

# **Exploring multi-ethnic younger and middle-aged adults' understandings of dementia and approaches to help-seeking**

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April 2021

**Thesis submitted in partial fulfilment for the award of Doctor of Philosophy**



## **Abstract**

This research involved the participation of a hitherto under researched groups, namely younger and middle aged adults from lay public multi-ethnic communities. The overall aim of this research was to explore understandings of dementia and approaches to help-seeking.

A qualitative study using grounded theory was conducted to develop insights about factors and issues that shaped understandings of dementia, including its framing to ageing and help-seeking. This research utilised focus groups with lay public participants to access a diverse range of perspectives and experiences. These were supplemented with interviews conducted with community workers to provide contextualised accounts of issues related to dementia help-seeking and care in diverse ethnic communities.

A life stage approach was used to denote generational age and used to recruit lay public participants to the following three generational groups, namely 18-30 years, 30-40 years, and 40-55 years, from white British, Indian and Caribbean communities. Five community workers and volunteers were also recruited to participate in face-to-face semi-structured interviews. The findings from the focus groups suggest that ethnicity did not play a mediating role in the possession of knowledge and understandings of dementia. Other factors were identified, including: exposure to the media; caring for relatives; dementia in their social networks; exposure to dementia in higher education studies, and; participants' own information seeking behaviours. Ethnicity and generational age was suggested to adversely mediate access to mainstream health and media information for older generations from ethnic minority groups outside of this research sample.

Two forms of conceptualisations of dementia were evident. These included the concept of dementia as a mental illness and as a normal consequence of ageing, although their expressions were nuanced. These concepts of dementia were inextricably linked to old age but there were indications of generational changes in the way old age was conceptualised. There was a move away from chronological age definitions to an emphasis on the ageing process, including how well individuals took responsibility for managing their own ageing process and mitigating their risk of developing dementia.

A typology of help-seeking approaches and care strategies was developed. This consisted of four types; traditional, flexible, constrained and individualised, which were developed to convey differentiated approaches to help-seeking by ethnicity and generational age. These types encompassed adaptations and reinforcement of filial piety in response to structural changes and factors. These encompassed perceptions and experiences of racism in the mental health system and the availability of care home support.

This research emphasises the importance of future research encompassing intersectional approaches to research design to capture the heterogeneity of perspectives within and across all ethnic communities. The key message to healthcare providers and commissioners is that they need to address structural barriers to diagnosis and care, some of which may be common across ethnic communities, whilst others maybe specific. This research makes a number of unique contributions to knowledge, one of which is the need for more nuanced approaches to

conceptualisations of dementia. It also explicates and interrogates how ageing is framed in relation to dementia, including individualised responsibility for ageing in a multi-ethnic research sample. Finally, this research also differentiates help-seeking strategies within and across ethnic groups by taking into account generational differences, dynamic interactions between culture and structural factors.

## Acknowledgements

I am grateful to CLAHRC East Midlands for funding this PhD. This funding was applied for and won by Professor Raghu Raghavan for a full-time studentship from 2015 to 2018. His achievement enabled me to undertake this PhD.

I am deeply appreciative and grateful to my PhD supervisory team, Dr Paula Wray (former supervisor) Professor Raghu Raghavan, Dr Scott Yates and Dr Latha Velayudhan for their expertise and support. In addition, to their patience and understanding with the many stops and starts to the PhD due to unanticipated events and challenges in my personal life. Dr Yates - thank you for believing in me when I faltered with the complexity of this PhD. Your simple but powerful sentence during one of our many PhD discussions was 'I believe you can do it' was a lifeline. It rejuvenated my flagging self-belief and helped me to soldier on. I have learnt so much from you, and for that I shall be forever grateful.

The recruitment of focus group participants in this PhD would not have been possible without the tireless efforts and commitment of a number of community workers and volunteers to whom I owe a great debt of gratitude. They include Pamela, Val, Kirit, the late Jaybhai, Anne, Lucie and Kiran. Thank you!

I also wish to acknowledge my appreciation and gratitude to Leicester City Clinical Commissioning Group, in particular Professor Azhar Farooqi for allocating funds to this PhD to support the recruitment of participants and transcriptions of interviews and focus groups discussions. These funds were invaluable as they enabled me to recruit ethically. I was able to pay towards some of the costs incurred by community organisations and charities for their assistance with recruitment of focus group participants. I know from experience this task is not easy to undertake amidst the day-to-day demands on their time and resources. I would not have wanted to 'put upon them' without some form of reciprocity, however small.

I am truly humbled and deeply appreciative of the focus groups participants, who not only gave their time, but engaged in discussions with honesty and clarity about a range of issues. The openness of some of the focus group participants who had been carers of family members with dementia added a valuable dimension to my understanding of the issues and the challenges faced by carers of people with dementia.

I am also grateful to the community workers and volunteers who gave me time and space to participate in interviews despite their demanding and busy schedules.

The journey to completion of this PhD was not easy and took longer than anticipated. The fact that I completed it is actually a testimony to the unfathomable patience of my partner Ballu Patel. His maturity, infinite acts of kindness, care and support during this journey was invaluable and given in an understated manner, as his style. I also wish to recognise the immeasurable encouragement and practical support I received from my sister Lina Patel, and my dear friends Sharmila Master and Ravi Fernandez. They kept me going and focused on the end goal. My youngest son, Jinay who has me in awe with his calmness and logical approach to life, was a ray of light in moments of darkness. Thank you to Akshay, my oldest son, a true gentleman with a lovely soul, who was instrumental in persuading me to realise my dream of pursuing a PhD. A huge thanks go to my amazingly resilient parents for their practical support with finances and warm meals, especially during

the latter days of the PhD. Words will never fully convey how I feel about their presence and contributions in my life.

Also, my research ex-colleagues who have remained lifelong friends. Dr Margaret Stone who has been a wonderful mentor and taught me so much during my research career. Drs. Paula Wray, Alison Dunkley and Michelle Hadjiconstantinou who have quietly in the background, over the years, shared their wisdom, expertise, experience and offered a listening ear and practical advice. Nasima Miah - thank you for your encouragement and faith. Pamela Campbell Morris my dear friend - you are such an inspiration with your tireless efforts to campaign for prostate cancer awareness in the Black community. Now, you battle with your own fight with cancer with a deep sense of faith and prayers from so many people. God bless you and thank you for the weekly 'how are you?' phone calls'. I shall not forget your kindness and warmth and feel blessed to know a true community activist.

Thanks also to my PhD friends Dee Bij, Kris Fearon and Janice Chen, with whom I have spent many a happy hour simply enjoying their peer support over a cup of a masala chai and breakfasts.

Several colleagues within DMU Health and Life Sciences Department have been amazing and I wish to thank you all. Dr Chris Knifton spent time with me to educate me about dementia, and how to conduct research with carers and people with dementia. His expertise and experience in dementia was an invaluable source of knowledge and insights during the early days of the PhD. My thanks go to Professor Jayne Brown, Dr Kathryn Hinsliff-Smith and Dr Andrew Clifton for going out of their way to keep me financially afloat with short-term contracts. It has been a real pleasure working with you all. Professor Kay De Vries, my postgraduate tutor/ pastoral care, who has been a great listener and supporter, alongside Professor Jayne Brown and Dr Kathryn Hinsliff-Smith.

I am also grateful to Dr Emma Rowley for organising some really useful training courses for CLAHRC funded PhD students and Alice Philips for her wonderful administrative support for CLAHRC PhD students. As well as Dr Sally Ruane for organising some really helpful training courses for DMU PhD students.

Finally, much appreciation and thanks go to Jaqui Long, an ex-DMU researcher and friend who lately spent some of her weekends proof reading my PhD. Thanks also go to Dee Bij for proof reading an initial draft chapter. Thank you to Yoon Kim for taking the time out to help with formatting the PhD.

As I end this PhD journey I realise that although completing a PhD is a solitary pursuit and achievement, it has taken a raft of supportive people in the background to make it a reality for me.

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# Abbreviations

|              |  |
|--------------|--|
| <b>AD</b>    | Alzheimer's Disease  |
| <b>APPG</b>  | All Parliamentary Group                                    |
| <b>BAME</b>  | Black, Asian and Minority Ethnic                           |
| <b>CERAD</b> | Consortium to Establish a Registry for Alzheimer's disease |
| <b>CONGT</b> | Social Constructionist Grounded Theory                     |
| <b>CSF</b>   | Cerebrospinal Fluid  |
| <b>DMU</b>   | De Montfort University                                     |
| <b>GT</b>    | Grounded Theory  |
| <b>HRA</b>   | Health Research Authority                                  |
| <b>IMD</b>   | Index of Deprivation                                       |
| <b>LMIC</b>  | Low, Middle Income Countries                               |
| <b>MRI</b>   | Magnetic resonance imaging                                 |
| <b>NHS</b>   | National Health Service                                    |
| <b>HRA</b>   | Health Research Authority                                  |
| <b>NICE</b>  | National Institute of Health and Care Excellence           |
| <b>PET</b>   | Positron emission tomography                               |
| <b>PIS</b>   | Participant Study Information Sheet                        |
| <b>PWD</b>   | Person with Dementia                                       |
| <b>UK</b>    | United Kingdom   |
| <b>US</b>    | United States  |

# Chapter 1: Introduction

**Dementia has a physical, psychological, social, and economic impact not only on people with dementia, but also on their carers, families and society at large.** (World Health Organisation, 2020)

As the above quote illustrates the impact of dementia is far reaching, going beyond those affected by it and their families, to include wider society as well. However, much of the research that is currently undertaken is conducted with older members of the lay public, people with dementia and their carers. This is understandable, given the risk of dementia increases with ageing. Although, if we are to fully understand the impact of dementia in wider society research also needs to include the perspectives and experiences of young and middle-aged people from the lay public.

The saliency of doing so is emphasised in Black, Asian and minority ethnic communities (BAME) in the UK as much of the existing research is conducted with older members of these communities. The emphasis in these studies has been on eliciting cultural understandings of dementia and how culture affects help-seeking. However, little is known about how these issues may differ or remain the same amongst younger members of BAME communities due to the intersection of ethnicity with characteristics such as generational age, socio-economic status, and migration history (Jutilla, 2015). The neglect of this can lead to findings derived from older people's perspectives and experiences being applied across the board to BAME communities. These not only produce homogenised accounts and understandings that fail to take account of diversity within ethnic groups but also pathologise cultures (Torres, 2015; Zubair and Norris, 2015). In addition, they highlight a failure to establish commonalities in understandings and help-seeking within white British communities. They also deflect attention away from how the health system addresses diversity and inclusion in dementia diagnosis and

provision of care support.

This research addresses this marginalisation and neglect through the design of a qualitative exploratory study involving multi-ethnic participants from different generational ages to explore understandings of dementia and approaches to help-seeking. The findings of this research challenge cultural reductionist approaches that characterise so many studies conducted with mainly older generations from ethnic minority groups. In doing so, it does not negate the influence of culture, but instead offers more nuanced insights and perspectives. It achieves this by drawing attention to complex interactions of other factors and issues including the intersection of ethnicity and generational age that influence and shape understandings of dementia and approaches to help-seeking. It also highlights how ethnicity confers discrimination, disadvantage and inequity in the dissemination and content of information about dementia and culturally appropriate care.

This chapter begins by locating this research in a global and national context with regards to ageing and dementia. It will subsequently involve a brief discussion about the historical development of Alzheimer's and dementia, including its conceptualisation as a disease. I shall also briefly highlight why its conceptualisation as a disease has been contested. This will be followed by a summary of key points from the research conducted with ethnic minority groups about their conceptualisations of dementia and help-seeking. Thereafter, I shall discuss the aims and objectives of this research, followed by my motivations for undertaking this research. Finally, an overview of the thesis structure and content is presented.

## **1.1 Global and national context**

The risk of developing dementia increases exponentially with age (Wittenberg et al., 2019a:1). This is concerning as globally, almost every country in the world is experiencing a growth in the size and proportion of the older population, as illustrated in Table 1.1 below. Increased life expectancy resulting in ageing populations is attributed to the success of global efforts to eradicate infectious and parasitic diseases (World Health Organization 2011). In addition to the reduction of child mortality, increased

access to education and employment opportunities, improvements in reproductive health and access to family planning have all led to an increase in life expectancy (United Nations, 2019: 3).

Table 1.1: Estimates of population ageing, globally and in the UK

| <b>Global ageing estimates</b>                   | <b>UK ageing estimates</b>   |
|--|--|
| 2019: 703 million persons aged 65 years and over | 2016: 11.8 million UK residents aged 65 years and over, 18% of the total population  |
| 2050: 1.5 billion persons aged 65 years and over | 2066: 20.4 million UK residents aged 65 years and over, 26% of the total population. |
| Source: (Storey, 2018)                           | Source: (Storey, 2018)   |

These global achievements are leading to an epidemiological transition (World Health Organization, 2015: 9), in which the likelihood of dying from infections and acute conditions decreases, whilst the likelihood of chronic and neurodegenerative diseases such as dementia increases. Currently, on a worldwide basis around 55 million people have dementia, with over 60% living in low- and middle-income countries (World Health Organization, 2021). The prevalence of dementia is projected to increase globally as well as nationally in the UK, as the figures in the table below illustrate:

Table 1.2: Estimates of dementia prevalence, globally and in the UK

| <b>Estimates of Global dementia prevalence</b>  | <b>Estimates of UK dementia prevalence</b> |
|---|--|
| 2030: 78 million  |  |
| 2050: 139 million<br>(much of this attributed to rising numbers of people with dementia in low- to middle-income countries) | 2019: 885,000<br><br>2040: 1.6 million     |
| Source: (World Health Organization, 2021)   | Source: (Wittenberg et al., 2019b)         |

For people diagnosed with dementia and their carers, dementia confers significant

personal and socio-economic burdens, in addition to considerable financial costs to wider society (Brayne et al., 2020; World Health Organization, 2015) as illustrated by the figures in the table below:

Table 1.3: Estimates of Global and UK dementia costs

| <b>Estimates of Global costs of dementia</b> | <b>Estimates of UK costs of dementia</b> |
|--|--|
| 2018: 1 trillion dollars                     | 2015: 26 billion pounds                  |
| 2030: 2 trillion dollars                     | 2040: 55 billion pounds                  |
| Source: (Prince et al., 2014)                | Source: (Prince et al., 2014)            |

Cognitive decline associated with ageing was discussed by physicians in ancient times, although in some of these discussions the distinction between dementia and normal age-related cognitive decline is not clear. These discussions were highlighted by Karenberg and Forst's (2006) analysis of Greco-Roman physicians' medical texts between 500BC and 500AD. These texts portrayed in-depth accounts of how Greco-Roman physicians recognised and associated ageing with abnormal changes in behaviour and cognitive decline. Although, Karenberg and Forstl (2006) argued that whilst various terms were used to name these deficiencies, dementia was only one of many and this term did not have a radiating or summarising function (Karenberg and Förstl 2006: 7). Their analysis also encompassed literary texts, and the following excerpt from the Roman poet Juvenal illustrates how old age was associated with cognitive decline, *diseases of all kind dance around him (i.e., the old man) in a troop ... But worse than any loss in the body is the failing mind which forgets the name of slaves and cannot recognise the face of the old friend who dined with him last night, nor those of the children whom he has begotten and brought up* (Karenberg and Förstl 2006: 7).

Clarity about the distinction between normal age-related cognitive decline and dementia is attributed to Galen, who is deemed the father of medicine and neuroscience. He is cited to having paved the way for dementia to be conceptualised as a disease (Berthold, 1998) as far back as 129 AD-200/216. For Galen, dementia was articulated as encompassing a

loss of memory, judgement and learning (Balyonnis, 2016: 2) as distinct from normal age-related cognitive decline. He described dementia as a mental disorder called Morosis. If it existed in melancholy it was deemed by Galen to be reversible (Balyonnis, 2016:2). This suggests that he may have also categorised irreversible dementia.

Over time, the conceptualisation of dementia as a mental disease became just one of many conceptualisations that were identified during Knifton and Yates' (2019) analysis of historical texts up to the modern day. Other scholars have discussed a range of conceptualisations including, for example, as a natural consequence of ageing; a biomedical disease; a neuro-cognitive disorder; a disability; and a terminal illness. Its current alignment to biomedicine, with its emphasis on neuro-pathologies and biomedical therapeutics (Fletcher, 2019), has not been linear but as a consequence of convoluted social processes (Knifton and Yates, 2019). A discussion of which goes beyond the scope of this thesis.

A key moment in this transition in conceptualisation of dementia that cannot go without a mention is Alois Alzheimer's contribution. This, according to Ballenger (2006), laid the clinical and pathological foundations of dementia (Ballenger, 2006: 6). This came about from Alzheimer's post-mortem analysis in 1906 of a 51-year-old woman's brain who exhibited hallucinations and delusions. His analysis, through the use of a newly developed silver staining technique, found evidence of dense amounts of neurofibrillary tangles and plaques (Ballenger, 2006: 7). It was of interest to him as these symptoms were usually associated with senility in old age but were present in a younger subject (George et al., 2013). Consequently, for much of the 20th century Alzheimer's disease was predominantly used to describe young onset dementia (George et al., 2013). This changed in the latter half of the 20th century due to a range of cultural forces, most notably an increase in longevity in developed countries, advances in scientific research technology, and astute political advocacy (George et al., 2012: 2). These changes resulted in Alzheimer's replacing the use of senile dementia and it became to be conceptualised as a disease that affected older people (George et al., 2012: 2). This change in conceptualisation has attracted criticism, mainly from those who argue that it has medicalised ageing (George et al., 2013; Hashmi, 2009; Katz, 2008; Lock and



Nguyen, 2018; Whitehouse et al., 2005). So what was once perceived to be natural progression and an outcome of ageing is now postulated to be an incurable disease of epidemic proportions (Fletcher, 2019: 422). These critiques are countered by an argument that posits that the biomedical concept of dementia removes dementia-related stigma when it is perceived to be a disease (Fletcher, 2019).

Against the backdrop of contestations about the biomedical conceptualisation of dementia, it progressed to become a major public health issue in the last half of the 20th century. This was due to, as we have read above, the rise in life expectancy and the concomitant rise in numbers of people with dementia (Ballenger, 2017). Also, as a consequence of its links to ageing, it is argued the *reframing of dementia was not merely of changing medical concepts but linked to a broader social transformation and discourse on ageing* (Ballenger, 2017: 713). The implication of which is that discussions about understandings and concepts of dementia are often inextricably linked to those of ageing.

Biomedicine's concept of dementia has influenced treatment modalities and approaches to dementia research that place an emphasis on the prevention and early detection of dementia, in addition to considering how to support a person with dementia (PWD) once diagnosed (Brayne et al., 2020). Research has also explored whether some groups in society are at increased risk of developing dementia, for example, as a consequence of a decrease in oestrogen due to the menopause (Hogervorst and Bandelow, 2010) or ethnicity (Adelman et al., 2011; Mayeda et al., 2016). Emerging research evidence also suggests that if modifiable risk factors such as chronic health conditions for dementia are identified and addressed early enough in the life course of individuals, it can reduce their likelihood of developing dementia by 40% (Livingstone et al., 2020).

However, biomedicine's conceptualisation and understandings of dementia and ageing are not universally shared, as highlighted by findings from a plethora of worldwide empirical research conducted with minority ethnic groups in Europe, the US and Australia and from majority populations in countries such as China and India. Overall, research evidence highlights that these communities: (1) do not conceptualise dementia as an illness; (2) believe dementia is a normal consequence of ageing; (3) think

dementia has spiritual, psychological, physical health or social causes; (4) feel that caring for the person with dementia is a personal or family responsibility; (5) experience shame and stigma within the community about dementia and seek help outside of the family; (6) believe there is nothing that could be done to help; and (7) have negative experiences of healthcare services (All-Party Parliamentary Group on Dementia, 2013; Berwald et al., 2016; Czapka and Sagbakken, 2020; Sun et al., 2015). As discussed earlier, much of this global research with ethnic minority groups has been conducted with older lay study participants, PWD and carers, in which overall, studies from the United States (US) predominate.

The saliency of conducting research with younger generations within BAME communities in the UK is further emphasised, because the prevalence of dementia is estimated to increase in some BAME communities, such as the Indian, Irish and Caribbean communities, from 25,000 in 2015 by almost seven-fold to 172,000 by 2051 (Prince et al., 2014). This is in sharp contrast to the two-fold increase in dementia prevalence for other ethnic groups in the UK. These prevalence figures may be underestimated as emerging evidence suggests an increased prevalence of early onset dementia in BAME communities at 6.1% compared to 2.2% for the general population (Prince et al., 2014). A higher risk of early onset dementia more specifically in African-Caribbean communities (Adelman et al., 2011) has been identified.

As dementia prevalence increases, BAME younger and middle-aged adults are likely to be tomorrow's carers for people with dementia, along with younger generations from white British communities. If they are to gain access and support to dementia diagnosis and care, it requires congruency in the illness beliefs between the lay public and those underpinning the biomedical model of the healthcare system (Wade and Halligan, 2017). Yet, there is a paucity of research undertaken with younger generations in the UK with both BAME and white British communities.

## **1.2 Aims and objectives of this research**

### **1.2.1 Aims**

The above issues highlight the importance of widening the existing empirical knowledge base to take account of different generational perspectives in dementia research. Therefore, the overarching aim of this research was to explore younger and middle-aged participants' understandings of dementia and approaches to help-seeking. A further aim was to explicate aspects of understanding through an investigation of the knowledge participants possessed as well as what they understood about dementia. The research also sought to examine how they conceptualised dementia and ageing, and to explore how participants approached help-seeking for dementia, which includes diagnosis as well as care strategies.

A further goal of this research was to explore and clarify the factors and issues that shaped and influenced knowledge and understanding, concepts of dementia and ageing, and help-seeking. This exploration also sought to encompass the role played by ethnicity and generational age. Through the process of achieving these goals, it was envisioned that the research would provide clarity about whether understandings of dementia and approaches to help-seeking are similar or different to those discussed in the empirical literature.

In view of the overall aim of this research, and in the light of the above issues and considerations, I set out to specifically answer the following research questions:

1. What is the knowledge and understanding of dementia in younger and middle-aged adults in multi-ethnic communities ?
  - (a) What factors influence and contribute to this knowledge and understanding?
2. How is dementia conceptualised by younger and middle-aged adults in multi- ethnic communities?
  - (a) What factors and issues shape and influence these conceptualisations?
3. How is old age and ageing conceptualised in younger and middle-aged adults in

multi-ethnic communities ?

(a) How is old age and ageing framed in relation to dementia?

4. What are help-seeking strategies for dementia within younger and middle-aged adults in multi-ethnic communities?

(a) What factors and issues shape and influence these?

### **1.2.2 Objectives**

An initial and critical review of the empirical studies, including the grey literature, was undertaken. The grey literature comprises research that is often conducted by academic researchers, in partnership with community and voluntary sector organisations, but the articles and reports are not peer reviewed. The research questions were developed to address the knowledge gap within the literature, as discussed above. This led to the selection of multi-ethnic and generational groups as the research sample. The following objectives were the concrete steps taken to address the research questions:

- A decision to select a qualitative methodology was made as there is a paucity of qualitative research studies on dementia with BAME communities in the UK.
- Grounded theory was selected as the methodological framework, in particular Social Constructionist Grounded Theory (CONGT) by Charmaz (1995), on the basis of the research goals and my positionality. The emergent CONGT approach to analysis led to the formation of a typology which drew upon the methodological and theoretical literature on typologies during its development.
- Focus groups were selected as the most appropriate method for the research with lay participants. A decision to conduct interviews with community workers and volunteers was taken to facilitate contextualised understandings of current care and support in BAME and white British communities.
- Analysis of the findings from the focus groups and interviews was guided and informed by CONGT (Charmaz 1995).
- Thereafter, the findings were interpreted, compared and contrasted to the existing

empirical literature. A review of the theoretical literature was also conducted to facilitate critical and evaluative perspectives of my findings. The quality of the research was evaluated using CONGT criteria and conclusions were made, including recommendations for future research and healthcare.

### **1.3 My motivation for conducting this research**

This research was funded by a full-time studentship from Collaboration for Leadership in Applied Health Research and Care East Midlands (CLAHRC-EM). This financial assistance helped to make the decision to pursue a PhD. Although the subject 'dementia' was different from my professional research interest of diabetes, it was in keeping with my experience and expertise of research with BAME communities. I was also motivated by the prospect of further developing my qualitative research skills and social science perspectives in my research.

For me too, the importance of studying dementia was becoming increasingly apparent, as I was aware in my social networks that many of my parents' first generation peers were being diagnosed with dementia. One of these was particularly close to home, literally and metaphorically, as my next-door neighbour's mother was diagnosed with dementia prior to the commencement of this PhD. I witnessed her physical and mental decline over the years. Through the journey of my neighbour's mother's diagnosis and progression of dementia, I witnessed first hand the devastating impact of dementia, on not only the mother but my neighbours as they cared for her until the end.

So, my motivation was partly personal, to be ahead of the curve as it were, to enable me to be prepared in case my parents were diagnosed, and also as I was in my mid-50s, to enable me to have an insight on issues related to its prevention.

Additionally, my focus throughout my research career has been on translational research, the outcomes of which have been adopted nationally to assist BAME communities in risk assessment of Type 2 diabetes and insulin initiation. My fervent wish is to do the same with this research, to use it as a basis to support both white British and BAME communities with translational research.

## 1.4 Overview of the thesis

This thesis encompasses a further eight chapters. The purpose of this overview is to briefly describe the key contents of each chapter.

**Chapter 2: Literature review** offers a theoretical discussion about how and why the category of dementia is contested as a conceptual and diagnostic category; an issue highlighted in this Introduction chapter. It also explores the implications of the biomedical model of dementia on concepts of ageing, and the role of the media. A review of key findings related to conceptualisations of dementia, knowledge, and help-seeking is provided from the empirical literature, including the grey literature. This review identified gaps in the existing research and led to the development of the research questions. At the end of this chapter, within the section on the theoretical orientation I shall discuss the critical sociological perspectives that guided my selection of concepts of ethnicity and generational age. I will also provide an overview of the theoretical and methodological contributions that underpinned the development of the typology on help-seeking approaches and care strategies. These methodologies and theoretical discussions are based on the seminal work of sociologists such as Weber (1988), McKinney (1969) and Schutz (1972) on typologies. The contributions of these sociologists were drawn upon to assess the best fit for my data on help-seeking approaches and care strategies.

**Chapter 3: Methodology** provides explanations and justifications for the selection of a qualitative approach, and Grounded Theory as the methodological framework. There are also explanations for the use of focus groups and intensive interviewing. A discussion of how theoretical perspectives informed my operationalisation of ethnicity and generational age in this research is also included. Issues related to ethical conduct are also discussed, including those that apply to research with BAME communities. The chapter ends with a discussion on the selection of the quality criteria to evaluate this research.

**Chapter 4: Methods** encompasses discussions on the methods employed to address the research questions. It covers issues related to sampling strategies including theoretical sampling, recruitment processes and challenges encountered. In addition to the detailed discussions about the process of analysis involved in the generation of themes and the

typology of help-seeking approaches and care strategies.

**Chapter 5: Research Context and Participant Characteristics** provides an overview of the city of Leicester, in which the research took place, including information on ethnicity, ageing and dementia prevalence. Demographic information pertaining to the focus groups and community workers is also provided.

**Chapter 6: Findings on Knowledge & understanding, and conceptualisations of dementia and ageing.** This chapter is organised under three sections with themes for knowledge and understandings related to the acquisition of information and knowledge, possession of knowledge, and knowledge and understanding. The section on conceptualisations of dementia encompasses discussion of the two conceptualisations found in this research, namely dementia as a mental illness and as a normal consequence of ageing. The last section, conceptualisations of ageing, is presented in themes which indicate changes to the ways in which ageing is conceptualised over time and how these were framed in relation to dementia.

**Chapter 7: Findings for a Typology of Help-seeking approaches and Care Strategies.** This findings chapter provides a discussion of the findings related to the typology that was developed to explain how help-seeking approaches differed along the intersections of ethnicity and generational age. The four types that constitute this typology include Traditional, Flexible, Constrained and Individualistic, and these convey the interactions between values and structural issues.

**Chapter 8: Discussion.** This chapter provides a summary of the key findings, and then moves on to an interpretation of these findings, including a comparison with existing empirical and theoretical literature.

**Chapter 9: Conclusions.** This chapter concludes this research by considering its contribution to knowledge as well as its limitations. Recommendations for healthcare organisations and commissioners of dementia services are made, as well as for future research. A reflective account of my thoughts on the processes and outcomes of this research is also shared.

# Chapter 2: Literature Review

## 2.1 Introduction

This literature review chapter provides an overview of theoretical perspectives on dementia as a concept and as a diagnostic category, as well as ageing. It also encompasses an overview of findings from empirical studies conducted with a range of multi-ethnic communities on a global scale. The purpose of this review is to contextualise this research within both the theoretical and empirical literature and to identify gaps in published empirical literature to address through this research study.

Much of the published empirical research evidence with diverse ethnic communities on dementia and care emanates from the United States (US) and the paucity of studies in the UK is recognised (Downs, 2000; Hossain and Khan, 2019; Mukadam et al., 2015).

This chapter is presented and organised in sections to delineate between the review of the theoretical and empirical literature. Although this is not a hard and fast separation as some of the theoretical discussions also draw upon empirical studies to assist with supporting the arguments. In particular, those made by anthropologists and researchers about the cultural transferability of the concept of dementia in non-Western cultures. The theoretical discussions on the role and function of the media regarding dementia and ageing have also been combined with empirical studies to support arguments.

## 2.2 Approach to the literature review

Grounded Theory (Glaser and Strauss, 1967) eschews undertaking a literature review prior to data collection and analysis to ensure an inductive approach to the generation of theory or concepts for further research, i.e., research is grounded in the data and not 'contaminated' by prior exposure to research. This is to ensure the researcher



approaches the data without prior theoretical concepts and, in doing so, remains open-minded to emergent concepts (Glaser and Strauss, 1978). However, institutional and ethical requirements necessitate the researcher develops the proposed research that is cognisant of existing research to avoid its duplication. In addition, PhD students are also required to design their research based on informed decisions about research strategies that can contribute new knowledge to the existing evidence base and, without an exploration of existing literature, efforts to achieve this are compromised (Nagel et al., 2015).

To balance these opposing demands, my literature review process was organised in two stages. Stage 1 encompassed an initial review of empirical studies and grey literature, and this was undertaken between February 2016 to September 2016. The rationale for this stage was to review the literature to help identify gaps in the existing research to address in this research, including an insight on the most appropriate research methodology to address an identified gap.

This search strategy involved developing inclusion and exclusion criteria and the search terms used to search electronic databases (see Appendix A). I extracted 170 worldwide empirical studies which I uploaded to NVivo (QSR International 2021) to help me manage the large number of studies. The use of NVivo for literature reviewing is not an uncommon practice (Di Gregorio, 2000; O'Neill et al., 2018). It has been recognised that NVivo can help to manage and organise large amounts of literature as well as assist with summarising findings thematically. The findings from these studies were then coded and organised under descriptive themes and a draft literature review chapter was written.

To respond to the low number of empirical studies conducted within BAME communities in the UK, I searched on Google to identify any grey literature conducted in the UK. This Google search enabled me to access the grey literature in other countries too. The findings from these grey literature reports and studies were also uploaded into NVivo and coded under descriptive themes.

The electronic database searches also identified theoretical papers, including on ageing and dementia, the concept of dementia, and those charting its development as a

diagnostic category historically to the present. These theoretical papers were kept to one side until September 2020 to ensure I upheld the advice imparted by Charmaz (2006) which was to be cognisant of the literature but not to immerse yourself fully to avoid developing preconceived ideas (Dunne, 2011).

During this initial literature search phase, between February 2016 to September 2020, I set up electronic database alerts to flag up new empirical studies. I saved these new studies in an electronic folder entitled 'new papers' for any that were identified after September 2016 when my initial write up of the literature review was completed.

Stage 2 involved a more comprehensive literature review and was the final stage of the literature review process. This was undertaken after the data collection and data analysis phase was completed in September 2020. The rationale for this stage was to familiarise myself with the key findings from new empirical studies. It was during this stage that the theoretical literature that I had saved and put to one side was also coded in NVivo (QSR International, 2021). I also uploaded the new papers that I had accumulated through the alerts on the electronic databases and added these to the initial coding framework developed for the empirical and grey literature in 2016. These steps were designed to enable me to develop a critical oversight and interpretation of my own research findings for the discussion chapter.

## **2.3 Translation and synthesis of findings**

The analysis of findings from empirical studies and the grey literature was informed by the guidance from Thomas and Harden (2008) on conducting a thematic synthesis of qualitative research in systematic reviews. In accordance with this guidance, findings from all studies were imported to NVivo (QSR International 2021). The synthesis of findings from peer reviewed empirical studies and the grey literature was organised thematically, but unlike Thomas and Harden's (2008) development of conceptual categories from this synthesis, descriptive themes were developed and subsequently presented in Section 1, 2 and 3.

## 2.4 Overview of chapter

This section of the chapter will provide an overview of the presentation of the findings of the literature review.

In Section 1, I present descriptive themes that demonstrate that this research takes place against a backdrop of theoretical perspectives that contest the concept of dementia and Alzheimer's at a conceptual level as well as a diagnostic category (Zeilig, 2015a; Downs, 2000). The argument presented here is that Alzheimer's, for example, is not a clear-cut diagnosis. Rather, it is subject to differences in interpretation. Therefore, it is not altogether clear whether dementia is pathological ageing as life expectancy increases or a distinct disease entity.

It is also argued that dementia as a concept has changed the societal approach to ageing, largely because it is a risk factor for dementia, but also because it is paralleled by a societal discourse on ageing well. Thus, dementia is in danger of being used to conceptualise individuals as failing to age well, without taking on board the wider socio-economic determinants of ageing well, including risk factors for dementia.

The critical engagement of dementia as a concept also continues with respect to its transferability to non-Western cultures, because it's argued that it has been developed in Western societies that culturally value individuality, productivity and hyper-cognition. Nevertheless, through globalisation and increased life expectancy in many non-Western countries, dementia as a concept and diagnostic category has been exported. As a consequence, it has been cross culturally explored in those countries and also with respect to BAME communities in Western countries and colonised indigenous communities. Some of the arguments that contest the diagnostic category of dementia are addressed through a discussion of dementia diagnosis, including how a range of assessments are undertaken to enhance the process of diagnosis, including the use of medical technology.

In Section 2, the argument presented here through an overview of empirical studies and the grey literature conducted within BAME communities, colonised indigenous communities and countries such as India, China and South Korea, is that there are

many ways in which dementia is conceptualised. In some ethnic groups, including white Anglo-American, Irish and white British communities, dementia is also conceptualised as a normal consequence of ageing.

Dementia was found to be conceptualised in different ways, including pejoratively as a mental illness, through folk explanatory models and in biomedical terms. The implications of these conceptualisations are explored with respect to help-seeking behaviours, including the contribution of these conceptualisations in the generation of stigma.

In Section 3, I turn to the help-seeking behaviours and in particular the saliency of early diagnosis for ethnic groups at high risk of developing dementia. The findings of this review suggest that help-seeking is challenged in many ethnic minority groups for a number of reasons, which include lower levels of knowledge and understanding of dementia in keeping with the biomedical model of dementia, the cultural value of filial piety as well as stigma. However, the tools utilised for the exploration of help-seeking behaviours such as acculturation have not been subjected to critical scrutiny. For example, ethnicity is used to associate differences in knowledge, understanding and help-seeking with cultural explanations, at the expense of casting a critical eye on the role of issues such as a lack of access to culturally appropriate information, experiences of racism and poverty.

In Section 4, I shall conclude by critically reflecting and commenting on both the theoretical and empirical reviews of the literature to highlight key points.

In the final section of this chapter, Section 5, after summarising this chapter I set out my rationale for taking a multi-generational perspective to this research, which is partly formed in response to the critiques of acculturation and to address a gap in the existing research. In this section, I will also state the overall research question after I provide a summary of the theoretical orientation that guided and shaped this research.

## **2.5 Section 1: Contestations and uncertainties about dementia and Alzheimer's**

### **2.5.1 Blurring the boundaries between ageing and dementia**

The National Health Service (NHS) uses the World Health Organization's International Classification of Diseases and Related Health Problems (ICD). The ICD-11 states that dementia is an acquired brain syndrome. It is characterised by a decline from a previous level of cognitive functioning with impairment in two or more cognitive domains (such as memory, executive functions, attention, language, social cognition and judgement, psychomotor speed, visuoperceptual or visuospatial abilities). The cognitive impairment is not entirely attributable to normal ageing and significantly interferes with independence in the person's performance of activities of daily living. Based on available evidence, the cognitive impairment is attributed or assumed to be attributable to a neurological or medical condition that affects the brain, such as trauma, nutritional deficiency, chronic use of specific substances or medications, or exposure to heavy metals or other toxins (World Health Organization, 2020).

Outlined in the table below is the diagnostic and statistical manual of mental disorders (DSM-5) (American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders (DSM-5) 2013). This is used in the diagnosis of dementia in the US and Australia.

At the heart of debates about dementia as a diagnostic category is the concern that dementia has blurred the boundaries between normal age-related degeneration and pathological changes associated with dementia (Davis, 2004). This is attributed to the lack of a standard referent to delineate the boundaries between ageing and dementia, the absence of which has led the ageing process to be 'biologised' and deemed to be pathological (Davis, 2004; Whitehouse et al., 2005a; George et al., 2013).

These boundaries are challenging to establish when the evidence from autopsies of the brains of older people with and without dementia demonstrate plaques, tangles can be found in all ageing brains (George et al., 2011a; Brayne et al., 2006; Lock and Nguyen,

2018). This suggests a degree of uncertainty about when and how the ageing brain becomes diagnosed with dementia and led Hashmi (2009a) to ask just how many plaques and tangles does it take, how much does one have to forget to attract a diagnosis of Alzheimer's disease (Hashmi, 2009a: 209)?

The diagnostic category of Alzheimer's has also generated controversy, even though there are standardised definitions of Alzheimer's and associated diagnostic criteria, based on clinical measures of symptoms and observations (Brayne and Davis, 2012). This occurs because it is open to differences in interpretation at a clinical level (George et al., 2013). These differences can arise even within fairly homogeneous cultural settings because the diagnostic criteria have the potential to be interpreted differently by individual clinicians and researchers (Brayne and Davis, 2012:2). Consequently, these differences in interpretation have given rise to scepticism as to whether dementia is a disease or simply pathological ageing as our life expectancy increases (Lock and Nguyen, 2018).

