise Bronfenbrenner's ecological systems theory as a theoretical framework, focusing primarily on the microsystem (immediate and extended family, friends and neighbours, religious

groups, school, leisure and social groups) and the exosystem (health services, social services), to map the strengths and weaknesses of the systems of BME families who participated in this research, as well as utilising data from the MCS regarding BME children with LSIs. As stated in Chapter 2, for the purposes of this study, the child and immediate family are placed at the centre of the ecological system. The rationale for this is that due to the symbiotic nature of family life, what impacts on one member of the family will also impact on others (Brown and Warr, 2007). This is also relating to cultural issues in that Bronfenbrenner's framework could be considered to be influenced by Eurocentric values regarding the needs of individuals, whereas BME families (not all, so a possible generalisation), may have different cultural values and expectations regarding the child being part of a unit of the immediate family. Experiences of racism may lead families to form a closer bond or adopt a protective group approach. For this reason, the child and the immediate family's needs are seen as being the same. However, in the Western European context, the child would be at the centre, and the parents and siblings would be part of the microsystem.

The emergent themes from this study are: social isolation, impact of caring on parental physical and mental health, the role of religion and culture, informal support and BME families, and formal support and BME families.

9.3.1. Social isolation

There is general acceptance and awareness of the negative psychological impact of social exclusion (Kurzman and Leary, 2001). A recurrent theme in the literature

regarding families of disabled children is their experience of social isolation (Pelentsov, 2016; Chadwick, 2013; Whiting, 2012; Russell, 2003). This was reinforced by data from the parent interviews. Aisha's mother stated that the family did not get invited to family events; Hanif's father spoke of challenges of socialising as a family but he had family living locally who the non-disabled siblings could visit; Iona's mother stated that she could only leave Iona with someone for a short period of time so was restricted in terms of socialising; Dana's mother also mentioned social isolation and the need for respite so that she could spend some time with the non-disabled siblings. Dana's mother stated that the majority of her friends were parents with a shared experience, who due to their own caring role had little or no capacity to socialise. Parent carers often report feeling isolated in their carer role, at a time when they need greater social support (Stozier, 2012). Fiaz's mother mentioned social isolation. She came to the UK as a student and had no family in the UK, neither did she have any links or connections with other families or opportunities to build social capital. To protect herself and her family from stigmatising or hurtful comments, she did not socialise outside the immediate family; as a hijab-wearing Muslim, she also feared Islamophobia. Although social isolation is an issue common to many carers, there is added complexity for this group, linked to their ethnicity or 'race'. For example, their family and social networks may not be local but instead be geographically further afield. The families may be vulnerable to institutional and other forms of racism, inhibiting their access to social and recreational opportunities.

Data from the MCS (Chapter 4, Table 26) show that BME children see their friends less often than white children. Twenty-seven percent of white children with LSIs have daily contact with their friends outside of school, compared with nineteen percent of BME children with LSIs. Twenty percent of BME children with LSIs never saw friends outside of school. It would appear that ethnicity and having an LSI are both factors that affect a child's interactions with their peers. Fear of racism and of disability discrimination could be a further barrier. It could be said that ethnicity has a greater impact on contributing to social isolation, in comparison to having an LSI.

When applying ecosystems theory, it is the microsystem that addresses the social aspect of family life. The meso level then looks at the interactions between elements of the microsystem. For many parent participants, these elements of their microsystem were weak in terms of opportunities for respite and socialising. The social isolation is not unique to these families due to their ethnicity, as disabled children of all ethnicities can experience high levels of social isolation and stigma (Weiserbs and Gottlieb, 2000). However, Katbamna, et al. (2004) found BME groups faced greater barriers to informal social networks, as their caring role restricted their capacity to build friendships and thus social networks of support. Disabled children are said to experience higher levels of social exclusion, due to lack of disability friendly services (Morris, 2001). Children with physical disabilities are particularly considered to be at risk of social exclusion from commonplace social activities (Law, et al. 2006).

Ethnicity may impact, or contribute to forming a barrier, if assumptions are made by professionals in health and social care that BME families may not need this type of support; and also due to the fact that some of the families participating in the research did not have family or friends living nearby. There was evidence from some of the qualitative interviews with parents of geographically dispersed friends and family networks. Elements of the microsystem for these families may not be linked or working together in the mesosystem, to support this group of families. For example, Eshan's extended family (part of the microsystem) may have language (and geography) as a barrier to forming links with other elements of the microsystem such as friends and neighbours. These interactions would occur in the mesosystem and may benefit the child and family at the centre. Ethnicity could be a factor here. Elements of the exosystem (health, hospice, social services) could work together in the macrosystem to support the family to access peer support, and address any needs they may have in terms of social isolation.

9.3.2. Impact of caring on parental physical and mental health

The existing research literature refers to the negative impact of caring on the physical and mental health of parent carers (Whiting, 2012; 2011; Cantwell, Muldoon, and Gallagher, 2014; Vonneilich, Ludecke, and Kofahl, 2016). In terms of data from my interviews with parent carers, the issue of poor physical and mental health came to the fore, and supported findings from the literature. Aisha's mother mentioned that her husband had a nervous breakdown when

Aisha's condition was diagnosed; he continued to need medication for his mental health. Farhan's mother spoke of challenges she faced to her mental health and how she now sought support mainly from her husband. Dana's mother mentioned she had experienced a serious mental health incident and had been hospitalised for a short period of time; she related this to a lack of support and self-care. Rishi's mother cited physical health issues as a result of manual handling of her growing son. Nadir's mother also spoke of the negative impact on her mental health and her concerns for her ability to care for her family. Eshan's mother stated that Eshan's father experienced mental health issues and struggled to come to terms with Eshan's diagnosis. Hanif's mother did not wish to participate in the research and his father cited the reason was that she was emotionally struggling with Hanif's diagnosis and was not ready to discuss this with anyone as she found it distressing. As stated in Chapter 5, many of the parents interviewed cried during the interview process. A number of parents (Rishi's mother, Fiaz's mother, Iona's mother, to name a few) mentioned how they missed the support of their own parents (extended family, part of the microsystem), however, they tried various strategies to overcome these.

Data from the MCS were unavailable in relation to this topic. Many of the issues identified above are common to parent carers and are not unique or specific to BME families. The negative impact on the parental well-being might suggest a weak microsystem for these families, or if the microsystem is strong, this support may not be enough to mitigate the challenging emotional impact of diagnosis and caring.

9.3.3. Religion and culture as a barrier to formal services

The research literature refers to religion and culture as a potential barrier to accessing formal support services for BME groups. This is used to justify and explain low service use and engagement with formal services (Bywaters, et al. 2003; Giunta et al.2004; Ahmed & Rees-Jones 2008). This theme also appeared in interviews with the professionals where some believed that religion was a barrier to engagement with BME service users (see Chapter 8). However, the data from the parent participants challenged this theory. Unequivocally, all parents stated that religion and culture did not form a barrier or prohibit them from engaging with formal support services. In fact, parents spoke about the value they attached to formal support services. Parent carers spoke of the positive relationships they formed with professionals who supported them, and their kindness. Formal support was seen as a positive, and participants expressed the need for such services.

Religion played a key role in the lives of some of members of these families. It was utilised in a range of ways. Some used it as a source of comfort, some for sense making. Some made no reference to religion and it did not feature much in their lives. Religion was not seen as a substitute for medical treatment or formal support. Although the parents in this study are placed with the child in the centre of the ecological framework, typically parents would be in the microsystem, as would be religious institutions. The interactions between these two elements would occur in the mesosystem. Practitioners working with BME families may

wish to explore parents' interactions with this element of their microsystem (religious organisations) and the support they may or may not be receiving, in order to establish how strong or weak this element of their ecological system is.

The data from the quantitative element of this study (Chapter 4, Table 25), in relation to this element of the microsystem, reveal that BME children have higher levels of engagement with religious services than white children do. However, it is important to note that what these institutions can offer may differ considerably from the UK Christian sources. The close connections could influence the child and their family's values, however, does this translate into practical support? Ethnicity appears to impact in terms of engagement with religious institutions. It is worth guarding against Eurocentric assumptions about what these institutions can offer families in terms of support. From the parent interviews, there was no evidence of practical or emotional support from religious institutions. However, Aisha's mum mentioned that Aisha would sometimes contact a local Imam (through text) to seek support. Abbas' parents mentioned that Abbas was unable to attend mosque as he uses a wheelchair and their mosque had no disability access. At Eid his family (who were practising Muslims) would go to say Eid prayers in the mosque, but he was unable to attend. Ruby's mother no longer attended her temple after someone told her that her daughter was disabled due to some bad act in her past. Religion was important to families, but they did not mention any practical support.

9.3.4. Informal support for BME families

The literature refers to greater availability and access to informal, family and community support for BME families (Atkin and Rollings, 1996; Chevannes, 2002; Guinta et al. 2004; Bhui, et al. 2012; Chow, et al. 2010). This view was also reinforced by some of the professionals interviewed for this study. Mary spoke of BME families being a lot closer, compared to white groups. Angela also mentioned greater availability of informal support in BME families. Karen and Anna, however, questioned this assumption, which they were aware of. Maria mentioned how staff at the organisation she worked at were unsupportive of what they perceived as large families who converged on their service. Hema and Radha spoke of the complexity of family dynamics being ignored by this assumption, which could not be made across all BME families, just because some families are found to have this support (see Chapter 8). The interviews with parent carers provided rich data which revealed the complexity around accessing informal support from family members to be more complex. The experience varied from family to family. Parent participants identified barriers they faced to accessing this type of support. The assumptions made by some of the professionals regarding the greater availability of informal support for BME families form a barrier to them accessing formal support and could be considered as examples of microaggressions.

Grandparents can play an important role in supporting families (Mitchell, 2008), and form part of their microsystem. From the parent interviews, it is clear that there are challenges for some families to accessing this support. The quantitative data, which relate to the wider category of BME children with long-standing

illnesses rather than only life-limiting conditions, also showed that BME children with LSIs had relatively fewer contacts with wider family. Table 15, in Chapter 4, shows that of those children with LSIs, 27% white and 19% BME are looked after by grandparents during term-time weekdays, and white children see grandparents more frequently than BME children do. A higher proportion of BME children did not see their grandparents at all. The interviews with parents also spoke of challenges to support from the extended family. Elderly and ill parents were cited as being unable to provide practical support and adding to the responsibilities of some parent carers; however, these family members were willing to provide emotional support which was valued. Chand's mother spoke of the spiritual guidance and support she received from her elderly father. This demonstrated how values from the macrosystem (religion) were passed on by part of the microsystem.

In the case of Eshan, Zidane, Fiaz, Aisha, Farhan and Ruby, the barrier to this support was due to one or more parent not having family in the UK, either because they came to the UK as a result of marriage, to study, or as economic migrants. However, there were other families who were well supported by extended family. Hanif's parents were both born and raised in the UK and had family who lived locally. They were able to access family support in the form of financial support, his sister collected the children from school, both their mothers provided respite and emotional support for the parents. Despite this informal support, Hanif's parents, devout Muslims, also accessed formal support. This challenges the beliefs expressed by some professionals regarding BME families choosing not to access formal support due to their religion.

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Eshan and Ruby's mothers were further disadvantaged by the fact that they did not speak English, which may have impacted on their ability to build social capital and form friendships. Both these barriers (language and migration) are related to ethnicity. Other barriers to informal support included extended family members having work commitments and commitments to caring for their own family. Ruby's mother spoke of how all her in-laws worked and were busy. Rishi's mother mentioned family who lived locally, but worked and had their own busy lives, making it difficult for them to support her. Parents mentioned barriers to accessing this support which included a lack of knowledge, confidence and skills of family members to provide practical care and support for a child who had complex support needs. There were also some attitudinal barriers to accessing formal support.

Parent participants identified reasons for the weaknesses in this aspect of their microsystem. These included: not wishing to be indebted to family, personal pride, loss of agency, fear of not being able to reciprocate, fear for their child's safety, and having to accept help on terms which may not be in the best interest of the child or family. For example, Nadir's mother spoke of how her sister-in-law would offer to look after Nadir but only if he was taken to her house, which Nadir's mother found stressful and too disruptive, so she did not take up this offer of help. Adnan's father mentioned that his family were willing to support him, but on their terms. When Adnan was initially in hospital being diagnosed, the extended family asked that he be moved to a local hospital. Adnan's parents chose not to accept

family support and instead kept Adnan in a hospital many miles from home, as it had a specialist team who could best address Adnan's medical needs. The data drew attention to what could be referred to as an issue that mainly impacted on BME families, namely that parent participants spoke of family in South Africa, India, Pakistan, America, and Canada, amongst others. This posed challenges to accessing practical support and maintaining relationships.

In terms of the mesosystem, there appears to be potential for ethnicity to impact in terms of the interactions between parent carers and extended family members. This would be negative and a weak mesosystem for families who do not have other family members nearby. Lack of English could be a barrier to forming friendships with neighbours; as could be perceived, fear of, or experiences of 'racism'.

This lack of support from family would indicate a greater need for formal support services for this group of families, from the exosystem. Health and social care agencies could provide access to childcare and respite for the families of BME children with LLCs. They may also introduce parent carers to peer support and opportunities to socialise with other families, or even access specialist holiday accommodation which meets the needs of disabled children and children with complex support needs.   This finding has important implications in terms of highlighting the increased need for respite from formal services such as hospices that BME families may have.

The MCS provided data on input from friends and neighbours in the context of providing childcare. BME children with LSIs are the category who are least likely, of all four categories, to receive support from friends and neighbours. Considering the qualitative data, this would make sense. There are challenges to the belief that BME families may have greater access to informal childcare support through friends and family. There is no evidence that BME children, compared to white children, have greater access to support from friends and neighbours, challenging the notion of BME communities supporting each other.

9.3.5. Formal support for BME families

Formal support through health and social care would form part of a family's exosystem. The quantitative data I have from the MCS did not provide information regarding this area of interest, other than school settings, which are part of the microsystem but remain a source of formal support. Schools often provide a much more holistic and specialist service to disabled children and their families. The quantitative data in Chapter 4 (Table 8) indicates that whether they have an LSI or not, white children have greater access to the support of a teacher or assistant in class. It could be said that white children (with or without LSIs) have an advantage over BME children, as they are more likely to receive help in school from school staff. This aspect of the microsystem is weaker for BME children. It is unclear why, but ethnicity does appear to impact on the availability of this resource.

From the qualitative data, I am able to discuss some elements of this system. For example, in terms of health services, most participants spoke positively about their experience of accessing help and support from professionals. There were some negative experiences around diagnosis, but generally this element of their exosystem was strong. In terms of social services, the parent participants did not appear to feel supported by social services. Few had a social worker, and those who did stated that they had very little contact and did not feel supported. Families interviewed had closer relationships with health and education and hospice services who addressed the needs a social worker would. Interactions between these professions in the macrosystem could benefit families and create value.

In Chapter 8, two strong themes emerged from interviews with professionals regarding 'racial' and ethnic stereotyping of BME service users, and the stigma and blame experienced by some BME parent carers. Also, as stated in Chapter 2, racism can be subtle and take a range of covert forms. The issue of microaggressions and asking questions during assessments (or otherwise) around consanguinity are important to high-light, as this practice may be contributing to poor engagement with BME families. This is an example of personal prejudice or discrimination seeping into practice, and there would be no way for the organisation to know this has occurred or that this is an issue, thereby creating an invisible barrier. It can lead to isolation for the family and could be a factor contributing to low engagement or take up of vital services. It was noteworthy that none of the 20 parent carers interviewed claimed to have experienced direct racism from service providers. Had it not been for the

inclusion of interviews with professionals, this may not have come through. Dominelli (2018) refers to 'racial' stereotyping as a form of racism. There was very little data from the interviews with parent carers that referred to professionals' stereotyping. This highlights the disjuncture between parent carers being mostly satisfied with the formal services they received, and the stereotypical judgements made by some of the professionals.