Table 2.1: DSM-IV and DSM-5 criteria for dementia

| <b>DSM-IV criteria for dementia</b>  | <b>DSM-5 criteria for major neurocognitive disorder (previously dementia)</b>  |
|--|--|
| A1. Memory impairment  | A. Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains:<br>- Learning and memory<br>- Language<br>- Executive function<br>- Complex function<br>- Perceptual-motor<br>- Social cognition |
| A2. At least one of the following:<br>- Aphasia<br>- Apraxia<br>- Agnosia<br>- Disturbance in executive functioning  |  |
| B. The cognitive deficits in A1 and A2 each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning. | B. The cognitive deficits interfere with independence in everyday activities. At a minimum, assistance should be required with complex instrumental activities of daily living, such as paying bills or managing medications.                        |
| C. The cognitive deficits do not occur exclusively during the course of delirium.  | C. The cognitive deficits do not occur exclusively in the context of a delirium.   |
|  | D. The cognitive deficits are not better explained by another mental disorder (e.g, major depressive disorder, schizophrenia).   |

There is also some uncertainty about the contribution of genotyping in dementia within the diagnosis process, even though progress has been made to identify potential genes implicated in the development of dementia. This progress involves the knowledge that the Apolipoprotein E (APOE) gene is implicated in the susceptibility/risk of developing Alzheimer's disease (Reiman et al., 2020). What is currently known is that there are three alleles or variants of the APOE gene and they include  $\epsilon 2$ ,  $\epsilon 3$ , and  $\epsilon 4$  (Largent et al., 2020). The  $\epsilon 2$  and  $\epsilon 3$  alleles can provide protection, or are neutral protective or neutral, respectively, whilst the  $\epsilon 4$  alleles increase the carrier's risk of developing AD (Largent et al., 2020:5). For the 1% to 2% of individuals who are APOE  $\epsilon 4$  homozygotes (Largent et al., 2020:5) i.e., who have inherited this variant from both biological parents (The National Human Genome Institute, no date), their risk of developing AD for the APOE  $\epsilon 4$  allele increases up to 12 times (Serrano et al., 2021:12) as well as the development of young onset dementia (Reiman et al., 2020). In contrast, possessing one APOE  $\epsilon 4$  allele increases the risk of developing Alzheimer's disease by approximately 3.7 times (Reiman et al., 2020).

The uncertainty about genotyping relates to its transferability to therapeutics, which is still in its infancy (Serrano et al., 2021). This is because the knowledge about the process by which gene susceptibility operates or contributes to causality is unknown (Kenigsberg et al., 2016: 9). This uncertainty and complexity in genotyping research was highlighted by Largent (2020) who stated that carrying an APOE  $\epsilon 4$  allele is neither necessary nor sufficient to cause AD: not all people with AD have an APOE  $\epsilon 4$  allele, and not all people with an APOE  $\epsilon 4$  allele develop Alzheimer's (Largent et al., 2020: 5). Thus, given the uncertainties in the role and contribution of the APOE gene and its alleles, caution is advised about genetic testing for Alzheimer's disease (Largent et al., 2020). This is because genetic testing can have ramifications for those identified with a higher risk of developing Alzheimer's, such as social stigma, implications for insurance, housing, employment and self-identity. However, it has been acknowledged that the advantage of genetic risk screening is that when higher risk is disclosed it may lead to an increase in access to social support (Largent et al., 2020).

## **2.5.2 Challenges to the biomedical model of dementia**

As well as the uncertainties about dementia as a diagnostic category, it has been argued that its use has resulted in a reductionist view of human beings (Elliott and Minno 2006). The implications of which has involved a move away from developing holistic approaches to human brain health (Elliott and Minno, 2006) to an emphasis placed on the mental capacities of the mind and the biological and chemical processes of the brain (Grigorovich, 2020:5). Such an approach, with its focus on the brain and memory, can result in the isolation and the marginalisation of people, which contributes to cognitive harm (Katz, 2013). What is argued for is a broader approach to memory so that it is considered to be multi-faceted, not simply arising out a focus on the physiological function of the brain but connected to emotions as well (Katz, 2013). By not emphasising the link between memory and emotions, it can result in a failure to understand memory as an art as well a science (Katz, 2013: 311). Whilst Katz's critique may well be deservedly targeted to societal approaches to human brain health, its relevance to the diagnostic process can be contested because attention is paid by clinicians to the relationship between brain health and emotional well being. The discussion about how this is undertaken during the diagnostic process is discussed in Section 2.5.7.

The approach that did broaden the scope of clinical and communities of practice to look beyond the biomedical perspective came from Kitwood's (1997) seminal work using a biopsychosocial approach to develop the concept of personhood (Innes and Manthorpe, 2013a). Whilst he did not challenge the biological basis of dementia, he directed attention away from treatment and care approaches that emphasised decay, decline and deficiency, which he argued resulted in a loss of self-hood in the person with dementia (Baldwin, 2008; Innes and Manthorpe, 2009; Kontos, 2013). He defined personhood as status and coined the term social psychology of dementia. It entails personhood or standing bestowed upon one being by others, in the context of social relationships and social being (Kitwood, 1997: 8). Consequently, his work directed a focus on the relational aspect of dementia because he posited the deterioration of the PWD is not simply indicative of neuro-biological impairment but also as a consequence of the negative and dehumanising interactions and relations with key people in their environment (Kontos, 2013).



When these interpersonal relationships consist of a malignant social psychology (Kitwood, 1997) such as abuse and infantilism by carers (Brijnath and Manderson, 2008) it can have a negative impact on the self-hood and functional abilities of the PWD (Kitwood, 1997). Therefore, for Kitwood (1997) the process of dementing involved a dialectical inter-play between neurological and social-psychological factors and, by emphasising the latter, highlighted their role in the neurological impairment of the PWD (Kontos, 2005: 554). Kitwood (1993) developed a model of dementia care called the 'Enriched Model', and it was influential at a policy level in bringing about changes to a framework of care for people with dementia that embraced values that are ethical, humanitarian and respectful (Innes and Manthorpe, 2012a: 687). This led to person-centred approaches to care that took into account the person with dementia's personality, biography, general health and the social psychology in the person's environment (Botsford et al., 2011). This model has been recognised as being instrumental in directing the attention of professional and family carers to seek and implement tailored therapeutic strategies to promote self-hood and mitigate the impact of neurological symptoms of dementia (Innes and Manthorpe, 2012a).

However, Kitwood's (1997) contribution on personhood has been critiqued because, for example, it does not widen the lens far enough to include the impact and influence of the wider system of care provision and support for people with dementia (Innes and Manthorpe, 2013a). It has also been criticised because personhood is perceived to be bestowed by others on the person with dementia, denying the PWD any agency (Tolhurst et al., 2017) in the process of developing it. Additionally, it has been posited that what's missing from Kitwood's (1997) contribution is the inclusion of wider sociological perspectives. These would situate the experiences and interpersonal relationships between carers and people with dementia within socio-cultural structures and understandings (Tolhurst et al., 2017). These critiques were addressed in the development of The Dementia Care Practice Recommendations (Fazio et al., 2018), which encompass a holistic approach to the care of the PWD, putting more emphasis on working with a PWD in care and its therapeutic potential in care homes and community settings. This includes an emphasis on care for behavioural and psychological

symptoms of dementia, as well as support for activities of daily living. It also requires recognising and accepting a PWD's perspective on reality (Fazio, 2017: S1).

### **2.5.3 The implications of the medicalisation of ageing**

The biomedical model of dementia and the medicalisation of ageing has resulted in the consequences of ill health in old age, including dementia, being attributed to the 'tragedy' of the individual's pathology. As a consequence, positive features of ageing, such as the development of wisdom that accompanies seniority, is diminished in a discourse of decline and dysfunction (Whitehouse et al., 2005b: 320).

The emphasis on an individual's pathological ill health in old age can place the responsibility for well-being in old age on the individual and, by doing so, detracts from the role played by wider society in shaping health outcomes in old age (Hulko, 2004; Innes, 2009). This includes the influence of the wider psycho-social context in which the person with dementia is located (Innes and Manthorpe, 2012b: 687).

It has also been suggested that the medicalisation of ageing has shifted and changed the concept of 'normal ageing' and old age. This is because in the past our entry into old age and its stages was normalised by commonly held assumptions, cultural understandings and expectations about when a person is perceived to be old and what old age means (Jones and Higgs, 2010). These expectations are now challenged with the advent and impact of medical advances in the prevention and management of illness, including chronic health conditions (Jones and Higgs, 2010). This has led to destabilising our expectations about what constitutes natural and normal ageing as life expectancies and quality of lives have improved (Jones and Higgs, 2010).

This destabilisation is challenging our previously held understandings of normal ageing, such as the association between the loss of cognitive, social and physical functioning (Bowling and Dieppe, 2005), including the role played by the loss of this functioning by external factors such as poverty and lack of agency (Higgs et al., 2009b). Now, attention has increasingly shifted in policy and media discourse to concepts such as successful ageing and active ageing (Timonen, 2016).

Successful ageing is attributed to the seminal work of Rowe and Kahn (1997), who

proposed that ageing successfully is possible through the avoidance of disease and disability, making lifestyle changes to address modifiable risk factors such as diet, maintaining high-level physical and cognitive functions, and sustained engagement in social and productive activities to avoid social isolation (Rowe and Kahn, 1997). Unlike the past when there was an assessment of the role played by external factors, within the concept of successful ageing external factors are posited as playing a neutral or positive role (Bowling and Dieppe, 2005: 1549). The concept of active ageing developed by Robert Havighurst (1963) is at its core, which is similar to successful ageing and rests on the view that physical and social activity in middle age also needs to be extended and maintained in old age.

Jones and Higgs (2010) posited that these new ways of conceptualising ageing have now become the new gold standard for normal ageing, instead of understanding the body as “just being”, essentially following its natural course of ageing (Jones and Higgs 2010: 1517). The concept of successful ageing has also been critiqued for failing to take account of a myriad of factors, such as socio-economic disadvantage, gender, ethnicity and genetics (Holstein and Minkler, 2003) over a life course that can affect an individual’s experience and ability to age successfully. Moreover, it neglects to include the contributions and responsibilities of political, economic and social organisations and their concomitant structures in wider society towards ageing individuals (Holstein and Minkler, 2003). These arguments are of particular relevance to low and middle income countries (LMIC) in which the the risk of developing dementia is increased. This is due to higher levels of prevalence of diabetes and mid-life hypertension, hearing loss and obesity, high levels of illiteracy and low incomes (Sczufca et al., 2010; WHO, 2017). Many of these risk factors are experienced over a life course, and are also found amongst BAME communities in the UK (Tra My Pham et al., 2018; Dodd et al., 2020). The WHO (2017) argued that it requires a multi-agency approach to ensure these modifiable risk factors are addressed, especially amongst people on low incomes, as these can pose barriers to the affordability to pursue lifestyles associated with a reduced dementia risk (Sczufca et al., 2010; WHO, 2017).

Nevertheless, these concepts have wide currency in both the media and national

governments policies as a way of modelling behaviour amongst older people to alleviate the burden and costs of increasing older populations (Timonen, 2016).

Concepts such as successful ageing and active ageing at a societal level obligate older people to lead active and independent lives (Higgs et al., 2009a: 690) during their third age. This is viewed as the life stage after retirement when individuals are free from familial and work-related obligations and offers an opportunity to pursue self-fulfilment (Higgs et al., 2009a). This stage precedes the fourth and final stage which is characterised by frailty, decline, disability and, ultimately, death (Katz and Peters, 2008: 689). These conceptual approaches to ageing have led to what McParland (2016) called 'dichotomising dementia' as it is associated with the fourth age which is perceived as the 'failed third age'. It can contribute to stereotypes of older people who have little autonomy and agency, and where people can be perceived as being unsuccessful agers (McParland et al., 2016). This, she argued, leads to people with dementia being excluded and subject to care practices that negate individuals' agency to make decisions for themselves. As such, in the fourth age individuals with dementia become 'othered' and rejected by society for being different because this state of being challenges the accepted ways of being (McParland et al., 2016). This stage may involve a move to care homes, often when they are most cognitively impaired and thus most vulnerable. In this stage, people with dementia are not regarded by the general public as 'of our world', nor considered to be bound by the same rules, nor are their human or citizenship rights respected to the same extent as those without dementia (McParland et al., 2016: 5).

#### **2.5.4 Role of the media in the construction of conceptualisations of dementia and ageing**

It is only recently that the academic gaze has turned to the role (Bailey, 2021; Peel, 2014; Ratnakaran et al., 2018) played by the media in the construction of the public's conceptualisation and understanding of dementia and ageing (Gerritsen et al., 2016; Kessler and Schwender, 2012; Lawless and Augoustinos, 2016). The media is suggested to perform several functions, such as, in the absence of the lay public's direct communication with healthcare professionals, it operates to perform the translation, negotiation, and dissemination of scientific and health information about dementia

(Lawless and Augoustinos, 2016: 3). This is undertaken through its cultural script, the content of which is derived from multiple influences including historical, political and medical sources (Zeilig, 2014:19). It is suggested to influence our conceptual constructions about ageing and dementia (Peel 2014), and the ways in which the public interact with people with dementia (Zeilig, 2015b).

The media's discourse about dementia is posited to be infused with biomedical concepts of dementia, conveying information about signs and symptoms, and its progressiveness. Amidst these, it transfuses negative stereotypes and associations of old age and dementia (Bailey et al., 2021; Kirkman, 2006). As a consequence, in the popular media dementia and AD have become part of a discursive practice that conflates old age with crisis and disaster (Zeilig, 2014: 19). Moreover, through tales of negligent care homes, positive stories about care home provision for people with dementia are drowned out in a sea of negative generalisations about care support within the care home sector (Kirkman, 2006). This has resulted in people with dementia often being objectified by the media and described as experiencing a living death because of a loss of cognition, memory, autonomy and independence as a consequence of the cultural script of personhood and self-hood in Western society (Zeilig, 2015b).

Findings which support the above arguments are found in a study Lawless and Augoustinos (2016) on the techniques and content of the cultural script about brain health. Their study used conversation analysis and found that *specific linguistic and rhetorical devices are used to place a moral responsibility in the hands of individuals to undertake preventative measures to preserve their brain health as they age* (Lawless and Augoustinos 2016: 10). Similar findings were reported by Peel (2014) that concur with Lyon's (2000) proposition that the moral undertone framing individualised responsibility for brain health is reflective of Western liberal humanistic discourses for self-responsibility for health and well-being (Lyons, 2000). This moral framing, however, is most likely to disadvantage people that are the most economically, socially and physically vulnerable (Hillman and Latimer, 2017).

Also evident in media portrayals, according to Peel (2014) through her analysis of newspaper headlines, is the presence of negative and emotive descriptions of dementia.

For example, a Daily Express (2011) headline described it as a ‘crippling brain-wasting disease’ (Peel 2014: 890), whilst people with dementia are depicted as empty shells, zombies, or the living dead (Grigorovich, 2020). Such headlines and accompanying narratives generate feelings of powerlessness, revulsion and fear amongst the lay public about dementia, making it difficult to process and manage their emotions (Zeilig, 2015b). The effect of this is that people may maintain a distance from the PWD, isolating them and denying them social support (Peel, 2014; Zeilig, 2015b). The feelings of fear and revulsion are partly promoted by portrayals of dementia during the last, terminal stages of dementia. This then becomes the basis upon which the lay public form their understanding of dementia (Van Gorp et al., 2012).

Both politicians and the media have also been observed using catastrophising language that convey the calamitous impact of dementia on society through the use of metaphors (Bailey, 2021). These metaphors operate on different levels: firstly they resonate with the lay public because they help to make information about dementia accessible, but they also provoke a semantic and sensory reaction (Williams, 2013:1405). So for example, metaphors such as such as a ‘time bomb’, ‘rising tide of people suffering with dementia and the silent tsunami’ (Kirkman, 2006; Zeilig, 2014) can contribute to feelings of powerlessness and fear.

However, it has been noted that people with dementia are increasingly represented in the media, sharing their experiences and advocating on behalf of people living with dementia (Zeilig, 2014; Kessler and Schwender, 2012). In doing so, they are helping to challenge some of the negative stereotypes of dementia and portrayals of dementia, such as living a death (Zeilig, 2014; Kessler and Schwender, 2012). However, this increased representation has been suggested to be a double-edged sword as overly positive portrayals may lead to the public being under-prepared and underestimating the true challenges posed by dementia on both the person with dementia and their carer/s (Kessler and Schwender, 2012).

Whilst appreciating the research community’s exploration of the role played by the media viz a viz dementia is relatively new and emerging, one of the gaps that needs to be addressed is to understand how the mainstream media impacts on multi-ethnic

communities' concepts and knowledge of dementia (Lawless and Augoustinos, 2016; Peel, 2014), such as those in the UK. Furthermore, BAME communities in the UK and elsewhere in Western countries also have access to BAME media networks consisting of television channels broadcasting films and dramas made in India and Pakistan that are screened to British Asian audiences. There is a gap in the knowledge about how these BAME media networks inform and influence the constructions and understandings of dementia in multi-ethnic communities. There is also a vibrant BAME print media in the UK for different ethnic BAME communities, such as The Black VOICE, Asian Voice and the Garavi Gujarat (for Indian Gujarati readers). As such, the current research focuses on Western mainstream media and neglects the impact of the BAME media on constructions of dementia.

### **2.5.5 The transferability and appropriateness of the Western concept of dementia**

Anthropological perspectives contend that implicit in Western concepts of dementia is the underlying belief that because biomedicine is grounded in science, it has a special technical status. This is based on objectivity and standardisation, independent of society and being culture free (Lock and Nguyen, 2018), enabling it to be universally and globally shared (Lamb, 2015). However, the assumption that a standardised approach to dementia can be transferred across a wide range of diverse ethnic groups and in different cultural contexts (Lock and Nguyen, 2018) is challenged. This is because it is argued that the diagnostic and conceptual category of dementia has been developed in Euro-centric Western societies that culturally place a high value on cognitive functioning, autonomy and independence rooted in Western understandings of personhood (Hashmi, 2009b). These are argued to have been developed from a Western cultural framework that reflects the Cartesian dualism, inherent in Western biomedicine, i.e., the separation of the mind and body (Hashmi, 2009b). The transferability of which is problematic to non-Western cultures that are more likely to take (Hashmi, 2009b:211) an integrative approach to medicine incorporating the body, mind and spirit (Bradby and Nazroo, 2010), such as, for example, Ayurvedic medicine in India.

Furthermore, dementia is argued to be reflective and culturally constructed to reflect the

Western culture of hyper-cognitiveness, so that it places a higher value on rational thinking (Hashmi, 2009b). This encompasses the notion of self based on Descartes' "*cogito ergo sum*" *I think, therefore I am, and when I do not think I am not* (Post, 2000: 6). As a consequence, when viewed from a Western perspective, self-hood is perceived as individualistic (ego centric), whereby individuals value self-control, independence and productivity (Post 2000b). Hence, Alzheimer's is said to resonate with Western societies because it *embodies simultaneously the fear of ageing, fear of becoming dependent, and the fear of losing ourselves* (Hashmi 2009b: 211). In contrast, in Eastern cultures self-hood is actualised on a relational basis through interdependence within families, including in old age (Hashmi, 2009b).

The premise that the concept of self-hood is culturally constructed can be practically illustrated with respect to the Chinese and Vietnamese cultures' approach to dementia. These cultures are infused with Confucian and Taoist philosophy (Ikels, 2002; Liu et al., 2008a; Chiu and Tsoh, 2009a) and are centred on the concept of moral status which influences 'the self'. Ikels (2002) explained there are 'two kinds of self'. They are the 'essential' and 'particular self' and achieving a balance between the two kinds of self is facilitated through the fulfilment of roles and functions in social relationships. In order to fulfil these, the individual is required to harmonise individual desires with 'doing what is right' to fulfil those roles and functions. In this way the self is interconnected to the whole i.e., family and society (Ikels, 2002); self-hood is relational and not individualistic (Chiu and Tsoh, 2009a).

In these cultures, individuals are given the responsibility to undertake a balanced and disciplined approach to their mind and body with a view to preventing illness (Liu et al., 2008a). It also behoves the person to act with "li" which is a highly valued virtue which requires propriety and may involve subduing oneself (Chiu and Tsoh, 2009: 325). Ikels (2002) explained why the earlier stages of dementia cognitive decline is less salient and significant because the self is still evident. At this stage, symptoms may be attributed to normal ageing and this creates what Liu termed 'a buffer' that entails a low level of stigmatisation or soft stigma (Liu et al., 2008b: 2). During this stage there is an acceptance of physical and emotional decline, including the brain slowing down and a regression to



childlike behaviours (Hinton et al., 2000). This is because it is in accordance with a belief that such decline is synonymous with increased age.

It is only when the harmony of relations within the family are challenged because of behavioural problems caused by dementia that families experience distress, and it is at this point that they are likely to seek diagnosis. This may explain, for example, why the 'threshold' for seeking assistance in some ethnic groups may be at least partly culturally rather than medically determined (Mahoney et al., 2005; Schrauf and Iris, 2011a) and at a higher point compared to white British/Anglo American communities. This higher threshold derived from a reluctance to accept dementia as a pathology can also lead to missed opportunities to receive assistance for the treatment of reversible dementias. These include thyroid disease, lack of B12/folate, urinary tract infection or depression masking as dementia (Tripathi and Vibha, 2009; Gagliardi, 2008).

Whilst the above example highlights the value of understanding the relational approaches to self-hood in non-Western cultures, Chui and Tsoh (2009) warned against taking a too narrow and simplistic approach to the construction and experience of dementia. This is because socio-cultural variables other than self-hood and personhood come into play and these can include socio-economic factors such as generational age, acculturation, gender and social class (Chiu and Tsoh, 2009). Furthermore, industrialisation in non-Western countries is changing and eroding traditional values, norms and family support systems (Chui and Tsoh, 2009: 326).

Nevertheless, anthropological perspectives (George et al., 2011b; Hashmi, 2009b), whilst not denying the biological basis for dementia, call for a recognition that it's a Western culturally constructed concept, and that there are other ways to comprehend cognitive ageing. These calls led Whitehouse (2005) to argue for a move away from the atomistic, reductionist focus on the biology of cognitive decline that deflects attention from the potential for individual cognitive and social development to one that recognises *the vast cultural variations in understanding, emphasis, and the experience of age-related cognitive changes* (Whitehouse et al., 2005b: 320).

### **2.5.6 Socio-cultural perspective on constructions of dementia and caregiving**

To respond to these calls, it is suggested that a non-medicalised cultural lens is taken to understand how dementia is constructed. This can facilitate, according to Henderson and Traphagan (2005), an opportunity to understand how culture serves as a category of differentiation, discrimination, and ascription of cultural values that shapes the experience and interpretation of functional decline in old age (Henderson and Traphagan, 2005: 272). It also allows the possibility of exploring cultures in which dementia is not conceptualised as a disease (Downs, 2000; Henderson and Traphagan, 2005). Studies taking this perspective involving a focus on the socio-cultural context are perceived as advantageous as they go beyond the focus on individual responses to dementia, which is common in studies utilising health psychology theories and a biomedical approach to dementia (Antelius and Kiwi, 2015). They can enable an insight into the cultural values and norms that influence interactions between carers and PWD, and their engagement with healthcare professionals (Garcia et al., 2014; Turner et al., 2005; Mukadam et al., 2011). Socio-cultural perspectives can also facilitate an insight into how universally shared and common caregiving practices may be understood differently on a culturally conceptual level (Narayan et al., 2015: 509).

In empirical dementia research, this has been undertaken through the association of ethnicity with culture. However, inherent challenges and problems have been highlighted with this approach in the wider scholarly ethnicity literature (Salway et al., 2011a; Torres, 2015; Zubair and Norris, 2015). In this body of literature there is a recognition that ethnicity in research has been established as a problematic concept, as it is often used as a reified category associated with, for example, a one-dimensional approach to classification such as participants' country of birth or their culture.

The use of a standardised biomedical lens with which to gauge and demarcate different cultural perspectives gives rise to the assumption that different ways of conceptualising dementia can be seen as 'deviant' and 'problematic' from the biomedical model. Consequently, it engages in 'othering' and the 'positioning' of older people, their ethnicity

and their culture as being problematic (Torres, 2015). It can detract from the wider causes of inequalities of health outcomes, such as social and economic exclusion and marginalisation over a life course (Fassin, 2001; Zubair and Norris, 2015).

In relation to dementia help-seeking behaviours, empirical research that associates ethnicity with *culture also runs the risk of presenting culture as a unified entity to fully account for people's behaviour* (Lock and Nguyen, 2018: 8). Yet, these unified accounts often fail to take into account how cultures differ due to the impact and influence of migration, socio-economic positioning and gender (Dogra, 2010) within an ethnic group. An over-emphasis on culture on help-seeking, for example, can also draw attention away from the perceptions and experiences of racism that have been shown to play a role in a reluctance to seek diagnosis of dementia and the receipt of equitable care (Beattie et al., 2005; Mahoney et al. 2005b).

### **2.5.7 A discussion on dementia diagnosis and addressing critiques**

This literature review has discussed a number of criticisms about the conceptual category of dementia from sociological and anthropological perspectives, herein called social science approaches. The key area of contention is that biomedicine has medicalised ageing, and so that those who do not age well have the potential to be stigmatised by society. There are also concerns raised about the transferability of dementia as a conceptual and diagnostic category to non-Western societies because it is deemed to be underpinned by Western societal values and norms. Some of this social science discourse advocates for a non-medicalised acceptance and supportive approach to ageing and dementia rather than the treatment approach advocated by the disease model (Dassen et al., 2021). Whilst these debates and discussions are valuable in highlighting how knowledge and understandings of dementia are socially constructed, what they risk doing is positioning discourse about dementia both conceptually and as a diagnostic category in narrow binaries and opposites (Kampf and Botelho, 2009: 188). What we should be reminded of, as Dijk (2016) stated, is that societal developments and values also influence the practice of medicine (Dijk, 2016: 206). These polarised debates also risk the diagnostic model of dementia being portrayed in a simplistic and reductionist manner and, in doing so, minimise the complex and holistic approach to the

diagnostic process for dementia that focuses on brain pathology, behavioural and psychological well-being of the PWD, as well as the inclusion of carers/relatives.

In an effort to address this polarisation within this literature review the following section will entail a discussion about some of the issues related to the diagnosis of dementia, including innovations in medical technologies that are continually improving understandings of the ageing brain and dementia. Amidst this discussion I shall address some of the critiques that are levelled against the diagnostic process of dementia.

One of these critiques is that the demarcation between normal cognitive ageing decline and dementia is being blurred or diffused. Whilst these arguments highlight the complex relationship between biomedicine and wider societal norms and values at a societal level, it can be challenged at the micro level within the diagnostic process. This is because diagnosis of dementia is not undertaken until there is a clear impact of cognitive decline on activities of daily living, as indicated by the ICD 11. However, as we have read in Section 2.5.5, the threshold of what constitutes an acceptance of normal age-related changes in cognition and behaviours can be culturally defined and will inform the point at which families seek diagnosis.

Another critique levelled at the dementia process is that diagnosis is not consistent and varies by how each clinician interprets the results of assessments and these can differ even within the same clinic (George, 2013). However, in the last decade or so, considerable progress has been made which has provided definitive guidance and characterisation of various dementias to clinicians through the use of biomarkers. Some of these are illustrated in Figure 2.1 below including, for example, Dementia with Lewy bodies, Vascular Dementia, Behaviour Variant Frontotemporal Dementia and Primary Progressive Aphasia (McKhann et al., 2011:2).

That is not to deny the existence of challenges for clinicians in their interpretations within the diagnostic process as these can arise, for example, when some patients present for diagnosis but have not yet developed sufficient Alzheimer's pathology at their first clinical assessment. However, these patients can almost always be correctly identified at later stages when the progression of disease has become established, indicating

pathological processes (Hogervorst, 2000; 2003). Therefore, there is a willingness to accept that the only definitive means of establishing diagnosis in some cases is through post-mortem examination of brain tissue, with the exception of individuals with genetic mutations (Harper, 2013).

The diagnostic process can be further complicated in some instances when patients are diagnosed with Alzheimer's but also have other concomitant neurodegenerative disorders that may also contribute their cognitive impairments. These can have a negative impact on treatment approaches (Toledo, 2012). Esri (2012) also drew attention to situations in which clinicians may be faced with a few patients that present atypically or have a rare disease which masquerades clinically as Alzheimer's. These types of cases may represent an important subgroup in clinical cohorts, but are often not identified correctly with the current biomarkers (Toledo, 2012: 8). Also challenging to diagnose in the initial stages are patients with cognitive reserve, such as those with higher education whose clinical presentation of dementia may be unclear until the stage where pathological changes progress, whereupon cognitive reserve is then overridden and cognitive decline becomes apparent, including at post-mortem (Hogervorst, 2003; Esri, 2012).

Whilst acknowledging these challenges, over the last decade there have also been (Márquez and Yassa, 2019) scientific advancements in the use of imaging and biomarkers, which has led to significant developments in the improvement of diagnostic assessments. These developments address to some extent the critique expressed by Hashmi (2009) in Section 2.5.1 about just how many plaques and tangles it takes to have a diagnosis of dementia. These scientific advancements provide greater clarity about the types and contribution of plaques, tau proteins in neurofibrillary and tangles (Toledo, 2012) in different types of dementia than at the time of Hashmi's writing in 2009.

These scientific advancements encompass diagnostic tools that enhance the ability to detect the differences between normal age-related deterioration and dementia. They include structural imaging such as the use of Magnetic Resonance Imaging (MRI), which can be used to identify or rule out causes of memory loss such as a stroke, other vascular brain injury, tumours and brain shrinkage (The National Institute for Ageing, no

date). The UK National Institute of Health and Care Excellence (NICE) recommends that structural imaging (non-contrast enhanced CT or ideally MRI) should be performed in the evaluation of patients with suspected dementia (Ahmed et al., 2014; Hogan et al., 2020). Another diagnostic tool is the Positron Emission Tomography (PET) scan which can assist with measuring abnormal deposits of beta-amyloid that may be consistent with the presence of Alzheimer's disease (Ahmed et al., 2014). The use of biomarkers can also be part of the diagnostic process and they are obtained through cerebrospinal fluid (CSF) from a lumbar puncture (Ahmed et al., 2014). The analysis of CSF biomarkers (see Figure 2.1 below) can help to identify different aspects of the underlying pathology, detect pre-symptomatic pathological changes, predict decline or conversion between clinical disease states, and/or monitor disease progression and response to treatment (Ahmed et al, 2014). However, there is a recognition that these biomarkers and scans should not be used for diagnosis by themselves (Ahmed, 2014) but constitute part of the diagnostic process which can encompass a range of other assessments. This is because studies have documented frequent occurrence of AD pathology in cognitively unimpaired older adult patients, as well as the presence of non-AD pathologies. This can complicate clinical stratification of patients with cognitive disturbances based on scans and biomarkers alone (Ahmed, et al., 2014; Harper, 2013; Jack 2014; Esri, 2010; Hogervorst, 2000; 2003). Latimer and Hillman's (2020) ethnographic study of two memory clinics demonstrated that when biomarkers and scans are used in conjunction with evidence of symptomatic expression of diseases causing dementia, they may provide credence and a greater degree of certainty to a diagnostic label in the clinic.

The diagnosis process besides the inclusions of scans and biomarkers may also involve the use of standardised instruments and assessment procedures developed by the Consortium to Establish a Registry for Alzheimer's disease (CERAD). These are used in research in the United States, and in translated versions around the world. They encompass a range of domains, including clinical/neuropsychology, behaviour rating scales for dementia, family history interviews and an assessment of service needs (Fillenbaum et al., 2008). Thus, Katz's (2013) concerns about emotions and their connections to cognition are addressed through the use of CERAD in research and

through neuropsychological assessments conducted in the clinical setting (Arvantikakis et al., 2019).

Ultimately, as Latimer and Hillman (2020) observed, the diagnostic process requires a substantial degree of interpretive work to bring together and assign significance to the various pieces of the puzzle that help to articulate dementia diagnostically (Latimer and Hillman, 2020: 7). This process usually commences with a cognitive examination, such as the Addenbrookes cognitive examination-III (ACE-111), which is available in different languages. This is considered to be the gold standard for screening and diagnostic accuracy of cognitive impairment (Mirza et al., 2017). Alternative cognitive examinations in different language versions can also be used, with each having cut-off points to assist with specificity and sensitivity (Velayudhan et al., 2014). Throughout this process of putting pieces of the puzzle together, clinicians' engagement with patients and carers plays a key role in identifying their meanings and significance (Latimer and Hillman, 2020: 8). This interaction also entails taking a good clinical history, and Latimer and Hillman (2020) observed that patients are brought into play in the interactions in the clinic as subjects who are situated in their biography and milieu, but also as having the capacity to reason, think, feel, will, perceive, judge, sense and make sense of what is happening during the diagnosis process (Latimer and Hillman, 2020: 8). Additionally, patients are encouraged to bring a family member or friend who can provide a collateral history, and this is particularly important in instances when patients are in denial about their symptoms (Latimer and Hillman, 2018).

The above discussion, whilst acknowledging George et al.'s (2013) and Hashmi's (2009) critiques that the diagnostic process requires clinicians to undertake interpretative work, does provide a counter argument to these critiques by facilitating an insight of the complexity and range of multi-disciplinary assessments. These include the use of neuropsychological assessments for behavioural and psychological symptoms, as well as the use of technologies that can be undertaken before presenting symptoms are interpreted and a diagnosis of dementia is given. The above discussion, by integrating biomedicine's approach to diagnosis with findings from an ethnographic study (Latimer, 2018) on the diagnosis process, promotes a more nuanced and balanced understanding

of biomedicine's approach to dementia.

| Criteria  | Comments  |
|---|---|
| <b>AD</b>   |   |
| Biomarkers of amyloid pathology: Low CSF A $\beta$ 1-42 on CSF examination Positive amyloid PET scan  | Either evidence of low CSF A $\beta$ 1-42 or positive amyloid PET scan required for diagnosis of amyloid brain deposition <sup>15</sup> |
| Biomarkers of neuronal injury: Elevated CSF tau and phospho-tau; Hypometabolism on FDG-PET; Disproportionate atrophy of medial, basal and lateral temporal lobe, and medial parietal cortex on structural MRI   | Either elevated CSF tau, FDG-PET changes or structural MRI changes required for a diagnosis of neuronal injury <sup>15</sup>            |
| McKhann criteria <sup>15</sup> require evidence of amyloid pathology and neuronal injury to support a diagnosis of highly probable AD (biomarker evidence only recommended in individuals who do not meet the core clinical criteria for probable AD dementia).Dubois criteria (IWG2) <sup>26</sup> require specific clinical features of AD (typical or atypical) plus evidence of in vivo AD pathology. Evidence of in vivo AD pathology: low CSF A $\beta$ 1-42 together with increased total-tau or phospho-tau or positive amyloid PET or proven mutation in <i>PSEN1</i> , <i>PSEN2</i> , or <i>APP</i> or other proven genes (including Down's syndrome trisomy 21). |   |
| <b>Frontotemporal dementia</b>  |   |
| <b>bvFTD</b>  |   |
| Frontal and/or anterior temporal lobe atrophy on MRI or CT  | Either structural or PET imaging changes required for a diagnosis of probable bvFTD <sup>100</sup>                                      |
| Frontal and/or anterior temporal lobe hypoperfusion or hypometabolism on PET or SPECT   |   |
| <b>Progressive non-fluent aphasia</b>   |   |
| Predominant left posterior frontoinsular atrophy on MRI   | Either structural or PET imaging changes required for an imaging supported diagnosis <sup>58</sup>                                      |
| Predominant left posterior frontoinsular hypoperfusion or hypometabolism on SPECT or PET  |   |
| <b>Semantic dementia</b>  |   |
| Predominant anterior temporal lobe atrophy  | Either structural or PET imaging changes required for an imaging supported diagnosis <sup>58</sup>                                      |
| Predominant anterior temporal hypoperfusion or hypometabolism on SPECT or PET   |   |
| <b>Dementia with Lewy bodies</b>  |   |
| Relative preservation of medial temporal lobe structures on CT/MRI  | Supportive feature (commonly present but not proven to have diagnostic specificity)   |
| Generalised low uptake on SPECT/PET perfusion scan with reduced occipital activity  | Supportive feature (commonly present but not proven to have diagnostic specificity)   |
| Abnormal (low uptake) MIBG myocardial scintigraphy  | Supportive feature (commonly present but not proven to have diagnostic specificity)   |
| Abnormal uptake on PET/SPECT (eg, 123 I-FP CIT- DaTSCAN)  | Supportive feature (used to differentiate DLB from AD and some forms of FTD)  |
| AD, Alzheimer's disease; APP, amyloid precursor protein; bvFTD, behavioural variant frontotemporal dementia; CSF, cerebrospinal fluid; FDG, 18-F-fluorodeoxyglucose; MIBG, metaiodobenzylguanidine ; p-tau, tau phosphorylated at 181; PET, positron emission tomography; SPECT, single photon emission tomography; t-tau, total tau.   |   |

Figure 2.1: Biomarkers used in diagnosis from Ahmed et al., 2014

## 2.6 Section 2: Conceptualisations of dementia and their implications

Despite the concerns expressed in the wider scholarly literature about the pitfalls of culturalist explanations, empirical studies conducted with multi-ethnic populations on a worldwide basis have predominantly based their work on the association of ethnicity with culture. The benefits of taking a culturalist perspective are suggested to be a facilitation of an understanding about how culture shapes and informs the conceptualisation of dementia.

A word of caution here is required at this juncture, as the following section involves a review of findings from peer-reviewed empirical studies conducted on a worldwide basis. This involves the inclusion of studies which interpret and use ethnic categories differently. These categories are very much specific to the context in which they are conducted. For example, delineations such as Black and Asian and Minority ethnic



(BAME) are relevant to Western countries such as the US, UK and Denmark but are not applicable to countries such as China and India. The category of BAME covers a heterogeneity of ethnic groups based on migratory patterns, such as refugees, asylum seekers and economic migrants as well as communities that migrated from a diverse range of countries such as India, Pakistan, Bangladesh, Ireland and from the African continent. The term South Asian is used in some studies conducted in the UK, and again that encompasses a heterogeneity of people whose origins are from India, Bangladesh and Pakistan but also include subsequent generations born in the UK.

In studies involving indigenous communities in Australia, Canada and the US, these colonised people are classified as indigenous ethnic groups, not as BAME groups. The terms 'Anglo American' or Caucasian are also often used in studies conducted in the US. These terms are ambiguous and broad categories of ethnicity and not always clearly explained, as they may refer to people who are white English-speaking people of British or northern European origin (Oxford Dictionary; Bhopal, 2004a). Studies from the US also use the category 'white' Americans, and it's not clear whether this includes people whose skin colour passes as 'white', because some Arab and Turkish communities are categorised in this way (Ajrouch and Jamal, 2007). The terms Hispanic and Latino are frequently used inter-changeably but the former actually refers to Spanish-speaking people of Latin American descent or Spanish descent, whilst Latino refers to people in general of Spanish descent (Bhopal, 2004a). The implication of these differences in terminology is that it is challenging to undertake a comparative approach, which causes difficulties in the reporting of findings. To address this issue, I have used where possible BAME groups or ethnic minority groups with reference to European countries and specified indigenous colonised groups where appropriate. I have also clarified when the research took place in India or China.

Thus, this review does not undertake comparative understandings across ethnic groups across countries because they are so diverse, and their findings emerge from highly contextualised study settings. Instead, in the following Section 2, I have highlighted findings from studies conducted with the lay public, carers and people with dementia from a range of ethnic groups. Some of the findings do not align with the biomedical

model of dementia, in particular the distinction between normal age-related cognitive decline and dementia. In order to provide a contextual understanding of the studies included in this section, a table of studies is provided in Appendix.B. This includes information about the studies' participants, such as age and ethnicity, the countries in which the studies were conducted and recruitment strategies for study participants.

### **2.6.1 Dementia: As a normal consequence of ageing**

One of the more common conceptualisations amongst a range of ethnic groups such as Latino, African American including BAME groups, and colonised indigenous ethnic groups, is the conceptualisation of dementia as a normal consequence of ageing (Antelius and Kiwi, 2015; Botsford et al., 2012; Garvey et al., 2009; Lawrence et al., 2010). The ageing process has been associated with forgetfulness (Fontaine et al., 2007; Jones et al., 2006; Laditka et al., 2013) and memory loss (Jolley et al., 2009; Jett,2006). This conceptualisation was also evident amongst older white Irish, Australian (Kim et al., 2015; Corner and Bond, 2004) and white British ethnic groups (Clare et al., 2006; Turner et al., 2005).

The lack of clarity about the distinction between age-related cognitive decline and dementia was evident in the empirical literature too, and gave rise to confusion and uncertainty about what constitutes normal age-related forgetfulness compared to dementia as a disease (Corner and Bond, 2004; Devine, 2016). This led to viewing ageing a continuum in which Alzheimer's was likely to occur at a later stage in life (Kim et al., 2015; Liu et al., 2008c).

The biomedical concept of dementia, as previously discussed, is argued to be associated with a loss of self and cognition (Whitehouse et al., 2005b; Downs, 2000), and the condition can amplify loss of esteem as a consequence of losing the ability to make decisions (Clare, 2003). This loss of self-esteem is further compounded by symptoms of dementia such as incontinence and behavioural problems (Narayan et al., 2015), which result in feelings of shame, guilt and embarrassment for the person with dementia and their families, irrespective of ethnicity. This can contribute to families developing strategies of concealment of dementia to avoid experiencing courtesy stigma

(All-Party Parliamentary Group on Dementia, 2013a; Van Wezel Francke et al., 2018; Bhandari and Joshi, 2010). Courtesy stigma refers to the stigma that affects the family of people affected by a mental illness or dementia (Corrigan and Miller, 2004).

Liu's study (2008) involving Chinese and Vietnamese caregivers of people with dementia in the US focused specifically on stigma. The study found dementia was viewed as a normal consequence of ageing, but disability, cognitive decline, and even the behavioural changes of older persons with dementia were viewed as a less desired trajectory of ageing (Liu et al., 2008a: 8). This was signified by the use of disparaging terminology by older family members to describe PWD as becoming childish, confused, foolish, or just difficult, or baby number one and her behaviour is just like a child (Liu et al., 2008a: 8) These stigmatising views of the person with dementia can lead to the 'personhood' of the adult being diminished (Liu et al., 2008a; Baghirathan et al., 2020).

## **2.6.2 Biomedical conceptualisations of dementia**

Some studies also found that carers and PWD discussed dementia using language and terms that were in keeping with biomedical conceptualisations of dementia, such as a disease of the brain (Chee and Levkoff, 2001; Corner and Bond, 2004), effects of illnesses such as a stroke (Schrauf and Iris, 2011a; Low and Anstey 2009a), thyroid problems (Leung et al., 2011) heart disease and the side effects of medication (Adamson, 2001; Morhardt et al., 2010a), and the effects of the use of illicit drugs on the brain (Hinton et al., 2005). Congruency with the biomedical model of dementia was demonstrated by the use of terms such as tangles in the brain and chemical imbalance in the brain, head injury, build-up of plaque (Laditka et al., 2013; Haralambous et al., 2014; Turner et al., 2005) and death or loss of brain cells leading to the brain not working (Parveen et al., 2016). A genetic link to dementia was also discussed by some participants (Jett, 2006; Laditka et al., 2013; Parveen et al., 2016).

In a multi-ethnic study population, biomedical conceptualisations of dementia were more commonly evident in white British and Anglo Americans than BAME groups (Hinton et al., 2005, Turner et al., 2005). This alignment with biomedical interpretations of dementia may be due in part to receiving knowledge about dementia in different languages via the

media (Neary and Mahoney, 2005), the effect of which remains under-explored in relation to its influence in BAME communities and indigenous colonised groups. It could also be a consequence of exposure to biomedical understandings and terms used during the process of diagnosis and treatment.

### **2.6.3 Dementia conceptualised as mental illness**

Very few studies explicitly found symptoms of dementia to be viewed as a combination of old age and mental illness (Adebiyi et al., 2016; Ahmed et al., 2014; La Fontaine et al., 2007). Most often, dementia was found to be conceptualised as a mental illness only, and in a pejorative way by lay people, PWD and carers (Antelius and Kiwi 2015; Chee and Levkoff, 2001; Liu et al., 2008a). As a consequence, caregivers, in several studies, discussed that people in the wider community would likely view the PWD as being crazy, and 'dementia as getting off your brain' and this was attributed to a lack of understanding about dementia (Adamson, 2001; Roberts et al., 2003; Neary and Mahoney, 2005). This pejorative conceptualisation can make families reluctant to seek diagnosis and this may be exacerbated in some cultures due to a perception that it can hamper marriage opportunities for younger people if someone in their family is diagnosed with dementia (Bhandari and Joshi, 2010; Mackenzie' 2006; Hinton et al., 2005).

The lack of a direct conceptual and linguistic equivalent name for dementia in many cultures often leads to the use of pejorative terms for mental illness (Ahmed et al., 2014; Berisic and Nesvadba, 2008). The words in Chinese for cognitive impairment, such as *lao hu tu*, or *chi dai* ('senile stupidity/silly' or 'confused/stupid and losing one's mind/catatonic'), thus discourages many Chinese families [from seeking] ...dementia services until the disease is quite advanced (Zhan, 2004a: 21).

### **2.6.4 Folk explanatory conceptualisations**

Folk explanatory models encompass spiritual and religious causal attributions of dementia and include perceptions that dementia was a punishment from God (Mazaheri et al., 2014; Czapka et al., 2020; Narayan et al., 2015) was God's will (Neary and Mahoney, 2005) a result of bad Feng shui (Zhan, 2004a) and possession by evil spirits (All-Party Parliamentary Group on Dementia, 2013b; Van Wezel et al., 2016). These

explanations are attached to stigma in a number of different ways, by conferring a diminished status on the PWD (Shaji et al., 2003; Narayan et al., 2015). Courtesy stigma (Goffman, 1997) can cause a family's honour and reputation to be reduced (Mackenzie, 2006; Mahoney et al., 2005a; Shaji et al., 2003). Consequently, families can find themselves without social support (Berisic and Nesvadba, 2008; Liu et al., 2008b, Parveen et al., 2016) for the PWD and their carers, as they are likely to be blamed for developing dementia. Adamson (2001) found that spiritual explanations for dementia amongst South Asian and African Caribbean carers resulted in a few carers blaming the PWD, although this was more common amongst South Asian carers.

However, not all ethnic communities stigmatise dementia, as shown by a case study involving a member of a Native Indian community in which Henderson (2002) found dementia was perceived as a normal process of ageing. One particular symptom of dementia, hallucination, was actually revered and deemed as 'supernormal' because it is perceived as a stage in which a person is in communication with the other side (God) (Henderson, 2002).

### **2.6.5 Psycho-social conceptualisations**

The biomedical model includes a focus on depression and anxiety and these are recognised to be risk factors for dementia and often precede dementias (Burton et al., 2013). This association was also evident in studies in which participants associated brain health with psycho-social factors. These included explanations about the negative effect of social isolation on brain health and functioning (Uppal et al., 2014; Jett, 2006; Fontaine et al., 2007).

Stress caused by a number of factors, including pressures of work and an accumulation of stressful experiences over an individual's course of life, was attributed to cause pressure on the nervous system and impact negatively on the brain. Other psycho-social contributory factors included depression, anxiety (Corner and Bond, 2004; Fontaine et al., 2007; Jones et al., 2006), and life events such as bereavement, family tensions (Fontaine et al., 2007, Patel and Prince, 2001) and family neglect (Fontaine et al., 2007).

Other findings suggest the biographies of PWD made them 'candidates for dementia'.

These biographies related the impact of migration (Antelius and Kiwi, 2015) and bereavement (Adamson, 2001; Parveen et al., 2016), as well as family issues (Fontaine et al., 2007, Patel and Prince, 2001), traumatic events and abuse (Chee and Levkoff, 2001; Morhardt et al., 2010b).

### **2.6.6 Mixed explanatory models of dementia**

Whilst the above discussion delineates each conceptualisation separately, Hinton (2005) found multi-ethnic carers in his study used a combination of conceptualisations, such as biomedical terms indicated by the use of the term 'Alzheimer's' and 'memory loss syndrome' (Hinton et al., 2005: 1407). These terms were accompanied with explanations of the causes such as normal ageing or psycho-social causes, such as stress over a life course (Hinton et al., 2005).

## **2.7 Section 3: Help-seeking including diagnosis and care strategies**

Early diagnosis forms a key component of the biomedical approach to treatment. In the following section I shall briefly discuss and define early diagnosis, in addition to how it is affected by differences in conceptualisations, knowledge and understandings about dementia amongst a range of ethnic groups. These differences are attributed as causing delays in the diagnosis of dementia as well as affecting care strategies.

### **2.7.1 Early diagnosis and its benefits**

Early diagnosis for dementia is postulated as conferring a range of benefits, such as identifying treatable conditions that may have similar symptoms to dementia but different causes (Chambers et al., 2017; Milne, 2010a). These include, for example, depression, vitamin B12 deficiency, or the side effects of medication (Watari et al., 2004). For those diagnosed with dementia it is presented as opportunity to slow down the progression of the disease and improve the quality of life with medication (Leifer, 2003; All-Party Parliamentary Group on Dementia, 2012). It can enable both carers and the PWD to have time to come to terms with the condition (Leifer, 2003) and undertake preparations

for caregiving, access to care support, and access to educational and psycho-social support (Iliffe et al., 2009). It can also assist with financial planning, provide time to prepare end-of-life care plans and may also delay admittance to care homes (Milne, 2010b; Iliffe et al., 2009). The findings from studies conducted across a range of countries suggest that the average time between symptom recognition and the point at which diagnosis is sought has been found to vary, ranging from 27 months to 6-7 years (Brossard and Carpentier, 2017; Clark et al., 2005a; Corcoran, 2009; Rimmer et al., 2005; Bond, et al., 2005).

### **2.7.2 Saliency of early diagnosis in ethnic groups**

The saliency of early diagnosis is emphasised for particular ethnic groups as the epidemiological evidence, much of it derived from the US, suggests that ethnicity is associated with a higher risk and prevalence of dementia (Mayeda et al., 2016; Barnes, 2022; Richards et al., 2000). In the UK, of the few multi-ethnic/ethnic specific epidemiological studies that have been conducted, findings suggest a higher prevalence of dementia within the African Caribbean population (Adelman et al., 2011; Tuerk and Sauer 2015a; Livingston et al., 2001). In the US, the risk of developing dementia for African Americans is deemed as twice as likely than Anglo Americans, while Hispanics and Latinos are more than 1.5 times as likely to develop dementia (Alzheimer's Association, 2014). Elsewhere in the world, ethnic differences in risk have also been found between Aboriginal communities in Australia and the general population, with the former being up to 3 to 4 times more likely to develop dementia (Radford et al., 2014).

A number of factors are posited as raising the risk for certain ethnic groups. These include, for example, the high prevalence of chronic health conditions such as hypertension (Lane et al., 2002) and type 2 diabetes, which raises the risk of dementia between 1.5 to 2.5 times (Diabetes UK, 2019). There was also some evidence regarding the raised genetic risk amongst African Americans for dementia in a recent genome-wide study (Hale et al., 2020).

However, an emphasis on vascular health may deflect from other risk factors such as socio-economic factors, lower educational attainment (Stewart et al., 2001), and the

cumulative effects of a lifetime of discrimination and stress (Beatty et al., 2019) that some ethnic groups experience. Furthermore, the use of standardised data to indicate socio-economic position may not fully capture the effects of socio-economic status as it reflects current status and does not consider a range of factors contributing to social disadvantage over a life course (Bradby and Nazroo, 2010). Therefore, Barnes (2022) called for strategies to address the raised dementia risk for African American populations and that these should go beyond linking ethnic differences to biology or genetics but involve a focus on the common social forces that cause differences, such as poverty, racism and inequitable access to educational opportunities over a lifetime (Barnes, 2022).

Despite the raised risk of dementia in some ethnic groups, a range of ethnic groups present later for diagnosis. Consequently, PWD from BAME communities are likely to present at an advanced stage of the illness even though they are more likely to have younger onset dementia when compared to white British communities (Adelman et al., 2011; Tuerk and Sauer, 2015b). The later presentation at an advanced stage of the condition makes it challenging for both PWD and their carers to benefit from some of benefits associated with early diagnosis.

### **2.7.3 Explanations for delayed diagnosis amongst BAME groups and other multi-ethnic groups**

The reasons for delayed diagnosis within some ethnic groups are complex and multi-factorial, making it difficult to generalise across a diverse range of groups and countries. In the following section, as with Section 2.6, information about studies in this Section 7, from which the findings have been drawn, are provided in Appendix B, including details of study participants' age and ethnicity.

Some of factors associated with delays can be attributed to different healthcare systems (Czapka et al., 2020; Bowes and Wilkinson, 2003; Mukadam et al., 2015). Nevertheless, there are some commonalities, for example, life expectancy in some BAME and multi-ethnic communities has only recently risen (Singh et al., 2017) and, therefore, individuals may not have lived long enough to be at risk of dementia previously. This could also in



part explain why they would be unfamiliar with the biomedical model of dementia. In the absence of this familiarity, they are more likely to conceptualise symptoms of dementia as being the normal consequences of ageing, and only pursue diagnosis when symptoms are exacerbated (Berwald et al., 2016; NÆSS and MOEN, 2015; Patel and Prince, 2001).

Other contributory factors include language and communication difficulties (Seabrooke and Milne, 2004; Garcia et al., 2014) and perceptions of racism in healthcare services amongst African American and African Caribbean groups (Jett, 2006; Beattie et al., 2005; Mahoney et al., 2005b). These result in some ethnic groups being wary and distrustful of seeking diagnosis when experiencing symptoms. Poverty and structural issues can dissuade families from seeking diagnosis and care, as they worry about the financial implications of treatment and care costs in countries such as the US and India (Gelman, 2010; Brijnath and Manderson, 2011).

By far the most common factor to explain delays to diagnosis was the lower level of knowledge and understanding in keeping with biomedical understandings of dementia (Bowes and Wilkinson, 2003; Hughes et al., 2009; Neary and Mahoney, 2005, Van Wezel et al., 2016). The implications of this include carers experiencing conflict with family members who lack an understanding of dementia (Gelman, 2010; Adamson, 2001; Neary and Mahoney, 2005; Zhan, 2004). It can also give rise to a failure of carers to understand the progressiveness of dementia, including implications for changes to behaviour and cognition (Narayan et al., 2015; Gray et al., 2009). Although it may be that when compared to non-carers, carers may still possess higher levels of knowledge (Carpenter et al., 2011). The possession of knowledge and understanding in the wider community, when cited as low, acted as a barrier for carers to access social support and contributed to stigma (Mahoney et al., 2005, Van Wezel et al., 2016).

In order to understand the factors for lower levels of knowledge in BAME groups, in non-Anglo-American ethnic groups some studies have explored the role and contribution of acculturation in BAME groups. It is often utilised in health research to explain the role and contribution of culture in health disparities within BAME communities. At its core, acculturation explains culturally based knowledge, attitudes and beliefs that cause people to make behavioural choices that result in the observed health patterns. Acculturation as a

concept presumes individuals choose or reject behaviours based on their cultural beliefs, and that such choices are a prime factor affecting their health (Hunt et al., 2004: 973).

The development of the concept of acculturation is attributed to anthropologists but it has been increasingly used in a wide range of disciplines, such as sociology, psychology, psychiatry and education (Trimble, 2003). The definition of acculturation adopted for a research study is dependent upon the discipline in which its framed (Trimble, 2003). There are also a number of theories, models and processes to study acculturation, some of which are multidimensional whilst others are linear (Abraído-Lanza et al., 2006).

Studies in dementia involving BAME and multi-ethnic groups have not defined acculturation but have measured it through the use of linear indicators such as years in the US and the use of English (Ayalon and Arean, 2004; Gray et al., 2009b). Others have used cultural beliefs, such as Alzheimer's being caused by fate, as well as aspects such as media consumption, food consumption, social relations, sense of belonging, and familiarity with the host culture (Low et al., 2011; Jang et al., 2010a). Some studies have used validated acculturation scales (Schrauf and Iris, 2011b; Watari and Gatz, 2004). As such, these illustrative studies have overcome a major limitation of the 'culturalist approaches' to dementia by avoiding essentialist (Zubair and Norris, 2015) explanations and offer more nuanced understandings of the differences in knowledge between ethnic groups as arising out of education (Jang et al., 2010b; Low and Anstey 2009b; Sun et al., 2014) and the role of English language (Gray et al., 2009a).

However, Hunt (2004) argued that researchers often use acculturation as a concept and tool of measurement uncritically, and this critique can be seen to apply to studies involving ethnic groups on dementia with their use of acculturation as a concept and measure. The saliency of critically examining the use of acculturation is emphasised for a number of reasons. For example, acculturation measures, such as income and fluency in English, have been critiqued because they provide a snapshot of a point in time, and thus reify antiquated notions of acculturation as a linear process (Rudmin, 2003). Whereas acculturation as a concept is argued to be an evolving and dynamic process and responsive to context (Unger and Schwartz, 2012; Rudmin, 2003; Viruell-Fuentes, 2007; Schwartz, et al., 2010). Moreover, the use of static measures

such as income and education imply it's the ethnic group's fault, suggesting that if BAME or colonised indigenous groups were more educated they would be knowledgeable. This ignores these groups' socio-economic position and the role racial discrimination plays in the formation of knowledge and responses to health conditions (Rudmin, 2003). Furthermore, acculturation as a concept implies that only ethnic groups are subject to acculturative influences, and yet it's argued that we currently live in an era characterised by global travel and globalised marketing strategies making very few societies immune to inter-cultural contact and influences (Rudmin, 2003). Hunt (2004) was particularly critical of the use of acculturation, arguing that characterisation of ethnic groups by their culture is often *accompanied by a pernicious failure to define what might constitute the host or "mainstream" society, erroneous assumptions about the historical origins and movement of the populations in question, can result in a dubious undertone of ethnic stereotyping* (Hunt et al., 2004: 973). The above criticisms of acculturation in dementia studies suggest that, much like the use of ethnicity, it is a contested concept that needs careful consideration before it is applied in research studies involving BAME groups.

#### **2.7.4 Generational differences in knowledge and understandings of dementia**

There is some very limited evidence about generational differences in knowledge and understandings of dementia. One of the few example of studies was Sang Lee's (2010) cross-sectional study conducted with Korean Americans about casual attributions of dementia. It found that younger and more educated participants amongst the first generation of participants were more likely to attribute causes of dementia to physical and environmental factors such as hardening of the arteries and toxic pollutants. Liu's study (2013) involving Chinese Americans found that younger participants were more likely than older adults to attribute cardiovascular disease as a risk factor for dementia. However, Fontaine's study (2007) conducted with lay British Indian and Punjabi multi-generational participants aged between 17 years to 61 years found no generational differences in understandings of dementia.

## **2.7.5 Contribution of conceptualisations of dementia and filial piety on delays to diagnosis and care strategies**

### **2.7.5.1 Conceptualisations of dementia**

A major contributory factor for delays to diagnosis is linked to how dementia is conceptualised. When the symptoms of dementia are attributed to normal signs of ageing, these led to an acceptance of symptoms such as a decline in cognitive and physical health and a losing of faculties (Corner and Bond, 2004; Rust et al., 2007). These symptoms are not framed as an illness (Dai et al., 2015a; Hughes et al., 2009; Lanting et al., 2011; NÆSS and MOEN, 2015) and so changes in behaviour, such as speaking to dead relatives (Antelius and Kiwi, 2015), behaving like a child (Dai et al., 2015a; Lanting et al., 2011) and acting crazy (Cloutterbuck and Mahoney, 2003; Liu et al., 2008a), are accepted and associated with normal ageing.

The implications of such normative views of ageing are that carers initially undertake a range of coping strategies and actions to mitigate and alleviate a family member's symptoms and behaviours, such as putting locks on doors to prevent a PWD from wandering (McCleary et al., 2013). Studies involving white British carers as well as other ethnic groups found that carers may go into denial (Bond et al., 2005) when observing changes in a PWD that go beyond normative understandings of ageing (Chee and Levkoff, 2001; Mahoney et al., 2005b; Neary and Mahoney, 2005). Therefore, putting the pieces of the dementia puzzle together to differentiate from normative ageing can take time for carers (Adamson, 2001), because changes during the early stages of dementia can be difficult to discern (Bond, et al., 2005; Rimmer et al., 2005). Often, it is only when distinctive and severe changes to personality and behaviour that go beyond normative understandings of ageing are observed or experienced, that they act like trigger events or precipitous events (Mahoney et al., 2005b) for seeking diagnosis. Carers in various studies described examples of trigger events, such as aggression, paranoia (Cloutterbuck and Mahoney, 2003), social withdrawal (Hughes et al., 2009; NÆSS and MOEN, 2015; Zhan 2004b), and distinctive memory loss (Clark et al., 2005b; Neary and Mahoney, 2005; Koehn et al., 2016).

### **2.7.5.2 Filial piety**

Familial obligations to take care of elders, imbued in the cultural belief of filial piety, also play a pivotal role in seeking diagnosis and care strategies. It forms the cornerstone of Confucian philosophy, in addition to religions such as Islam, Sikhism and Hinduism (Victor et al., 2012). It is an enculturated belief that is evident in communities across the globe including, for example, in Latino and Native Indian cultures, where it is expressed in the form of a commitment to provide inter-generational care within families (Jett, 2006; Mahoney et al., 2005b).

Filial piety, combined with a conceptualisation of dementia as a natural progression of ageing or a mental illness, has also been attributed as causing delays in diagnosis as it entails families continuing to look after a family member with dementia symptoms rather than seeking diagnosis and care support. This decision to provide family care may also be driven by the need to avoid stigma about a mental illness, in addition to the stigma associated with help-seeking, because the wider community may perceive a family to have failed to uphold its filial piety (Adamson, 2001; Jutlla, 2015). This approach to care can therefore contribute to delays to diagnosis and access to care support (Antelius and Kiwi, 2015; Haralambous et al., 2014; Dai et al., 2015b). However, whilst these studies included a positive commitment to care for older family members with dementia (Ngoro, 2004), there were reports from both carers and PWD of family neglect, blame and recriminations (Mahoney et al. 2005b; Patel, and Prince, 2001; Shaji et al., 2003).

Filial piety is still considered to be influential in many cultures, particularly in societies where state support for elder care is financially prohibitive or lacking (Levande, et al., 2000). In contrast to the literature on conceptualisations of dementia which risks portraying cultures as static, the concept of filial piety has received more of a critical gaze by highlighting changes and adaptation of this belief. This suggests the influence of filial piety is on the wane because of changes brought about by modernisation and industrialisation of societies, thereby illustrating the impact on values brought about by structural changes in societies (Cheng et al., 2011; Chiu and Tsoh 2009b; Chow, 2004).

## 2.8 Section 4: Conclusion

The justification for taking socio-cultural approaches in studies to explore ethnic minority groups' understandings and conceptualisations of dementia is that they do not align with the biomedical model of dementia. Therefore, these studies involve explorations of the role and contribution of cultural beliefs to explore reasons for this misalignment. The findings from these studies suggest that dementia is mainly conceptualised as a normal consequence of ageing and/or a mental illness. They have also found stigma and delays to help-seeking, as well as healthcare system barriers to accessing early diagnosis and care support. Many of these studies have used questionnaires and surveys to assess different ethnic minority groups' dementia literacy, some of which have used linear acculturation measures (Rudmin, 2003) to take into account diversity within minority ethnic groups. Whilst this thesis does not challenge the biomedical model of dementia, it does however, highlight a need for caution as there is a potential for ethnic minority groups' understandings and conceptualisations to be problematised for their deviation from biomedical understandings (Torres, 2015). It also has to borne in mind that it is only relatively recently in the early 20th century (not withstanding Galen's identification of dementia as a distinct disease) that Western biomedicine and therapeutics (Ballenger, 2017; Fletcher, 2019) have developed to a point in which dementia is argued to be distinct from normal age-related cognitive decline due to changes in brain pathology. Until then age-related decline in cognitive functionality was amongst other conceptualisations (Knifton and Yates, 2019) perceived to be senility and accepted as such, in both Western and non-Western countries (Fletcher, 2020). Additionally, caution is also advocated to avoid findings from these studies being used to explain away low levels of ethnic minority groups' engagement with dementia services without a focus on structural inequalities that affect access to culturally appropriate care. These studies also unproblematically accept that the biomedical model of dementia can be successfully transferred to other cultures. Yet, as we have read in the theoretical review, its transferability is challenged. This is because Western psychiatric classifications such as dementia that are developed in contexts with a specific set of

values are not ontologically and epistemologically neutral and therefore cannot be universally applied to distinctly different cultures (Fletcher 2020: 714). This critique speaks to a wider debate of the transferability of Euro-centric psychiatric classifications to non-Western countries, including mental illnesses (Fletcher, 2020; Hashmi, 2009; Lamb, 2015). Whilst acknowledging this debate needs to be had, it is not to deny the existence of the pathological changes to the brain that constitute dementia, a point that has also been made by Hashmi (2009) and Fletcher (2019).

What is noticeable is that the approach to problematising and 'converting' people to biomedical concepts and understandings is not extended to majority populations such as white British communities. This is because there is an assumption that they share biomedicalised concepts of dementia. Yet, the evidence to support this assumption is not explored with the same level of depth and parity accorded to minority ethnic populations. This argument is further substantiated when one finds a plethora of studies with minority ethnic groups on a worldwide basis, but in contrast there is a paucity of studies focusing on Western majority populations about their concepts of ageing and dementia. The research that is conducted with the latter population tends to coalesce on issues related to management of dementia and dementia literacy. So much so, I was only able to locate a small number studies involving white British communities that specifically focused on their concepts and beliefs about dementia with the same level of scrutiny and focus BAME communities have been subjected to.

Theoretical perspectives and empirical studies do share some commonality though, in that they both discuss how the concepts of dementia and ageing are inextricably entwined. However, in the empirical studies, the concept of ageing is not interrogated or explored. There is an assumption that it refers to ageing or chronological age but meanings attached to these are rarely explored or interrogated. In contrast, the theoretical review on ageing and dementia presents a discussion of how dynamic and responsive Western societal discourse has been on ageing and its framing to dementia. It also dissects concepts of successful and active ageing and the role they play in promoting individualised responsibility for ageing. This type of critical discourse is not found in the context of discussions on ageing and its framing to dementia within studies

conducted with ethnic minority groups.

The theoretical review also discussed how the media powerfully shape beliefs and attitudes to ageing and biomedical understandings of dementia. Yet, the influence of the media, particularly specialist media catering for minority ethnic groups, is sadly lacking in empirical studies.

To counter balance the above critiques and debates one can argue that in a globalised world (Chow, 2004) it may no longer be feasible to see hard and fast distinctions between non-Western and Western countries. Moreover, in many Western countries there are several younger generations from ethnic minority groups who are born and educated there. They may have been socialised through the media which, according to the theoretical review, disseminates biomedical concepts and understandings of dementia. Consequently younger generations may well share and align themselves to biomedical understandings and concepts of dementia, in contrast to older members of their communities. Both the theoretical papers and empirical research rarely focus on the implications of these generational perspectives.

Finally, in the theoretical review we find that ethnicity as a construct is contested (Salway, 2011). There is a suggestion that it needs to be treated as problematic, particularly when it is used on its own without intersecting characteristics such as age, migration and socio-economic status (Salway 2011). However, in the empirical literature we find that many studies, with the exception of cross-sectional studies, use ethnicity as the sole category of differentiation. As a consequence, it is challenging to find informed discussions about the impact of socio-economic status on, for example, older South Asians' understandings and concepts of dementia. Such approaches lead to reified accounts of study findings that do not take into account the heterogeneity of diversity within and across all ethnic groups.



## **2.9 Section 5: Summary, Rationale and Theoretical Orientation of this Research**

### **2.9.1 Summary**

This chapter, through its discussion of the theoretical perspectives, facilitated an opportunity to interrogate and challenge biomedical understandings of dementia, including Alzheimer's, and their implications. It also highlighted how both the concepts of ageing and dementia are culturally constructed and inextricably linked and examined the consequences of this linkage for both people with dementia and their carers at a societal level. In highlighting the role and influence of the media, it emphasised the processes by which these linkages are conveyed in the media and their impact. Some of the arguments related to the contested nature of dementia as a diagnostic category were countered through a discussion on dementia diagnosis.

The empirical studies and the contribution of the grey literature have demonstrated that there are a variety of ways in which dementia can be conceptualised. These have implications for the support of people with dementia and carers, including the role and contribution of stigma. This chapter also provided the critiques from anthropologists who have highlighted the challenges about the cross-cultural transferability of concepts of dementia, due to differences in beliefs, understandings and values about age-related decline. In addition, the chapter examined the role of the family in supporting older members of the family with dementia.

Whilst there is no cure for dementia, early diagnosis for dementia forms a cornerstone for dementia treatment as it can eliminate other causes for dementia-related symptoms as well as facilitate access to medication to delay the progressiveness of dementia symptoms. It can also give families time to plan care and make financial arrangements. The saliency of early diagnosis is emphasised in ethnic groups that have a higher risk of developing dementia due to vascular disease and genetic susceptibility. However, a number of barriers to early diagnosis have been identified, including racism, language and communication difficulties, and the cost of treatment. One of the more common

barriers is the low level of knowledge and understanding of dementia in keeping with the medical model of dementia. Studies employing acculturation measures suggest biomedical understandings may be greater amongst people with higher incomes and education. However, the uncritical use of acculturation measures in these studies is problematic. Some studies have highlighted generational differences, but the findings are contradictory within what is currently a very small evidence base.

A significant barrier to early diagnosis and care support strategies is the cultural value of filial piety associated with spiritual and religious teachings within some ethnic groups. This cultural value is thought to cause delays to diagnosis and a reluctance to seek formal care support. However, an undue emphasis on filial piety has been critiqued as globalisation and industrialisation is purported to erode affiliation to this cultural value as well as reducing the availability of familial support to people with dementia.

### **2.9.2 Rationale for this research**

The literature review has clearly demonstrated that some members of the lay public are likely to conceptualise dementia differently from the biomedical model of dementia. It is important therefore to explore lay conceptualisations and understandings of dementia because evidence suggests that they influence help-seeking behaviours and care strategies. The need for such an exploration is accentuated in BAME communities because their conceptions of dementia are more likely to differ from biomedical understandings due to a range of factors, including culture. However, there is a paucity of this type of research within the United Kingdom. This exploratory study will contribute to the research evidence base in the UK about lay conceptualisations and understandings of dementia in multi-ethnic communities.

This research involved a study population drawn from Indian Hindu Gujarati, Caribbean and white British communities. These three communities were selected because they are ageing the fastest, alongside the white Irish community. By 2051, these three ethnic groups are projected to have the highest proportion of people aged over 50 years, alongside the white Irish population (Lievesley, 2010). The saliency of engaging with Indian and Caribbean communities in dementia research is emphasised not only on the

basis of demographic changes but also because of their higher risk of developing dementia (Adelman et al., 2011).

The existing empirical evidence is mainly drawn from the cultural perspective of PWD, their carers, and older lay members of the public in a range of multi-ethnic groups. It has inevitably captured the perspectives of an older generation, many of whom are first generation migrants in countries such as the US and UK. However, it can lead to 'reified' and 'static' impressions of cultures as the perspectives and experience of UK-born ethnic minorities may differ from their grandparents' and parents' generation (Bradby and Nazroo, 2010), but these are under-explored. By engaging with younger generations from ethnic minority groups, research can contribute to new knowledge by providing a more dynamic approach to the exploration of the role played by culture through the inclusion of multi-generational participants.

The inclusion of multi-generational perspectives in this research will involve a focus on both micro- and macro-level influences on the experiences and responses of generations over time to dementia, as well as help-seeking strategies (Heese, 2015). In this way, it goes beyond an acculturation approach which focuses primarily on cultural factors within BAME groups but will not negate these either (Hudson, 2008). It will also include the involvement of white British participants who are often neglected in cross-cultural research. The implicit temporal perspective in this research facilitates the inclusion of interactions of different generations with a range of macro-structural forces including race discrimination, socio-economic positioning, social policy and the influence of technological changes within society. In this way, it is envisaged that some of the criticisms from ethnicity scholars about the simplistic association between ethnicity and culture in research conducted with BAME communities will be addressed by taking a wider perspective.

### **2.9.3 Theoretical Orientation**

In this section of the chapter, I shall introduce how critical theoretical perspectives informed and guided this research, including the selection of the concepts of ethnicity and generational age. Also in this section, I will discuss how my preliminary analysis of

the findings related to help-seeking and care strategies led to a seed of an idea to use a typology as a way of interpreting and conceptualising my data. Thereafter, I will explain how this preliminary stage of analysis was followed by a review of the methodological and theoretical literature on typologies. This review contributed to my confidence and skills to subsequently develop four types within this typology. The analytical stages of the typology's formation and its four types can be found in the Methods chapter in Section 4.11.2.10.

Firstly though I shall explain my motivation for undertaking a qualitative approach, which was to overcome the limitations of the many cross-sectional worldwide studies that have been conducted with lay public participants. These provide descriptive findings that cannot provide in-depth explanations of why, for example, levels of knowledge about dementia may be low or high amongst participants. A qualitative approach facilitates the opportunity to explore lay participants' perspectives and experiences, including the factors and issues that shape their conceptualisations, knowledge, and understandings, as well as caring strategies on a more in-depth basis.

This research has also been designed to respond to calls to explore inter-ethnic group and intra-group differences and commonalities with regards to ageing and dementia, incorporating the impact of inter-sectional factors such as age and social positioning (Victor, et al., 2012; Downs, 2000). In order to respond to these calls, I drew upon critical sociological theoretical perspectives on ethnicity and generational age in research. In relation to ethnicity I wanted to ensure I was cognisant and responsive to the critiques of ethnicity and the use of acculturation as discussed in the literature review, including the reasons for why ethnicity is a contested concept. These critiques highlighted the saliency of providing clarity and transparency about my understanding of ethnicity and its operationalisation within this research. In the following discussion I will provide some insight into the theoretical grounding of my choices with regards to ethnicity and generational age as conceptual constructs.

### **2.9.3.1 Conceptualisation of ethnicity**

As has been established in the literature review, ethnicity as a concept in research is contested (Salway et al., 2011b) and is often taken for granted and uncritically

examined. Ethnicity scholars (Torres, 2015; Zubair and Norris, 2015) have called for the impact of mediating factors such as gender, socio-economic status, age, migration and generational age to be taken into account with ethnicity. This is to avoid essentialist explanations in which undue emphasis is placed on culture as an explanatory factor for disparities in health inequalities. In view of the preceding discussion, I utilised the following conceptualisation of ethnicity which encapsulates the dynamic and situationally contingent nature of this contested concept but also recognises the agency of people to define their own ethnic identity. It also encompasses a reference to its function for exploring discrimination and disadvantage. *Ethnicity is thus a dynamic concept, characterised by its relationship to forms of heritage (national, linguistic, cultural), notions of belonging and external recognition of such claims, but also by its malleability, flexibility and situationality. Contemporary notions of ethnicity show it as a marker of identity, a vehicle for community mobilisation and a possible indicator of disadvantage, discrimination or privilege (Ahmad and Bradby, 2007: 796).* However, whilst I was clear about my concept of ethnicity, achieving clarity about how to operationalise it within this research proved to be more elusive until I drew upon the contributions of Torres (2015) and Gunaratnam (2003). The details of how this was achieved and its impact in the operationalisation of my research are elaborated in the Methodology chapter in Section 3.6.1.

#### **2.9.3.2 Conceptualisation of generational age**

The idea of using generational age as an intersecting factor with ethnicity came from drawing upon my positionality as a second generation migrant when reviewing empirical studies on dementia. This positionality alerted me to consider that the portrayal of cultural beliefs and practices were primarily derived from perspectives of mainly older lay public, people with dementia and carers within the literature. This was contributing to narrow and static portrayals of culture with the implication that they were generalisable to ethnic groups as a whole. By using generational age, I aimed to balance these approaches by including more dynamic and inclusive approaches to this research, through the exploration of the impact of generational changes. This is because my own generational positioning and lived experiences have enabled me to witness and experience generational changes

with respect to knowledge and understanding of health conditions, family structure and occupational mobility on help-seeking, including cares strategies. Whilst I acknowledge that some of these issues are discussed in the literature (Liu et al., 2008a; Patel and Prince, 2001; Roberts et al., 2015) they are not widely represented. The inclusion of white British participants was undertaken to imbue both ethnic and generational diversity and to capture insights about commonalities of meanings, experiences, and differences within and across ethnic and generational groups.

The use of a generational approach as a discursive construct in research is not new (Timonen and Conlon, 2015). It is attributed to Mannheim (1970) in his seminal sociological text, *The Problem Of Generations* (Mannheim, 1970). He described generations as based on the existence of *biological rhythm in human existence-the factors of life and death, a limited span of life, and ageing* (Mannheim, 1970: 167). This entails people who share the same year of birth having a common location in the historical dimension of the social process (Mannheim, 1970: 167). In this context, a generation is described as a birth cohort.

The reason his treatise was called 'a problem' was that sociologists were asked to consider how biological factors of a birth cohort affect the experiences, thoughts, and feelings arising from a generation's location (Mannheim, 1970). He addressed this by suggesting that an individual's early lifetime experiences and impressions create *common perspectives of the social world, and become the basis upon which meanings are formed, and used to make sense of future experiences* (Mannheim, 1970). When individuals from an actual generation respond from the standpoint of a generational consciousness to their common experiences in different specific ways, they can be conceptualised as a generational unit (Mannheim, 1970: 187). This can be illustrated by the current furore amongst younger generations who view some of the Bond movies as sexist in the Me Too era, whereas previous generations may have viewed them as acceptable. This is because the norms and values about gender in previous generations will have differed to those in the current social context (Child, 2018).