There was an incident cited by Eshan's mother of when she had to travel to India for a family emergency and Eshan, a young Sikh boy, was left at a hospice for a short stay. When she returned to collect him, she found that the staff there had not been able to look after his long hair as was required by his religion, and had put it in a ponytail. She had his hair cut after that incident. This could be an example of a microaggression, subtle but which had a profound impact on the family. Adnan's father felt BME families accepted a lower standard of service and did not challenge. Maria gave examples of staff making negative comments about BME families who attended hospice, within earshot of such families. This may have led to families no longer engaging with a vital service. However, there were also examples of efforts made by organisations to meet diverse cultural and religious needs, which came from both the parents and the professionals. For example, hospices providing religiously appropriate food, and religious artefacts. Parent carers expressed appreciation of the inclusion of their religious and cultural needs. However, they mentioned how they would like to be consulted and given choice. For example, Hanif's father stated that the hospice assumed they would only wish to eat South Asian food, whereas they would have like a choice; to be consulted and asked.   This sentiment was echoed by Chand's mother.

Parent carers wished to be consulted and asked their opinion. Even when well-meaning, assumptions made by professionals based on 'race', religion and culture, can be disempowering, In line with anti-racist and anti-oppressive theory, it is vital to identify what these may be by involving them in assessments and decision-making. Each family's needs are likely to be unique. This point links to CRT, which advocates for the inclusion of the voices of marginalised groups.

9.3.6. General observations about findings

From the interviews with parent carers, there appears to be a diversity of experience in terms of support needs, access to support, and barriers experienced. Generalisations and assumptions based on ethnicity alone cannot be made. Ethnicity impacts in two ways: views and beliefs of professionals regarding greater availability of informal support, and a geographically dispersed informal (extended family and friends) support network. Families, irrespective of ethnicity, access support in diverse ways. They will have a range of personal preferences. In the case of BME parent carers interviewed in this thesis, some experienced challenges to certain elements of their ecological system, due to for example, their microsystem being spread across the globe. A number of parents spoke of receiving most of their emotional support from friends and family abroad, with whom they communicated on an almost daily basis. This was particularly the case for parents such as the mother of Fiaz, who had no friends or family in the UK. They were reliant on technology to access support from some members of their family. However, because of the complexity of the needs of children with LLCs, and the issues faced by this group of families, formal / professional

services have an important role to play in working with diverse families and helping to address their needs. BME families of children with LLCs should not be excluded from accessing formal support services due to assumptions made by professionals linked to their 'race' and ethnicity. This would result in racial discrimination and exclusion.

Parent participants did not raise issues regarding unmet religious or cultural needs. That is not to say that they never experienced racism or prejudice. They may have but not been aware of it, or they may have had experiences that they chose not to mention for fear of negative repercussions such as service withdrawal. Not speaking English could be a reason why some parents felt that they had not experienced racism or prejudice. It is also important to note that just because someone claims not to have experienced racism, this may not necessarily be a true reflection of their experience. Denial of racism, and the experience of this, can be a coping strategy (Caughy, et al., 2004). There may also be other reasons for not disclosing personal experiences of racism, including stigma, fear of negative repercussions, or withdrawal of services. An individual may not have experienced direct discrimination, and therefore may not be aware of this occurring or affecting them. In this thesis, a strength of the data from the interviews with professionals is that it highlights some incidents of racism, in particular microaggressions, which the families themselves did not mention in interviews, or may not have been aware of.

There are risks associated with labelling groups and 'othering' them due to their 'race' and ethnicity. The risk is that we dehumanise them. For example, the negative impact on physical and emotional health and well-being will be a shared experience across parent carers. Why would it be any different for BME groups? Why and how would receiving a diagnosis of your child having an LLC be different for BME parents. Concerns for the non-disabled siblings, and impact on the parental relationships are potentially likely to impact on families, irrespective of ethnicity. However, there are certain issues which may be considered unique to BME families, and there is some ethnic variance. For example, the issues around diagnosis and language barriers are specific to this group.

An important finding from the parent carers interviews was that much of the experience of parent carers of BME children with LLCs is not very different from that of white families of disabled children or children with LLCs. Many of the challenges faced by families and their concerns and worries for a child with an LLC and other family members were common to those mentioned in the literature. However, how professionals and services perceived BME families was sometimes 'different', with an element of 'othering'.

It is helpful to use the Bronfenbrenner framework in understanding families' lived experiences, as it allows one to consider the range of different more proximal and more distal influences on the child and family, and how these interact. It is also important to integrate anti-racist and anti-oppressive theory in relation to practice with this group of families. Health and social care professionals need to adopt a

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reflective approach in terms of how they work with minority groups, in this case BME parent carers of children with LLCs.

Adopting an anti-racist perspective, closely linked to and informed by CRT, is also useful to ensure appropriate and equitable assessment of needs, and allocation of appropriate resources and interventions. There is a need to ensure that practitioners do not (knowingly or unknowingly) discriminate against marginalised groups. Public services have a legal duty to not discriminate.

9.4. Implications for practice and policy

Agencies who participated in this study were keen to encourage greater uptake of services, and improve engagement with BME groups. Some acknowledged that they needed to work further on 'race' and ethnicity issues to improve engagement with the families of BME children with LLCs. Professionals working front line in formal support settings were working to ensure services were inclusive, and to address the diverse needs. Organisations and professionals were genuinely keen to identify barriers to accessing formal services, and strategies for addressing these.

There are three key points / recommendations which I wish to make: Avoid 'racial' and ethnic stereotypes and assumptions when assessing and addressing the needs of BME families; ensure information regarding organisational policies and processes in relation to working in an anti-racist and anti-discriminatory manner

are communicated throughout the organisation, and in particular to frontline staff; and monitor, assess and address training needs of staff in relation to working with diverse groups, with access to regular training, whether requested or not. Anti-racist and anti-discriminatory training and support should be an integral part of professional development, undertaken on a rolling basis, in particular due to the dynamic nature of a changing society, and to guard against reinforcing outdated racial stereotypes and beliefs.

It is important that professionals working with this group of families do not make assumptions based on 'racial' and ethnic stereotypes. There needs to be a whole organisation approach, permeating every aspect of practice: strategies, policies, and practice, rather than allocating all responsibility for diversity issues to BME staff. For example, Radha mentioned that senior management in her organisation had provided a cupboard which contained a range of religious artefacts, available to children and parents accessing the hospice. However, staff had not been provided training on how to help families to access this resource, resulting in low usage of this facility. It would be recommended that a family's religious needs are assessed (sensitively and appropriately) and that they be made aware of relevant religious books/artefacts and prayer rooms available to them, as well facilitating access to a chaplain of their religion and choice (with their permission). This will be particularly relevant to families attending a hospice, or if their child is admitted to hospital. In terms of assessing the needs of a family, there are practical strategies to avoid 'racial' stereotyping and causing offence around issues such as consanguinity. A multi-faceted approach could be adopted – training to educate and inform professionals and dispel any myths, written policies

and processes to address oppressive practice, supervision and support for those working with BME families, induction processes addressing these issues, standardised assessment processes and procedures. This is an example of an issue which potentially affects only BME families.

A clearly communicated strategy, focusing on anti-racist and anti-oppressive practice and policy, and regular training need to be in place, on working effectively with BME families would help reduce some of the barriers to engagement with this group. Commitment to resources such as interpreters, diverse dietary needs, etc. is also necessary, for this to be effective. Senior members of staff participating in this study felt confident and committed to explore, address and meet the needs of diverse families, however, they were unaware of some of the challenges faced by frontline staff and the negative impact this had on service provision for diverse groups. In this study a number of professionals stated they would like diversity training addressing 'race' and ethnicity issues, but none had actually requested this. A recommendation of this study is to review training needs and facilitate access to more information and further training for frontline professionals.

For a number of different reasons, including personal discomfort, professionals do not always assess the religious needs of patients and their families (Nash, Parkes, and Hussain, 2015). In terms of assessing and addressing diverse needs, even if we are familiar with a family's religion or culture, we would do well to ask them to explain it to us - how it is applied or utilised by them. It is important

not to make assumptions. In order to practice in an anti-racist and anti-oppressive manner, each family needs to be assessed individually. There may be different or additional needs that BME families have, which can be related to culture and religion (for example dietary needs). However, by adopting an evidence-based approach to assessment, avoiding 'racial' and ethnic stereotypes and assumptions, and linking this to a person-centred approach, the unique needs of each family and their outcomes can be identified and addressed. The application of Bronfenbrenner's ecological theory can be useful in understanding the different levels of social context that affect child and family experience. Access to support may be hindered by outdated 'racial' and ethnic stereotypes and assumptions. Social workers need to reflect on their values and their own identity and privileges (Parrott, 2016). There is a large body of literature on anti-racist and critical race theory, which would provide practitioners theoretical knowledge and understanding of the way 'race' impacts on BME individuals and groups.