Mannheim's concept of generation has been challenged by sociologists for his deterministic view of a shared consciousness amongst a generation (Timonen and

Conlon, 2015). Burnett (2016) contended that generational consciousness can change or even adapt as a consequence of technological advancements. This may make someone able to reinvent or establish a generational consciousness for the first time at a different age, such as in their 30s, and this change may be in response to fast changing technologies (Burnett, 2003). These responses to contextual factors in society may make generational boundaries more permeable. Therefore, Burnett (2016) argued, that generational boundaries may be elastic and have uncertain edges (Burnett, 2003: 2). This research study was undertaken in recognition of generational age as being permeable and was not used in a deterministic way. It also takes note of France's (2015) critique that generational perspectives also need to take account of the impact of socio-economic differences on inequalities experienced by people within a generation (France and Roberts, 2015a). Whilst I had taken account of the critiques of Mannheim (1970) I wanted to retain his idea of a generational consciousness, but I surmised that I required a more flexible approach to generational age boundaries. Therefore, I drew upon the life cycle approach advocated by Dimock (2019) which involves the use of age delineators to signify generational age, underlined with assumptions about their positioning within a life cycle which may lead to generational consciousness. The assumptions that guided the operationalisation of my generational age categories within the research sample are explained in the Methodology chapter in Section 3.6.2.

The interaction of generational age and ethnicity played an intrinsic role in the development of a typology during the analytical process. It helped to conceptualise my data on help-seeking and care strategies. In the remainder of the section below, I shall introduce what is meant by a typology, thereafter explain how the idea of using a typology came about and how my typology was aligned to the theoretical and methodological literature.

### **2.9.3.3 Theoretical and methodological literature on typologies**

Typologies are frequently described as ubiquitous in day-to-day life and are also increasingly used in a range of qualitative and quantitative research as ways of explicating patterns of human action (Elman, 2005; McKinney, 1969). A vast array of labels are used to describe typologies, such as empirical, ideal, heuristic, and

classificatory to name but a few (Kluge, 2000). In order to ensure my use of a typology was based on an informed theoretical understanding, I developed my knowledge of Weber's treatise on typologies (1988), drawing heavily upon the work of theorists who provided a cogent and accessible interpretation of Weber's original work (Kalberg, 2000; Swedberg, 2018). Weber developed his seminal work on typologies, the Ideal Types, over 150 years ago and it was translated from German to English (Kalberg, 2000). Other notable theorists associated with typologies include Schutz (1972), a philosopher who is also described as a social phenomenologist (Kim and Berard 2009) and more recently McKinney (1969), who drew upon both the work of Schutz (1932) and Weber (1904) to contribute a methodological focus in the construction of typologies (Kim and Berard, 2009).

#### **2.9.3.4 Emergent typological approach, a seed of an idea**

The seed of an idea to use a typology grew from the preliminary analysis of findings from the focus group discussions in which many participants had taken up a range of distinct and opposing positions with older generations in their communities and with other ethnic groups. These positions served to be insightful on two levels. Firstly, they illuminated and revealed their own beliefs, values and experiences. Secondly, in the process of articulating these, they helped to highlight their perceptions about the similarities and contrasting positions within other generational/ethnic groups. It was evident that both ethnicity and generational age were key components in the positioning of participants to explain their behaviours and actions on issues such as disclosure and stigma based on their beliefs and values and when comparing these with other generational/ethnic groups.

CONGT (2008) facilitated the development of the typology, and as Charmaz (2008) explained *it is a method of explication and emergence, it is inductive, indeterminate and open-ended* (Charmaz, 2008: 156), and thus did not preclude the use of typologies. The way in which these types that constituted the typology developed was congruent with Charmaz's (2008) view that *GT as an emergent method encourages researchers to make conjectures and check them and therefore engage in deductive reasoning as inquiry proceeds* (Charmaz, 2008: 156). The typology thus formed part of the theory



developed through the analysis process.

I was unaware during the preliminary stage of the analysis that typologies as methodological tools are situated within a rich and complex historical methodological and theoretical body of literature (Kalberg 2000). In keeping with GT methodology, it was only after the initial draft data analysis of the types had been developed that I reviewed this literature, the key tenets of which are discussed below.

#### **2.9.3.5 Aligning my typology to the theoretical and methodological literature**

I reviewed some of the key writings from these theorists to establish whose body of work my emergent typology findings were most closely aligned to, in relation to their development purpose, theory and methodology. I found the process of development of my types within the overall typology most typically aligned to Weber's Ideal Types, as interpreted by McKinney (1969). As the founding father of interpretative sociology, Weber (Weber, 1981) advocated that the core purpose of sociology was to undertake an interpretative understanding 'Verstehen' of how people's beliefs and actions are influenced and shaped (Kalberg, 2000). He suggested that this can be achieved by reconstructing the milieu of their values, traditions, interests and emotions (Kalberg,2000: 55). In contrast, Schutz's work (1932) reflected his phenomenological and philosophical background (Psathas, 2005) and his gaze was said to be on foundational issues such as the relevance of meaning and interpretation for social sciences (Kim and Berard, 2009:265) This signified an emphasis on the micro level of analysis in contrast to Weber's macro-sociological level approach (Kim and Berard, 2009). Unlike Weber, Schutz's contribution to the theoretical literature of typologies was not based on empirical work (Kim and Berard, 2009).

Weber's seminal work on the Protestant Ethic during 1904 and 1905 was a methodological tool that aimed to capture subjective meaning and relating it to action. In Protestant Ethic he created ideal types for a range of groups, such as Lutherans, Puritans, and Baptists, and emphasised that the key characteristics of these groups are essential to the theme of that particular ideal type (Ritzer and Stepnisky, 2011; Kalberg, 2003). So, for example, the ideal type of the Puritan had the key characteristics of leading a methodical and pious life (Ritzer and Stepnisky, 2011; Kalberg, 2003).

Weber was not intending to develop grand sociological theories from Ideal Types, but he did ascribe them as having an explanatory and theoretical purpose so that they can be evaluated for their utility to ascertain whether or not they correspond to empirical reality (Kalberg, 2003). He recognised that there is a danger of them being used as reified categories, but maintained that although they are grounded in reality, in their purest conceptual form their construct cannot be found empirically anywhere in reality (Kalberg, 2003; Rosenberg, 2016). Thus, typologies are not meant to replicate reality, but serve as an analytical instrument for the intellectual mastery of the empirically given, and only that (Kalberg, 2003: 146).

Nevertheless, according to Weber (Kalberg, 2003) they do have a theoretical purpose as a valid sociological concept because they emerge from a reality that is visible to the observer. They emerge from shared meanings, motivations and experiences amongst a group of people and are situated within the contexts in which they occur (Kalberg, 2003; Rosenberg, 2016). They also facilitate an understanding of how and when changes occur (Rosenberg, 2016).

Rosenberg (2016) highlighted criticisms of Weber's Ideal Types, in particular that they were developed on an ad hoc basis, with the criteria upon which they are based being arbitrarily selected (Rosenberg, 2016). Another common criticism is that they are classificatory categories rather than explanatory categories (Rosenberg, 2016). To counter these, Rosenberg (2016) suggested that researchers need to ask themselves whether their typologies are simply classifying their data for the purposes of presentation or are developing criteria used to differentiate the types central to the theoretical argument being advanced (Rosenberg, 2016:15). In this research, I have used the typology as a way of developing my theory on help-seeking approaches and care strategies to highlight the differences between ethnic and generational groups vis a vis values and structural influences. In the data analysis section of the Methods chapter at 4.11.2.10, I shall provide a more detailed discussion about how these types were developed.

#### **2.9.4 Research question**

In the light of above discussion, this research will aim to address the paucity of qualitative studies conducted with younger generations. It will aim to explore multi-ethnic younger and middle-aged adults' understandings of dementia and approaches to help-seeking. The methodological framework to address this aim including its objectives will be fully explained in the next chapter.

# Chapter 3: Methodology

## 3.1 Introduction

In the preceding literature chapter, the review of empirical studies conducted with people with dementia, carers and lay public on a worldwide basis identified a paucity of qualitative studies conducted with the lay public. Furthermore, there was a gap found in this body of literature relating to younger generations from a range of ethnic groups, with regards to conceptualisations, knowledge and understandings of dementia. An under-explored area of research is the help-seeking strategies amongst younger generations of the lay public. This research addresses this gap in knowledge using a qualitative approach and CONGT developed by Charmaz (1995) to inform the design of this study.

This chapter is organised and presented in five sections. An overview of these sections will be provided after discussing the following research questions:

1. How is dementia conceptualised by younger and middle aged adults in multi-ethnic communities?
  - (a) What factors and issues shape and influence their conceptualisations of dementia?
2. What is the knowledge and understanding of dementia of younger and middle aged adults in multi-ethnic communities?
  - (a) What factors influence and contribute to this knowledge and understanding?
3. How is old age and ageing conceptualised in younger and middle aged adults in multi-ethnic communities?
  - (a) How is old age and ageing framed in relation to dementia?

4. What are help-seeking strategies for dementia within younger and middle aged adults in multi-ethnic communities?
  - (a) What factors and issues shape and influence these?

## **3.2 Overview**

In the following section I shall explain how this chapter is presented, including an outline of the main arguments.

In Section 1, I shall discuss the use of a qualitative approach for this research, and this is justified on the basis on that there is a paucity of studies using this approach, particularly in the UK with lay BAME communities.

In Section 2, I shall explain why amongst the broad spectrum of qualitative approaches, I selected Grounded Theory (GT) (Glaser and Strauss, 1967). It offers an inductive approach that has the potential to identify and incorporate fresh perspectives in dementia research. After evaluating a range of different strands of GT, I selected CONGT (Charmaz, 1995). The decision to do so was based on a range of factors, but primarily because it aims to develop an interpretative approach to the understandings, meanings and interpretations of participants' perspectives and experiences. Also, because it helps to address the power imbalance that is inherent in the design and conduct of research in which research is conducted to rather than with BAME communities.

In Section 3, I discuss the selection of focus groups as the data collection method. This method was chosen as it facilitates access to multiple and diverse participants within one research encounter. As a method, it also facilitates the opportunity to capture through group interaction access to diverse perspectives, helping to nullify an essentialist approach to ethnic groups' experiences and perspectives. I also employed the use of face-to-face interviews, with five community workers and volunteers that work with the communities represented in this research. These were designed to facilitate the contextualisation of my focus group findings and enhance understandings of help-seeking behaviours in diverse ethnic communities.

In Section 4, I shall explain how I operationalised the concept of ethnicity as it is often used uncritically and taken for granted. In addition, I will discuss how I operationalised generational age using a life cycle approach.

In the final Section 5, I discuss and explain how qualitative research by its very nature gives rise to different ethical concerns to that of quantitative research. In addition, I also argue the saliency of ethical reflexivity is enhanced when conducting research with BAME communities. This is due to a number of reasons which include the need for inclusive practice, transparency and accountability in the use of ethnicity as a concept and its operationalisation in the analysis process.

I finish this section with a discussion of the criteria used to assess the quality and validity of this research using Charmaz's (2006) criteria of credibility, resonance and usefulness.

### **3.3 Section 1: Selection of an interpretative qualitative approach and grounded theory**

#### **3.3.1 Interpretative qualitative research**

An interpretative qualitative methodology was employed in this research because it can facilitate an understanding of how and why (Bryman, 2016a; Barbour, 2013) conceptualisations of dementia are constructed, through the exploration of participants' beliefs, attitudes, experiences and their meanings of dementia (Barbour, 2013; Fossey et al., 2002a; Miles and Huberman, 1994). As this research involves generational perspectives these meanings and actions can be framed, interpreted and situated in relation to factors such as temporality and history (Holloway and Galvin, 2016).

However, qualitative research is not a unified and monolithic methodological approach (Ravitch 2015, Maxwell 2012). It encompasses a range of theoretical and epistemological perspectives (Barbour 2013). The selection of which theoretical perspective to adopt within this broad spectrum can be determined by the ontological stance of the researcher and the researcher's stance on epistemology (Guba and Lincoln, 1994).

In addition to these considerations, an account of the positionality of the researcher

(Jackson, 2013) as well as the aims of the research and the insights it hopes to gain (Jackson, 2013) needs to be taken. As a consequence of considering these issues, I was keen to ensure that the methodological approach to this research should be one that aimed to develop *concepts, hypotheses, and theories from data that are contextualised and emerge from engagement with research participants* (Ravitch and Carl, 2015: 102).

### **3.4 Section 2: Selection of Grounded Theory**

Based on the aforementioned issues, the importance of selecting an inductive methodological framework was further emphasised after scoping some of the existing literature on conceptualisations of dementia. Some of the research studies within this body of literature (Laditka et al., 2013; Parveen et al., 2016; Roberts et al., 2003) have been conducted using pre-existing theoretical frameworks such as Leventhal's The Common Sense Model of Self- Regulation (Leventhal, Brissette et al., 2003) and the Health Belief model (Hochbaum et al., 1952; Hughes et al., 2009). These approaches prompted me to consider whether the application of these pre-existing theoretical frameworks to the design of this research may constrain the direction and scope of the under-researched area of BAME lay public conceptualisations of dementia (Whitman, 2019). In addition, many of these theoretical frameworks have not been developed from research involving a multi-generational ethnic sample. Therefore, an inductive and emergent approach to the research design was explored. In this way the inclusion of potentially fresh and different perspectives from under-researched populations (Whitman, 2019) could be gained.

Moreover, the existing research on conceptualisations has emphasised the processes involved in the construction of stigmatising beliefs and attitudes about dementia, as well as their influence on help-seeking and care strategies. It was therefore important to ensure the selection of a methodological approach that encompassed a focus on explicating and contextualising the processes (Maxwell, 2012) involved in the formation of stigma.

In the light of the above considerations, GT (Glaser and Strauss, 1967) was selected for this research, not only because it facilitates an inductive approach, but because it offers

detailed guidance for the process of generating middle range theory development by explicating the data collection and data analysis processes involved in a research project (Bryant and Charmaz, 2007).

### **3.4.1 Background to Grounded Theory**

Charmaz (2006) provided a comprehensive overview of why Glaser and Strauss's Discovery of Grounded Theory (Glaser and Strauss, 1967) was a seminal moment in the history of qualitative research. One of the reasons for this is they advocated an explicit systematic-inductive approach that links data collection to analysis, the purpose of which is to develop theories that are inductively derived from the data without a priori assumptions of the researcher or theoretical frameworks (Nagel et al., 2015) Thus, the process and outcome of theory generation was to promote a conceptual understanding and analytical explanations of the phenomenon being studied (Annells, 1997). This is in contrast to descriptive explanations of social phenomena that are deductively reached through hypothesis testing or verification of theory within positivism (Charmaz, 2006b).

The core components of GT include systematic and concurrent data collection and analysis processes (Glaser and Strauss, 1967). It also involves theoretical sampling, which is for the purposes of theory generation and not for population representativeness (Glaser and Strauss, 1967). The development of theory is integrated within the process of data collection and analysis. Analytic codes and categories are constructed from the data using a constant comparison approach (Glaser and Strauss, 1967). In addition, the use of memos which describe and explain relationships between categories is also a distinguishing feature of GT (Charmaz, 2006b; Glaser and Strauss, 1967). Glaser explained that undertaking GT procedures based on the *constant comparison method can result in a smooth, uninterrupted emergent analysis and the generation of substantive or formal theory*(Glaser and Holton, 2007: 50). Glaser advocated for exercising patience with the process of transition from providing descriptive accounts to concept development that facilitates theoretical emergence (Glaser and Holton, 2007).

What is well documented in the literature is the discord about the divergent grounded theories that have been developed over the years (Glaser, 2009; Glaser and Holton,



2005; Bryant and Charmaz, 2007). One source of this discord involved Glaser (2009) consistently maintaining the argument that there is no requirement for an ontology or epistemology within Classic Grounded Theory. It is the data that guides the generation of theory as opposed to the researcher's epistemological stance. Otherwise, a researcher with an a priori theoretical lens, such as a constructivist, *pre-frames the lens through which data are processed* (Breckenridge et al., 2012a: 6). However, Bryant and Charmaz (2007) countered Glaser and Holton's (2005) argument that GT is ontologically and epistemologically neutral by suggesting GT is underpinned by a positivist epistemology that perceives social reality as *unitary, knowable and waiting to be discovered* (Bryant and Charmaz, 2007: 34).

### **3.4.2 Traversing the terrain of Grounded Theory**

It is these philosophical differences and controversies about the product of inquiry that have led to different strands of GT, or as Glaser scathingly called them remodelled versions (Glaser and Holton, 2004). Evans (2013) outlined these different strands of GT. These include Classic Grounded Theory, Struassian Grounded Theory (Strauss and Corbin, 1990), Social Constructionist or Social Constructivist Grounded Theory (Charmaz 1995), Feminist Grounded Theory (Wuest, 1995), and Situational Grounded Theory (Clarke, 2003).

However, traversing the maze of different strands of GT (Nagel et al., 2015) with their different methodological and philosophical orientations was challenging and my experience resonated with the sentiments expressed in the following statement by Breckenridge et al. (2012b). They argued that new PhD researchers are faced with the challenge of navigating their way through the methodological mire in order to arrive at an informed decision about which 'version' of Grounded Theory to use (Breckenridge et al., 2012b: 2).

To traverse this methodological mire and fully comprehend the nature and origins of these divergent strands, I reviewed the three main strands of GT - Classic Grounded Theory, Struassian Grounded Theory (Strauss and Corbin, 1990), and Social Constructionist or Social Constructivist Grounded Theory (Charmaz, 1995) - to ascertain the best fit for

this research. The coverage of these strands, including critiques in the methodological literature, has been well established, prolifically discussed and described, in contrast to some of the newer strands of GT such as Feminist Grounded Theory (Wuest, 1995) and Situational Grounded Theory (Clarke 2003, Higginbottom and Lauridsen, 2014).

In making my decision about which strand of GT to select from these main strands I took heed of Higginbottom and Lauridsen's (2014) advice when they advocated that *when selecting an approach to GT, researchers should strongly consider their own worldview and ensure there is congruence between it and the chosen methodology* (Higginbottom and Lauridsen 2014: 13).

### **3.4.3 Selection of Social Constructionist Grounded Theory**

After carefully evaluating the divergent approaches to GT, the selection of CONGT (Charmaz, 1995) to inform this research was undertaken for the following reasons. Firstly, the CONGT relativist ontology states *that the world consists of multiple individual realities influenced by context* (Mills et al., 2006: 26). As such this challenges the notion of objective truth or single reality. In taking a relativist approach Charmaz (1995) countered Classic Grounded Theory's (1967) positivism which, she argued, implies a reified view of reality (Charmaz, 2006). This results in an emphasis on elucidating facts hypothesised as separate from the values of the researcher (Annells, 1997). In CONGT, the researcher's values enable them to process the facts before them, using a reflexive approach to the researcher's positionality (Charmaz, 2006b).

CONGT's (1995) relativist position aligns with my worldview, in particular the inclusion of multiple realities resonates with my personal background as a bi-cultural researcher. This is because it felt intuitively aligned to my world view which is underpinned mainly by my bi-cultural identity, which involves negotiating and mediating between multiple identities and their concomitant realities. An example relates to my own culture in which caring for older parents requires me to be cognisant of the values under which they were brought up, such as interdependence amongst family members, yet as a child and adult growing up in Western society independence and individuality are promoted throughout your life. So, I am conscious that I am constantly negotiating multiple identities derived

from my professional roles, parental status, and intersecting factors such as my social class, gender, age and generational age, and ethnicity. I believe that the interaction of these factors in particular contexts gives rise to viewing the social world through multiple lenses, which leads to insights from a number of vantage points and differences in perspectives.

However, like Charmaz, I too disagree with the radical form of relativism underpinning Social Constructionism (Guba and Lincoln, 1994) which argues that reality does not exist (Charmaz, 2006b). Instead, I take the salient feature of this paradigm which is a *recognition that knowledge and social reality arises out of human experience, including perceptions that are mediated historically, culturally and linguistically* (Willig, 2013: 7). The implication therefore, is that there are various ways in which the social world and knowledge can be understood and conceptualised. The role of the researcher is to explore how these constructions arise and these may *be local and specific, and/or shared among individuals and cultures* (Guba and Lincoln, 1994: 110).

The underlying philosophical approach of Constructivism to CONGT (Charmaz, 2006b) purports the view that perceptions of realities are socially constructed and experienced, shared amongst individuals and groups, are dynamic in that they can change and are temporally situated (Guba and Lincoln, 1994). This is particularly relevant to the exploration of multi-generational ethnic groups' conceptualisations of dementia because it fosters and imbues a dynamic approach to the research, rather than portraying, for example, static portrayals of cultural perspectives of dementia.

Classical GT aims to extrapolate theoretical understandings of behaviour rather than participant meanings about phenomena (Glaser and Strauss, 1967). Glaser (1967) has been very adamant about this point, stating that the purpose of GT is to develop a *set of carefully grounded concepts organised around a core category and integrated into hypotheses. The generated theory explains the preponderance of behaviour in a substantive area with the prime mover of this behaviour surfacing as the main concern of the primary participants. It is just straightforward conceptualisation integrated into theory - a set of plausible grounded hypotheses* (Glaser and Holton, 2007: 14).

As a consequence, the core differences in the purpose of CONGT (1995) and Classical Grounded Theory (1967), argued Breckenridge et al. (2012), is that CONGT represents a significant deviation from Classical GT (Breckenridge et al., 2012a: 3). This is because Classical GT aims for a conceptual understanding of social behaviour rather than the Constructivist focus on interpretative understandings of participants' meanings. As this research is focused on understanding meanings of conceptualisations of dementia and how it influences behaviours such as help seeking, CONGT (1995) provides more of an appropriate methodological framework than Classical GT (1967).

Furthermore, the emphasis within CONGT (1995) on the process of meaning making is particularly salient in this research because dementia evokes different meanings and experiences at an individual level and across cultures (Hashmi, 2009b). This diversity of meaning has, as we have read in the literature review, given rise to different perspectives about the causality of dementia, which continues to change and evolve (Whitehouse et al., 2005b). These differences in perspectives take place in a context in which there is no conclusive evidence to disprove or confirm whether it is related to ageing and longer life expectancy or a distinctive pathological disease (Lock and Nguyen, 2018).

The focus on meaning making within CONGT is derived from the influence of Symbolic Interactionism and its emphasis on the micro level of participants' perspectives. It can help to reach an *interpretative understanding of the studied phenomena that accounts for context* (Charmaz, 2014: 14). This influence facilitates an alignment with the aim of this research, which is to ensure that conceptualisations of dementia are contextualised in relation to generational experiences. Thus, utilising CONGT facilitates the avoidance of unethical, essentialist cultural (Zubair and Norris, 2015) explanations of ethnicity in relation to constructions of dementia, the possibility of which may be raised when taking a de-contextualised approach. A contextualised approach may also be possible with the application of the Struassian conditional matrix (Strauss and Corbin, 1990) which takes into account the different contextual layers within the data such as micro and macro-level factors (Rieger, 2019).

Charmaz's (2014) emphasis on researcher positionality acknowledges the influence the researcher has in determining research questions and choosing the research design

(Charmaz, 2012) and the analytic strategies to be used (Charmaz, 2014). As a consequence, the research process is treated as a social construction (Charmaz, 2006b) so that its outcomes are considered not to be a depiction of a reified social reality but a recognition of the pragmatist influences underpinning CONGT (1995) and are perceived to be an interpretative portrayal (Charmaz, 2014) of it.

The choice of CONGT was also strongly motivated by its commitment to ensure participants' voices feature strongly in the findings, as *constructivist grounded theorists are impelled to be analytical in their writing but that their style of writing needs to be evocative of the experiences of their participants* (Mills et al., 2006: 31). This represents an ethical approach to conducting research which can lessen the privileged perspective of the researcher over and above the participants (Bryant and Charmaz, 2007). This is of particular importance as this research involves communities that are often marginalised and not visible in relation to their involvement in research, as evidenced by the paucity of research with lay BAME communities in the UK (Whitman, 2019). It is therefore vital to ensure that when they do participate, their voices are evident in the findings and the dissemination of the research.

CONGT (1995) also offers a flexible and simpler approach to research. Charmaz proposed a *set of principles and practices, not as prescriptions or packages... I emphasise flexible guidelines, not methodological rules, recipes, and requirements* (Charmaz 2006b: 9). This simplicity is particularly helpful in the dating coding processes, and in sharp contrast to that of Strauss and Corbin's (1990) approach, which has been described as prescriptive and cumbersome (Rieger, 2019).

Despite utilising CONGT (1995) as the methodological framework for this research, I cannot claim to have taken in this research a 'pure' CONGT (1995) approach. The reason being that I was unable to go back to the field to explore some of the emerging concepts and themes with the same focus groups. This is a key feature of GT, called theoretical sampling which involves seeking and collecting pertinent data to elaborate and refine categories in your emerging theory (Charmaz 2006b: 96). The opportunities to go back into the field were challenged by the difficulties with the recruitment process for the focus groups. Although this was addressed to some extent with interviews with

community workers. Nevertheless, despite the externally imposed constraints and challenges to conducting a truly CONGT approach I ensured that the main tenets were adhered to. This included data collection undertaken concurrently with preliminary data analysis to identify emerging themes that were explored with subsequent focus groups, such as the role of the media as well as changing beliefs about ageing. In addition, the inductive and emergent approach to data analysis led to the development of a typology consisting of four types of help-seeking approaches and care strategies. The process of how these were developed will be discussed in more detail in the methods chapter.

### **3.5 Section 3: Selection of methods**

#### **3.5.1 Focus groups with lay public participants**

Charmaz (2014) acknowledged that there is an assumption amongst some scholars that CONGT (1995) is associated with conducting interviews only. However, Charmaz (2014) suggested that researchers can utilise other methods, such as ethnographic approaches. Therefore, the use of other methods of data collection are not precluded, but Charmaz advised that the *selection of the data collection method should be determined by how it can help you answer your research question with ingenuity and incisiveness ... so that the data collection methods emerge from the research question and where we go with it* (Charmaz, 2014: 26-27).

In the light of this advice, my decision to use focus groups as a data collection method was driven in part by the purpose of the research questions, which was to explore lay public attitudes, beliefs and experiences. At the same time, I sought a method that enabled greater access to lay perspectives in a dynamic way based on interactions with diverse perspectives. This may not have been possible in interviews with participants on a one-to-one basis, as the researcher is tasked with *aggregating individual data in order to speculate about whether or why interviewees differ* (Morgan, 1996: 272). In contrast, focus groups provide an opportunity to understand the process of construction, defence, interrogation and modifications of concepts and views through group interactions (Morgan, 1996; Kitzinger and Barbour, 1999; Silverman, 2013). They provide a unique opportunity for the researcher to directly explore with participants convergent and

divergent views, to uncover reasons for why (Morgan, 1996), for example, they conceptualise dementia in the ways that they do, as well as the basis for stigma and disclosure strategies regarding dementia in their families.

The use of focus groups with CONGT (1995) was also possible because as a method it is not aligned to any *major methodological traditions of qualitative research and thus relatively agnostic in terms of the methodologies attending them* (Kidd and Parshall, 2000: 296). They were also selected as a way of enabling communities that are marginalised in research (Morgan, 1996) to participate and *are purported to be a powerful, versatile, and effective research tool in accessing community attitudes* (Culley et al., 2007: 110) and group norms (Kitzinger and Barbour, 1999).

### **3.5.2 Face-to-face interviews with community workers**

As stated previously, I could not go back to the focus groups to undertake theoretical sampling, to refine my data and increase my knowledge (Charmaz, 2014: 26). I therefore selected to use a qualitative mixed-methods approach combining interviews with focus groups. Morse (2009) defines this mixed qualitative methods approach in the following way, saying it consists of *one complete project (called the core component), and strategies from a different method used as a supplementary component (conducted simultaneously or sequentially to the core component)* (Morse, 2009: 1523). In this research, the core component was the focus group and a supplementary component consisted of face-to-face interviews with community workers using a topic guide (Appendix I and J).

The purpose of these interviews was to elicit an understanding of the wider context in which, for example, the factors that shape or influence help-seeking within the communities they work with could be explored. This mixed-methods approach was utilised not as a method of triangulation to validate the findings from focus groups but to seek complementary information (Hammersley, 2008) that could *illuminate different facets of situations and experiences* (Fossey et al., 2002b: 11).

Charmaz (2014) provided a considerable amount of guidance about the purpose and function of interviews, which she described as 'intensive interviewing'. The participant, in keeping with the subjective epistemological approach of CONGT (1995), is recognised

as the co-creator of knowledge with the researcher, and therefore Charmaz described intensive interviews as *contextual and negotiated* (Charmaz, 2014: 71). Therefore, findings from interviews are viewed as a construction or re-construction of reality (Charmaz, 2014).

Intensive interviewing in CONGT (1995) has two functions, firstly to explore the world and secondly to create a theory through the development of tentative theoretical categories (Charmaz, 2014: 83). This can involve the researcher using theoretical sampling to select participants that may not have been included in the original research plan (Charmaz, 2014).

In this research, a similar approach was undertaken, as the initial interviews were invaluable in helping me to understand *what is happening here* (Charmaz 2014: 87) in relation to the areas of research interest. They also influenced the content of my topic guide (Appendix I) to facilitate focus group discussions. My interviews included a focus on understanding and exploring some of the emergent concepts from the focus groups, such as changing values about familial care amongst younger generations within Indian communities. This process will be explained in more detail in Section .6.1 of the methods chapter. As a consequence, I selected participants whom I considered would be most likely to contribute to some of the tentative concepts I was developing as the research progressed. This is in keeping with the CONGT (1995) approach to interviewing, in which early interviews guide and focus subsequent interview questions.

## **3.6 Section 4: Ethnicity and generational age**

### **3.6.1 Operationalising ethnicity**

In the theoretical orientation section of the Literature Review chapter in Section 2.9.3.1 I discussed how I drew upon critical sociological perspectives to guide my choice about a concept of ethnicity and its use within research. Whilst these perspectives were helpful, it was challenging to find a way to operationalise this concept. However, despite the challenges I persevered and found a Social Constructionist approach advocated by Torres (2015) to draw upon. This involves a recognition of ethnicity as bi-dimensional. The first



dimension consists of the way in which ethnicity is ascribed by others, for example, on the basis of common ancestral origins, religion and language (Torres, 2015). In this research my use of ethnic categories such as Indian or Caribbean was on the basis of common ancestral origin and was used to identify and recruit participants.

The second dimension involves a recognition that participants themselves may not self-identify with the category used for recruitment, for example, the white British category is an umbrella term for distinct ethnic groups such as the Welsh and Scottish, who may prefer not to be identified as white British. This is because ethnic categorisation can be contested, fluid and situationally contingent. As a consequence it depends upon how participants themselves negotiate and identify with them (Torres, 2015). Therefore, in recognition of the criticism targeted to my approach of using ascribed or *pre-designated taxonomies* (Bradby, 2003: 6) of ethnicity categories, I ensured there was an opportunity at the end of each focus group to ask how participants themselves defined their ethnicity and what it meant to them (Bradby, 2003; Smith, 2002). Their responses to this question will be discussed in following chapter entitled participants' characteristics and research context. I also used some of their responses as data for my analysis.

There also seems to be little definitive practical guidance on how to operationalise ethnicity during the analytical process, although Gunaratnam's (2003) advice for researchers is helpful, as she suggested illuminating the *heterogeneity, areas of ambiguity and partiality within any category of difference* (Gunaratnam, 2003:49). This guards against making the inference that for any individual or social group their difference can solely be attributed to one single category, such as ethnicity. This requires attention being paid to the relational nature of social difference. When patterns do emerge amongst individuals and groups of people, the task is to ensure the associations/relationships are linked or identified in circumstances or instances found in the wider social contexts (Gunaratnam, 2003).

### **3.6.2 Operationalising generational age**

As we have read in the theoretical orientation section of the Literature Review chapter, generational age can be used as a research category, but there seems to be little or no consensus about what constitutes a generation (France and Roberts, 2015b; Burnett,

2003). As a consequence, it is advised that as a conceptual category it should be wide enough to include chronological age and encompass referents that are cultural, social indicators of age, as well as meanings assigned to ageing (Grenier, 2007). Based on this advice, I operationalised generational age using age denominators combined with my assumptions about the impact of the life cycle effect (Dimock, 2019). This entailed delineating a difference in generational age on the basis of their positions within the life cycle, so for example the age group 18-30 years are assumed to be in education, during the early stages of their careers or in jobs. The 30-40 years group are assumed to be at a stage where they may have spousal relationships and young families, whereas the older age group between 40-55 years are assumed to have older children and possibly care for their older parents.

### **3.7 Section 5: Ethical Framework, and issues of quality and validity**

#### **3.7.1 Ethics in qualitative research**

Ethical issues in qualitative research can arise as it is often conducted in naturalistic settings, which may be characterised by fluidity and uncertainty (Miller et al., 2012a). Unlike in a research lab, researchers are likely to be interacting with people in their homes, and discussing emotive issues which may spontaneously give rise to disclosure about sensitive matters or safeguarding issues which cause emotional harm and distress (Richards and Schwartz, 2002; Miller et al., 2012a). Furthermore, researchers are involved in the creation of knowledge about the private lives and perspectives of participants with a view to sharing these, and this can raise ethical concerns with regards to the misinterpretation of data by the researcher and misrepresentation in publications (Richards and Schwartz, 2002).

Ethically, the researcher must also attend to the power imbalance which is inherent in qualitative research such as interviews (Brinkmann and Kvale, 2005), as the researcher, given their social class (Fontes, 1998) and their 'expertise' in a given area, can influence the agenda in terms of the discussion and also directing the enquiry to meet the end goals

of the research (Brinkmann and Kvale, 2005). In relation to structural aspects of power, researchers are also aligned with academic institutions which yield power and influence in comparison to socio-economically disadvantaged communities (Brinkmann and Kvale, 2005). The inherent power imbalance behoves researchers to consider how participants are empowered through their participation in the research process (Fontes, 1998). The ways in which I practically sought to address these issues during the fieldwork will be discussed in section 4.8.

In the light of such issues, I therefore agree with Ryen's (2011) assertion that qualitative research engages in a *social reality which is complex, multi-dimensional and contextual phenomena* (Ryen 2016: 35). In view of this complexity, Guillemin (2004) called for a different approach to ethics within qualitative research, distinguishing between procedural ethics, which refers to the ethics committee's guidance and procedures, and 'ethics in practice'. The latter refers to those unexpected incidences such as a line of questioning that distresses a participant or a spontaneous disclosure of abuse. Whilst Guillemin and Gillam (2004) acknowledged such incidences cannot be planned for, they called for reflexive ethical practice that is considered throughout the research process. This entails *researchers reflecting to foresee prior to conducting their research how it may affect participants, and how as researchers they envisage responding to potential ethical concerns should they arise* (Guillemin and Gillam, 2004: 277).

### **3.7.2 Reflexive ethical practice for research with BAME communities**

Guillemin and Gillam's (2004) suggestion about the need to engage in ethical reflexivity is of particular relevance when conducting research within BAME and socially economically disadvantaged communities. This is because ethical processes and procedures are not designed to take into account the realities of ethical practice in multi-ethnic communities. So, in reality *ethics is nothing universal, but a constructed product of cultural discourse* (Brinkmann and Kvale, 2005:159).

Consequently, the researcher not only has to respect the integrity of the research participants but also pay heed to the cultural context in which the research takes place (Brinkmann and Kvale, 2005). Currently, ethical guidance can be construed as a

tokenistic nod to this call, in that it provides little beyond directing researchers to be inclusive of diverse communities on account of characteristics such as ethnicity and age. This is further compounded at the micro level in that little advice and guidance is provided beyond advising that research study documentation is translated to promote accessibility to research (Allmark, 2004).

In practice, being ethical in research conducted with BAME communities entails the researcher considering the ethical dimensions of using ethnicity and ethnic categories in research. This involves providing clarity on how ethnicity is conceptualised and operationalised to avoid essentialist approaches to findings, and attributing differences in health outcomes to culture without contextualising the impact of factors such as socio-economic, migration, gender and age (Vickers et al., 2012). Failure to do so can lead to 'group harm' at a macro level even if at a micro level individual participants have been treated with respect and dignity (Brinkmann and Kvale, 2005). An example of macro-level group harm may be when findings perpetuate stereotypes of ethnic groups and cultures, as well as pathologise them (Salway et al., 2011b). Therefore, with respect to the issues identified in the preceding paragraphs, as part of the methodological framework my conceptualisation and operationalisation of ethnicity is clearly articulated.

Also important to consider when conducting cross-cultural research involving BAME communities and socio-economic disadvantaged white British communities is that the implications of power in relationships, as discussed in the preceding paragraphs, can be accentuated. One way to address this is to ensure there is an ongoing relationship with community based partnerships that foster dialogue and relationships with BAME communities about the research to reduce imbalances in power (Marshall and Batten, 2004).

There are also micro-level ethical issues to consider when conducting research with BAME communities. For example, with regards to informed consent the researcher may need to be aware that the ethical principle of autonomous decision making may not be compatible with collectivist values amongst some members of BAME communities (Williams, 2005). Consequently, as Bhopal (2004b) explained, the decision to participate in research may be more of 'a communal decision' e.g., with members of a family, rather

than an individual decision. Moreover, conventional ethical guidance emphasises written participant information sheets as a way of informing potential participants about a research study. This may not always be considered appropriate as some members of BAME communities may favour an initial face-to-face approach with researchers to establish trust and rapport (Das, 2010) before choosing to engage in a research study. In addition, written ethics documents can pose barriers to understanding about research and also act as barriers to research participation (Macneill et al., 2013). I shall discuss in the methods chapter how I sought to address some of above issues in section 4.8.

### **3.7.3 Ethical process and procedures**

#### **3.7.3.1 Informed consent**

According to the National Health Service Research Authority (HRA) (NHS Health Authority, 2019) for informed consent to be legal and ethical it has to be: given by a person with capacity; voluntarily given, with no undue influence, and; given by someone who has been adequately informed and fair choice is made.

In light of this guidance, to ensure potential participants were adequately informed and to allow them to make a fair choice, the research study materials, including the participant study information sheet (PIS) (Appendices B & C) and consent forms (Appendices D & E), were written as much as possible in plain English to cater for different levels of literacy and comprehension in English. Additionally, translators for these research study materials were already identified prior to them being written. This was to ensure I was prepared in case recruiting organisations identified a need for them to be translated, however, they did not identify this need.

Several copies of the PIS were given to each recruiting organisation in advance of the focus groups for them to distribute to potential participants. A minimum of three weeks was given to each recruiting organisation to ensure they had enough time to distribute the PIS to potential participants. The attention to the time frame was also designed to facilitate an informed choice amongst potential participants about whether or not to participate. In furtherance of participants making an informed choice, I inserted my mobile phone number within the PIS so that potential participants could contact me in case they had

any questions prior to their participation in the research.

### **3.7.3.2 Protecting participants from harm**

When using gatekeepers (Rugkása and Canvin, 2011a) for recruitment to a study, there is always the potential of participants being unduly influenced or coerced into participating in research by gatekeepers. To counteract this, I enlisted the assistance of staff and volunteers that I were familiar with and trusted to behave in an ethical manner with regards to the recruitment of participants. The trust of these 'gatekeepers' had been mutually cultivated over many years and, as they had recruited participants in previous studies I had conducted, they had a proven track record.