An integrated approach which is a combination of both formal and informal support systems, responding to that particular family's needs has the potential to meet the needs of all families, irrespective of ethnicity. Ecological systems theory adopted during the assessment process can help challenge assumptions based on 'racial' and ethnic stereotypes. This approach allows practitioners to test assumptions regarding family and community support. Ecomaps and culturagrams are tools which can be utilised in this context, and are transferable across health, education, and social care settings.

The next section will briefly focus on recommendations and implications for social work in particular. However, they may also be relevant to other professionals working in education, health, and social care. Links are made to anti-racist and critical race theory. This research has made reference to a range of professionals in health care, education and social care. However, as a social work lecturer, with a professional background as a social work practitioner, I have particular interest in that field, so the next section focuses on implications for social work. Racism embedded and perpetuated within institutions, structures and systems has significant implications and cannot be ignored. Social workers are well positioned to address racism, given their work with marginalised groups, coupled with the profession's commitment to social justice (Kolivoski, et al. 2014).

CRT advocates for the need for all research to conclude by outlining actions which would help address the issues and problems being studied (Daftary, 2018). Findings from the research with parent carers highlighted concerns relating to social workers. As a result, there are some recommendations for social work. Key messages include the need for more frequent contact with families, which would include visiting the family in their home and during hospital stays, meeting the child in order to get to know them better and help explore the needs of the family. A proactive approach would help to engage families before they reached a crisis point, such as that experienced by Dana's mother. Social workers could build links with the child's school, as well as with consultants and nursing staff who may provide relevant information on the issues faced by families of children with LLCs.

The presence of a social worker at the time of diagnosis (or very soon after) could help support a family during this challenging time. They could help identify further sources of formal support for the family members, from a range of services, including referral to hospices and other third sector agencies. A multi-agency approach should be adopted across social care, health and education. Religious organisations attended by BME families could be a network through whom social workers could highlight the support they offer to families of BME children with LLCs. Communication would need to be clear and accessible, and devoid of medicalised terminology and language. It should also be available in a variety of languages and formats, to ensure accessibility. This information could include examples of the type of support available to families of children with LLCs.

There is a need for practitioners to demonstrate anti-racist and anti-oppressive practice, and to utilise resources such as culturagrams to support the process of assessment. This would help address cultural and religious needs, and challenge stereotypes and assumptions based on 'race' and ethnicity. Social work is essentially concerned with maximising the potential of all humans to lead healthy, productive, and fulfilling lives. To this end, it is important to identify, and address barriers faced by marginalised groups by reflecting on professional practice, as well as teaching practices and training materials (Abrams and Moio, 2009). Social work practice needs to develop a wider understanding of the complexities faced by BME children with LLCs and other family members, including issues faced by the parent carers and siblings such as social isolation, as well as barriers they

may face to access informal support. According to Einbinder (2020), although students are willing to utilise CRT in their careers, they can find it confusing and challenging to learn and therefore apply to their practice. Other issues include lack of clear guidance on how to address intersectionality, reluctance of students or lecturers to centre 'race' in discussions of oppression, the challenge of incorporating another theory into an already crowded curriculum, and insufficient time and resources to adequately address CRT in classes (Constance-Huggins, 2012). However, overlooking issues of racial inequalities has serious implications in social work education, and does not align with social work values which emphasis social justice. A focus on anti-racist education and training could contribute to addressing the gaps in knowledge of student practitioners, as well as increasing their confidence to work with BME families of children with LLCs.

Social work education has a lengthy history with diversity and social justice (Nakaoka and Ortiz (2018). Social work education would benefit from inclusion of discussions on issues faced by this group of families. Ortiz and Jani (2010) argue for social work educators to adopt a CRT approach. As well as adopting anti-racist perspectives, the integration of CRT would help develop the discourse on this topic. Social work has its own traditions of scholarship that challenges oppressive and discriminatory practices (Abrams and Moio, 2009). Theories adopted include anti-oppressive practice; a model which not only scrutinises social work practice, but also related professions such as education and health settings. The fact that CRT includes reference to intersectionality and the reinforces that a person is composed of multiple identities which either privilege or marginalise, makes this a theoretical framework of relevance for this group of

families, based on their plural identities. CRT has a focus on moving beyond discussion to taking action that challenges discriminatory practices to achieve social justice (Kolivoski, et al., 2014). This could be a useful approach to help social work students to consider and formulate solutions to address barriers faced by families and to challenge the status quo. There are, however, challenges to incorporating CRT into a social work programme. According to Einbinder (2020), although students are willing to utilise CRT in their careers, they can find it confusing and challenging to learn and therefore apply to their practice. Other issues include lack of clear guidance on how to address intersectionality, reluctance of students or lecturers to centre 'race' in discussions of oppression, the challenge of incorporating another theory into an already crowded curriculum, and insufficient time and resources to adequately address CRT in classes (Constance-Huggins, 2012). However, overlooking issues of racial inequalities has serious implications in social work education, and does not align with social work values which emphasis social justice. A focus on anti-racist education and training could contribute to addressing the gaps in knowledge of student practitioners, as well as increasing their confidence to work with BME families of children with LLCs.

There was also an issue regarding diagnosis of a child's condition, and the distress caused to some parents by the manner in which this was done. This issue requires sensitive handling by those in health care settings.

9.5. Limitations

There are limitations to the research undertaken with this group. For example, the participants of this research were mainly individuals accessing some form of formal support. It would be useful to interview families who had no contact with formal services. They may present a different perspective, and identify barriers missing from this study. The research could be done with a larger group of parent carers, which included greater ethnic diversity. For example, the inclusion of Gypsy Traveller groups, refugees and asylum seekers, as well as Eastern European migrants. A larger and more ethnically diverse sample size would yield useful data, potentially demonstrating the diversity of experience amongst BME groups. Undertaking the research has given me the opportunity to build links with organisations and professionals across the UK who would be willing and able to assist in accessing future participants. The findings from such research may vary across different groups.

There is also the issue of exploring the socio-economic status of families, and their experience relating to poverty. In terms of the socio-economic profile of the parent carer participants, the majority were well-educated, middle class individuals. It has been observed that the socio-economic position can be a determinant of participation in research, with participation rates lower in households with a lower socio-economic profile (Demarest, et al. 2012). Future research could address this issue by utilising specific strategies targeting the

participation of lower socio-economic groups. I would be keen to address this aspect of the research.

Chapter 4 highlighted the paucity of existing quantitative ethnicity data, as well as data on children with LLCs. Chapter 2 drew attention to the challenges of finding statistics and data relating to prevalence of child disability and ethnicity. Accurate ethnicity data would enable experts to assess inequalities in health and access to services and help to ensure resources are targeted appropriately. Discrimination can routinely and successfully only be challenged if organisations are able to demonstrate this in the analysis of their ethnically coded datasets. An additional limitation was that the data from the MCS did not always cover the themes from the qualitative interviews.

9.6. Future research

In terms of future research on this topic, there is a need for more quantitative data availability in terms of administrative datasets from health and social care, with ethnicity identifiers. It would also be useful to undertake research into the socioeconomic characteristics of the parent carers of BME children with LLCs. The economic and social costs to families caring for children in the context of paediatric palliative care constitute an important area for future research. There appear to be links between poverty, ethnicity, and prevalence of disability where further research is needed. Gender bias and caring responsibilities (women and gendered expectations) would also be interesting to explore, as well as

quantitative research in relation to children with LLCs (irrespective of ethnicity). Research with siblings of BME children with LLCs would provide insights which are currently missing. However, this would need sensitive handling, if researching children, therefore may be best done with young adults. Engagement with a broader range of ethnic groups, as well as the role of peer support are also areas for further exploration. The experience of being a BME father and carer and the impact on gender roles and expectations is another topic I am keen to address.