Research on health conditions has the potential to invoke distress and anxiety amongst research participants (Richards and Schwartz, 2002). During the written informed consent process, participants were overtly alerted to this possibility in the PIS, with reassurance that participants could leave the discussions at any point without giving an explanation for why they chose to leave. Additionally, I emphasised immediately prior to the discussions that participants could say as much or as little as they wanted to in response to any line of questioning, and they were reminded of this intermittently throughout the focus groups and interviews.

Ethical practice also involved ensuring that the participants led the focus group discussions as much as possible, whilst balancing the need to address the research goals. While conducting the focus groups I decided that I would follow up on points where possible for clarity and expansion of issues, rather than using the topic guide rigidly to structure and force lines of questioning. In this way, the imbalance of power (Miller et al., 2012b) between the participants and the researcher could be partly addressed. Although that is not to say that attentiveness to these processual issues obliterates the inherent structural power imbalances between the researcher and the researched.

### **3.7.3.3 Confidentiality and Data Protection**

At the time of conducting this research, The Data Protection Act (Data Protection Legislation, 2018) informed the requirements for the implementation of research studies. It encompasses eight principles, and those that were of relevance to this research

included the following; data pertaining to the research is processed fairly and that participants are aware of how it will be used; that it is appropriate for the purpose of the research; not kept longer than necessary for the purpose; accurate and up to date, and,; kept securely to safeguard participants' confidentiality and privacy (Data Protection Legislation, 2018).

The written informed consent process detailed the purposes for which any personal data would be used, including anonymised demographic information (Appendices F & G), the use of anonymised quotations, and details of who within the research team will have access to the data. Finally, the written informed consent process also informed participants that should any audit of this research take place, the individuals or team auditing the research would have access to all the information pertaining to this study. The ethical review process also took into account the fact that the participants' information collected during the course of the study was relevant and appropriate to the purpose of the study.

To safeguard privacy, security and confidentiality I ensured that each participant's signed consent form was kept separately to the location of the demographic details form so the two forms could not be linked. Both these forms are kept securely in locked filing cabinets in offices that have secure and restricted entry. The transference of audio files of the focus groups and interviews were undertaken in person by the researcher to the transcriber, and the transcriber's written transcripts of audio files were given number identifiers. The transcripts of interviews and focus groups were stored on password-protected computers in a locked office.

A key requirement of the National Research Advisory Service (NRES) guidance on ethical practice is to ensure the personal information of participants is kept confidential. However, as Wiles et al. (2008) pointed out, *confidentiality is also linked to anonymity, and that involves ensuring the presentation of findings does not enable participants to be identified (chiefly through anonymisation)* (Wiles et al., 2008: 418).

The challenges to the above requirements come from the nature of interpretative qualitative enquiry itself, because researchers are urged to provide thick descriptions

which may inadvertently disclose participants' identities in the reporting of findings (Damianakis and Woodford, 2012). This risk may be exacerbated when research is conducted with a small sample of participants. A further risk is posed during the publishing of researching findings when researchers are often asked to provide demographic data, and again this may breach the confidentiality and anonymity of research participants (Damianakis and Woodford, 2012).

I addressed the issues raised in the preceding paragraph by reporting findings with the use of anonymised quotes, without identifiable information relating to distinctive and identifiable individual circumstances. In addition, the reporting of demographic information pertaining to the characteristics of the research sample will be in generalised categories such as ethnicity, age, country of birth, and level of education, rather than linking these categories to specific focus groups and gender.

I was also mindful of confidentiality issues that are likely to arise when conducting research with participants living in connected communities by virtue of, for example, living in geographical proximity and therefore likely to know each, or through an affiliation to a community and voluntary sector organisation (Damianakis and Woodford, 2012). In all focus groups I asked participants to be mindful of the disclosure of personal and confidential information during discussions and for each participant to respect the confidentiality of discussions outside of the focus group.

#### **3.7.4 Quality and validity**

The evaluation of scholarly scientific quantitative research underpinned by positivist research focuses on whether research findings can be generalised and replicated in other research studies (Cresswell, 1994). This involves employing criteria such as validity and reliability. The former refers to internal validity which pertains to whether the causal relationships between variables are robust, whilst external validity refers to whether the results of a study are generalisable beyond the research context of the study (Bryman, 2016b: 28). Reliability relates to whether the results of a research study can be repeated (Bryman, 2016b: 28).

During the early era of qualitative research, researchers such as LeCompte and Goetz



(1982) applied the above criteria to qualitative research (Bryman, 2015; Cresswell, 1994). However, the landmark work of Guba and Lincoln (1984) highlighted that because the aims of qualitative research are fundamentally different to quantitative research, it requires a different set of evaluative criteria (Bryman, 2016b). This is because unlike quantitative research, qualitative research aims to gain insight into participants' meanings, actions and perspectives (Flick, 2018).

Several scholars have suggested alternative ways in which qualitative research can be evaluated. These suggestions emanate from the philosophical positions they hold (Mays and Pope, 2000a). Hammersley (1990), taking a subtle realist approach (Seale, 1999), argued there should be two elements to assess validity and credibility. The claims of validity made by the research should be assessed for their plausibility in the context of current knowledge (Hammersley, M. 1990:61). The assessment of credibility involves a focus on the nature of the phenomena within studies and the circumstances of the research (Hammersley, 1990:61). A contrasting philosophical position was highlighted by Mays (2000), who suggested *extreme relativists argue all research perspectives are unique and each one is equally valid on its own terms* (Mays and Pope, 2000a: 50).

Seale (1999) though, argued that methodological discussions need to be balanced so that errors can be avoided but, at the same time, anxieties are alleviated by not getting too deeply mired in philosophical debates (Seale, 1999). He argued, therefore, for a more pragmatic approach to consideration of evaluative criteria. This involves researchers considering the strengths of various methodological positions such as positivism and constructivism, but then to develop their own style which consists of principled decisions rather than a uniform set of beliefs (Seale, 1999: 476).

#### **3.7.4.1 Selection of quality criteria to evaluate this research**

It is with Seale's (1999) advice in mind that I referred to criteria suggested by Charmaz (Charmaz 2006a) for CONGT and these include credibility, which is evaluated with reference to the rigour and robustness of the analysis process. Other criteria include resonance, which encompasses criteria that enables it to be assessed from the perspective of its applicability and relevance for external audiences. This is an important criterion for this research as it needs to contribute to the existing body of applied health

research in dementia and provide insights to commissioners and healthcare practitioners who provide dementia support and care to multi-ethnic communities. Finally, it also includes 'originality of contribution' and this is highly relevant to a PhD research project in relation to whether it offers new insights or extends existing knowledge (Charmaz, 2006a).

### **3.8 Summary**

This chapter has discussed the justification for using a qualitative approach to this study with lay public participants and community workers. Amongst the diverse spectrum of qualitative approaches, the rationale for using GT has been explained, and after scrutiny of the various strands of GT, the choice and justification for CONGT was articulated. This methodological framework also involved the use of focus groups as a way of accessing diverse lay public generational perspectives within multi-ethnic communities because it was considered to be expeditious as well as inclusive. This approach was complemented by interviews with community workers. There is also coverage of the concepts and operationalisation of ethnicity and generational age used in this research to facilitate transparency and accountability for how these concepts were used. These clarifications have also been undertaken to explain how the intersection of ethnicity and generational age has been an active research design strategy to avoid essentialising cultural explanations as a way of explaining differences in conceptualisations and understandings of dementia, as well as its constructions. The issues related to the ethics of conducting research with BAME communities and socio-economically communities, including those from white British communities, have been discussed in detail. Finally, a brief discussion about the debates and discussions of criteria by which to appraise qualitative research has been undertaken. In lieu of this discussion, criteria from CONGT (1995) has been chosen to assess the credibility, usefulness and resonance of this research. In the next chapter on methods, I shall describe the operationalisation of this methodology with respect to data collection and analytical processes.

# Chapter 4: Methods

## 4.1 Introduction

The methodological framework for this research was discussed in the preceding chapter. It included a justification for the selection of a qualitative approach and the use of CONGT (Charmaz, 1995) to inform the data collection and analytical strategies to address the research questions. In this chapter I shall explain how the methodological framework informed the delivery of this research, including recruitment stages, ethics in practice and process, conduct of the focus groups and interviews, as well as data analysis. Before I go onto these, here is a reminder of the research questions:

1. What is the knowledge and understanding of dementia in younger and middle-aged adults in multi-ethnic communities?
  - (a) What factors influence and contribute to this knowledge and understanding?
2. How is dementia conceptualised in younger and middle-aged adults in multi-ethnic communities?
  - (a) What factors and issues shape and influence their conceptualisations of dementia?
3. How is old age and ageing conceptualised in younger and middle-aged adults in multi-ethnic ethnic communities?
  - (a) How is old age and ageing framed in relation to dementia?
4. What are help-seeking strategies for dementia amongst younger and middle aged adults within multi-ethnic ethnic communities?
  - (a) What factors and issues shape and influence these?

## **4.2 Overview**

I will demonstrate how CONGT (1995) informed my recruitment strategies which resulted in a final sample of ten multi-generational ethnic focus groups and five face-to-face interviews with community Workers and volunteers that provide support to Indian, Caribbean and white British communities.

In keeping with GT (Glaser and Strauss, 1967) I conducted the preliminary data analysis concurrently with data collection, using memos to inform a theoretical sampling strategy which involved the recruitment of an additional group of focus group participants aged between 30-40 years. The data collection process was guided by the ethical framework discussed in the Methodology chapter in Section 3.7. This involved ethical recruitment strategies, informed consent and a commitment to provide feedback of findings to participants who indicated their agreement to receive it.

During the substantive stage of data analysis after the data collection process was completed, memos were used alongside constant comparisons to guide the data analysis process. The large amount of data and its complexity involved a number of different stages within the analytic process and led to the development of themes to address questions related to knowledge and understanding of dementia, as well as conceptualisations of dementia and ageing. The creative, systematic and emergent approach, which is an integral part of GT (Glaser and Strauss, 1967), led to the development of a typology to explain help-seeking approaches and care strategies in this research sample. In addition, the perspectives and experiences of Indian and Caribbean focus group and interview participants about help-seeking in older generations and their wider communities were examined. These types offer new and fresh insights on help-seeking strategies in hitherto under-researched lay public multi-generational communities in the UK.

## **4.3 Rationale for selection of study sample**

The study sample of white British, Indian and Caribbean participants were selected on the basis that they, along with white Irish communities, have the highest percentage of older

people in the UK population.

Locally in the city of Leicester, the Joint Strategic Needs Analysis (JSNA) (Leicester City Council 2016b) identified a greater rate of early onset dementia at 6.1% amongst BAME communities in Leicester, in comparison to 2.2% for the UK population as whole. This may be accounted for by the higher rates of cardiovascular disease and diabetes in Leicester amongst its BAME population, which are above the national average (Leicester City Clinical Commissioning Group and Leicester City Council, 2016b: 1).

## **4.4 Study sample**

The research sample comprised two components involving the following:

1. Community workers and volunteers from the voluntary sector and charity staff organisations
2. Lay members of the public from Indian Hindu Gujarati, white British and Caribbean communities.

This research sample was recruited in two phases, with community workers in phase one and focus group participants in phase two. These phases ran concurrently, with interviews initially conducted in phase one with two community workers to inform the focus group topic guide (Appendix I). The final three interviews with community workers were conducted in phase one to facilitate a deeper exploration of emerging issues from the focus groups.

### **4.4.1 Inclusion criteria and exclusion criteria**

The following tables provide details of the selection of study participants based on the following criteria:

Table 4.1: Inclusion and exclusion criteria for community workers and volunteers

| <b>Inclusion criteria</b>   | <b>Exclusion criteria</b>  |
|---|--|
| Experience of providing support and services to PWD and/or their carers and wider community | Those who do not have direct experience of working with PWD and carers |
| Age 18 yrs. and over  |  |
| Read and write English and/or Gujarati  | No fluency in written English or Gujarati                              |

Table 4.2: Inclusion and exclusion criteria for lay public focus groups

| <b>Inclusion criteria</b>              | <b>Exclusion criteria</b>                          |
|--|--|
| Lay public                             | Healthcare professionals                           |
| Age 18 yrs. and over                   | Family or professional carers                      |
| Read and write English and/or Gujarati | Not able to read and write English and/or Gujarati |

## 4.5 Sampling strategy

### 4.5.1 Phase 1: Interviews with Community Workers

In this phase, a purposive sampling strategy (Ritchie et al., 2003) was initially employed to select two community worker participants. Later on, during phase 1, a theoretical sampling approach informed the selection of three additional community workers. This made the final sample of community workers for this research number five in total. Theoretical sampling is a component of grounded theory and entails a concurrent process of collecting data and data analysis for the purposes of generating theory, so that this process informs *data to collect next and where to find them, in order to develop his theory as it emerges* (Glaser and Holton, 2007: 59).

To facilitate this approach to sampling, the recruitment strategy was staggered and took place over the course of one year. It involved the identification and selection of a sample of participants who could contribute their professional perspective to help *densify and refine* some of the emerging concepts from the focus group discussions and vice versa

(Breckenridge and Jones, 2009: 3). In this respect, it fulfilled the criteria for theoretical sampling in that the data from interviews and focus groups informed who I needed to interview and also the issues I wished to explore in subsequent interviews. For example, interim analysis of the first two community worker interviews contributed to developing questions relating to issues such as stigma, privacy and disclosure in the focus groups.

Conversely, focus groups with younger participants in the 18-30 year age range (Indian Hindu Gujarati and white British) alerted me to further explore the impact of occupational mobility, financial prosperity and poverty during some of the interviews with two community worker participants during the later stages of the research. As discussed in the methodology chapter in Section 3.5.2, these interviews were not designed to 'validate' the focus group findings. Instead, they sought to facilitate an 'in-depth' coverage and contextualisation to some of the emerging concepts from the focus groups as part of the theoretical sampling strategy.

#### **4.5.2 Phase 2: Focus groups**

The selection of participants based on generational age using a life stage approach (Dimock, 2019) was undertaken. Consequently the sampling strategy was purposively driven from the outset of the research to include participants within the following age groups 18-30 years and 40-55 years.

Another factor taken into account in the sampling strategy was to ensure both age and gender were evenly balanced within each focus group age group. To facilitate this, a quota sampling frame (Bryman, 2016a) was designed and shared with the recruiting community and voluntary sector organisations. However, this approach to sampling had to be abandoned as the recruiting community and voluntary sector organisations experienced difficulties recruiting male participants.

### **4.6 Sample size**

#### **4.6.1 Phase 1: Interviews**

In this research the final sample of five community workers was small. However, small sample sizes do not pose a methodological challenge in grounded theory studies, as the

purpose of a sample is to provide an insight on categories to elucidate *properties of categories and relationships between them* (Charmaz, 2006b: 18). In this respect, the depth of information from the interviews was sufficient to provide rich and contextual data (Charmaz, 2014) to aid the development of types to inform the typology. This approach to sample size was particularly welcome given there are so few voluntary and community sector organisations who fulfilled the inclusion criteria, in particular, from Caribbean communities that support older people, including people with dementia and their carers. As a consequence, the sample size for this group of participants was inevitably going to be small.

#### **4.6.2 Phase 2: Focus groups**

In line with focus groups guidance from the supervisory team, the aim was to recruit four to six participants for each focus group, although each recruiting organisation was asked to recruit eight participants in anticipation of a dropout rate of two people per focus group.

### **4.7 Recruitment strategy**

#### **4.7.1 Phase 1: Face-to-face interviews with community worker participants**

I contacted five voluntary and charity sector workers individually to arrange a mutually convenient time and place to hold meetings to explain the purpose of the research, to discuss the process of informed consent including audio recording the interview, as well as preferences about the venue for the interview. Each participant at the end of the meeting indicated their willingness to participate in an interview and a mutually convenient time and place were agreed for the interview. One community worker preferred to discuss the details about the interview over the telephone due to her busy work schedule and agreed a date and time for an interview at the end of the telephone conversation. All interviews were conducted at least a minimum of one week after the initial face-to-face meeting and telephone conversation to give participants time to withdraw from participation in the interview if they wished to do so. The final and fifth participant was identified from one of the organisations that recruited the focus groups. She agreed to participate in an interview once my final focus group was held at their organisation. Upon her agreement, I sent her



the participant information sheet via email and after several weeks I was able to arrange a mutually convenient date and time in which to conduct the interview. Four interviews were conducted at the participants' place of work. One interview was conducted at a local Sainsbury's café upon the request of a participant.

#### **4.7.2 Recruiting 'gatekeeper' organisations for focus groups and ethics in practice**

This phase of the research involved enlisting the assistance of voluntary and charity sector organisations to undertake recruitment of focus group participants. I held a number of meetings with community workers and volunteers from these organisations. They were supportive of the research and regarded it to be a relevant and worthwhile project as they perceived dementia to be increasingly prevalent in these communities.

During these meetings I explained the purpose of my research and requested their assistance with the recruitment of participants. These community workers and volunteers, on behalf of their organisations, were undertaking a role as described in the research literature - a gatekeeping role (Rugkåsa and Canvin, 2011b). Whilst the disadvantages of using 'gatekeepers' in research studies is well documented, such as blocking access to potential participants (Sixsmith et al., 2003), this was not my experience. Instead, I was able to benefit from the advantages of engaging with gatekeepers, which included access to participants from socio-economically deprived backgrounds who may not ordinarily have access to participate in research (Lata, 2020). Furthermore, they also helped to 'legitimise' my position and credibility as a 'safe' researcher with communities who may have a distrust of research (McAreavey and Das, 2013), as I was known to them from my previous job and volunteer roles. These meetings with community workers and volunteers who worked with Indian communities also helped to establish whether I would need to translate the study documents into Gujarati.

As discussed in the Ethics Framework section in Section 3.7 in the Methodology chapter, I ensured that I did not exploit the good will of the recruiting organisations, who are overstretched and poorly funded. Therefore, a payment of £150 per generational

age group was discussed and agreed with each organisation in the spirit of reciprocity and support. I supported them to navigate the procedure to claim these monies from De Montfort University (DMU). I also discussed how the focus groups would take place, including the informed consent procedures, use of a topic guide and explained that the focus group discussions will be digitally audio recorded. I also informed the community workers and volunteers that each focus group participant would receive a £20 store voucher at the end of the focus group, and they would be required to sign and date a form to verify they had received the £20 store voucher for DMU's financial audit purposes.

Once a verbal agreement had been reached to support this research, I dropped off multiple copies of the PIS to each organisation for them to distribute to potential participants to ensure they were fully informed about the research before agreeing to take part.

#### **4.7.3 Challenges to recruitment of focus group participants**

The recruitment process for participants aged 30-40 years proved to be very challenging for Indian and white British focus groups, but after much persistence on the part of the recruiting organisations it was achieved.

All of the recruiting organisations involved in this research shared their difficulties in recruiting male participants to the research and consequently. As a result, the 'balanced' gender representation I required for the research was not achievable. In addition, within the Caribbean focus groups, two people who identified as African took part in the research, and their contributions to discussions served to highlight commonalities with perceptions and experiences with participants from a Caribbean background rather than differences. As a consequence these two participants, who are identified as African, were included in the final sample of 14 Caribbean participants.

### **4.8 Process of data collection**

#### **4.8.1 Conducting the interviews**

In the interviews with charity staff and volunteers, full written informed consent with permission to digitally audio record the interview was undertaken immediately prior to

conducting each interview. All participants were also given a copy of the 'information about participant' form (Appendix H) to complete after informed consent was undertaken. This requested demographic information (age group, gender, and ethnicity), in addition to information about their current job role and its duration. The interviews ranged from 45 minutes to one hour in duration.

My approach to conducting the interviews was informed by Charmaz's (2014) guidance on intensive interviewing, as described in section 3.5.2 in the Methodology chapter. It involved the use of a topic guide (Appendix J) that was iteratively developed in response to some of the interim findings from the focus groups, but I used this flexibly. It was an aide-mémoire that consisted of a few questions to break the ice and put the participant at ease. Thereafter, I 'let go' and let the participant take the lead. I would then ask follow-up questions which either sought to elaborate on the reflective comments they made or sought clarification about the meaning of statements. This style of interviewing fits quite closely with my natural style of interviewing and entails paying close attention to *eliciting the participant's definition of terms, situations and events with a view to tapping into their assumptions, implicit meanings and tacit rules* (Charmaz, 2014: 95).

That being said, I was also mindful during these interviews that I also had to 'balance' facilitating participants' contributions with the pursuit of my own Grounded Theory explorations about some of the categories and concepts I wished to explore. I was able to achieve this delicate balancing by 'weaving them in' at appropriate junctures, such as when a participant's responses naturally coincided with my interest to further explore these, or towards the end of the interviews when I asked specific questions.

#### **4.8.2 Conducting the focus groups**

Prior to commencing the planned six focus groups, I convened a pilot focus group with Indian participants aged 40-55 years with the assistance of the South Asian Health Action Group. This pilot focus group provided an opportunity to re-familiarise myself with conducting focus groups and to trial the topic guide with questions arising from my first interviews with community workers.

The participants in the pilot Indian Hindu Gujarati focus group also knew each other and

that affected the dynamics of the group discussion positively. As did the fact that two of the participants had family members with dementia and were able to reflect and share their experiences with other participants. Whilst I was informed that this group of participants were fully conversant and confident to speak in fluent English, a few of them when discussing some of the issues spoke bilingually in English and Gujarati. This focus group was two hours in duration with a ten-minute break for refreshments.

#### **4.8.2.1 Setting the scene**

For each individual focus group, I had prepared in advance a plastic folder containing a pack of study documents for each participant. Once all participants were seated and ready to commence, I introduced myself and shared information about the research, as well as details about the anticipated length of the focus group, including a break for refreshments. This was followed by introductions led by the participants themselves.

#### **4.8.2.2 Ethics in process: undertaking written informed consent**

I conveyed a summary of the PIS and I invited questions about the research. Thereafter, I asked each participant to refer to the consent form and went through each line of the consent form with the whole group, requesting them to sign their agreement by placing their initials in the boxes, only and if they were happy to proceed. I also informed them of the optional clauses to receive feedback in writing and/or to attend a feedback event to find out about the key findings from the study. Once participants had dated and signed their consent forms I asked them to complete the 'information about participant' form (Appendix G).

Once the paperwork had been completed, prior to commencing discussions I asked for ground rules to be respected, including confidentiality as participants had been drawn from small and tightly knit communities and spontaneous disclosures of a sensitive nature may take place (Damianakis and Woodford, 2012). All the focus groups took between one hour and 45 minutes to two hours with a ten-minute break for refreshments.

#### **4.8.2.3 The balancing act**

I had drawn upon the wider literature on the social constructionist theoretical approach to guide my approach to focus groups. I was aware this required a greater emphasis on

the researcher's *skilful facilitation of the group dynamic... to support participants to progressively take responsibility for managing group dynamics as well as the topic of discussion by the participants* (Millward, 1995: 28). In this way, it can assist with supporting participants to introduce sensitive issues because the participants themselves create the rapport to enable these to be discussed rather than the researcher 'forcing' the issue (Millward, 1995).

Therefore, my intention with the topic guide was to use it to stimulate the initial discussions within focus groups and then to 'let go' and enable participants to take the lead and responsibility for the discussion, as outlined in the previous paragraph. My preference for this flexible approach was in contrast to the vignette approach used in a UK study on dementia involving BAME multi-generational lay public participants, as a way of eliciting participants' engagement and responses (Fontaine et al., 2007). Whilst I recognised the benefits of using a vignette, such as enabling comparisons of responses across groups to the same vignette (Barbour, 2008), I felt it had the potential to impose a structure on the discussions, potentially limiting new avenues of enquiry in this under-researched study population. It is also not in keeping with the CONGT (1995) approach which facilitates both participants and researchers to co-create the flow and content of the discussions.

I was also attentive to visible cues of disengagement with the discussions, as a minority of participants initially chose to position their chair away from the tables when all the participants were seated at the commencement of focus groups. However, in all such instances, I observed as their confidence and trust grew during the course of discussions, their body language and the positioning of their chairs signalled a more active engagement.

Nevertheless, despite my best intentions about wanting to conduct all the focus groups characterised by 'free-flowing' discussions between the participants and myself, the reality was very different, as the dynamics in each focus group were unique. I found the older age groups for all ethnic groups engaged in more free-flowing discussions with each other, and my role in these focus groups was simply to clarify statements and meanings. Whilst I was pleased to see such rapport and engagement brought to the fore

one of the difficulties in using a CONGT (1995) approach was the tension between encouraging free-flowing discussions and exploring in depth some of the newer lines of GT enquiry that had emerged, such as the impact of the media. This delicate balancing act was acknowledged by Charmaz (2014) with reference to conducting interviews, as she stated this *challenges grounded theorists to create a balance between asking significant questions and forcing responses-more so than other forms of qualitative data collection* (Charmaz, 2014: 95).

My response to this challenge was to, for example, ensure that the impact of the media came to the fore as naturally as possible during the discussions. If this did not occur, only then did I intervene and employ the use of questions relating to these issues at appropriate junctures within the discussions or towards the end of the focus groups.

#### **4.8.2.4 Addressing myths and misconceptions**

I had anticipated that the focus group discussions would entail questions about dementia being directed at me and/or would involve some participants discussing misconceptions about dementia with other participants. In the latter situation, I was mindful that these misconceptions *can be implicitly legitimised by the presence of the researcher* (Culley et al., 2007: 110). My strategy was to address these as and when they occurred during the focus group, by providing the correct information. In addition, I also shared at the end of each focus group some information about the facts about dementia from the Dementia UK leaflet. I also gave this leaflet to each focus group participant at the end of the discussions. I also advised all focus group participants to contact their general practitioner if they had any concerns and questions about dementia for themselves, or family members.

## **4.9 Theoretical saturation**

### **4.9.1 Interviews with community workers**

Theoretical sampling occurs when theoretical explanations of categories or phenomena do not yield any new theoretical insights and/or new properties, in relation to the emerging grounded theory (Charmaz, 2014: 254). Theoretical saturation as a concept, however, has generated much debate and discussion amongst grounded theorists as it

is a complicated concept to grasp for several reasons. Breckenridge and Jones acknowledged *that theoretical saturation has become somewhat ambiguous, ill-defined and frequently misconstrued* (Breckenridge and Jones, 2009: 2). However, Breckenridge and Jones (2009) offered some clarification about data saturation within qualitative research more generally, as well as within GT (1967). Theoretical saturation in the former refers to descriptive saturation, whereas in the latter it pertains to a conceptual level (Breckenridge and Jones, 2009).

Charmaz (2014) recognised that practical concerns can serve to challenge the implementation of a theoretical sampling strategy, for example, it can be difficult to anticipate the size of a research participant sample at the outset of the study when using theoretical sampling to achieve theoretical saturation. Other challenges stem from ethical requirements and institutional requirements that require some degree of precision about sample size (Charmaz, 2014) prior to commencing the fieldwork, in addition to restrictions in funding and time-limited studies (Charmaz, 2014). Nevertheless, Breckenridge and Jones (2009) encouraged researchers to be transparent by justifying how and why the process of theoretical sampling informed their theoretical insights (Breckenridge and Jones, 2009).

Heeding Breckenridge and Jones' (2009) advice about transparency, whilst the small sample of five voluntary and charity sector participants were theoretically sampled, I cannot claim to have achieved theoretical saturation in this phase of the research. This is due to a number of reasons, firstly because of time restrictions and secondly because there are a restricted 'pool' of potential participants that work with BAME communities who support PWD and their carers. Thirdly, to achieve theoretical saturation of some of the emergent categories I would have been required to conduct a greater number of interviews with voluntary and charity sector workers who work within one ethnic group (as a sub-group), in order to develop with confidence a saturation of concepts and categories that had theoretical reach, within and across the range of ethnic groups (Morse et al., 2002). This would have taken an inordinate amount of time and an extensive number of interviews and would have been beyond the scope of this research timetable.

Lastly, and most importantly, as stated in section 3.5.2 in the Methodology chapter, my purpose with this small sample of participants was to enhance and contextualise my theoretical insights about the emergent findings from the focus groups. Charmaz (2014) clarified that a small research sample does not preclude construction of theory and advocated *do the best you can with the materials you can construct or already have* (Charmaz, 2014: 108).

#### **4.9.2 Focus groups**

In October 2017, preliminary analysis of the findings led to me pursue a theoretical sampling strategy which involved broadening my recruitment to include lay public participants aged 30-40 years from each community. This is because my interim analysis of the findings from the white British and Indian 18-30 years focus groups led to the development of an analytic category of 'balancing'. A category is developed in CONGT from codes that have overriding significance and it functions to move the analysis from description to more of an abstract and analytical concept (Charmaz, 2014). I wanted to saturate this category of balancing by including the values and beliefs that influenced and shape their approaches, through the involvement of participants aged 30-40 years. This sample of participants, according to my life stage generational demarcation, were most likely to illuminate my analysis about 'balancing', as they were experiencing the possibility of caring for young families and taking care of older parents. Theoretical sampling in this case was driven by how their life stage could help, as suggested by Charmaz, to check, qualify and elaborate the boundaries of my category of balancing (Charmaz, 2014: 205). Consequently, the theoretical sampling approach to my research expanded the total number of focus groups to nine from the original six focus groups that I had anticipated.

#### **4.10 Transcriptions of interviews and focus groups**

The process of obtaining the transcriptions involved hiring a professional transcriber who was known to DMU's Department of Health and Sciences and came recommended by my supervisor. I contacted her and agreed with her in writing a confidentiality agreement, and how I wanted the transcriptions presented when written up. The written transcripts of the



focus group discussions were given anonymised identifiers and stored on a password-protected computer.

The recording of the pilot focus group of 40- 55 year olds had sections of discussions in English and Gujarati and almost all of the recording of the Indian focus group (40-55 years) was in Gujarati. For both of these recordings, I had to transcribe them using a process of simultaneous translation from Gujarati to English. I have many years of experience of writing transcriptions using this approach and knew that my aim within this transcribing process was to ensure that I undertook a translation that was conceptually and linguistic equivalent (Weidmer, 1994).

I experienced some challenges with the transcribing process, as the transcriber found it difficult to understand some of the differences in English dialect in the Caribbean and Indian focus groups (40-55 years) This resulted in her being unable to identify which participant was speaking in the focus groups. One of the major and unforeseen challenges of the transcribing process was that the transcriber, due to a heavy burden of transcribing work, was unable to quickly turn around the written transcripts of the focus groups and interviews. Consequently, it took some weeks before I received my written transcripts and I quickly learned to rely on my reflective journal, memos, and notes from audio recordings. This delay compromised my ability to undertake the deeper level of analysis that I would have liked and benefited from during the initial analytical process during data collection. Nevertheless, it sharpened my ability to 'home in on' during the focus group discussions as well as the interviews on aspects of discussions that served to densify some of the emergent categories, such as televised depictions of dementia, and sensitised me to be more vigilant about new lines of enquiry to pursue for subsequent focus groups and interviews.

#### **4.11 The data analysis process: from data to themes and types**

The following section of this chapter provides an explanation of how the analysis of findings was undertaken and the decisions that guided the analytic process. I shall

explain how the analysis was conducted in three phases, reflecting different stages of the coding processes. I will also examine how the analytic process led to two different approaches to conveying the findings, which involved a presentation of the findings in themes and development of the theoretical concepts in the form of types.

#### **4.11.1 Stage 1: Preliminary analysis, including the role of memos during the process of data collection**

##### **4.11.1.1 The Pilot Indian focus group 40-55 years**

The challenges with obtaining transcriptions of my focus groups and interviews on time prevented detailed analysis of them prior to conducting my next focus group or series of interviews. I therefore used a combination of my reflective journal, memos and notes from listening to my audio recordings of focus groups to inform iterative exploration of some of the issues that were being raised in focus groups. The following two memos were written after conducting the pilot Indian focus group. These led to an exploration with all focus groups of issues related to the conceptual category of 'age is just a number' and the descriptive category related to the influence of the media. These memos, as Charmaz (2014) stated, enabled me to be taken to unforeseen areas and opened up new research questions (Charmaz, 2014: 114).

**Analysis Memo 1: Age is just a number: (Indian Gujarati Pilot focus group 40-55 yrs.) for exploration with all focus groups (May)**

Age is just a number was a powerful statement made by one of the participants of the pilot focus group and evoked a number of responses from other participants and inspired discussion on range of issues from other participants. For example, resilience in older people, using brains to their full potential and the role of education, and how these shape and influence the likelihood of someone getting dementia in the future. This links to beliefs about individuals ageing well and was linked to examples of politicians such as Margaret Thatcher and Ronald Reagan who took up leadership positions in later stages of their lives. These views point to a more individualised ageing trajectory of physical and mental health rather than one determined by societal cultural expectations of what an older person can and cannot do. So, what they are saying seems to suggest a contradiction between expectations of chronological age-related deterioration and psycho/social perspectives. These point to individuals being responsible for how they age and the likelihood of them developing dementia.

This needs to be explored further with all focus groups as it signals changes to attitudes and beliefs about ageing particularly if dementia was an expected part of ageing, then how does dementia fit in if beliefs about ageing have changed when what is being suggested is that the onus is on the individual to age well?

**Analysis Memo 2: Media influence (Indian Gujarati pilot focus group 40-55 yrs.) for exploration with all focus groups**

This is an unexpected finding on so many different levels. The pilot Indian focus group (40-55 yrs.) discussed the influence the Angela Rippon documentary had on their understanding of dementia as well as the Emmerdale soap drama. The latter provided an insight into the progressiveness of dementia from the standpoint of the person affected by the illness, including the implications of the memory loss such as forgetting who he was married to. These programmes clearly have an influence of developing peoples understanding of dementia, but at the same time, the rest of the focus group discussions indicate that it helps with providing a snapshot, but does not influence a coherent understanding, in the case of this focus group, a few of the participants who watched this programme could put together that dementia caused white patches on the brain, and the Emmerdale soap portrayed the progressiveness of the disease and how it impacts on the person's life. Rather than wait for the media's role to emerge from discussions I need to explore the effects of soaps and other sources of media influence on participants' conceptualisation.

Definitely not expected this to come up in the way that it did as thus far my understanding of media coverage of dementia in research studies has been that it's a negative influence, scaring and putting off people from obtaining diagnosis. The dramatisation in Emmerdale and the documentary can be further explored, but maybe it be worth focusing on the soaps as this may have more reach. Anyway, definitely one to explore on a deeper level.

After completion of the pilot Indian focus group (40-55 years), my reflections involved a focus on the process of the discussion as well as the content of the focus group. As a consequence of these reflections, I changed the ordering of the topic guide in subsequent focus groups to commence with dementia first and then to pursue an exploration of ageing. Additionally, I noted that this group of focus group participants knew each other well, and whilst it helped with the flow of discussions, issues related to caring could not be explored as time ran out.

#### **4.11.1.2 The Caribbean focus group 18-30 years**

Soon after the pilot Indian focus group, I conducted my first focus group with Caribbean participants aged between 18-30 years. Discussions about the conceptualisations of dementia elicited by the question 'what do you understand dementia to be' resulted in some of the participants' immediate responses, indicating that it was conceptualised as a mental illness because of its symptoms of memory loss. Despite my best efforts to elicit a deeper level of understanding about this conceptualisation, it was difficult to do so. It led me to write the following memo, which as I wrote helped me to consider pursuing supplementary questions to produce more substantive explanations. I subsequently took this approach with other focus groups that conceptualised dementia as a mental illness. These supplementary questions involved asking participants to think about how it was different from other mental illnesses such as schizophrenia or depression, or spiritual explanations. Responses from other focus groups as a consequence of this memo helped develop more nuanced understandings of why dementia is conceptualised as a mental illness across a range of focus groups:

**Memo: Dementia as a mental illness: for further exploration with all focus groups Focus group with Car 18-30 yrs. 17/08/19.**

In the Caribbean focus group (18-30 yrs.) the labelling of dementia as a mental illness almost immediately upon commencement of the focus group, was intriguing and in much the same way as the In Vivo category of age being just a number, this merits further exploration of why participants were describing it as a mental illness, rather than assuming it to be label which has universally shared understanding. It's been really difficult trying to stimulate discussions about why the participants beyond discussions of symptoms, are there any reasons?

I am unsure of how to do this but may consider comparisons with other mental illnesses or use different frames such as a hex or organic brain illness as a way of drawing out why participants conceptualise it as a mental illness.

**4.11.1.3 Indian and white British focus groups 18-30 years**

My reflections after conducting these focus groups led me to write a memo signalling the need to explore further this concept of 'balancing' as participants in both these focus groups discussed that they would need to balance their educational and employment priorities with caring demands. These priorities and their positions within their life stage would influence how they would approach seeking informal and formal care, such as care homes. This reflection, indicated by this following memo on 'balancing', led me as previously discussed to pursue the recruitment of additional focus groups between the ages of 30-40 years, who may be in a position during their life stage to be faced with juggling demands for caring for young children and possibly thinking about balancing these needs with future care demands of parents or grandparents:

**Memo: Balancing**

It's evident that for these younger participants their care strategies entail taking into account balancing their professional and educational ambitions and jobs with the prospect of caring. This means unlike some of the older generations, they will be proactive in looking for care support outside of the family. They seemed to have thought about these considerations well in advance considering they are still in higher education but what about the generation above them in their 30s who are likely to have younger children how will they balance their jobs with care demands? Will they pursue the same strategies or not? Not known, might be helpful to recruit 30-40 yr. olds to explore their care strategies.

## **4.11.2 Stage 2: Substantive analytical process for focus groups**

### **4.11.2.1 Tools for analysis**

In this section, I shall discuss how both NVivo and memo writing were invaluable tools of analysis. The data collection process involved handwritten notes within the transcripts and memo writing, rather than NVivo. After completion of data collection, I used NVivo software to manage the process of the analysis of an immensely large body of data from ten focus groups as well as five interviews. There were certain aspects of NVivo I found particularly helpful, that included framework matrices which visually depict the spread of coding across a category within and across the focus groups.

Memo writing is an intrinsic component of all strands of grounded theory, a point vociferously made by Glaser (1978) saying that the writing of theoretical memos is the core stage in the process of generating grounded theory (Glaser, 1978). According to Lempert (2007) *memos serve to function in two ways, firstly as a methodological practice and secondly to simultaneously assist with the exploration of processes in the social worlds of the researcher's data to assist with conceptualising the data in narrative form* (Lempert, 2007: 245). I found the practice of categorising memos as undertaken by Mills (2008) particularly helpful as it consists of organising and categorising memos either as operational, coding and analytical (Mills et al., 2008). During the data collection stage my memos were both operational and conceptual, and in the substantive data analysis stage my memos facilitated the raising of descriptive coding to conceptual categories.