9.7. Reflexivity

As a reflexive researcher and practitioner, I was able to consider the impact of undertaking the research on my own learning and development. It was very much like falling down the rabbit hole; there were many layers to the knowledge I acquired about myself and others. I got to 'go behind the curtain' and hear how professionals in health and social care perceive the needs of BME families, and the challenges they face. The research process has made me more aware of the complexity faced by BME families when navigating a complex health and social care system whilst juggling multiple identities and family commitments and priorities. I over-estimated the importance of their ethnic identity for these parents and learned that this was but one aspect of their identities. I also underestimated how challenging this would be for me psychologically, as a parent myself. I had assumed that as I had previously worked with families of children with LLCs, that I would not experience any difficulties. However, the problem here was that in

my previous role as a practitioner, I could 'check in' on families to ensure they were ok. I could put things in place to help meet their needs. In the case of this research, I had no further contact with any participant. There was a strong temptation to 'social work' them, which I managed to avoid. I felt great waves of empathy for parents and guilt at the thought of taking up their time, causing them upset, and walking away without offering them further support. This would last a while.

I learned that people speak to you and share different information with you if you are a researcher, as opposed to a practitioner. The temporary nature of the researcher / research participant relationship has an impact on the dynamic. I found people were more open. This had not always been the case when I was a practitioner. This may have been due to power imbalances. Professionals spoke more openly about how they felt about working with BME families, more openly than I had experienced previously in practice. Or it is possible I may just have had better questions and have become better skilled at extracting such data. CRT researchers acknowledge that all research, including the application of theory and methodology, is impacted by the lens adopted by the researcher (Lawless, et al., 2006). Self-reflexivity needs to take a central role in undertaking research (Daftary, 2018). This reflection by researchers on their position and positionality can help address power imbalances inherent in the system.

9.8. Conclusion

What you have read is my original contribution to knowledge. This thesis sheds light on a hitherto under-explored area of looking at the caring experiences of parents of BME children with LLCs, and the issues that are of importance to them in addressing the needs of their child. The findings provide a contrast between previously held beliefs regarding the availability of family and community support for this group of families and the accounts of the families themselves, both in qualitative interviews and in responses to the Millennium Cohort Study questionnaires. The findings of this study may challenge academic discourse and expectations, as some of the findings from the interviews with parent carers of BME children with LLCs are true for all parent carers of children with LLCs, and are not necessarily distinctive to BME families. The parent carers of BME children with LLCs identify similar challenges in their caring role, to those mentioned in the literature regarding the families of white children with LLCs. There are, however, some differences, impacted by ethnicity.

The support systems of the families of BME children with LLCs vary. They are supported by a mix of both formal and informal support. There appear to be some barriers to accessing formal support which include perceptions of less need due to greater availability of informal support, and some professionals not feeling confident to assess and meet diverse needs, as well as 'racial' and ethnic stereotyping around religion and culture being a barrier to formal services. Society is dynamic and changes are frequent, thus the need for on-going training.

The specialist BME worker faced challenges in addressing these wide-ranging needs in isolation. BME workers also had training needs.

To refer back to the research question, "Who supports the families of BME children with LLCs?" The answer has to be a mix of formal and informal support. It cannot be assumed BME families have greater recourse to informal support. This may be the case for some families but cannot be generalised across populations based on their 'race' or ethnicity. What support do families value? Support valued included opportunities to socialise for the whole family; financial support; access to respite so that parent carers can focus on other family members such as siblings, or attend to their own mental/physical health. Parents would value emotional support; an opportunity to discuss their worries and concerns. Hospice services located in the community would help address fears regarding the distance of hospices and anxiety expressed by some parents about leaving their ill child too far to get to in an emergency. Barriers to accessing support varied. In terms of formal support, barriers identified included: attitudes and beliefs of staff; 'racial' and ethnic stereotypes; 'othering' and stigma, manifesting in micro-aggressions by staff; as well as a lack of confidence on the part of staff to assess and address diverse needs. In terms of informal support, barriers identified included: extended family and friends spread around the world; extended family members having their own family and work commitments and responsibilities; family not knowing how to attend to the child's complex care needs; and stigma.

Professionals can unknowingly practise in an oppressive and discriminatory manner; only by analysing their approach will it become clear where these discrepancies lie (Minghella and Benson, 1995). From some of the contributions from professionals, it would appear that 'racial' and ethnic stereotypes persist amongst staff in health and social care, which are open to challenge. People represent multiple identities which may incorporate ethnicity, religion, disability, class, and culture. A way of demonstrating commitment to respecting diversity is by accepting that the values of the person we are assessing may be different from ours. There needs to be a shift in focus in terms of stereotypical views and assumptions of BME families, towards a renewed focus on the holistic needs of vulnerable children and their families. Expectations that these complex issues could be addressed through one specialist BME worker were unrealistic. A combination of both would provide families with a rich, balanced, reliable, diverse, and wide range of support. There is a need to build sustainable and enduring support for families through both formal and informal sources.

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Appendix A: Table of participants

		PARENTS INTERVIEWED (20)				
Pseudonym of Child	**Age of child**	**Mother / Father interviewed**	**Ethnicity**	**Language interviewed in**	**Religion**	**Resident in England or Wales**
Aisha	17	Mother	Indian	English	Muslim	England
Farhan	6	Mother and Father	Pakistani	English (mother) Urdu (father)	Muslim	England
Hanif	5	Father	Bangladeshi	English	Muslim	Wales
Dana	9	Mother	Pakistani	English	Muslim	England
Rishi	6	Mother	Indian	English	Sikh	Wales
Iona	8	Mother	African	English	Christian	Wales
Abbas	16	Mother and Father	Pakistani	Urdu (father) and Punjabi (mother)	Muslim	England
Zidane	7	Mother and Father	Indian	English and Urdu (both parents used a mixture of both languages)	Muslim	England
Eshan	8	Mother	Indian	Urdu / Hindi	Sikh	England
Nadir	5	Mother and Father	Pakistani	English	Muslim	England
Chand	18	Mother	Indian	English	Sikh	England
Adnan	18	Father	Pakistani	English	Muslim	England
Rehana	13	Mother	Pakistani	English	Muslim	Wales
Ruby	16	Mother and Father	Indian	English	Hindu	England
Fiaz	12	Mother	Arab	English	Muslim	Wales

	PROFESSIONALS INTERVIEWED (10)			
Pseudonym	Type of organisation	England / Wales	Social care, health, education professional?	Ethnicity
1. Angela	Hospice (Charity)	England	Social worker	African-Caribbean
2. Maria	NHS	Wales	Nurse	White
3. Teresa	Hospice (Charity)	Wales	Social worker	White
4. Karen	Hospice (Charity)	Wales	Nurse	White
5. Nadine	School	Wales	Teacher	White
6. Radha	Hospice (Charity)	England	Social worker	Indian
7. Hema	Hospice (Charity)	England	Social worker	Indian
8. Rosie	Health	Wales	Nurse	White
9. Mary	Health	Wales	Social care	White
10. Anna	Hospice (Charity)	England	Nurse	White

Appendix B: Interview Schedules

Version 1

11 September 2015

INTERVIEW SCHEDULE

(PROFESSIONALS)

1. What services do you offer?

2. Where do your referrals come from (who are the partners you work most closely with? GPs, Special Needs Health Visitors, social workers, et al)?

3. How do you produce, market and disseminate information regarding your services (and other specialist services)? What languages and formats and networks do you utilise?

4. How frequently do you come into contact with the families of BME children with life-limiting conditions? (Do you feel BME families are under-users of services? What informs your view/opinion/knowledge?) What do you think are actual or perceived barriers?

5. Monitoring and evaluation (in relation to ethnicity and religion) – do you know if your organisation gathers such information? When and who from? What do you do with this information?

6. What do you see as the different needs of BME families?

7. How do you ensure cultural, religious, communication (language and literacy), and spiritual needs are met?

8. How do you assess such needs?

9. Do you feel you have the skills and knowledge and confidence to raise such issues with families?

10. Do you use interpreters? Where do they come from? Have you had training? How do families know they can access this service?

11. Is it harder to work with such families (Is it harder to understand symptoms? Explain medication? Support carers? Address social needs of family? Disclosure of diagnosis and of prognosis)?

12. Have you had training on working with diverse communities? How has this helped you? If not, would you like training? Is this something which you have requested or has been offered to you?

13. If there are conflicting views (between the parents themselves; between you and the parents; between parents and child/other family members, or any other parties), how do resolve these issues?

14. How do you think you could increase or improve engagement and take-up of services from BME groups?

15. Who do you think supports BME families (in place of specialist services such as hospices, etc.)?

16. How confident do you feel about approaching the subject of Advanced Care Planning (ACP) and Emergency Care Planning (ECP) with BME families? How confident do you feel about asking questions relating to end-of-life care, location of death, hospice care, etc.?

End of interview schedule

INTERVIEW SCHEDULE

(PARENT CARERS)

I would like to start by asking a few questions about your child:

1. What is your child's name? [Record gender of child]
2. How old are they?
3. What is their condition?

I would now like to ask some questions about your child's illness, and how it affects you and your family:

CHILD'S CONDITION

I would like to ask some more questions regarding your child's illness? Would that be ok? [*Check if they need a break*]

1. How did you discover your child had an illness?
2. Who gave you the news?
3. How did you feel about the way it was done?
4. Could it have been done better?
5. What do you know about your child's illness?
6. Where did you get this information from?
7. How does [insert name of child] illness affect you and other family members? [Emotionally and practically]
8. How has this affected you in terms of money - your income, and money in general? Has anyone had to give up work to help care for [insert name of child]? Have you experienced any money problems? If yes, who, if anyone, have you asked for help? Who has been able to help? In what way?

SUPPORT SYSTEMS

The next set of questions are about supports for you and your family.

1. Who helps and supports you and your family?

2. In what way?
3. Who are the professionals and organisations involved in trying to help you?
4. Do you have a social worker?
5. Are you happy with these services? What is good about them? Could they be improved? If so, how?
6. Are the services and help you receive suitable for you in terms of your culture, religion, food choices, and language?
7. Do you receive any help from people who live in your neighbourhood? Are these people from the same culture, religion, and background as you? Are they relatives or friends? In what way do they help you and your family (prompt: financial, practical, emotional, etc.)?
8. Does your GP know about your child's illness? What help have they provided?
9. Who has been the most helpful to you and your family? How have they been helpful?
10. Where do you look for information regarding services that may be able to help you and your family? [GP, TV – which channels, family, community, newspapers – which)?

LANGUAGE AND COMMUNICATION NEEDS

I will now like to ask some questions about speaking, reading, and writing in English. Would that be ok? [*Check if they would like to take a break*]

1. Where did you learn to speak English? [Only ask where interviews are conducted in English]
2. Do you feel confident speaking in English? [Ask regarding educational level, etc.]. Does your partner speak good English?
3. Are you both able to read and write comfortably in English? [Ask re: educational level and confidence]
4. Do you understand the information that is given to you?
5. What is your preferred format of information (written, spoken, DVD)?
6. Have you had the experience of using an interpreter (ask where? Was it requested or offered?) Were family members ever used? Children?

DECISION-MAKING AND CONFLICT

1. How do you make important decisions about your child's care, treatment, and their future, etc.?
2. Who else is involved (both parents; extended family; community; imam; hospital Muslim chaplain, etc.)?
3. How do you deal with differences in opinion between say you and the hospital or other care staff?
4. Can you give me an example of when this has happened and how you dealt with it?
5. What about difference in opinions (regarding your child) between you and your husband? [Other members of the family/community?]

RELIGION, CULTURE, SPIRITUAL NEEDS

1. Do you think you have any special or different needs, because of your religion, or culture?
2. Does your religion, culture, affect the services you may need for your child?
3. Are there any religious duties and practices that are important to you when someone is ill?
4. Do you feel confident to ask for the right kind of services for your religion or culture?

FORMAL SUPPORT THROUGH HOSPICES

1. What do you think a hospice is?
2. Has hospice care been mentioned or offered to you? By whom?
3. Have you ever used their services?
4. Was that services in your home or at the hospice?
5. Would you consider using one? Why?
6. Where do you prefer your child to be cared for? Home? Hospital? Respite house through a charity or local authority? Why?

FINALLY…

1. What are your hopes and wishes for the future of …….. ? [Insert child's name]

N.B. Ask the family if they have any questions. Is there any information they would like you to get for them?

Thank you!

Appendix C: Participant Information Sheets

Version 2

2 November 2015

Cardiff University
School of Social Sciences
Glamorgan Building
King Edward VII Avenue
Cardiff
CF10 3WT
Email:
KentWS@cardiff.ac.uk
Tel: 07813 612550

PARTICIPANT INFORMATION SHEET

(Parents/carers)

Study title: Black and Minority Ethnic (BME) children with life-limiting conditions – a mixed methods study

INTRODUCTION

Hello, Assalamualaikum السلام عليكم ورحمة الله وبركاته **, Namaste, Is ka warran, Hallow, Sat Sri Akal**

My name is **Mrs Wahida Kent** and I am a PhD student at Cardiff University. I would like to meet with BME families to find out who helps them when their child has a life-limiting condition. Some of the questions I would like to ask include: 'What services do you use and why?' 'Which do you find most helpful, and why?' 'How did you know about these services?' I am also interested in hearing about any bad experiences you may have had, or difficulties in getting help, and looking at ways of improving this for you and other families like yours.

I hope to interview one or both parents for about one hour, using a short questionnaire. This could take place either in your home, at the hospital, or any other location, date and time that suits you best.

I would like to ask you to take part in this research. I can assure you that all information you give me will remain confidential. I am a social worker, registered with the Care Council for Wales and am bound by a Code of Conduct which includes keeping client confidentiality. At any point during the research if you decide to change your mind, you are allowed to and no information will be used.

I am happy to meet with you to answer any questions you may have, before you decide if you wish to be interviewed or not. You may also call me on this number with any questions you have: 07813 612550. I have 13 years' experience of working with families like yours with sick and disabled children, and completely understand your situation and wish to help to improve services.

I am able to speak Urdu, Punjabi and Hindi, and am happy to do interviews in any of these languages, if you prefer. If you would like to be interviewed in any other language, please let me know so I can make the necessary arrangements.

All interpreters will sign a confidentiality agreement.

On the following pages, there is further information about the research study. Please let me know if you would like me to go through it with you to explain anything.

WHAT IS THE PURPOSE OF THE STUDY?

To look into the support needs of the families of BME children with life-limiting conditions and to look at the difficult experiences of such families and what they think about specialist services. Also to identify where support for you comes from, and to discuss any good or bad experiences and beliefs you may have about these services. It is also to gather better knowledge of your religious and cultural beliefs and needs.

WHY HAVE I BEEN SELECTED?

You have been selected because you have experience of caring for a child with a life-limiting condition, and are from a BME group. You have knowledge and experiences of using or not using services in this area, and have important and useful information which could help improve services for other families like yours.

WHAT WILL HAPPEN IF I TAKE PART?

I will arrange a suitable date, time and location to interview you. Interviews will take place at a location of your choice. I will then go through an interview schedule with a short list of questions. Interviews should last no longer than one hour. All interviews will be recorded. Information about the organisations or professionals you speak about in the interviews will be kept confidential at all times.

I will also be contacting your GP, with your permission, to inform them that you are taking part in this research.

HOW LONG WILL THE STUDY TAKE?

It should take one hour of your time.

WHAT WILL HAPPEN IF I DECIDE NOT TO TAKE PART?

You can decide not to take part, but if you do take part, this will help shed light onto an area where there is little or no evidence, and could lead to positive improvements in policy and service delivery.

If you decide not to take part, your child's medical care will not be affected.

WHAT IF I AGREE TO TAKE PART BUT DECIDE TO PULL OUT DURING THE STUDY?

If this happens then your part in the study, and any information you shared, will not be included in the research.

WHAT ARE THE POSSIBLE ADVANTAGES OF TAKING PART?

It is hoped that the study would add to the knowledge and expertise on how best to support the families of BME children with life-limiting conditions, and improve training for professionals, leading to better services for families, and better communication and relationships.

WHAT ARE THE POSSIBLE DISADVANTAGES OF TAKING PART?

Every effort will be made to ensure there are no disadvantages to you, or distress caused. However, this is a highly sensitive area, and I would envisage recalling certain situations may occasionally be upsetting. Every effort will be made to ensure I am sensitive to your needs and I will work to limit any upset or distress.

WILL MY TAKING PART IN THE STUDY BE KEPT CONFIDENTIAL?

Every person (and the place names mentioned) in this research will be given made up names and all identifiable information will be changed before the research is published.