### **4.11.2.2 Analytical decisions**

Before commencing this stage of the analysis, I had to make some decisions about my approach to the analysis, one of which involved the decision to include the findings from the pilot Indian focus group 40-55 years within the substantive analysis stage. This was because, unlike the Indian focus group 40-55 years, it consisted of some participants who were Indian second-generation migrants who had migrated from East Africa and had been educated in this country. Thus, their perspectives consisted of generational perspectives developed over time in this country, and they were effectively, like myself, the 'sandwich

generation' between parents who had migrated here and children who were born here. In contrast, the participants in the Indian focus group 40-55 years, with the exception of one participant, were all from India who had arrived here on the basis of marriage. My Indian 'insider experience' suggested their perspectives would be unlikely to have an oversight of generational changes in the Indian community in the UK, to the same degree as the pilot Indian focus group 40-55 years.

I also decided to wait to undertake the analysis of the community worker and volunteer interviews as these were complementary until my analysis of the focus groups had been completed.

During the coding process, when encountering the variation within and between focus groups with respect to knowledge and understanding and conceptualisations of dementia, I decided the best way to represent the findings was thematically. This was in contrast to the findings relating to the help-seeking approaches and care strategies, where I could identify through my interrogation of the data similarities and differences by ethnicity and generational age within the dataset. As stated in the methodology, that is when the idea of using a typology came to mind, and this involved initially an inductive analytical process through coding and constant comparison. This was followed by a deductive process of analysis to gauge whether there was a 'fit' between the data and my idea of using a typology. The following section of this chapter will provide more details of the analytic process for both the development of themes and types.

#### **4.11.2.3 Overall analytical process**

I shall begin by giving an overview of the overall substantive analytic process that I followed which, according to Kenny and Fourie (2015), in CONGT should have encompassed the following stages (Kenny and Fourie, 2015: 1279):



Figure 4.1: Kenny and Fourie's illustration of the CONGT analytical process

My coding process involved an additional stage that I called progressive coding, which was needed after my open coding because there was so much data to process and analyse, characterised by complex and interweaving relationships. The difference between the progressive frame and the re-focused coding frame was that in the latter I started to make connections or establish relationships between coding categories. This will be explained under the refocused coding stage. The following illustrates the stages of the analytical process in this research:

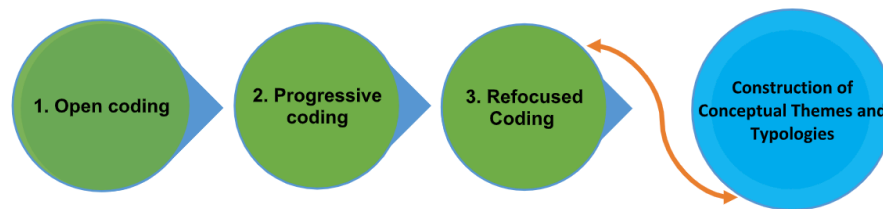


Figure 4.2: My analysis process

Whilst these constituent parts of the coding process look quite distinct and neatly categorised, the reality is the process of analysis, particularly the relationship between the focused coding stage, conceptual themes and the construction of types, was characterised by a cyclical process. This process of analysis was conducted as I acted on hunches and used my memos to assist with identifying and developing relationships between coding categories to develop overarching themes, themes and types. These stages encompassed the following types of coding:

#### **4.11.2.4 1st stage: Open coding**

Once all the transcriptions of focus groups and interviews were completed I used NVivo software to commence a process of coding which, according to Charmaz, is the key link *between collecting the data and developing an emergent theory to explain these data* (Charmaz, 2014: 113) as it helps to understand what is going on in the data and its significance (Charmaz, 2014). As it would have been too time consuming and impractical to code all ten focus groups transcripts using the open coding process, I selected three focus groups in total for open coding, one transcript from each of three ethnic groups, reflecting a diversity of the following age ranges: 18-30 years (Indian), 30-40 years (white British), and 40-55 years (Caribbean).



The coding process for these focus group transcripts commenced with open coding, or initial coding as Charmaz (2014) defines it. I called it open coding as I attempted to remain open to the data as much as possible but also took the advice from Charmaz (2014), which is to code for gerunds. These are words and sentences that convey an action and sequence (Charmaz, 2014: 120). For the open coding process, I commenced with line-by-line coding which, according to Charmaz (2014), assists with helping to grasp meanings, actions and future directions to explore. The use of a constant comparison approach was an integral part of this process, and this resulted in the generation of 333 codes. Constant comparison, according to Charmaz (2014), entails, for example, the inductive comparison of data with data, codes with other codes, and a comparison of categories with each other, and finally categories with concepts during the last stages of analysis. It assists with raising analysis from descriptive to analytical concepts (Charmaz, 2014: 360).

#### 4.11.2.5 2nd stage: Progressive coding

At this stage of the analytical process, progressive coding entailed creating coding categories for the most frequent and significant codes (Kenny and Fourie, 2015). At this stage, I remained open to the data, so my coding strategy was not guided by my research questions but simply organising the data into descriptive themes and, where possible, conceptual categories as indicated by memoing.

Outlined below are some of the conceptual (age is just a number) and descriptive categorisations (impact of the media) used in the progressive coding process:

| Name   | References | Created On      | Created By | Modified On     | Modified By |
|--|------------|-----------------|------------|-----------------|-------------|
| age is just a number   | 5          | 23/08/2018 18:5 | N          | 03/09/2018 17:2 | N           |
| why  | 2          | 01/12/2018 01:4 | N          | 01/12/2018 01:4 | N           |
| impact of role models  | 0          | 01/12/2018 01:5 | N          | 01/12/2018 01:5 | N           |
| older people striving to achieve dreams                          | 3          | 01/12/2018 01:5 | N          | 28/08/2018 17:5 | N           |
| resilience   | 5          | 01/12/2018 01:5 | N          | 03/09/2018 17:4 | N           |
| active   | 8          | 01/12/2018 01:5 | N          | 10/01/2019 10:3 | N           |
| reporting on health  | 1          | 01/12/2018 01:5 | N          | 23/08/2018 15:3 | N           |
| motivating and aspirational force                                | 1          | 01/12/2018 01:5 | N          | 23/08/2018 18:4 | N           |
| living longer and healthier                                      | 1          | 01/12/2018 01:5 | N          | 01/12/2018 01:5 | N           |
| ageing gracefully  | 1          | 01/12/2018 01:5 | N          | 01/12/2018 01:5 | N           |
| affecting imagery and appearance                                 | 2          | 01/12/2018 01:5 | N          | 10/01/2019 14:1 | N           |
| power of celebrity   | 3          | 01/12/2018 01:5 | N          | 03/09/2018 17:3 | N           |
| been told to get fit and healthy                                 | 4          | 01/12/2018 01:5 | N          | 01/12/2018 01:5 | N           |
| working longer and volunteering                                  | 4          | 01/12/2018 01:5 | N          | 01/12/2018 01:5 | N           |
| mindset  | 6          | 01/12/2018 01:4 | N          | 06/02/2019 18:4 | N           |
| seeing older people with different levels of activity and health | 2          | 10/01/2019 11:2 | N          | 10/01/2019 11:2 | N           |
| originally ascribed roles and functions of older people          | 7          | 23/08/2018 18:4 | N          | 30/08/2018 17:4 | N           |

Figure 4.3: Age is just a number coding frame

| Name   | Files | References | Created On        | Created By | Modified On     | Modified By |
|--|-------|------------|-------------------|------------|-----------------|-------------|
| Impact of media  |       | 1          | 19/07/2018 11:0   | N          | 19/07/2018 11:1 | N           |
| ● googling   |       | 3          | 5 19/07/2018 11:4 | N          | 31/07/2018 12:4 | N           |
| ● realisation that young people can get it too                   |       | 2          | 3 19/07/2018 11:5 | N          | 26/07/2018 13:0 | N           |
| ● raised awareness of social interaction between generations     |       | 1          | 1 19/07/2018 14:2 | N          | 19/07/2018 14:2 | N           |
| ● Impact of Emmerdale  |       | 3          | 5 20/07/2018 15:2 | N          | 27/07/2018 12:0 | N           |
| ● why Emmerdale was more effective than newspaper                |       | 1          | 1 20/07/2018 15:2 | N          | 31/07/2018 13:1 | N           |
| ● highlighting mental illness makes people think of its as a men |       | 1          | 1 20/07/2018 16:0 | N          | 20/07/2018 16:0 | N           |
| ● raising awareness of illnesses in young people such as strokes |       | 2          | 2 23/07/2018 11:3 | N          | 31/07/2018 13:4 | N           |
| ● films  |       | 1          | 1 23/07/2018 14:1 | N          | 23/07/2018 14:1 | N           |
| ● watching Indian dramas and films                               |       | 2          | 3 24/07/2018 10:2 | N          | 24/07/2018 16:5 | N           |
| ● providing a lot of information                                 |       | 4          | 5 24/07/2018 16:4 | N          | 31/07/2018 13:1 | N           |
| ● directing older generations to it                              |       | 1          | 2 24/07/2018 16:4 | N          | 24/07/2018 16:4 | N           |
| ● Asian channels dont discuss relevant information               |       | 1          | 1 24/07/2018 16:4 | N          | 24/07/2018 16:4 | N           |
| ● challenging you to think dramas on TV                          |       | 1          | 1 24/07/2018 16:4 | N          | 24/07/2018 16:4 | N           |
| ● changed acceptance of it amongst older generations not a sp    |       | 1          | 1 26/07/2018 11:4 | N          | 26/07/2018 11:4 | N           |
| ● impact of Angela Rippon show                                   |       | 1          | 3 27/07/2018 11:0 | N          | 06/08/2018 12:5 | N           |
| ● doesnt cater for African and Caribbean people                  |       | 2          | 5 31/07/2018 12:3 | N          | 31/07/2018 14:0 | N           |
| ● Raising awareness through TV                                   |       | 1          | 2 31/07/2018 15:2 | N          | 01/08/2018 12:1 | N           |
| ● changing views about ageing                                    |       | 2          | 2 01/08/2018 12:3 | N          | 01/08/2018 16:1 | N           |

Figure 4.4: Progressive coding frame: Impact of media

I used 'age is a just a number' as an In Vivo category in the progressive frame but took on board Charmaz's advice, which is to treat this statement as a *symbolic marker of participants' meanings needing further comparative and analytic treatment* (Charmaz, 2006b: 55).

#### 4.11.2.6 3rd stage: Focused coding

This next stage involved drawing on my memos more comprehensively and using them as data analytical tools to guide the formation of conceptual categories, which are significant and bring together codes to develop analytical concepts (Charmaz, 2014). Here is when the creativity inspired by the memos came into full effect, and these generated avenues to be explored using constant comparison. To illustrate this process, in the following section I shall provide details of how the thematic analysis developed in relation to the themes of knowledge, understanding, and conceptualisations of dementia and ageing.

#### 4.11.2.7 Developing the theme of Knowledge and understanding

This was the most challenging theme to develop a coherent and logically structured narrative for. There was so much variation and commonalities were difficult to identify, much less the factors causing the vastly different and fragmented data I had coded under the progressive coding frame. My initial impressions were that the Caribbean focus group 18-30 years were the least informed about dementia and the Indian focus group 18-30 years seemed to be the most informed because of their higher education, but there was a lot of variation across and within other focus groups that I found difficult

to account for.

My first step to achieving some clarity in identifying the causes of this variation was to develop a case classification system within NVivo for each individual participant. This was designed to enable me to identify any particular issues within the background of participants that was causing the variation, because my research journal had noted that previously held caring roles played an influential role in many ways. Secondly, I coded all the transcripts wherever knowledge and understanding about dementia was indicated under the following coding categories:

- Low levels of knowledge
- Medium levels of knowledge
- High levels of knowledge

Once all the transcripts were coded line by line, I started to interrogate each of the above categories and cross reference them with case classifications to understand the variation. Once this was achieved, I printed out the above coding categories so I could read and extrapolate the key issues from the narrative. It was from reading each of these coding categories that I could identify exposure as the key common identifier in relation to three issues that were responsible for the variation i.e., caring experience and hearing about dementia through social networks, education and the media. Confirmation of these factors came from checking each case classification to identify, for example, whether being an ex-family carer facilitated an understanding of symptoms.

These coding categories of levels of knowledge also led to mapping or capturing aspects of the data, to identify what aspects of dementia knowledge participants possessed with certainty and uncertainty. These were subsequently coded as certainties and uncertainties of knowledge. As I had already asked many focus groups about whether they were aware dementia is an umbrella term, as well as whether they knew diabetes and high blood pressure were risk factors for dementia, it was relatively easy to code these responses.

This 'refocused stage of analysis' is also the stage where I looked for relationships

between other coding categories within the coding frame to knowledge and understanding. This is where the category of differences in generational sources of knowledge was interrogated to help develop my overarching theme development of knowledge and understanding.

The most startling link to my developing an overarching theme came from the coding category 'dementia on the doorstep' which during the progressive coding stage I had left to one side not realising its significance. My diagramming, which builds the connections and relationships between these coding categories and makes them visible, helped to understand that I needed to explore this in more detail. Charmaz (2014) recommended the use of such diagrams as they *enable you to see the relative power, scope and direction of the categories in your analysis* (Charmaz, 2014: 218).

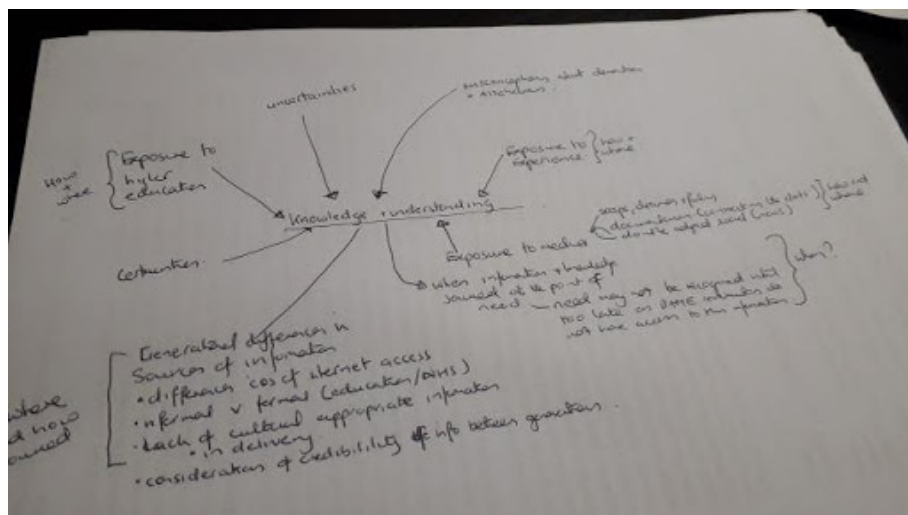


Figure 4.5: Diagramming for Knowledge and Understanding Theme

I was slowly building linkages based on what, where and how, and I remembered that the 'dementia on the doorstep' category spoke to *when* participants are likely to seek information and knowledge. I followed up on this hunch, using the process of constant comparison to reveal what to me seemed to be a very important finding. This finding spoke about participants searching for information and knowledge at the point of need because it is perceived to be a specific illness, and this might explain why some family members may not recognise symptoms of dementia until a late stage. In addition, the search for information and knowledge was also linked to conceptualisations of dementia.

#### **4.11.2.8 Developing the Theme of Re-defining Ageing**

This was one of the most populated conceptual themes and it was subsumed in the In Vivo category 'age is just a number' with data indicating juxtapositions with previous generations across all ethnic groups. These juxtapositions revealed cultural attitudes about ageing, as well as structural and societal cultural issues related to the past and the present. Data here also indicated detailed explanations of the factors that have led to different approaches to ageing in the present as a consequence of structural factors, extension of life expectancy and better health care. These led to perspectives about ageing as indicated by the 'age is just a number' theme. A memo developed from my reflections from the white British focus group 40-55 years also helped with the construction of this theme temporally to indicate generational changes in the form of the past, present and the future:

##### **Memo: Balancing**

Old ain't what it used to be (white British focus group 40-55 yrs.) to further explore with all focus groups under 'Age is just a number'.

This was a singular statement which conveyed so much, and it came about because I asked about generational differences in ways of thinking about dementia. This short passage of the discussion is conveying that ways of conceptualising ageing are changing in a similar in meaning to that of the Pilot Indian focus group when some of them stated Age is just a number. How does this have an impact on the way they see older people and implications for their susceptibility to develop illness such as dementia?

#### **4.11.2.9 Conceptualisation of dementia as a mental illness and as a normal consequence of ageing**

Whilst the purpose of the focus groups was to understand how participants conceptualised dementia, it was difficult during the initial data collection process to elicit detailed responses as to why they conceptualised mental illness in the way that they did. However, as indicated in paragraph 4.11.1.2, my memo during the data collection stage alerted me to consider a different way in which I could gain more insight in my explorations of mental illness conceptualisations. This led to framing my questions about the differences between dementia and mental illness, and the responses this

question elicited directly led to deeper insights that enabled me during the analysis process to take a more nuanced approach to the analysis. This nuanced analytical lens was also extended to the conceptualisation of dementia as a normal consequence of ageing and led to an important finding that indicated some focus groups held an amalgam of conceptualisations.

#### **4.11.2.10 Process of analysis leading to the formation of types**

##### Stage 1

In the progressive coding frame the category of caring was quite broad and, as I started to drill down into the coding, I made a note of the data relating to white British focus groups (18-30 years and 30-40 years) and Indian focus groups (18-30 years, 30-40 years and 40-55 years) in an analytical memo to capture what I categorised as pragmatic approaches to caring based on values linked to behaviours.

**Memo: Pragmatic (Indian focus group 18-30 yrs., 30-40 yrs and 40-55 yrs. White British 18-30 yrs. and 30-40 yrs.) Coding category**

I am struck by the way in which these (Indian) groups are unencumbered by cultural values when it comes to the possibility of looking after a parent with dementia and actually thinking about what is best for the PWD in the family. At the same time, they are acknowledging that within the community and their parents' and grandparents' generation are influenced in their caring approaches by what the community thinks. They themselves unencumbered by cultural values and community pressure and indicate they would take a pragmatic approach which may involve putting their own needs and the care needs of the PWD at the forefront.

The white British focus groups seem to suggest that caring is dictated by choices families make, interesting to see it's a topic of conversation amongst their peers in the WB 18-30 yrs. focus group. This alone justifies why it's important to involve younger people in dementia research. The choice to care is also influenced by balancing demands of caring with professional and educational ambitions and pressures. Also, feel that it's about who is better placed to care for a PWD in the family, so not averse to getting professional carers in so very pragmatic.

Use this lens of pragmatism to undertake a process of constant comparison analysis to explore whether it applies to all the other focus groups, particularly the Caribbean focus groups because they seem to be free of community pressures and prioritise the needs of the PWD. They don't seem to be hampered by what the community will think if they seek help.

This led to the interrogation of data to assess how I would characterise the Caribbean

focus group's approaches to see whether it was similar or different and the reasons why. The pragmatism evident in all the other focus groups did not apply, but the conceptual code that seemed to most aptly capture the Caribbean focus group's care strategies was 'constrained'. This was because they were constrained not by cultural rigidity but a lack of culturally appropriate information about dementia and care support in their own homes and in care homes. A similar process was undertaken with the white British focus group (40-55 years) and that too differed from the pragmatic and the conceptual code of 'realistic' was initially applied.

A draft of the write up of the findings pertaining to these three conceptual categories of care strategies was developed and presented for discussion with a supervisor, during which I presented the case that these concepts were types depicting approaches to care. As a result of this discussion, the names I had assigned for these tentative types were changed to the following:

- Pragmatic to flexible
- Realistic to individualised
- Constrained remained the same

During the discussion with my supervisor I was also advised to explore the theoretical literature on typologies, particularly the work of Max Weber (Weber, 1988) and Alfred Schutz (1964) to assess how my typology aligned with their work. In addition, I was asked to clarify the perspectives by which participants were framing their approaches to care, i.e., whether it was with reference to their own care or in relation to their care of older family members.

## Stage 2

The reading of the literature as advised was undertaken concurrently to refine these types and it was during this process that I started to explore the juxtapositions taken by participants in this research sample, in particular how they positioned themselves in relation to older generations outside of this research. During the course of this, I identified the word 'traditional' as a type to define Indian and Caribbean older

generations' approaches to care. This idea was inspired from my analysis of discussions held within the white British focus group 40-55 years, in which they took a reflective gaze and drew comparisons regarding filial piety between Eastern cultures and white British communities, concluding that this was not a traditional practice in their own community. The concept of a traditional approach did however seem to fit neatly with explanations about care strategies amongst older Indian and Caribbean generations outside of this research sample, as discussed by Indian and Caribbean participants.

### Stage 3

This stage involved developing a category for all Indian and Caribbean focus groups' perceptions and experiences of older generations, which led to the creation of the 'Traditional' typology. This, according to McKinney (1969), is an 'existential construct' because it is based on participants' *pre-constructed and pre-conceived reality* (McKinney, 1969: 2), derived from typifications participants made for themselves. I used the Traditional category as a heuristic device, as advised by Weber (Kalberg, 2001), to logically identify and intensify key elements (McKinney, 1969) such as approaches to disclosure, filial piety and stigma. The most densely populated data with respect to these significant elements was derived from the Indian and Caribbean focus group participants. This was because the issue of older generations' approach to care was not discussed to the same depth in the White British group and so it was challenging to 'densify' my codes for this group to the same degree.

It was during this stage that I was also able to broaden the scope of the coding to include strategies about diagnosis within the traditional typology. The following example in Table 4.3 depicts a draft coding category and comments for the Traditional approach to diagnosis:

After this Traditional typology had been developed, its key and significant elements were used to compare and contrast with the Flexible, Constrained and Individualistic types, through a process of constant comparison. As such, these three types were 'second order constructs' according to McKinney (1969), because they were logically synthesised interpretations developed through a combination of creative thinking on my



Table 4.3: Draft coding summary of Traditional typology approach to diagnosis

| Approach to diagnosis amongst older Indian and Caribbean generations | Sub-category                              | Comments   |
|--|---|--|
|  | Individual level                          | <p>The approach to diagnosis seems to link to a combination of factors such as conceptualisations of dementia, as well low levels of understanding, and internalised stigma. Quite nuanced and not simply cultural.</p> <p>Treatment preferences including alternative medicine and faith-based approaches are likely to be tried without recourse to medical aid.</p> |
|  | At the level of the family                | <p>Variation of knowledge and understanding in families can cause delays. Also, family conflicts as to who will deal with all the appointments in multi-sibling families</p>   |
|  | At the level of the community and society | <p>Lack of culturally appropriate information about how to distinguish between normal age-related forgetfulness and dementia. Additional layer is the impact of stigma related to genetic transmission within families and help-seeking</p>  |

part but also grounded in the data (Rosenberg, 2016: 5). They involved me attributing specifications and relationships within the data, based on my interpretation of the participants' articulations of their understandings and experiences of their social world (McKinney, 1969).

#### Stage 4

After this work was completed, I analysed my five community worker interviews inductively without reference to the types. It was only after the analysis was completed using constant comparison that I used the community worker and volunteers conceptual coding frame to

compare and contrast findings with the typological analysis. It was evident from these findings that the 'Traditional' approach not only applied as the focus group findings as suggested to older generations outside of this research sample but was a generalised approach that could be found within the wider community in all age groups in both Indian and Caribbean communities.

Other data facilitated a contextualised understanding about the Indian younger generation's help-seeking strategies. This was derived from community workers drawing on their experience of working with younger Indian generations who were willing to seek diagnosis for family members experiencing dementia symptoms. This willingness was attributed to education about dementia and access to the Internet to seek information about services to support people with dementia. In addition, Indian community workers highlighted their perceptions about changes in cultural values together with occupational and geographical mobility leading to a decline in filial piety in Indian communities. Barriers to culturally appropriate professional care at home and care homes were highlighted by both Indian and Caribbean community workers. The data pertaining to white British communities with regard to care strategies suggested it was influenced by individual families' choice and ability to provide care, rather than being driven by cultural values and norms. The data from the community workers were integrated into the presentation of the types.

## **4.12 Summary**

This purpose of this chapter was to discuss and explain how the methodological framework described in the Methodology chapter was operationalised. The rationale for a research sample comprising white British, Indian Hindu Gujarati and Caribbean participants was presented. This was formulated on the basis that these ethnic groups are characterised by an increasing number of older people, and to ensure I did not perpetuate the homogenisation of different ethnic groups with different migration histories, such as African-Caribbean, as one ethnic group to include African communities, many of whom are newly arrived in Leicester City.

The role of the methodological framework using CONGT (1995) in the design of the topic

guide and the recruitment strategies, including theoretical sampling, was discussed. Its influence during the conduct of the focus groups and interviews also informed the delicate balance between the pursuit of emerging concepts and participants being able to direct and influence discussions. This chapter also discussed how the ethical processes and practices were respected during the recruitment and conduct of the focus groups and interviews.

Finally, this chapter described the analytical process in this research, which comprised two stages, the first one being the preliminary process and the second being the substantive analysis which led to the construction of conceptual themes and formation of a typological framework on help-seeking approaches and care strategies. In the following chapter, I shall provide information and discussion of the research context, participant characteristics and participants' views about their own ethnic self-identification.

# Chapter 5: Research context and participant characteristics

## 5.1 Introduction

In the preceding Methods chapter, I discussed that I recruited ten focus groups and five community workers and volunteers. This research sample was drawn from Leicester city. The purpose of this chapter is to describe the study context. This will involve providing some information in relation to the setting and background to the study population, as well as the participant characteristics. A description of the study context is important as it enable other researchers to establish whether the findings of this research are relevant to other research study contexts (Mays and Pope, 2000b).

## 5.2 Study setting

### 5.2.1 Age profile of Leicester's population

Leicester has a younger population profile in comparison to the rest of the UK, with a larger group of residents aged under 40 years of age. The JSNA report stated that *only 11.6% of the population is aged 65 and over, equivalent to around 35,700 people, in comparison to around 16.5% for England as a whole* (Leicester City Council, 2012: 26).

The majority of the people over the age of 65 years are from white or white British ethnic backgrounds and constitute 10% of the total population. In contrast, the over 65 years age group from Asian ethnic groups form only 3%, with other BAME groups constituting only 1% of the population (Leicester City Council, 2012).

However, these figures will be changing particularly amongst the Indian and Caribbean

communities that arrived in the 1950s, 1960s and 1970s who are now ageing, and the JSNA stated that meeting their needs will become an urgent issue in the near future (Leicester City Council, 2012).

### **5.2.2 Ethnicity profile of Leicester's population**

Leicester's population is characterised by its rich ethnic and cultural diversity with residents that originate from over 50 countries around the world (Leicester City Clinical Commissioning Group and Leicester City Council, 2012). The 2011 census figures estimated its population to be in the region of 342,627. Approximately 51% of its total population is comprised of white British, followed by 37% Asian/Asian British (of whom 28% are of Indian heritage), 6% per cent Black/African/Caribbean/Black British, 4% mixed/multiple and 3% other ethnic groups (Leicester City Council, 2012: 26).

### **5.2.3 Areas of residency for ethnic groups and socio-economic deprivation**

There are reports of Indian families settling in Leicester as far back as 1920, with some community members recalling an Indian family starting a spectacle business in the 1920s (McLoughlin, 2013). In the 1950s, the presence of the Indian community consisted of soldiers from the Indian army regiments (McLoughlin, 2013). It was in the early 1960s that increasing migration from India took place and the Indian population of Leicester saw its numbers bolstered with the arrival of East African Asians arriving in greater numbers during the late 1960s and 1970s (Martin and Singh, 2002; McLoughlin 2013).

Much of the Asian/Asian British ethnic group reside in the east part of the city in the following wards: Latimer, Belgrave, Spinney Hills, Rushey Mead and Coleman (Jivraj, 2012). Whilst these areas continue to be populated by Asians, it's increasingly common to find that, due to a rise in affluence and occupational mobility, many people from these communities are moving to rural and suburban areas of the city and the county. Popular areas of suburban and rural residence are Oadby, Humberstone, Great Glen and Houghton on the Hill (Jivraj, 2012).

Whilst the presence of Caribbean people in the UK has been acknowledged as far back as 1670, the arrival of the Empire Windrush in 1948, saw a greater number of people

migrate from the Caribbean in the 1950s. This was in response to post-war labour shortages in the UK. Many people from the Caribbean, mostly from Jamaica, settled in the Highfields area and St Matthews's area of Leicester, areas characterised by poor housing and socio-economic deprivation. In 1995, a large number of people also migrated to Leicester from Montserrat, fleeing from the volcanic eruption that devastated their Caribbean island (Runnymede Trust, 2012).

The white British ethnic group areas of residence around the city are varied, ranging from affluent areas such as Stoneygate and Clarendon Park, to some of the most deprived wards in the city such as Braunstone, New Parks, Eyres Monsell, Mowmacre and Stocking Farm (Leicester City Clinical Commissioning Group and Leicester City Council, 2016a).

Deprivation is higher in the west of the city compared to the east, and it is the west of the city that the majority of the white working class reside. Leicester is ranked as the 20th most deprived local authority in the country, out of 354. The following figure depicts patterns of deprivation using Indices of Multiple Deprivation (IMD) scores in areas of Leicester (Leicester City Clinical Commissioning Group and Leicester City Council, 2016a).

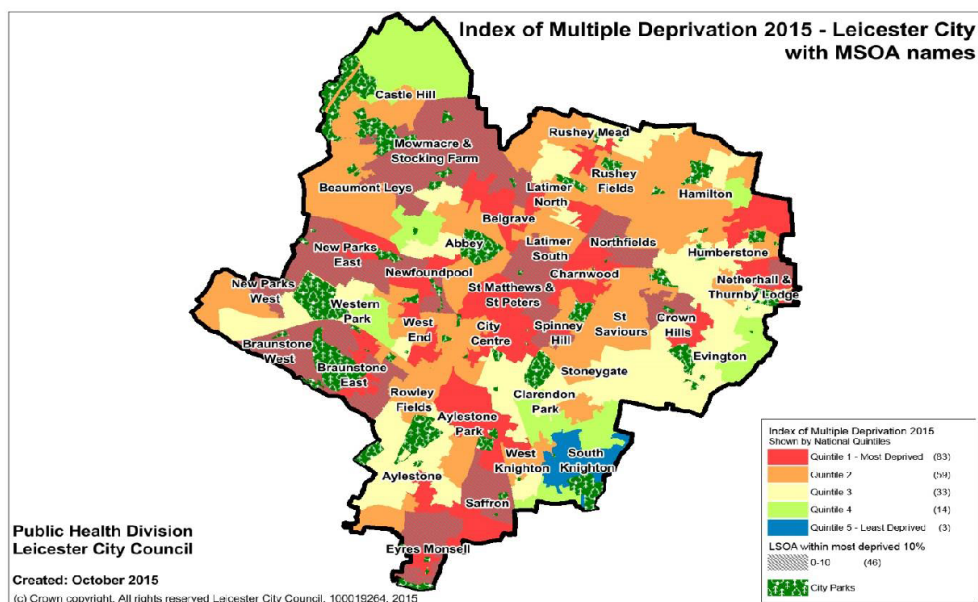


Figure 5.1: Index of Multiple Deprivation (IMD)

The focus group participants were recruited from organisations based in the Belgrave and Latimer wards for Indian Hindu Gujarati participants. The Highfields area, which

also encompasses Spinney Hill and St Saviours, is the ward in which the organisation that recruited for the Caribbean focus groups is located. Despite the fact that the focus groups were recruited from organisations that work in Belgrave and Highfields it may not necessarily entail all the participants the in Indian and Caribbean focus groups were residents in Belgrave and Highfields. In contrast, the white British participants for the focus groups were recruited by an organisation located in Braunstone and the majority of participants lived in that area.

Community workers and volunteers who participated in the interviews were recruited from organisations that work in Belgrave, Highfields and Braunstone, one of whom works across the city of Leicester and the county.

### **5.3 Research Sample: Participant Characteristics**

The following table illustrates the data pertaining to how many participants from each generational age and ethnic groups participated in this research. It can be seen that the majority of the participants were recruited in the 40-55 years generational group, in comparison to the younger generational focus groups aged between 18-40 years. In relation to ethnicity, the majority of the participants were Indian Hindu Gujarati, in comparison to the lower numbers from the Caribbean focus groups.

The following tables are populated from the information shared by participants on a voluntary basis in the 'Information about Participants sheet' which was completed at the beginning of the focus groups (Appendix F) and interviews (Appendix G). Some of the information is incomplete because participants may have chosen not to respond to the questions. The tables present responses to questions relating to the following: age group, gender, self-assigned ethnicity, country of birth and highest level of education (summarised as education level).

Table 5.1: Total number of participants in the focus groups

| <b>Overall Research Sample</b> | <b>18-30</b> | <b>31-40</b> | <b>41-55</b> | <b>Total</b> |
|--------------------------------|--------------|--------------|--------------|--------------|
| <b>White British</b>           | 4            | 5            | 7            | 16           |
| <b>Caribbean</b>               | 6            | 3            | 5            | 14           |
| <b>Indian Hindu Gujarati</b>   | 5            | 4            | 10           | 19           |
| <b>Total</b>                   | 15           | 12           | 22           | 49           |



Table 5.2: Caribbean Focus Group

|                                | <b>Characteristic</b>   | <b>n</b> | <b>%</b> |
|--------------------------------|-------------------------|----------|----------|
| <b>Age</b>                     | 18-30                   | 6        | 43       |
|                                | 31-40                   | 3        | 21       |
|                                | 41-55                   | 5        | 36       |
| <b>Gender</b>                  | Male                    | 5        | 36       |
|                                | Female                  | 9        | 64       |
| <b>Self-assigned Ethnicity</b> | Nigerian                | 1        | 7        |
|                                | British Caribbean       | 1        | 7        |
|                                | African Caribbean       | 2        | 14       |
|                                | Black British           | 2        | 14       |
|                                | Black British Caribbean | 2        | 14       |
|                                | Black African Caribbean | 1        | 7        |
|                                | Black British African   | 1        | 7        |
|                                | Black Caribbean         | 1        | 7        |
|                                | Black English Caribbean | 1        | 7        |
|                                | Black                   | 1        | 7        |
| West African                   | 1                       | 7        |          |
| <b>Country of Birth</b>        | Nigerian                | 1        | 7        |
|                                | England                 | 9        | 64       |
|                                | United Kingdom          | 2        | 14       |
|                                | Jamaica                 | 1        | 7        |
|                                | Cameroon                | 1        | 7        |
| <b>Education Level</b>         | Not Stated              | 2        | 14       |
|                                | GCSE/O-level/NVQ 2      | 3        | 21       |
|                                | A-level/NVQ 3           | 1        | 7        |
|                                | Diploma                 | 4        | 29       |
|                                | Degree                  | 3        | 21       |
|                                | C&G                     | 1        | 7        |

Self-assigned ethnic identity: There was some discussion about ethnic identity in all the focus groups and participants described which aspects of the ethnic identity they most strongly identified with. Some participants preferred to acknowledge their Caribbean and/or African heritage as well as their identity as a British person. A minority of

participants were also keen to identify as 'Black'. The self-assigned ethnicity on the information about participant forms confirms some of the points raised in the focus group discussions.

Country of birth: The majority of the participants were born in England/UK, whilst a minority were born in two African countries (Cameroon and Nigeria) and Jamaica.

Highest level of educational qualifications: The majority of participants possessed A-level qualifications (or equivalent) and above.

Table 5.3: Indian Hindu Gujarati Focus Groups

|                                | <b>Characteristic</b>        | <b>n</b> | <b>%</b> |
|--------------------------------|------------------------------|----------|----------|
| <b>Age</b>                     | 18-30                        | 5        | 26       |
|                                | 31-40                        | 4        | 21       |
|                                | 41-55                        | 10       | 53       |
| <b>Gender</b>                  | Male                         | 7        | 37       |
|                                | Female                       | 12       | 63       |
| <b>Self-assigned Ethnicity</b> | British Asian                | 6        | 32       |
|                                | Hindu                        | 1        | 5        |
|                                | British Indian Hindu         | 1        | 5        |
|                                | Indian                       | 3        | 16       |
|                                | British Indian               | 5        | 26       |
|                                | British Asian Indian         | 1        | 5        |
|                                | Hindu Gujarati               | 1        | 5        |
|                                | Hindu Gujarati British Asian | 1        | 5        |
| <b>Country of Birth</b>        | Kenya                        | 2        | 11       |
|                                | Tanzania                     | 1        | 5        |
|                                | Uganda                       | 1        | 5        |
|                                | India                        | 5        | 26       |
|                                | UK                           | 9        | 47       |
|                                | Africa                       | 1        | 5        |
| <b>Education Level</b>         | GCSE/O-level                 | 3        | 16       |
|                                | A-level                      | 1        | 5        |
|                                | Degree                       | 11       | 58       |
|                                | Postgrad                     | 2        | 11       |
|                                | MBA                          | 1        | 5        |
|                                | Professional Accreditation   | 1        | 5        |

Self-assigned ethnic identity: In a similar way to the Caribbean focus groups, participants during discussions highlighted what aspect of their ethnicity they most identified with. For some participants their British and Indian identity was important, whilst for others their religious and language/Indian state of origin was important to acknowledge.

Country of birth: The majority of the participants were born in the UK, with an even split

between the remaining participants between Africa and India as country of birth.

Highest level of educational qualifications: The majority of participants held A-level and above qualifications.

Table 5.4: White British Focus Groups

| <b>Characteristic</b>          |                | <b>n</b> | <b>%</b> |
|--------------------------------|----------------|----------|----------|
| <b>Age</b>                     | 18-30          | 4        | 25       |
|                                | 31-40          | 5        | 31       |
|                                | 41-55          | 7        | 44       |
| <b>Gender</b>                  | Male           | 6        | 38       |
|                                | Female         | 10       | 63       |
| <b>Self-assigned Ethnicity</b> | Not Stated     | 2        | 13       |
|                                | White British  | 9        | 56       |
|                                | White          | 1        | 6        |
|                                | Don't Know     | 1        | 6        |
|                                | English        | 2        | 13       |
|                                | British        | 1        | 6        |
| <b>Country of Birth</b>        | England        | 13       | 81       |
|                                | United Kingdom | 2        | 13       |
|                                | Wales          | 1        | 6        |
| <b>Education Level</b>         | Not Stated     | 6        | 38       |
|                                | GCSE/O-level   | 3        | 19       |
|                                | A-level        | 3        | 19       |
|                                | Degree         | 4        | 25       |

Self-assigned ethnic identity: The discussions about ethnic identity in all the white British focus groups highlighted that some participants wanted to identify as English, but felt hesitant as it was deemed not be politically acceptable, whilst others felt that due to their mixed heritage such as Scottish or Welsh it was difficult to identify as English only.

County of birth: The majority of participants were born in England/UK. England is specified partly in response to some of the participants wanting to articulate their English heritage.

Highest level of educational qualifications: In contrast to the Caribbean and Indian Hindu Gujarati focus groups, it was difficult to ascertain the qualifications that were held as six people did not complete this aspect of the information sheet.