Anything I use to store information e.g. laptops, notes, recording devices, etc. will be kept in a secure location where no one else will be able to find this information.

After completing the PhD, I will hold onto contact details for a period of 6 – 12 months, after which this will be deleted. The data collected would be kept for 5

years to allow for further research, but no participants would be identifiable from this data. It would then be destroyed.

WHAT WILL HAPPEN WITH THE RESULTS OF THE RESEARCH?

The information collected will form the basis for a PhD thesis, which I will write. It could also be included in research papers and book chapters, which I may write for peer-reviewed academic journals and books. However, in all circumstances, all participants and places that take part in this research will remain anonymous. All identifiable data will be changed before publication.

WILL I HAVE THE CHANCE TO READ THE RESEARCH?

The study will be made available on request to all participants of the research in a summary form.

WHO HAS REVIEWED THE STUDY?

North of Scotland (2) research ethics committee has reviewed the study

WHAT IF I WISH TO MAKE A COMPLAINT?

Hopefully there will be no problems. However, if you decide to be involved in the study and need to make a complaint then in the first instance please contact me on:

Mrs Wahida Shah Kent
KentWS@cardiff.ac.uk
Tel: 07813 612550
If you wish to speak to my supervisors then here are their details:

Professor Jonathan Scourfield
GlamorganBuilding
Cardiff   University
King   Edward   VII   Avenue
Cardiff
CF10 3WT
Tel: 02920 875402
Email: Scourfield@cardiff.ac.uk

Dr Surhan Cam

Glamorgan   Building
Cardiff   University
King   Edward   VII   Avenue
Cardiff
CF10 3WT
Tel: 02920 875402
Email: CamS@cardiff.ac.uk

Contact details below of an ***independent contact*** :

Dr Tom Hall
Director of Postgraduate Research
Room 1.26
Glamorgan   Building
Cardiff   University
King   Edward   VII   Avenue
Cardiff
CF10 3WT
Tel: 02920 876266
Email: hallta@cardiff.ac.uk

HOW DO I REGISTER MY INTEREST TO TAKE PART?

Please sign the Stage 1 Consent Form allowing your professional to pass on some basic contact details of yours so that I may contact you. Or you can contact me directly at the details at the front of this form. If after giving permission for your contact details to be shared with me, you change your mind, I will respect your decision and destroy all details.

If you decide that you wish to be interviewed, I will then request your consent and interview you at a location convenient to you.

Thank you.

Cardiff University School
of Social Sciences
Glamorgan Building
King Edward VII Avenue

Cardiff

CF10 3WT
Tel:07813 612550
Email:
KentWS@cardiff.ac.uk

PARTICIPANT INFORMATION SHEET

(Professionals working with BME children with Life-limiting conditions)

Study title: Black and Minority Ethnic (BME) children with life-limiting conditions – a mixed methods study

INTRODUCTION

My name is **Mrs Wahida Shah Kent** and I am a PhD student at Cardiff University. I am hoping to interview professionals working with Black and Minority Ethnic (BME) children with life-limiting conditions to find out what their experiences have been and to establish any training and development needs.

I would like to ask you to take part in this research. All information will remain confidential. If at any point you decide to change your mind and withdraw from the process, you are entitled to do so.

Interviews will take the form of a series of questions, and should take upto one hour to complete. These could take place either at your place of work, or at an alternative location which suits you best.

Any duty of care concerns raised during the interview will be passed to the Local Authority.

I am happy to meet with you to answer any questions you may have, before you decide whether you wish to be interviewed or not.

On the pages below, there is further information about the study. Please let me know if you would like me to go through it with you to explain anything or contact me at the above details with any questions you may have.

WHAT IS THE PURPOSE OF THE STUDY?

To look into the support needs of the families of BME children with life-limiting conditions, as perceived by professionals, and to look at the interface between such families and specialist services. Also to identify any training and development needs, and experiences, perceptions and beliefs professionals have regarding service take-up by such families.

The themes of ethnic stereotypes is to be explored.

WHY HAVE I BEEN SELECTED?

You have been selected because you work in the field of paediatrics and work with children with life-limiting conditions.

WHAT WILL HAPPEN IF I TAKE PART?

I will arrange a suitable date, time and location to interview you. I will then go through an interview schedule with a series of questions. Interviews should last up to one hour.

HOW LONG WILL THE STUDY TAKE?

It should take one hour of your time.

WHAT WILL HAPPEN IF I DECIDE NOT TO TAKE PART?

You are entitled to decide not to participate, however your involvement would help shed light into an area where there is a dearth of research, and could lead to positive policy changes.

WHAT IF I AGREE TO TAKE PART BUT DECIDE TO PULL OUT DURING THE STUDY?

If this happens then your part in the study, and any contributions you have made, will not be included.

WHAT ARE THE POTENTIAL ADVANTAGES OF TAKING PART?

It is hoped that the study would add to the knowledge and expertise on how best to support professionals working in this field, and also their capacity to support the families of BME children with life-limiting conditions, and improve service delivery.

WHAT ARE THE POTENTIAL DISADVANTAGES OF TAKING PART?

Every effort will be made to ensure there are no disadvantages to you, or distress caused. However, this is a highly sensitive area, and I would envisage recalling certain situations may occasionally be upsetting.

WILL MY TAKING PART IN THE STUDY BE KEPT CONFIDENTIAL?

All participants and places that take part in this research will be given different names and all identifiable information will be changed before publication.

Anything I use to store information e.g. laptops, notes, audio recording devices, etc. will be kept in a secure location.

After completing the PhD, I will hold onto contact details for a period of 6 – 12 months, after which this will be deleted. The data collected would be kept for 5 years to allow for further research, but no participants would be identifiable from this data. It would then be destroyed.

WHAT WILL HAPPEN WITH THE RESULTS OF THE RESEARCH?

The data collected will form the basis for a PhD thesis, which I will write. It could also contribute to papers and chapters which I may write for peer-reviewed academic journals and books. However, in all circumstances, all participants and places that take part in this research will remain anonymous. Al identifiable data will be altered before publication.

WILL I HAVE THE CHANCE TO READ THE RESEARCH?

The study will be made available on request to all participants of the research in a summary form.

WHO HAS REVIEWED THE STUDY?

North of Scotland (2) research ethics committee has reviewed the study

WHAT IF I WISH TO MAKE A COMPLAINT?

Hopefully there will be no problems. However, if you decide to be involved in the study and need to make a complaint then in the first instance please contact me on:

Mrs Wahida Shah Kent

KentWS@cardiff.ac.uk

Tel: 07813 612550

If you wish to speak to my supervisors then here are their details:

Professor Jonathan Scourfield
GlamorganBuilding
Cardiff   University
King   Edward   VII   Avenue
Cardiff CF10 3WT
Tel: 02920 875402   Email: Scourfield@cardiff.ac.uk

Dr Surhan Cam
Glamorgan   Building
Cardiff   University
King   Edward   VII   Avenue
Cardiff
CF10 3WT
Tel: 02920 875402   Email: CamS@cardiff.ac.uk

Contact details below of an *independent contact* :

Dr Tom Hall
Director of Postgraduate Research
Room 1.26
Glamorgan   Building
Cardiff   University
King   Edward   VII   Avenue
Cardiff
CF10 3WT
Tel: 02920 876266   Email: *hallta@cardiff.ac.uk*

HOW DO I REGISTER MY INTEREST TO TAKE PART?

Please contact me at the details at the top of this form. Email contact would be preferable, if possible. Thank you.

Appendix D: Consent Forms

Version 1

11 September 2015

<div align="right">

Cardiff University School
of Social Sciences
Glamorgan Building
King Edward VII Avenue
Cardiff
CF10 3WT
Email:
KentWS@cardiff.ac.uk
Tel:07813 612550

</div>

CONSENT FORM

(Professionals working with BME children with life-limiting conditions)

Study title: Black and Minority Ethnic (BME) children with life-limiting conditions – a mixed methods study

Name of researcher: Mrs Wahida Shah Kent

Please read each statement carefully. If you agree with the statement, please **initial** the box.

1. I have been provided with, read and understood, the information sheet for this study. I have had the opportunity to think about the information,

   ask questions, and have had these answered satisfactorily.   ☐

2. I understand that my participation is my own choice and that I am free to stop being involved in this project at any time without giving

   any reason, without my medical care or legal rights being affected.   ☐

3. If I withdraw from the study, I give my permission to allow any data collected so far to be used for the intended purpose of the research.