### 5.3.0.1 Community Workers

Table 5.5: Community Workers

| <b>Characteristic</b>             |                   | <b>n</b> | <b>%</b> |
|-----------------------------------|-------------------|----------|----------|
| <b>Age</b>                        | Under 35          | 1        | 20       |
|                                   | 35-60             | 4        | 80       |
| <b>Gender</b>                     | Male              | 1        | 20       |
|                                   | Female            | 4        | 80       |
| <b>Self-assigned Ethnicity</b>    | Indian            | 2        | 40       |
|                                   | African Caribbean | 1        | 20       |
|                                   | White English     | 1        | 20       |
|                                   | White British     | 1        | 20       |
| <b>Time in current occupation</b> | Unknown           | 1        | 20       |
|                                   | 0-5 years         | 2        | 40       |
|                                   | 6-10 years        | 1        | 20       |
|                                   | 11+ years         | 1        | 20       |

The information in this table is incomplete as one of the community worker's forms was illegible and it was not possible to complete the information sheet with the community worker after the interview. Overall, the number of years in their existing job role demonstrates that the workers that were interviewed shared their perspectives having been in their current job role involving a number of years. It is also interesting to see that under self-assigned ethnicity one of the participants stated white English as opposed to British, reflecting some of the discussions held in the focus groups.

# Chapter 6: Findings on Knowledge & Understanding, Conceptualisations of Dementia and Ageing

## 6.1 Introduction

There are many compelling reasons for gauging how and why the lay public know and understand dementia in the way that they do. One of the most commonly cited reasons is that it may assist in supporting the lay public and their families to detect signs and symptoms of dementia to obtain diagnosis early in the disease progression. However, the literature review of empirical findings also indicated early diagnosis is also influenced by the conceptualisations of dementia as well as the beliefs people hold about ageing. These findings predominantly emerged from studies conducted with older people, people with dementia, and their carers. There was a paucity of studies conducted with the lay public from different generations. In this chapter, this under-researched area of the perspectives of other generations is addressed through the presentation of my research findings.

This chapter will address the following research questions:

1. What is the knowledge and understanding of dementia of younger and middle-aged adults in multi-ethnic communities?
  - (a) What factors influence and contribute to this knowledge and understanding?
2. How is dementia conceptualised by younger and middle-aged adults in multi-ethnic communities?
  - (a) What factors and issues shape and influence their conceptualisations of

dementia?

3. How is old age and ageing conceptualised in younger and middle-aged adults in multi-ethnic communities?

(a) How is old age and ageing framed in relation to dementia?

## **6.2 Overview of chapter**

The research question relating to help-seeking strategies is addressed in the following chapter. This chapter is organised in three sections to address each of the above research questions. It will commence with an overview of each of the sections, including the key arguments. Thereafter, each of these three sections will be presented and organised to commence with tables that visually depict the themes, including their representation within focus groups. The latter has been undertaken to avoid obstructing the flow of the narrative with detailed explanations about which groups the findings pertain to. That being said, where the findings were uniquely represented or found to be represented in one or a few focus groups, it will be explicitly stated. The key to the abbreviations used for representation of focus groups in these tables and the narrative in findings is as follows: Caribbean focus groups- Car; Pilot Indian focus group- PIL IND; Indian focus groups- IND; White British focus groups- WB.

## **6.3 Overview of sections**

### **6.3.1 Section 1: Findings of knowledge and understanding of dementia**

This section presents three overarching themes: 'acquisition of information and knowledge', 'possession of knowledge' and 'exposure to knowledge and understanding'. In acquisition of knowledge, the key argument presented here is to emphasise the need to focus attention on what motivated participants to actively seek out information and knowledge, rather than simply what knowledge they possessed. Ethnicity and generational age were not factors in shaping knowledge and understandings of dementia but were highlighted by participants as affecting older generations outside of this research sample.

In the overarching theme of 'possession of knowledge' we turn to the knowledge participants did possess, with ethnicity or generational age not playing an influential role. There were variations in knowledge within and across all focus groups. What was common across the majority of focus groups was a lack of knowledge about the risks posed for dementia by chronic health conditions such as diabetes and hypertension. In addition, there were misconceptions that dementia and Alzheimer's were separate illnesses, even amongst former carers and trained ex-professional carers.

In the overarching theme of 'exposure to knowledge and understanding' we come to understand why there was this variation in knowledge in this research sample. This was identified as exposure to dementia through caring experiences and social networks, exposure to the media and exposure to education about dementia in higher education. These three factors meant that participants could develop their knowledge and understanding of dementia through different routes. Ethnicity and generational factors were not evident, for example, the Indian focus group 18-30 years were exposed to education about dementia through university courses, and it was exposure to dementia through higher education that was the key factor.

### **6.3.2 Section 2: Findings on conceptualisations of dementia**

In this section there is only one overarching theme of conceptualisation of dementia encompassing two themes, namely dementia as a mental illness (knowledge based) and as normal a consequence of ageing (belief based). In each of these, there were nuances in the way they were expressed. Also evident was the shifting and multi-layered aspect to conceptualisations amongst some of the participants in two of the focus groups, as discussions clarified or challenged participants' preconceptions.

Taking each conceptualisation in turn, the conceptualisation of dementia as a mental illness in old age was most commonly found across all generational ethnic focus groups. Some of the factors that influenced this conceptualisation related to symptoms of dementia as well as a consequence of mental health campaigns and the media attributing anything related to the mind to mental health. Other factors were related to the backgrounds of participants. Overall, this conceptualisation was shaped by



knowledge rather than beliefs and the use of bio-psychological terms with which to convey their understandings of dementia and other mental illnesses.

In contrast to the above, the conceptualisation of dementia as a normal consequence of ageing was primarily driven by beliefs that participants held about the ageing process resulting in a degeneration of the body and mind. For some participants these conceptualisations remained steadfast even when confronted with evidence that it can affect younger people. The most interesting conceptualisations emerged from the white British focus group 40-55 years and were also shared by participants in the same focus group who previously expressed that it was a mental illness (but different from depression and schizophrenia) and a progressive disease. In this focus group, it emerged that participants held multiple concepts of dementia, such as it being a disease and a coping mechanism for the brain because it has reached its capacity, partly due to old age and also due to the belief that the brain's storage is limited. Again, the overall argument here is that conceptualisations often shifted in light of focus group discussions and encompass a combination of beliefs about ageing, as well as alignment with bio-medical understandings such as progressiveness and genetic susceptibility. Nonetheless an explicit mention of dementia as a pathological disease was not evident amongst all participants.

### **6.3.3 Section 3: Findings on conceptualisations of ageing**

Thus far in the findings we have seen that concepts of old age and ageing were inextricably linked in both participants' information and knowledge-seeking strategies and their conceptualisations of dementia. The intrinsic role played by both old age and ageing merited further interrogation in the data in order to ascertain precisely how and why they were framed in relation to dementia. In order to achieve this, it required an exploration of participants' concepts of old age and ageing to uncover their connection. I also wanted to explore whether these concepts and their framing differed between focus groups and why.

In the overarching theme of generational shift in concepts of old age, ageing and their meanings encompasses two themes. The argument presented in this overarching

theme here is that there was a change in the concepts of old age and ageing that have changed generationally over time. Old age in the past was expected to lead to a decline in functionality of the mind, and signified a slowing down during old age so that older people were assumed to pursue 'old age' activities. These included, for example, bowling and pushing a shopping trolley, as well as behaving respectfully.

In the present, we see a generational shift in participants' approach to old age and ageing. The outcome of this shift is that, firstly, old age was not determined by chronological age nor does it equate to a decline in mental and physical functionality. Secondly, the move away from chronological age and life course markers has been re-directed to an emphasis on the process of ageing, hence it was this process of ageing that was conceptualised differently. The above argument is substantiated by findings which include participants' reflections and positioning on ageing derived from their direct experiences and observances of the impact of an array of structural influences, as well as factors such as personal exposure to healthy and resilient older people. The impact of these was that they assisted in the analysis process to understand why participants were consistently arguing 'age is just a number'. It was suggested that individuals were perceived to have the agency as well as a personal responsibility to maintain good physical and mental health. It was, therefore, interesting to note that a decline in functionality in both mind and body was not seen as inevitable but once ageing is accompanied with decline, then dementia (a random event) is perceived to be an inevitable side effect of it.

Given this re-defined approach to ageing, in the second overarching theme 'mitigating the ageing process as a risk factor for dementia', participants addressed the ageing process as a risk factor for dementia and other health conditions. This argument is supported by findings relating to participants' use and advocacy of lifestyle strategies to mitigate the possibility of themselves and others developing dementia, as well as other health conditions. This revised positioning on ageing was based on their own analytical framing of their experiences. In addition, their observances of older people in their family and the wider community prompted them to consider and take a pro-active approach to their own mental and physical well-being as they aged to minimise their risk of dementia in the

future.

## **6.4 Section 1: Findings on knowledge and understanding of dementia**

The table below presents a visual overview of the themes. The key to the abbreviations used for representation of focus groups in these tables is as follows: Caribbean focus groups- Car; Pilot Indian focus group- PIL IND; Indian focus groups- IND; White British focus groups- WB.

Table 6.1: Themes and representations of focus groups for Knowledge and Understanding

| Overarching Theme   | Theme  | Representation Focus Group   |
|---|--|--|
| <b>Acquisition of information and knowledge</b>               | Theme 1: Dementia on the Doorstep  | Car 18-30 yrs.; Car 30-40 yrs.; Car 40-55 yrs.; IND 30-40 yrs.; WB 18-30 yrs.; WB 30-40 yrs.   |
|   | Theme 2: Access to credible information and knowledge  | Car 18-30 yrs.; Car 30-40 yrs.; Car 40-55 yrs.; PIL IND 40-55 yrs.; IND 40-55 yrs.; WB 18-30 yrs.; WB 30-40 yrs.;  |
| <b>Possession of Knowledge</b>                                |  | Memory loss:<br>Car 18-30 yrs.; Car 30-40 yrs.; Car 40-55 yrs.; PIL IND 40-55 yrs.; IND 40-55 yrs.; WB 18-30 yrs.; WB 40-55 yrs.;                            |
|   | Theme 1: Certainties and uncertainties of knowledge  | Symptoms, including behavioural and personality changes:<br>Car 18-30 yrs.; Car 30-40 yrs.; IND 18-30 yrs.; PIL IND 40-55 yrs.; WB 30-40 yrs.; WB 40-55 yrs. |
|   |  | Younger people can have dementia<br>Car 30-40 yrs.; IND 18-30 yrs.; IND 30-40 yrs.; IND 40-55.; WB 18-30 yrs.; WB 30-40 yrs.; WB 40-55 yrs.                  |
|   | Theme 2: Lack of knowledge about specific health conditions as risk factors for dementia                                   | Car 18-30 yrs.; Car 40-55 yrs.; IND 30-40 yrs.; IND 40-55 yrs.; WB 18-30 yrs.; WB 30-40 yrs.   |
|   | Theme 3: Misconceptions about dementia as an umbrella term   | All PTs in Car 18-30 yrs.; Car 40-55 yrs.; All PTs in PIL IND 40-55 yrs.; IND 30-40 yrs.; All PTs in WB 18-30 yrs.; WB 40-55 yrs.;                           |
| <b>Exposure to knowledge and understanding about dementia</b> |  | Behavioural<br>Car 30-40 yrs.; PIL IND 40- 55 yrs.; IND 18-30 yrs.; IND 30-40 yrs.; IND 40-55 yrs.; WB 30-40 yrs.;   |
|   | Theme 1: Exposure to knowledge and understanding of dementia symptoms through the experience of caring and social networks | Memory loss<br>Car 30-40 yrs.;, Car 40-55 yrs.; PIL IND 40-55 yrs.; IND 30-40 yrs.; WB 18-30 yrs.; WB 30-40 yrs.   |
|   |  | Progressiveness of dementia<br>PIL IND 40-55 yrs.; IND 30-40 yrs.;   |
|   | Theme 2: Exposure to dementia in narrative plots in soap dramas, new and documentaries                                     | Car 18-30 yrs.; Car 30-40 yrs.; PIL IND 40-55 yrs.; IND 30-40 yrs.; IND 40-55 yrs.; WB 18-30 yrs.; WB 30-40 yrs.; WB 40-55 yrs.                              |
|   | Theme 3: Critical reflections on portrayal and information about dementia in the media                                     | PIL IND 40-55 yrs.; IND 40-55 yrs.; IND 30-40 yrs.   |
|   | Theme 4: Exposure to knowledge about dementia through higher education   | IND 18-30 yrs.   |

#### 6.4.1 Overarching theme: Acquisition of information and knowledge

This overarching theme speaks to the factors that influence and motivate participants to seek information and knowledge about dementia. It also includes a consideration of when, how and where they would be likely to acquire the information and knowledge. These

factors also suggest that there may be a generational divide in the way older people are able to access information and knowledge in comparison to younger people, and why this may affect the credibility of information older people receive about dementia.

#### **6.4.1.1 Theme 1: Dementia on the Doorstep**

The findings suggest that the point at which participants would seek to actively acquire information and knowledge about dementia is when it affects someone close to them, i.e., when it was on their doorstep, after their diagnosis (to assist with care etc.) The comments from the following participants are illustrative of these views, and the name of this sub-theme is derived from the comments of a participant from the Caribbean focus group 18-30 years:

*I suppose people only take an interest in it if it comes around in your own home or a friend or something or your wife, you would take an interest in dementia or cancer or something. PIL IND 40-55 PT4.*

*There is a lot of information out there, but I don't think it is, I think it's one of those things where you research it when it's on your doorstep, that's the impression I get where unless it's someone that you know, or you might suspect that someone might be getting a bit ill, or you are concerned about someone and you start looking into it. But apart from that I don't think it's something that you actively look to learn about just for general knowledge kind of thing. Car 18-30 PT6*

Up until that point, as the reflections from PT1 from the Indian focus group 30-40 years highlight her pre-diagnosis approach to information and knowledge acquisition, it was characterised by apathy. In particular, she indicated that she understood the apathy some people have about acquiring knowledge of dementia as well as the attitude 'why bother?' Even to the point of switching off to information about dementia, because it's perceived as not affecting them. However, her experience of dementia in the family prompted her to think that people should be receptive and open to learning even when it's not on their doorstep, because it can affect them too:

*Then urm I think for me personally going through something makes you more aware of it and then makes you more open urm to start talking about these things and getting those things out there and sharing experiences and stuff. So, I think yeah, it's probably a bit of both really like you don't know about it you just kind of switch off don't you and think well it's not affecting me so why should I bother, that kind of attitude urm. Whereas for myself it's like actually it could affect you so you should be more perceptive to it or receptive to it and be a little bit more open to it. IND 30-40 yrs.PT1*

When dementia was on the doorstep, it was deemed to play an instrumental role in the

search for information and knowledge to assist with caring for a PWD. After diagnosis, for a few participants their acquisition was motivated by the need to support their family member with dementia and acquire knowledge about dementia, including its progressiveness:

*Get as much information from libraries and sources and even nurses, when she was in hospital from the nurses themselves you know. Urm so I could, it gives you urm more of an insight to I was with her so to help me look after her better in knowing what condition what this was and how worse it was going to get. What levels we were going to go through. Urm and I think I passed that information on to my husband and my children so like we all became carers urm, so it just helped each other. And it helps us to you know pass that information on to someone else as well. IND focus group 40-55 yrs. PT3*

*I have done a bit of reading about this dementia saying you know give them puzzles to do, give them something to try and wrap their mind or whatever. I have done a little bit of reading about what they are eating, what they shouldn't eat..... PIL IND yrs. PT4*

The acquisition of information and knowledge was also linked to conceptualisations of dementia as a condition that affects older people only. The findings related to this factor were uniquely represented in the Caribbean focus group 18-30 years, where it was suggested that younger people are unlikely to be motivated and actively acquire information and knowledge about dementia because it was perceived not to affect them because of their youth, i.e., is not on their doorstep. The comments related to this finding emerged in response to the above participant's PT6 views in the Caribbean focus group 18-30 years:

***Excerpt: Caribbean focus group 18-30 yrs.:***

*Car 18-30 yrs. PT3: I don't think it really matters because at a certain age you don't really concern yourself with learning about things like that because generally it affects old people. So, you don't really think about it because unless you are in the medical field of some sort and you have to deal with something like that. Other than that, I don't think ... the younger generation don't tend to think about things like that. Illnesses in general we don't really tend to think about because you just deal with it and you know.*

*Car 18-30 yrs. PT4: I agree with what he said urm us young people we don't really see the importance I would say urm off different types of illnesses out there and urm .. yeah we wouldn't really take ... our you know social time or spare time that we have to actually sit down and research what it actually is.*

Whilst the search for specific illnesses such as dementia may be ruled out until required, it may not preclude accessing and acquiring general health and well-being information:

**Excerpt: Caribbean focus group 40-55 yrs.:**

*Car 40-55 yrs. PT2: But I think with any illness ... I think... I think people will look out for well-being information how to keep yourself well, but with specific illnesses I don't think you are going to research or read deeper into it unless you have got a family member or yourself or something so ... urm I wouldn't necessarily read up on certain things unless it affected somebody.*

*Car 40-55 yrs. PT1: Yes, that's what I mean.*

*Car 40-55 yrs. PT2: That I deal with, family, friends I don't think I would read into you know read into it, I don't think I would have the awareness of it until I possibly needed it. But general health and well-being information yes, I will read.*

**6.4.1.2 Theme 2: Access to credible information and knowledge**

Whilst the above theme discussed *when, why and how* participants are likely to seek information and knowledge, an additional finding was that *where* people acquire information also merits consideration. This finding emerged as a consequence of participants' discussions about their perceptions of where older people source their information and knowledge about dementia. As such, the following are not reflective of the findings about older people within this research sample but relate to participants' perspectives of older people in wider society.

There was a perception that access to technology and a greater number of resources for information and knowledge assist to better equip younger generations about dementia when compared to older generations in the present and the past. This is because, firstly, the availability of information is now deemed to be greater and faster with Google than it was for previous generations. Secondly, younger generations are now viewed as being supported to develop their knowledge and understandings about dementia through formal education and the availability of information from organisations such as the NHS, as this sample of comments illustrates:

*I would say from 25 to 40 that it's becoming more knowledgeable through like colleges, universities, the national health, through leaflets through what you hear in hospitals as well that you see massive leaflets saying oh dementia unit or this is dementia read up on it. Or you have, an example you have different other leaflets like cancer, and you do have leaflets for dementia as well which is bringing it up to more knowledge for the younger generation. IND 40-55 yrs.PT3*

*Yes, I think we are more clued up, we get more information, I think. Or maybe we just seek more information I don't know. Maybe we you know we seek things more, but I suppose we have seen a lot of different things that possibly our elders, and when I*

*say elders, I mean my grandma rather than my mum, they didn't see in their lifetime. Car 40-55 yrs.PT2*

**Excerpt: Pilot Indian focus group 40-55 yrs**

*PIL IND 40-55 PT3: Technological advances now mean that things that took me so much time to do in those days I can do it in at a fingertip. Children can learn much more faster. Look at the technological advances, anything you want to find just Google it Google it and you will read about it. But our parents or people from that generation didn't have those abilities or those facilities so that has got to do quite a lot, so when you look at technology the way it.*

*PIL IND 40-55 yrs. PT1: It's access to information isn't it.*

As a consequence of this generational divide, older people were thought to, by younger people more generally, obtain their information and knowledge about dementia from past experiences and informal sources rather than the Internet. It was implied that these informal sources were perceived to be less credible because they were unlikely to be factual and based on bona fide sources such as Google, according to the following participants:

*I think it's probably just hearing something, if so and so said something then you heard that and that's it, there is no way to qualify that information or check if its right or Google it, is this correct. It's just like oh yeah, I heard Miss So and So say this, and what Miss So and So said Mr So and So went through this, that's fact. Car 30-40 yrs.PT1*

*Probably past experiences from when they were growing up and probably their grandparents or their parents might have had dementia. I don't think they get it from the Internet as such, but I think it's their past experiences from when they were growing up and the conversations they had with their parents and grandparents. I think that's where they get their intel from. WB 18-30 yrs.PT4 Male*

Whilst there was an acknowledgement that some older people who may have medical training will have acquired credible sources of knowledge about dementia, in the main, other older people were perceived to be left in a knowledge wilderness, because they tended to watch familiar Bollywood programmes. These programmes were not viewed as credible sources of information and knowledge, in contrast to reality shows and soap dramas, according to the following participants:

*Them its more friends, the older generation doesn't really tend to, they only watch things on TV that they already know, and they don't really tend to ... they don't find out that way. I think it would be more from experience in terms of a friend had it or they know someone that did have it. I don't think, I could be wrong, but unless they*



*have had medical training Car 18-30 yrs.PT3*

*The older generation watch different programmes doesn't it, they don't watch urm reality shows and soap operas they watch Bollywood and that sort of stuff, so they don't teach them things in Bollywood, so you find that they are in the wilderness really. Car 30-40 yrs.PT2*

For older people from Caribbean communities, the lack of access to credible information and knowledge sources was perceived to be exacerbated because health organisations were thought to fail in providing culturally appropriate information and knowledge due to racism. This finding was uniquely represented in the following focus group:

***Excerpt: Caribbean focus group 40-55 yrs.:***

***INT:*** *So where do older generations get their information about dementia or any other health conditions.*

*Car 40-55 yrs. PT4 and PT3 : They don't.*

*Car 40-55 yrs. PT4: They don't, it's not aimed at them, when they walk past and pick up an NHS file as I said there is a nice white family on there or there is the black family dressed up as white people. What I am saying is, and they are not, I can't say that they are dressed in western clothing yeah. So, it's like you know as I said I think not long ago we called it racism.....*

#### **6.4.2 Overarching theme: Possession of knowledge**

Whilst the preceding theme discussed some of the factors that may need to be considered in the acquisition of information and knowledge, an exploration of the knowledge that participants held was also undertaken. The findings were characterised by variation in knowledge within and across focus groups about aspects of dementia and not influenced by ethnicity or generational age. The purpose of this overarching theme is also to facilitate an overview of the findings so that they can capture and 'map' the knowledge participants possessed as well as gaps and misconceptions that existed within the research sample.

##### **6.4.2.1 Theme 1: Certainties and uncertainties of knowledge**

The findings with regards to the possession of knowledge that participants held strongly suggest that it was characterised by variation, and amongst this variation the one aspect of dementia that was spoken about with certainty and frequency was forgetfulness and memory loss, as found in the following sample of comments:

*Loss of memory. IND 40-55 yrs.PT1*

*It's where you can forget things very easily, certain things, you will do certain things in life that you will realise, you won't realise that it's not there anymore. WB 18-30 yrs.PT2*

*Different things can happen like you can start wandering off, start forgetting little things or repeating things continuously. Car 30-40 yrs.PT1*

*They start losing their memory. Car 18-30 yrs. PT6*

Although there was also uncertainty and speculation about some of the more detailed aspects of memory loss amongst the following participants:

*So, do you eventually stop remembering to do things that keep you alive like breathing? WB 18-30 yrs. yrs.PT1*

*Sure, but is dementia urm get trapped in a certain period in time where they keep replaying it? Car 18-30 yrs. PT3*

*Does it start with memory loss, do they start losing their mind and then they don't quite do the normal everyday activities, you know? Car 18-30 yrs.PT4*

*Errrrr I am going to guess, it's something to do with the brain the way it works. So, it's in the part of the brain that can't remember stuff I think, that's my guess. Car 30-40 yrs. PT2*

Knowledge about symptoms including behavioural and personality changes was less commonly found but expressed with certainty in some of the focus groups:

*Different things can happen like you can start wandering off, start forgetting little things or repeating things continuously. Car 30-40 yrs. PT1*

*It's an impact on sort of, you're disorientated and general tasks a bit more sort of difficult. WB 30-40 yrs.PT3*

*Emotional outbursts one as well, for example they could be in a happy mood and then all of a sudden go to the other extreme where it's anger or upset and to everyone else they might not know what's triggered it. But kind of like an imbalance of themselves being able to handle or cope with different situations. Car 18-30 yrs.PT6*

Some participants were aware that younger people can be diagnosed with dementia, with a few stating that they obtained this knowledge from personal experience or from the media:

*I think it can happen to, it's for mainly old people but it can happen to younger people as well. IND 18-30 yrs. PT2*

*And it's not just in old people dementia, it's also younger people as well because it's less common but I do know one or two people that had it at a young age and passed away with it as well. IND 30-40 yrs. PT2*

*I've heard that people that have mental health are generally more prone to... although younger people do have dementia as well, early onset dementia, and he was only two. WB 30-40 yrs. PT5*

*I have seen on the news young people can get it, thirties I have seen people have it. WB 40-55 yrs. PT3*

#### **6.4.2.2 Theme 2: Lack of knowledge about specific health conditions as risk factors for dementia**

When it came to the risks that medical conditions such as diabetes and hypertension pose to development of dementia, there was noticeably less variation and ambiguity in the knowledge held within the six focus groups that were asked this question. In relation to these, the findings demonstrate that there was a discernible gap in knowledge about these chronic health conditions as potential risk factors. The following excerpt is illustrative of the responses received:

***Excerpt: Caribbean focus group 18-30 yrs.:***

***INT:*** *Did you know about medical conditions like diabetes and blood pressure contributed to your risk of dementia?*

*All: No.*

*PT3: That sucks.*

The findings also suggest that the gap in knowledge about these medical conditions may be partly related to the conceptualisation of dementia as arising from old age as well as a lack of knowledge about the specific risk factors for dementia that go above and beyond general risk factors for ill health. These issues were aptly illustrated and uniquely represented in the Caribbean focus group 40-55 yrs.:

***Excerpt: Caribbean focus group 40-55 yrs.:***

***INT:*** *Do you know which medical conditions increase your risk of having dementia?*

*Car 40-55 yrs. PT4: I don't, again I don't personally think there are any, I just think it's like again deterioration of the mind and it will come to some people before it comes to others. I strongly believe that, and I just think that.*

*Car 40-55 yrs. PT1: Isn't it always the same ones, smoking and drinking and overeating?*

The contrast between the medicalised knowledge versus more general health and well-being information was also evident in the Indian focus group 30-40 years. This is because one of the participants, PT3, who held a managerial professional healthcare background, was informed about the association diabetes and dementia, including an awareness of dementia screening in people with diabetes. She demonstrated her knowledge about the potential risk of mental health problems such as depression and anxiety pose for dementia. The following excerpt also shows that her professional background contributed to her use of technical medical jargon such as 'co-morbidities' that can, in combination, raise the risk of dementia. In contrast, PT2 male offered a less medicalised psycho-social explanation of stress which is often associated with general health and well-being information:

***Excerpt: Indian focus group 30-40 yrs.:***

***INT:*** *So, what kinds of things are likely to increase a person's risk of dementia?*

*IND 30-40 yrs. PT3: Other co-morbidities, other health problems.*

*IND 30-40 yrs. PT2: Its stress isn't it, stress.*

***INT:*** *So, you mentioned other health problems, like what?*

*IND 30-40 yrs. PT3: So, there is diabetes is linked with dementia urm, so they do try and screen more diabetic patients for memory clinics and memory loss. Urm ... mental health has quite a strong link as well with depression and urm anxiety. Urm so I have only seen that side of it that's the only area I have touched on. But urm they do say that actually if you have got a couple of conditions like you can have COPD and diabetes or you can have a heart condition, you are a little bit more likely to urm develop urm dementia as well. So, there is that element of it.*

As the discussion progressed in the above focus group, it became apparent that the knowledge of risk factors may be linked to conceptualisations of dementia that perceived ageing as a risk factor that was affected by mental health. Hence, for PT2, risk factors such as a lack of physical activity and mental stimulation were positioned as risk factors for not ageing well and leading to dementia. This association with ageing was further reinforced when PT2 shared his opinion that some older people do not fill up their time

with mentally and physically engaging activities, thus placing themselves at risk of dementia:

***Excerpt: Indian focus group 30-40 yrs.:***

***INT:*** So, you are at higher risk?

*IND 30-40 yrs. PT1:* Higher risk to have it yes.

*IND 30-40 yrs. PT2 Male:* Possibly they have not been keeping active as well maybe and maybe a lack of exercise and doing things and mental things to keep your brain ticking as well. There are all sorts of things you should be doing at a certain age and stuff just to keep your brain ticking. Because after you quit your job and retire for example a lot of people don't actually fill up their time as well at that age.

#### **6.4.2.3 Theme 3: Misconceptions about dementia as an umbrella term**

In eight of the focus groups (this was not possible in the others due to time limitations) participants were asked whether they knew that dementia was an umbrella term for different types of dementia. It was evident that there was confusion and misconceptions. A few participants in the Indian focus group 18-30 years were knowledgeable about this issue, and their responses will be covered under the theme of exposure to formal education.

As for the other focus groups, the following excerpt from a discussion typically illustrates this finding and also demonstrates that for one of the participants, knowledge of dementia symptoms was restricted to memory loss only:

***Excerpt: White British focus group 18-30 yrs.:***

***INT:*** So, do you know there are different types of dementia?

*WB 18-30 yrs. All:* No

***INT:*** Have you heard of different types of dementia?

*WB 18-30 yrs. PT2:* No, I thought dementia was just one part.

*WB 18-30 yrs. PT4:* I thought it was just memory loss.

*WB 18-30 yrs. PT3:* I think Alzheimer's has that got something to do with it.

***INT:*** Yes

*WB 18-30 yrs. PT1:* So, what is the difference between Alzheimer's and dementia?

What was interesting about this aspect of knowledge was that it gave rise to misconceptions even amongst participants within the Pilot Indian focus group 40-55 years and Indian focus group 40-55 years, who had been professional carers and informal carers of close relatives who had dementia. These misconceptions included Alzheimer's being the last stage of dementia; Alzheimer's being a symptom of dementia and finally that Alzheimer's and dementia are two separate illnesses:

*Alzheimer's, I think is the last stage of dementia. IND 40-55 yrs.PT2*

**Excerpt: Pilot Indian focus group 40-55 yrs.**

*IND 40-55 yrs. PT5: That is another thing you just mentioned, I think people... interlink or think dementia and Alzheimer's are one and the same thing. I have no idea myself.*

*IND 40-55 yrs. PT2: I think one is the symptom of...*

*IND 40-55 yrs. PT1: they are confused as well with the two illnesses, if they are two illnesses I don't know.*

*IND 40-55 yrs. PT4: I have asked that question before and I have been told one is the symptom of the other and I can't remember which way round it is.*

#### **6.4.3 Overarching theme: Exposure to knowledge and understanding about dementia**

In contrast to the theme related to acquisition of dementia, this theme is distinguished by participants' exposure to three discernible sources which on the whole were not actively pursued for the sole benefit of gaining information and knowledge. These three sources involved caring for a relative with dementia, finding out about it through social networks and through storylines in the media through soap dramas, films, news programmes and documentaries. It may be possible that participants who viewed documentaries and films may have exercised a deliberate choice to view these. However, it was not possible to establish this during the course of the focus group discussions. The following themes provides coverage of these issues in more detail.

#### **6.4.3.1 Theme 1: Exposure to knowledge of dementia symptoms through experience for caring for PWD and hearsay**

There were several examples of participants who had developed their knowledge and understanding of dementia from their experiences of caring for someone with dementia or finding out about it through their social networks. The following comments have been selected because these highlight an understanding of the impact they had on the family with a PWD. These experiences specifically highlight an understanding of personality changes in the PWD that led to, for example, tantrums, uninhibited speech and violence:

*My friends, a couple of my friends their mother in laws have got it and they have experienced violence as well. Urm. PIL IND 40-55 yrs. PT5*

*It starts off like your behaviours changes, you will forget one day and then you will forget another day and then maybe a month or two later you might get angry or violent and you will hit out on a loved one. Say something that you would never say as a normal person. It's just different in every other person. IND 40-55 yrs. PT3*

*And it is getting them to adjust to the change that we couldn't get to that point of having that we had carers coming into the house, but it just wasn't the same, he would not want to urm bath or have somebody get him ready unless it was a family member. And that was just the way it was, he had tantrums and it got to a point where it was just easier to say well actually, we will do it, you know we would come in and change our working hours and it was hard work. IND 30-40 yrs. PT3*

For a few participants their caring experiences generated an understanding of the severity of memory loss including its impact on the ability to communicate. This is illustrated by the following examples:

*A little forgetfulness, urm I suppose your temperament can change, but I think with dementia it's that, it's the drasticness isn't it. I think with normal ageing you expect to see certain little things but when you see something completely different to that person's characteristics then you think no there is something slightly different here. Like I said my grandma was getting up and talking about work, but you have been retired how many years, that's not normal ageing, something else is happening there. Car 30-40 yrs.PT1*

*They become a bit withdrawn as they get older because then there is the fear of not knowing or... urm... I noticed it with my mother-in-law that because she couldn't remember everything she wouldn't say much. And then that withdrawing into each other and you know afraid of talking. PIL IND 40-55 yrs.PT1*

Other participants who directly observed or indirectly heard about memory loss came to understand that it can result in the PWD experiencing a dislocation of time in their

memories and consequently resulted in one of the participants conceptualising dementia as a mental illness:

*My girlfriend tells me about her granddad like urm recalling memories that were years ago and sort of like acting like they were last week. So, he will just casually ah do you remember that thing in (name of a place) last year or whatever and it will be something from ten years ago. And I think that's not like a forgetful thing that's a different thing altogether. I guess that's another reason why I guess it was a mental health issue. WB 18-30 yrs. PT1*

*My granddad for example, he really believes it's 1940 in the war... well XXXXX dancers for one thing. Yes, he generally believes that, and he doesn't have a clue where he is. WB 30-40 yrs. PT5*

An understanding of the progression of dementia emerged in only two focus groups, namely the Pilot Indian focus group 40-55 years and Indian focus group 30-40 years. This is illustrated by the following participant, who developed her understanding of dementia's progressiveness based on her personal relationships with people who have dementia. She was aware that persons with dementia were wandering and walking out their homes, without knowing why. These symptoms of dementia signalled to the participant that these people had "proper" or serious dementia, and she suggested that it's only at this point that relatives are likely to realise the seriousness of the illness:

*I know people personally who are in an extreme stage and they will just leave the house not knowing they have left the house they will go walking, and then maybe the relatives are (...). And then they realise you know that is when they know this is actually proper dementia now setting in. PIL IND 40-55 yrs. PT1*

The reflections from the following participants indicate that their understanding about the progressiveness of dementia may not be possible during its early stage but something that occurs with hindsight. This was explained by PT1, who indicated that she now understood that the triggers/signs indicating dementia were evident when her relative was younger, but they were not identified and possibly dismissed because of an expectation and association of dementia with old people. Whilst PT3 concurred with PT1, she also highlighted the difficulty of identifying specific factors that enable relatives to develop a broad picture or understanding of what they observed was actually an illness. Consequently, she ruefully conveyed that it was only with reflection and hindsight that, despite noticing signs of dementia, the family did not notice something was amiss:



**Excerpt: Indian focus group 30-40 yrs.:**

*IND 30-40 yrs. PT1: I think you naturally think of dementia as an old person but the more you learn about it you realise that this is probably happening for a very very long time. And you start to reflect, and I think that's where I started to really identify actually this probably didn't happen in the last few years, and the trigger points were all there, but we just didn't identify with them. But when you sit and reflect that's when you start to think well this started to happen quite early.*

**INT:** *When you say trigger?*

*IND 30-40 yrs. PT1: So, like little things like forgetting things and you know in a way we were quite dismissive of oh it's fine don't worry about it. But actually, they wouldn't normally do it why were we so dismissive and was that one of the starting points, or you know we didn't really identify it fully until it was too far gone, and we got the diagnosis. But there was probably an element of it, and it was a very very long time coming.*

*IND 30-40 yrs. PT3: I think that's the tricky bit isn't it, because actually what would you class as and differentiate very specifically as it's this or it's that. Urm I think it's just having that awareness that actually there is a breadth of it there, it's not one thing that you can pinpoint urm. And I think when people do get the diagnosis you do, like you say, reflect back and you are thinking well actually I noticed this, so and so noticed that but we didn't connect the dots up. And it's only when you are reflecting that you have done that.*

**6.4.3.2 Theme 2: Exposure to dementia in narrative plots in soap dramas, news and documentaries**

Another source of knowledge that generated participants' understanding of dementia came from participants' exposure to dementia storylines in soap dramas, dramas in film and on stage as well as news and documentaries. A minority of participants had developed their understanding of dementia through watching stage plays and the film *The Notebook*, although it is unknown whether this exposure was actively sought. In any case, they generated an appreciation of the detrimental impact of dementia as well as generating empathy for the PWD and an understanding of the symptoms:

*Yes, little bits of reference from real life and them movies and stuff urm ... Notebook, in that the women has got dementia I think maybe that might have been the first case where I saw how detrimental it could be. WB 18-30 yrs. PT1*

**Excerpt: White British focus group 30-40 yrs.:**

*WB 30-40 yrs. PT4: We had like a production came in the uni and they did like, like you said, from the person's view. It was like err like a drama piece. That was really, really good, you know. ....*

**INT:** *What was the drama about?*

*WB 30-40 yrs. PT4: It was about erm, because the nan she had erm dementia and the nan always used to look after the little girl and then eventually she had to stop looking after the little girl because she kept wandering off. She just couldn't cope with the erm with the responsibility anymore of looking after her and the little girl couldn't understand what was going on. So, bit by bit erm she got worse and worse and worse so... That was kind of it really, it was just showing different areas where she was struggling like going out, getting lost, not knowing where to go to, forgetting like the little girl's name and family members' names, she was becoming quite aggressive as well sometimes. Yes, so it was just showing just from her point of view how dementia was affecting her.*

Soap dramas on television were also an important source of exposure and helped with understanding dementia. In general terms, they attracted some discussion about characters and storylines. A sample of some of the examples of storylines shared in the focus groups are illustrated below:

**Excerpt: Indian focus group 30-40 yrs.:**

*IND 30-40 yrs. PT2: I have watched bits of the Emmerdale one I think, urm that was portrayed quite well, I think.*

*IND 30-40 yrs. PT3: Ethel was the other one who was deteriorating (EastEnders).*

**Excerpt: WB focus group 40-55 yrs.:**

*WB 40-55 yrs. PT7: Do you watch Coronation Street; do you think Rita might have it?*

*WB 40-55 yrs. PT3: Yes, I think that's the storyline isn't it.*

*WB 40-55 yrs. PT1: Yes, they are going to do that.*

*WB 40-55 yrs. PT3: Yes, the storyline she is going out of it, so I presume that's ...*

*WB 40-55 yrs. PT6: I was saying to my daughter yesterday she might be coming out of it.*

*WB 40-55 yrs. PT3: Yes, I read she is coming out.*

One of the most influential sources of understanding of dementia from these soap dramas was Emmerdale and the following section of this chapter will focus on the impact this soap drama had on some of the participants. Its impact was not only in relation to promoting understanding but also the way it contributed to creating empathy for the PWD. For example, a participant from the Pilot Indian focus group 40-55 years gleaned

bits and pieces of knowledge about dementia from Emmerdale, including the progressiveness of dementia:

**Excerpt: Pilot Indian focus group 40-55 yrs.:**

*PIL IND 40-55 yrs. PT5: I don't know if anybody watches Emmerdale but how that was portrayed, Ashley.*