   This data would not be personally identifiable.   ☐

4. I acknowledge that my data may be used in the PhD thesis and academic/other publications. ☐

5. I agree that unidentifiable quotes may be used in the PhD thesis and academic/other publications ☐

6. I agree to participate in an interview, which will be audio-recorded and will be anonymised. ☐

7. I acknowledge that I can request a summary of the study and its findings. ☐

8. I agree to take part in the above study. ☐

Name of participant:---

Date:--

Signature:---

Name of Person Taking Consent:--

Date:--

Signature:---

When completed: 1 for participant; 1 for researcher (original)

Version 2

2 November 2015

Cardiff University School
of Social Sciences
Glamorgan Building
King Edward VII Avenue
Cardiff
CF10 3WT
Email:
KentWS@cardiff.ac.uk
Tel:07813 612550

CONSENT FORM (PARENT/CARERS)

Stage 1 – permission to allow contact details to be given to researcher for initial contact to discuss and consider participating in the research project

Study title: Black and Minority Ethnic children with life-limiting conditions – a mixed methods study

Name of researcher: Mrs Wahida Shah Kent

I have been given information about the above research project and agree to give permission for my contact details to be passed on to the researcher. This does **not** mean I agree to participate in the study. At this stage I agree only to be contacted and will make a decision once I have been given further information and the opportunity to ask any questions I may have.

I understand that my taking part is my own choice and that I am free to stop being involved in this project at any time without giving any reason, without my medical care or legal rights being affected.

Name of participant:--

Address:---

Telephone number (Mobile) ---

Telephone number (Home) --

Email address: ---

Date:--

Signature:--

Preferred language to communicate in:--

Name of Person Taking Consent:---

Date:--

Signature:--

I hereby give consent for my GP to be informed that I have participated in this research:

Signature:……………………………………………………………………………

Contact details of GP:

Name………………………………………………………………………………

Address:……………………………………………………………………………

When completed: 1 for participant; 1 for researcher (original)

Version 2

2 November 2015

Cardiff University School
of Social Sciences
Glamorgan Building
King Edward VII Avenue
Cardiff
CF10 3WT
Email:
KentWS@cardiff.ac.uk
Tel:07813 612550

CONSENT FORM (PARENT/CARERS)

(**Stage 2** – consent to take part in the study)

Study title: Black and Minority Ethnic children with life-limiting conditions – a mixed methods study

Name of researcher: Mrs Wahida Shah Kent

Please read each statement carefully. If you agree with the statement, please **initial** the box.

1. I have been given, read and understood, the information sheet

   for this study. I have had the opportunity to think about the information,

   ask questions, and have had these answered satisfactorily. ☐

2. I understand that my taking part is my own choice and that I am free to stop being involved in this project at any time without giving   any reason,

   without my medical care or legal rights being affected. ☐

3. If I decide to withdraw from the study, I give my permission to allow any data collected so far to be used for the intended purpose of the research.

   This data would not be personally identifiable. ☐

4. I understand that my data may be used in the PhD thesis and

   academic/other publications. ☐

5. I agree that un-identifiable quotes may be used in the PhD thesis and

   academic/other publications ☐

6. I agree to participate in an interview, which will be audio-recorded
   and will be anonymised. ☐

7. I acknowledge that I can request a summary of the study and findings. ☐

8. I agree to take part in the above study. ☐

Name of participant:--

Date:--

Signature:--

Name of Person Taking Consent:---

Date:--

Signature:--

I hereby give consent for my GP to be informed that I have participated in this research:

Signature:……………………………………………………………………………

Contact details of GP:

Name…………………………………………………………………………

Address:…………………………………………………………………………

……………………………………………………………………………

When completed: 1 for participant; 1 for researcher (original)

Appendix E: Letter for GP

Important Information for GP

Dear Sir/Madam,

I am a PhD student at Cardiff University, School of Social Sciences. My study will look at the support needs and support systems of Black and Minority Ethnic (BME) children with life-limiting conditions. I plan to interview parents of such children.

As a term of ethical consent (provided by the North of Scotland (2) Research Ethics Committee) I am informing you that your patient (details below) will be taking part in this research.

Name:……………………………………………………………………………….

Date of Birth:……………………………………………………………………..

Address:…………………………………………………………………………..

…………………………………………………………………………………..

If you have any questions, or concerns, please do not hesitate to contact me at the details above.

My supervisors are Professor Jonathan Scourfield (Email: Scourfield@Cardiff.ac.uk) and Dr. Surhan Cam (Email: CamS@Cardiff.ac.uk).

If you wish to speak with someone independent of the immediate research team, you may contact Dr. Tom Hall, Cardiff University Head of Postgraduate Study, Email: HallT@cardiff.ac.uk.

Kind regards,

Mrs Wahida Kent

Appendix F: Confirmation of Ethical Approval

North of Scotland Research Ethics Service

Summerfield House

2 Eday Road

Aberdeen

AB15 6RE

Telephone: 01224 558458

Facsimile: 01224 558609

Email: nosres@nhs.net

27 November 2015

Mrs Wahida Kent

Dear Mrs Kent

Study title: Black and Minority Ethnic children with life-limiting conditions – a mixed methods study

REC reference: 15/NS/0105

Protocol number: SPON 1391-15

IRAS project ID: 174874

Thank you for your letter of 22 November 2015, responding to the Committee's request for further

information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website,

together with your contact details. Publication will be no earlier than three months from the date

of this opinion letter. Should you wish to provide a substitute contact point, require further

information, or wish to make a request to postpone publication, please contact the REC

Manager, Mrs Carol Irvine, nosres@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above

research on the basis described in the application form, protocol and supporting documentation

as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the

study.

Management permission or approval must be obtained from each host organisation prior to the

start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved

in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research

Application System or at http://www.rdforum.nhs.uk.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on

a publically accessible database within 6 weeks of recruitment of the first participant (for medical

device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest

opportunity e.g when submitting an amendment. We will audit the registration details as part of

the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for

non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett

(catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made.

Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with

before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management

permission being obtained from the NHS/HSC R&D office prior to the start of the study (see

"Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Version Date

Evidence of Sponsor insurance or indemnity (non NHS Sponsors

only)

20 July 2015

GP/consultant information sheets or letters: GP Letter 1 22 November 2015

IRAS Checklist XML: Checklist 27112015 27 November 2015

Response to Provisional Opinion 22 November 2015

Consent Form - Parents/Carers - Stage 1 and 2 2 2 November 2015

Parents/Carers Interview Schedule 2 2 November 2015

Participant Consent Form: Professionals 1 11 September 2015

Participant Information Sheet (PIS): Professionals and Parents/

Carers

2 2 November 2015

Document Version Date

REC Application Form: REC Form 22092015 22 September 2015

Referee's report or other scientific critique report 1 11 September 2015

Research protocol or project proposal 2 2 November 2015

Summary CV for Chief Investigator (CI): Wahida Kent 1 11 September 2015

Summary CV for Supervisor (student research): Jonathan

Scourfield

1 11 September 2015

Summary CV for Supervisor (student research): Surhan Cam 1 2 November 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research

Ethics Committees and complies fully with the Standard Operating Procedures for Research

Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance

on reporting requirements for studies with a favourable opinion, including:

• Notifying substantial amendments

• Adding new sites and investigators

• Notification of serious breaches of the protocol

• Progress and safety reports

• Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes

in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all

applicants and sponsors. You are invited to give your view of the service you have received and

the application procedure. If you wish to make your views known please use the feedback form

available on the HRA website:

http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at

http://www.hra.nhs.uk/hra-training/

15/NS/0105 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

Mr Gary Cooper

Chair

Enclosures: "After ethical review – guidance for researchers" SL-AR2

Copy to: Helen Falconer

Ms Lee Hathaway, University Hospital of Wales

Appendix G: Culturagram

Time in the community

Values about family – structure, power, myths and rules

Values about education and work

Legal Status

Family Members

Reasons for relocating

Contact with religious and cultural institutions, holidays, food and clothing

Oppression and discrimination, bias and racism

Health beliefs

Languages Spoken at home and in the community

Impact of trauma and crisis events

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