**INT:** *What was it in Emmerdale sorry because I don't watch that, what happened?*

*PIL IND 40-55 yrs. PT5: Urm the local vicar urm got dementia, he got forgetfulness and that's when it was picked up. And it was just the process he went through, he would forget where he was, the day he got married. Urm and then she went upstairs, and he was remembering everything, and she came down downstairs and he couldn't understand why she was there. And then he tried to go to his previous partner, and you know not realising he had just got married. There were lots of bits in there and you could see the progressiveness and ... I can't remember the name.*

The Emmerdale soap was particularly memorable for two participants from the white British focus group 30-40 years because it portrayed dementia from the perspective of the person (Ashley) and in doing so demonstrated its effects, such as losing recognition of significant others in their personal lives:

*Yes so, it's like a day in the life of Ashley and everyone was strangers. I think that hit me more because you never see it from their eyes, you always hear about oh, you know, like they can't remember what they're doing or it's quite frustrating to look after someone that don't know who you are. But I think seeing it from the other angle was, like I just couldn't stop thinking about it afterwards. WB 30-40 yrs. PT5*

*Oh, it was so good. It was literally he, he was confused and came out of hospital, like not ran away but everything was, they'd changed all the characters like he knew into strangers. So, it took you a while to work out who was who but that's how he was seeing it and so in his head he thought like his erm his dad was his granddad and it was just like, and he kept going who are you. And I was thinking who is that but they'd changed the characters so you could see how a person that lived day by day not knowing who people are and saying this is, I'm your wife and you're like no you're not, or I'm your daughter, or how it affects them. It proper affected me. WB 30-40 yrs. PT2*

Further exploration with the white British focus group (30-40 years) was undertaken as more of the participants had seen the soap and had been affected by it. Their responses revealed that it was particularly poignant and insightful because, until they watched this soap drama, they had minimised and not fully considered how the person with dementia feels about their memory loss. It also enabled them to have an insight into the experiences of dementia through the eyes of a PWD as, until then, it was felt that people

generally focus on how the carers must feel. Consequently, seeing Emmerdale's portrayal of dementia was a revelation. It led to PT2 from this focus group not only concurring with the first participant but also reflecting that previously she'd only focused on how carers must be feeling tired, but since watching Emmerdale she was prompted to consider how the PWD with dementia must feel with particular reference to her nan (grandmother) who had dementia:

*I think we always see it from outside so like I say it's really tiring for the carer and so on, but you don't really think it's actually probably a lot harder for the actual person. WB 30-40 yrs. PT5*

*I'd just never looked at it from the eyes of a person suffering before. I just think, you know, you see people that look after people with dementia and see how tired they are. You know, like just going visiting me nan and she didn't even know who I was and it's quite awkward. You think because she's got memory loss you don't feel it as much as... WB 30-40 yrs. PT2*

Given the profound effect of Emmerdale on this focus group, I asked them to compare the impact a soap would have on their understanding of dementia in comparison to them having a leaflet about dementia. It's evident from the following excerpt that the soap provoked a strong memorable emotional reaction that indelibly conveyed an understanding and empathy about the effects of the illness, such as confusion from the perspective of the person with the disease, in a way that a leaflet could not:

***Excerpt: White British focus group 30-40 yrs.:***

*WB 30-40 yrs. PT2: Yes, because you actually saw it from someone else's eyes whereas you read it and you sort of take note and then you, it's never quite as hard hitting. So, you don't pick a leaflet up and think wow, where that I was like oh wow.*

*WB 30-40 yrs. PT4 : The emotion's not there in a leaflet is it as it is on TV.*

*WB 30-40 yrs. PT2: Yes. Everyone should watch that episode, it changed my view of actually people suffering with dementia because you just think of the people that are looking after them and how hard it is, not how hard it is to be so confused. I don't think a leaflet can capture that.*

In a similar way to the white British focus group 30-40 years, a participant from the Caribbean focus group 30-40 years shared that she was shocked to learn about the impact of dementia on the lead character within the Emmerdale soap. In particular, Emmerdale prompted her to consider aspects of dementia that she had not realised before, such as the loss of recognition of money, something she had found incredulous:

*I think there is probably more knowledge of it now because I think it's something that is in the media a lot more. And I think there are things that I've seen, and this sounds quite stupid, on soap operas that have made me think oh my gosh I never realised that. Like there was one show where the person didn't recognise money anymore and that really stuck with me because I don't think that's anything I even thought of before. That the fact that you then when you have dementia one of the things that you cannot start recognising, what you have always known. Car 30-40 yrs. PT1*

Whilst soaps such as Emmerdale and news coverage generated knowledge empathy and understanding, these nevertheless also generated fears and concerns about dementia for a minority of participants and on behalf of their relatives. From the white British focus group 40-55 years:

*It fills me with worry and fear to be honest the way the media put it um on the news you know. WB 40-55 yrs. PT3*

*Emmerdale and it was really, I know it's a soap, but they try and keep it as real as possible, but he played it good because I felt myself there is no way I would like to see my dad with that or my mum. WB 40-55 yrs. PT5*

#### **6.4.3.3 Theme 3: Critical reflections on media portrayals of dementia**

Not all media coverage was perceived to promote a coherent understanding of dementia as the findings relating to a discussion about a documentary by Angela Rippon (ex-newscaster) demonstrate. It was viewed by participants in the Pilot Indian focus group 40-55 years and shows that PT4 male from the Pilot Indian focus group found it difficult to assimilate and process the factual information that was conveyed. So much so that he would be unable to recount to someone else what exactly dementia is. As a consequence, beyond simple recall, his comments demonstrate the programme failed to generate an understanding of dementia:

*And like you said Angela Rippon did that great exercise and they dissected brains and there were gaps in it which defined...PIL IND 40-55 yrs. PT5*

*I can't remember what it was, but I can remember when they cut the brain and they showed these patches, white patches on the brain or whatever.....so we know that word we have learnt that word (dementia) but to get that breakdown on what we seen on that TV programme and to take it in and to take it in. I mean I watched it, but I still can't say to you exactly what it is. PIL IND 40-55 yrs. PT4*

There was a concern that Indian dramas would be unlikely to portray and generate an understanding of dementia effectively because they have music in the background and the storylines about dementia are likely to be poorly conveyed. This concern was developed

on the basis of participant PT2 male who critiqued a drama on an Indian channel which depicted a character with a head injury who subsequently developed mental illness:

*But it's all about getting the right... to do it as well and if you have it in Indian drama, I don't think they would portray it well, but I doubt it, with the music in the background and they won't portray it that well. There is one actually I think I have seen on the India channel only seen clips of it where the person had a head injury, and she has got a mental illness and it's sort of not portrayed that well. But yes, it's not very good. IND 30-40 yrs. PT2*

Nevertheless, the idea of an Asian soap, one that reaches Asian audiences across the board, was welcomed as one of the participants recognised the potential for such a programme, having watched 'Black', a Bollywood movie about an autistic child. This, she suggested, was considered to have a considerable impact on raising awareness about autism and an acceptance of people with autism in India and she implied something similar could be possible for dementia:

*It would be lovely if they made an Asian soap um ones that target how many audiences across the board, it would be lovely if they did do that. Because if you think about it Bollywood films that is (...) they talk about an autistic child with difficulties and guess what the whole of India is aware of autism all of a sudden. Urm when they made Black, it was acceptable to have somebody who was blind and couldn't hear but they could communicate, and they were a human being. So, there is a lot of strength in that aspect of it. IND 30-40 yrs. PT3*

#### **6.4.3.4 Theme 4: Exposure to knowledge about dementia through higher education**

Many of the participants in the Indian focus group (18-30 years) were noticeably more knowledgeable about dementia than any other focus group. This was because they had been exposed to dementia knowledge through their formal higher education. It was the *only* focus group able to distinguish that dementia and Alzheimer's are not one and the same:

*Alzheimer's as well, Alzheimer's is one of the biggest ones, I think. IND 18-30 yrs. PT4*

*Then there is vascular dementia as well. I have learnt a bit about this on my course at uni. IND 18-30 yrs. PT1*

There was also knowledge and understanding of symptoms such as memory loss, personality changes and the fact that it can occur amongst younger people, although

PT3 was uncertain about dementia in younger people:

**Excerpt: Indian focus group 18-30 yrs.:**

*IND 18-30 yrs. PT2: I think it can happen to, it's for mainly old people but it can happen to younger people as well.*

*IND 18-30 yrs. PT3: Fatigue, being tired a lot, even if you have not done anything. Also, bad, negative things rather than good things.*

*IND 18-30 yrs. PT4: Personality change is one, it would seem like you are just talking and cooperating with a completely different person... and changes really quickly.*

*IND 18-30 yrs. PT1: Like language difficulties.*

In addition to an understanding of some of the contributory causal factors for dementia through reading about dementia in academic research publications:

**Excerpt: Indian focus group 18-30 yrs.:**

*IND 18-30 yrs. PT1: There are different types of urm diseases that can cause dementia like Alzheimer's but there are also lifestyle factors that some people, I think I have read a few studies that say like exercising, diet that kind of thing can impact your risk factors for developing ...*

*IND 18-30 yrs. PT2: Yes, you can reduce your chances of having it or having it increased anyway. I read one article for the illness, if you exercise a certain amount every day, if your diagnosed with it then there is the chance of it decreasing and becoming even more severe reduces slightly.*

## 6.5 Summary

The above themes were presented to understand the knowledge and understandings participants possessed about dementia and the factors and issues shaped and influenced by them. For the knowledge that participants did possess, ethnicity or generational age did not play an influential role, as there were variations in knowledge within and across focus groups. These variations were influenced by three key factors: exposure to caring for a family member with dementia, hearsay in social networks, and exposure to the media and higher education. What was common across the majority of the focus groups was a lack of knowledge about the risks posed for dementia by chronic health conditions such as diabetes and hypertension, in addition to misconceptions that dementia and Alzheimer's were separate illnesses, even amongst former carers and trained ex-professional carers.

The findings have shown that possession of knowledge and understanding is a complex issue, that is also determined by factors such as acquisition of dementia at the point of need, and a perception that there are generational differences in relation to access to information about dementia, with older generations outside of this research sample having less equitable access to information. The following section will now turn to findings related to the conceptualisations of dementia.

## 6.6 Section 2: Conceptualisations of dementia

The table below presents a visual overview of the themes. Here is a reminder of the key to the abbreviations used for representation of focus groups in the table: Caribbean focus groups- Car; Pilot Indian focus group- PIL IND; Indian focus groups- IND; White British focus groups- WB.

Table 6.2: Themes and representation of focus groups for conceptualisations of dementia

| Overarching Theme  | Theme   | Representation Focus Group   |
|--|---|--|
| <b>Conceptualisation of dementia as a mental illness or a disease</b>  | Theme 1: External Classifications   | WB 30-40 yrs.  |
|  | Theme 2: Symptom based  | Car 18-30 yrs.; Car 30-40 yrs.;<br>IND 18-30 yrs.; IND 30-40 yrs.;<br>IND 40-55 yrs.; WB 18-30 yrs |
|  | Theme 3: Selecting the most appropriate label                             | WB 40-55 yrs.  |
| <b>Conceptualisation of dementia as a normal consequence of ageing</b> | Theme 1: Dementia as a random act of fate in old age                      | Car 40-55 yrs.   |
|  | Theme 2: Certainties about age-related deterioration amidst the confusion | PIL IND 40-55YRS.;<br>IND yrs.: 30-40yrs.  |
|  | Theme 3: Dementia as a coping mechanism for the ageing mind               | WB 40-55yrs.   |

### 6.6.1 Overarching theme: Conceptualisations of dementia as a mental illness or disease

By far the most common conceptualisation of dementia was that it was a mental illness or disease, mainly in old age, but there was nuance in the way this conceptualisation



emerged, as participants were employing and evaluating different criteria upon which to formulate their conceptualisation. The following discussion through the organisation of sub-themes focuses on the different criteria that were applied.

#### **6.6.1.1 Theme 1: External sources of information informing conceptualisations of dementia**

The discussion with the WB focus group 30-40 years to establish their conceptualisation of dementia led to an ambiguous description of dementia as a mental health condition, which did not assist with clarifying whether it was conceptualised as a mental illness or due to the ageing process:

***Excerpt: White British focus group 30-40 yrs.:***

***INT: How do you see it, what do you see dementia as?***

*WB 30-40 yrs. PT1: A mental health condition.*

*WB 30-40 yrs. PT4: I don't because I haven't had any family members. I probably would, if I had a family member that maybe had dementia, I probably would because some mental health problems can be genetic.*

The opportunity to clarify and explore why dementia was classified as a mental health problem rather than a brain disease was further explored with this focus group with a view to gaining an enhanced understanding of their conceptualisation. Their responses strongly suggest that they were taking cues for their conceptualisation of dementia from externally based sources rather than ageing beliefs they held, such as its association with normal ageing. These external sources acted as sources of authority from which to formulate their conceptualisations. These included mental health training which generated an understanding of its commonality shared with other conditions such as schizophrenia, on the basis of its uncontrollability. It was also informed by the location of its treatment in a mental health hospital, as well as the way in which the media categorises anything related to the mind as mental health.

***Excerpt: WB focus group 30-40 yrs.:***

***INT: So, it's really interesting because you talk about it as a mental health problem and not a brain disease. Why is it that people see it as a mental health problem and not a...?***

*WB 30-40 PT1: .... when I said that, but I think, because I went on mental health first aid training and you have mental health issues and...in general and the issues are more of like they can't actually control what it is, like schizophrenia, but then the mental health is more around well-being and quite often there is an overlap.*

*WB 30-40 PT4: I think for me the reason why I would say mental health is because I didn't know about it until I worked at the hospital and it's a mental health hospital and the patients are in a mental health hospital who have dementia. So, I'd associate it with a mental health condition.*

*WB 30-40 PT3: A lot more people think it's mental health. I think because a lot of awareness in the media, but I think the media has kind of put everything, anything to do with thinking or, I think everything's been sort of put together as mental health now, which is good that it's given a lot more awareness of things but again like the understanding is not really there.*

Despite the ambiguity in definition in the above discussions due to its definition as a mental health condition or problem, it's likely that it was conceptualised as a mental illness.

#### **6.6.1.2 Theme 2: Symptom-based conceptualisation**

For many other participants, dementia was conceptualised a mental illness on the basis of its symptoms such as memory loss and behaviour changes, or using terminology indicating an association with mental illness such as a chemical imbalance. A minority of these participants also understood dementia to be caused by changes in the brain and consequently dementia was conceptualised as a mental illness rather than a physical illness. Some of the comments below are illustrative of this conceptualisation:

*...it's a tipping of the unbalance, you know. Urm and that's why there is no age group where it just, obviously it happens more so in older people but is it that chemical unbalance that suddenly starts to trigger....IND 30-40 PT1*

*Mental illness, behaviour changes in the brain. IND 40-55 yrs.PT3*

*It's more about the deterioration, the mental state in slightly older people but also, I know it's not restricted to old people but generally speaking that's what I associate dementia with. Car 18-30 PT2*

*I would be very surprised if it was a physical thing, I could accept that might be the case, but I can't imagine that. It's like as you grow older there are chemical imbalances or something that would make it a physical illness rather than a mental illness. To me I can't see that it wouldn't be a mental illness because we are talking about memories, that's like the nature of what it is. Yeah, I don't ... WB 18-30 yrs.PT1*

#### **Excerpt: Caribbean focus group 30-40 yrs.:**

*Car 30-40 yrs. PT2: I would put it in the same for one reason because they don't, if you can't remember what you have done or what is going on then I would say it is a*

*form of mental illness.*

*Car 30-40 yrs. PT3: Yes, like the behaviour can just change so drastically just from, it can be just normal and the next they are getting cussed off for no reason yes, it's the same.*

Of those who conceptualised dementia as a mental illness, when asked whether they thought it was different or similar to other mental illnesses such as schizophrenia and depression, it was evident that participants were aware of its differences in relation to other mental illnesses. They understood that dementia was different to other mental illnesses such as depression, schizophrenia and psychosis on the basis of the following reasons: treatment differences; it usually occurs in people aged over 65 years, and; its causes and symptoms were different to depression. These differences are illustrated and represented by the following excerpt:

***Excerpt: Indian focus group 40-55 yrs.***

*All: Yeah different.*

*IND 40- 55 yrs. PT3: Depression you can control it with medication over time, to a certain degree schizophrenia can be as well. But dementia there is not a cure.*

*IND 40-55 yrs. PT1: Depression is anxiety.*

*IND 40-55 yrs. PT2: It can occur to anybody, depression can occur in anybody irrespective of age, even younger children can have it. Dementia can usually happen to over 65 the symptoms and causes can be different.*

### **6.6.1.3 Theme 3: Selecting the most appropriate label can be a struggle**

Further evidence of nuances in a mental illness conceptualisation came from the white British focus 40-55 years group. The following excerpt of a discussion between participants suggests the way in which participants selected and applied distinctions between the label of disease and illness differed. However, there was not sufficient time to explore in a substantive way the significance of these differences other than those reported below.

The discussion indicates participants utilised the disease label in different ways, for example, on the basis of dementia progressiveness, and the other as an illness because it's understood to be a genetically transmitted disease like diabetes.

Amidst this discussion, we can also see that two of the participants were struggling with how to label dementia, and consequently assist each other by considering the merits of their suggested criteria to try and establish the most appropriate label for dementia. In order to disentangle their confusion, they used the criteria of whether it can be fixed to decide whether it can be labelled as a disease. In this process of 'helping to understand', PT3's conceptualisation emerged, which suggests that she believes dementia occurs randomly in older people. Whilst PT6 labelled it as a mental illness:

***Excerpt: white British focus group 40-55 yrs.:***

***INT:*** So, what would, so basically would you see dementia as like as, you said progressive brain disease, so you see it as a disease?

*WB 40-55 yrs. PT1:* Yes, I see it as a disease, it's going to get worse it's not going to get better.

***INT:*** A mental illness, would you see mental illness as a disease?

*WB 40-55 yrs. PT6:* Mental illness yes.

***INT:*** So, what is the distinction, what ...

*WB 40-55 yrs. PT5:* Can mental health be fixed?

*WB 40-55 yrs. PT3:* Yes.

*WB 40-55 yrs. PT4:* It can be, so there are two kinds I think, because some of it can be fixed that would be a disease.

*WB 40-55 yrs. PT5:* Do they fix it, or do they treat it so it's not so prolific?

*WB 40-55 yrs. PT3:* We are all born with physical health and mental health like dementia develops err as we all get older maybe you know some of us get it. Like mental health is like .....

*WB 40-55 yrs. PT6:* It's an illness mental health.

*WB 40-55 yrs. PT3:* I think it can develop ....concentration memory.

*WB 40-55 yrs. PT6:* I have it, it's a disease and diabetic as well, that's a disease. And it runs in the family, my mum and brother and my dad have all had it. That's a disease it runs through your families. And I think dementia can run through families, it's as disease. It's in you and if it's in your family you could get it as well you know.

The above discussion highlights that in this focus group, there was no group consensus for dementia conceptualisation as, for some, their conceptualisations were shifting on the

basis of information and comments from other participants as the discussion progressed.

## **6.6.2 Overarching theme: Dementia as a normal consequence of old age**

Whilst this theme encompasses more broadly the conceptualisation of dementia as a normal consequence of old age, there was also nuance in the way it was expressed because of the emphasis participants placed on particular aspects of ageing. These factors gave rise to and revealed subtle differences in the participants' beliefs about the ageing process and what it entails in relation to dementia.

### **6.6.2.1 Theme 1: Dementia as a random act of fate in old age**

The following excerpt from the Caribbean focus group 40-55 years is fascinating because it highlights the interaction of beliefs and knowledge held by participants. So, for example, PT4 held a strong belief that dementia occurs randomly in old age, in a similar way to the experience of having bad backs, heart attacks and hearing loss. In addition, PT3 believed that dementia reverts a PWD to a baby stage.

However, the excerpt demonstrates that their beliefs were challenged by PT1 male and PT2 female who both possessed knowledge that it can affect younger people. The latter participant expected dementia to affect older people only but had this expectation challenged on hearing about her younger colleague's experience of memory loss through dementia:

#### ***Excerpt: Caribbean focus group 40-55 yrs.:***

*Car 40-55 yrs. PT4: My point is within old age, and I would probably say it affects people in old age more than it affects young people yeah, it's like anything isn't it, some people's back go, some people's arms go, some people's legs go, do you know what I mean, some people end up not being able to speak properly but it's still old age do you know what I mean. It's like dementia has always been there in terms of people reaching old age. (.....). Because it would just be identified as old, human beings unfortunately we don't know when the ticker is going to go but it's going to go. Same as people who have heart attacks, do you know what I mean, old age or people's backs go and they are like oh my back has gone and you know or their hearing goes do you know what I mean, their mind can go.*

*Car 40-55 yrs. PT3: Just like baby again, just going back.*

*Car 40-55 yrs. PT1: To me it's happening to younger people.*

*Car 40-55 yrs. PT2: Yes, I was just about to say that a work colleague has kind of forgotten a lot of things, she has been on long-term sick. Her husband will come and*

*talk to us and he is saying it's really hard basic things like she forgets that she has made a cup of tea, she has forgotten how to make a cup of tea. You know if someone asks her for a cup of tea. And I am thinking wow it's something that again I keep saying grandparents, I wouldn't say my mum's age group I would say older. But then to have a friend that's going through something like that makes me think well you know it's not necessarily ...*

*Car 40-55 yrs. PT3: Older generation.*

Despite acknowledging that dementia can occur in younger people, the belief that it was a normal, albeit random consequence of age-related deterioration persisted for both participants, there was no shift in their conceptualisations. Thus, dementia was not conceptualised as a disease that could be attributed to lifestyle factors or medical conditions:

***Excerpt: Caribbean focus group 40-55 yrs.:***

*Car 40-55 yrs. PT4: No some people will get bad backs, some people will go a bit deaf, do you know what I mean, some people ...*

*Car 40-55 yrs. PT2: I think everybody will deteriorate it's just how like you said some people will have a bad back, some people... heart attack but you know you are going to deteriorate. With dementia I don't think you can pinpoint and say that person has got it because when they were in their twenties, they drank loads.*

*Car 40-55 yrs. PT4: I don't think it's a disease.*

*Car 40-55 yrs. PT2: I don't think you can pinpoint how different people get it.*

*Car 40-55 yrs. PT4: I don't think it's a disease or a urm medical infliction I think it's like it, for some of us our minds will go before our bodies, sadly, physically we will be well mentally we will go. Others physically they will mentally they will still so it's almost like trying to cure fate.*

Yet, that despite this assertion that dementia can occur randomly in old age, we shall see in the following discussion on ageing that it became apparent that participants from this focus group also undertook a contradictory position to their conceptualisations as they discussed their efforts to minimise the risk posed by ageing to dementia through lifestyle changes.

### **6.6.2.2 Theme 2: Certainties about age-related deterioration amidst the confusion**

The expectation that dementia occurs in old age and is not a disease was also evident in the Pilot Indian focus group 40-55 years, and this belief was enculturated and

substantiated through personal experience, as in the case of PT1 and PT4. This conceptualisation of dementia was retained much like the Caribbean focus group 40-55 ywars, even in the face of contradictory evidence that it can affect younger people. This is demonstrated by PT3, who stated he had witnessed some people age well and retain their memory like the Queen, whereas others at a younger age seem to lose their memory at an early age. Despite these contradictions and the confusion it gave rise to, this participant maintained his belief that the brain deteriorates as you age so it functions differently and less efficiently than a baby who functions at an optimum level:

***Excerpt: Pilot Indian focus group 40-55 yrs.:***

*PIL IND 40-55 yrs. PT1: I always remember a comment that my father-in-law used to make, and I never really understood it until it was too late, always used to say I am going to say it in Gujarati "at sixty your brain goes" so you lost your brain well memory at 60. And I never really understood that until dementia, dementia kicked in for them. That I realised what that statement actually meant. So, to me always... that's what ageing process means but it doesn't have to be because if you keep your lifestyle changes then that helps.*

***INT: What do others think?***

*PIL IND 40-55 yrs. PT2: For me it's something different, when I was young, I wanted to grow up very quickly and now I want to grow slowly so... it's the fear of something whatever you said.*

*PIL IND 40-55 yrs. PT3: For me it's err a very difficult thing to understand, because if I look at people in general, I have seen some people lose their memory at quite an early age whereas some people have their memory for much longer. If you take an example of our queen, I don't think anything is wrong with her memory at the age of 92 or 93. But I have seen people who are much younger who lost their memory. So, to me what it is is slowing down of the brain as you get older and the brain slowly losing a part of its err function to remember things, and to assimilate things as well. So that what I define ageing as, the brain's ability to I wouldn't say malfunction but to function differently to like a little baby being born whose brain is functioning 100%.*

*PIL IND 40-55 yrs. PT4: I suppose for me if you look at the outside shell of a person and you think they are ageing, they are getting old. Until I have seen it in my own sort of surroundings with my own mum or whatever now, I can see with the err age the dementia has kicked in now.*

However, as the focus group discussion progressed and included an exchange of views about the Angela Rippon documentary in which PT4 male learnt about younger people being diagnosed with dementia, he did appear to have changed his mind and argued that it may not be age related but nevertheless retained the belief that it was a random occurrence:

*You know dementia coming on at a younger age and we don't realise. We keep going at the old age side of things it might not be. Because you can be the most cleverest person or the most richest person if it's going to come to you it's going to come to you, and you don't know about it. PIL IND 40-55 yrs.PT4*

Once again, in a similar way to the white British focus group 40-55 years, we see how the interactions with the focus group shifted aspects of conceptualisation, as in the case of the participant above, it shifted or was clarified on the basis of an association of old age with dementia.

### **6.6.2.3 Theme 3: Dementia as a coping mechanism for the ageing body and mind**

As we have seen some of the participants within the white British focus group 40-55 years conceptualised dementia as a disease and an illness that is inherited. It was those same participants who also held a belief that dementia is a coping mechanism for the ageing mind. It was suggested that dementia facilitates the regression of memories to enable the PWD to retreat to, and access happier and earlier memories as a way of dealing with the limited brain capacity brought about by age-related deterioration:

#### ***Excerpt white British focus group 40-55 yrs.:***

*WB 40-55 yrs. PT4: I think it's ... a sign of your body getting more tired i.e., it needs winding up.*

*WB 40-55 yrs. PT1: I think it's a bit of both, age, but I always think maybe it's a way your body coping with realising that you are getting old, and you are coming to the end. So, you would rather forget it and your mind goes back to things when you were happy in that kind of, if you are going to think of it in a nice way and not as in a horrible way.*

*WB 40-55 yrs. PT3: I have heard that its best to keep your brain active rather than .....*

*WB 40-55 yrs. PT4: Yeah keeping active but it's like .... your computer for example so it might have four gigabyte and it can only take so much.*

*WB 40-55 yrs. PT2: Yes, read or crosswords I am thinking of rather than use the computer.*

*WB 40-55 yrs. PT4: No using the memory, you can only ...*

*WB 40-55 yrs. PT6: Put in so much and it fills up.*

*WB 40-55 yrs. PT4: So is it a case of your brain will only take so much and then if you want to put more in something has got to come out. You have got to make*



*space somewhere so forgetting the things that probably aren't so ....*

*WB 40-55 yrs. PT3: Ingrained.*

*WB 40-55 yrs. PT5: Ingrained or important they are easier to lose so memory...*

The above beliefs attracted support and agreement within this focus group, thus suggesting that some participants may hold an amalgam of concepts that relate to ageing as well as dementia as a disease and illness.

## **6.7 Summary**

The findings indicate that there were two main conceptualisations of dementia, which were that it was a mental illness that can occur in old age and for others it was conceptualised as a normal consequence of old age and ageing. The nuanced analysis of each of these conceptualisations identified a number of different factors that influenced how participants formed their conceptualisations, but it was clearly evident that knowledge gained from different sources shaped the conceptualisation of dementia as a mental illness. Whereas the conceptualisation of dementia as due to old age or the ageing process was determined by beliefs about the ageing body and brain. Dementia as a pathological disease was not mentioned by all the participants. It was evident too that a few participants changed their conceptualisations or amalgamated their conceptualisations in response to the information and views they gained during discussions in the focus groups. I will now turn to the following section on re-defining ageing.

## **6.8 Section 3: Re-defining Ageing**

The table below presents a visual overview of the themes related to re-defining ageing. Here is a reminder of the key to the abbreviations used for representation of focus groups in the table: Caribbean focus groups- Car; Pilot Indian focus group- PIL IND; Indian focus groups- IND; White British focus groups- WB.

Table 6.3: Themes and representation of focus groups for Redefining Ageing

| <b>Overarching Theme</b>  | <b>Theme</b>  | <b>Representation Focus Group</b>   |
|---|---|---|
| <b>Generational shift in concepts of old age, ageing and their meanings</b> | Theme 1: The past characterised by chronological age and life course markers influencing meanings and understandings of old age | WB 30-40 yrs.; Car 40-55 yrs.; PIL IND 40-55 yrs.:  |
|   | Theme 2: Present times, a focus on individual responsibility for mental and physical well-being in the ageing process           | Car 18-30 yrs.; Car 30-40 yrs.; Car 40-55 yrs.; PIL IND 40-55 yrs.; IND 40-55 yrs.; IND 30-40 yrs.; IND 18-30 yrs.; WB 40-55 yrs.; WB 30-40 yrs.; WB 18-30 yrs. |
| <b>Mitigating the ageing process as a risk factor for dementia</b>          | Theme 1: Taking a balanced approach to life to minimise dementia risk   | IND 30-40 yrs.; IND 40-55 yrs.  |
|   | Theme 2: Focusing on mental and brain health  | PIL IND 40-55yrs.; IND 40-55 yrs.; Car 18-30 yrs.; Car 40-55 yrs.; WB 40-55 yrs   |
|   | Theme 3: Focus on physical health   | Car 18-30 yrs.; Car 40-55 yrs.; IND 30-40 yrs.; WB 18-30 yrs.; WB 30-40 yrs.  |
|   | Theme 4: The risk to health and mental well-being posed by giving up on life and social isolation                               | WB 18-30 yrs.; WB 30-40 yrs.; IND 30-40 yrs.; PIL IND 40-55 yrs.; IND 40-55 yrs.; Car 40-55 yrs.  |

### **6.8.1 Overarching theme: Generational shift in concepts of old age, ageing and their meanings**

This overarching theme introduces two themes which are linked temporally using the past and the present as reference points to signify generational shift in concepts of ageing. The first theme will explore how old age was perceived to be defined by society in the past and marked through chronological age and life course markers of old age. In addition, there will be a discussion about the meanings and understandings ascribed to old age.

The subsequent theme focuses on the present and we shall read how structural changes in wider society, personal interactions with healthy agers, as well as the influence of the

media contributed to an emphasis on the ageing process rather than chronological age or life course markers. This positioning contrasts with the societal influence seen in the past and emphasises individuals taking responsibility for their own ageing process.

#### **6.8.1.1 Theme 1: In the past, meanings and understanding of age determined through chronological age**

In the past, for previous generations (older people outside of this research age sample) the findings suggested that the age at which an individual was deemed to be at old age was collectively determined by societal values and norms. These were articulated on a practical level by the use of chronological age and life course markers. An example of a chronological marker to denote old age included the bus pass age (although the age used in the past for the bus pass may be incorrect). This was suggested by the white British focus group 30-40 years only:

***Excerpt: White British focus group 30-40 yrs.:***

***INT:*** *But your parents' generation, what would they have defined as old? I know you can't speak for them, but has it changed?*

*WB 30-40 yrs. PT2 Female: It's sixties.*

*WB 30-40 yrs. PT3 Male: Yeah, I think 65.*

*WB 30-40 yrs. PT4 Female: Yes.*

*WB 30-40 yrs. PT4 Female: Bus pass age.*

Indian participants in the Pilot Indian focus group 40-55 years suggested that, amongst older generations in their community, a life course marker denoting old age had been reached with a child's marriage. This belief was so strongly held, as illustrated by the example below, that even at the age of 47 years old there was an expectation that old age would be accompanied by a loss of functionality both physically and mentally, and so it became a self-fulfilling prophecy. However, it was unclear from the second comment below whether such beliefs currently exist amongst Indian older generations:

*My mother-in-law gave up at the age of 47, which is the age she was when I got married and that was it you know. This is it; my son is married and therefore I am old. And I always viewed her as old until I got to that age and thought I am still young, and I still think like I'm 18 or 30 you know. And it's just so, I think the older Asian population saw themselves as a lot older, and I am not saying everybody, but*

*most see themselves as older than what we see at the same age they are going through. IND Pilot 40-55 yrs. PT1*

*I think society sees ageing as... my generation saw ageing as a detriment, that physically you are going to be able to do less things um mentally you are going to remember less things. That is what I think the generation above us thought. And I think because they thought it um in reality they started acting like that.... IND Pilot 40-55 yrs. PT5*

Whilst the above comments related to health, the following sample of comments from other focus groups also demonstrated that old age in the past was associated with behavioural expectations that old people had to conform to societal norms and values about chronological age-related behaviours, such as playing bowls, using shopping trolleys and behaving respectably. These issues were discussed in the following focus groups:

*You just see a lot more old people doing different things now whereas I think before they were expected to just, I don't know, go to the shop with their trolley and do like certain things like play bowls. I think there's like a definite thing they had to go and do ..... WB 30-40 yrs. PT3*

**Excerpt: Caribbean focus group 40-55 yrs.:**

*Car 40-55 yrs. PT1: I was told that, I went to Barbados and I was in church and I was playing with the kids and all kind of stuff and then my sister told me there was, or people say um he don't act his age, he is weird because he is supposed to be acting a certain way. And I said, my sister said try and act more adult do you know what I mean. ....*

*Car 40-55 yrs. PT2: There is nothing wrong with playing with children.*

*Car 40-55 yrs. PT1: Not everybody, they didn't say it to my face, but they said it to my sister that I didn't act my age, they thought that was a bit weird. You have got pressure from the outside you have got to act in a certain way.*

*Car 40-55 yrs. PT2: I don't think there is nothing wrong with that.*

*Car 40-55 yrs. PT1: No not nowadays it is but back in the day, the elders you are supposed to be respectable.*

The findings in above theme focused on primarily on the past and highlights how society through a combination of cultural norms and values associated with chronological age and life course markers dictated when old age had been reached. It also influenced meanings, expectations and held implications for health and social behaviours.

I now turn to the next theme which pertains to the present-day concepts of old age and ageing. It encompasses a discussion of a range of factors to argue the reasons for a generational shift from defining old age using chronological and life course markers to an emphasis on the ageing process and individuals taking responsibility for their health.

#### **6.8.1.2 Theme 2: Present times, a focus on individual responsibility for mental and physical well-being in the ageing process**

In the present, for Indian people aged 40 years and under in this country, enculturated beliefs about old age held in the past were suggested to be eroding due to education transforming how old age is conceptualised. As a consequence, chronological old age was no longer believed to have an inevitable detrimental impact on the functionality of the body and mind, including memory. Instead, amongst Indian younger generations, age was viewed as just a number which no longer influenced what they can and cannot do. Consequently, the focus of younger generations was suggested to be the ageing process, not chronological age, and what they can do to keep themselves young. In contrast, Indian older generations outside of this research sample were suggested as continuing to use chronological old age as a key marker of old age that acted as a barrier for their ability to pursue and enhance their skills, for example, learning about information technology. The following comments capture the key points discussed by all the Indian focus groups:

*I think ... a new generation, probably people in their forties currently who have had the education here think differently. So, the way society views them as ageing, urm be it the generation below or the one above them is age is just a number, so they have turned it around. So, they are not viewing it as that their physical health has to deteriorate just because their age is increasing. Urm even with memory and that I don't think they view it as because you are this old you can't do certain things or remember certain things. So, I think throughout the times society is viewing age very differently. PIL IND 40-55 yrs. PT5*

#### **Excerpt: Indian focus group 30-40 yrs.:**

*IND 30-40 yrs. PT3: But I think from an ageing perspective for my generation and for me it's age is that number factor it's what I make of what I do and how I behave that counts more (.....). So actually ageing, we don't accept the ageing process, but we look at graceful ageing as a concept but actually we all want to stay young. And I think there is that divide actually when people get to a set age and I look at my mum and dad and go yes that's just age. I have got to this age I have got to accept this; this is what I am. I am not prepared to learn IT I am not prepared to have a go with my mobile phone to Skype. It's they put that age barrier upon themselves and I don't think we do that.*

*IND 30-40 yrs. PT1: I agree, I think culturally the older generation do use that as an excuse. But I think our generation kind of goes age is just a number we can do it, that's the mindset that we generally have.*

What also became apparent in all of the focus groups was the fact that additional structural factors were implicated in re-defining old age and ageing. These included longer life expectancy as a consequence of medical advances and access to better healthcare, and when combined were cited as pushing back the boundaries of old age through access to better healthcare and extending life expectancy. These changes prompted people to focus on ameliorating the effects of the ageing process on their increased lifespans through the pursuit of healthy lifestyles. To some extent this focus on the pursuit of healthy lifestyles was also perceived to be pushed by the NHS. The impact on their conceptualisations of old age and the ageing process were found in many of the focus groups and can be illustrated by the following sample of participants' comments:

*Yes, but I think it's because people live longer now as well so by prolonging your life probably you get illnesses but years ago you wouldn't have been alive at sixty would you you were lucky to get to sixty. WB 40-55 yrs. PT2*

*We are living longer as well um because we are living longer (...). The generation like my grandparent's their life expectancy was at a set level and if they made it past that point, they felt that was a milestone for them. For us um actually going beyond the hundred mark is achievable now isn't it, you know our lifestyles and our health habits have improved to a point where I think we don't look at it as just a number. IND 30-40 yrs.PT3*

*Previously also I think because their forefathers etc. etc. there was not that much medical um help around as well. They just took it for granted that as you aged your knees go, you do get larger. Exercise wasn't a big thing although they physically did have to work to survive, they didn't physically go and do something with a remit to lose weight etc. Although part of their lifestyle allowed them to do that. Urm so education I think has helped as we have gone forward in terms of how to look after yourself to prevent some of the ageing process coming on sooner rather than later. IND Pilot 40-55 yrs.PT5*

*A lot of people have been told keep fit, keep fit, you know you live longer so a lot of the, I think nowadays as you get older you start to look after yourself a bit better. I mean over the diabetes, they are putting that down your throat all the while, eat properly, go to the gym. You know do all this walking thing. WB 40-55 yrs.PT5*

The structural changes described above, when combined with participants' exposure and interactions with older workers working past their retirement age, also demonstrated to participants that chronological old age did not necessarily limit functionality of the mind and body. Their experiences also visibly signalled to them that it was how an individual

engaged with their ageing process that determined whether they remained healthy and productive as they aged. The following comment captures the key tenets of the arguments vocalised by participants of other focus groups:

*I think for me working where I work urm you are interacting with people like all the time and there are different people of different age groups and ... You know urm there is this whole kind of you know you retire at 65 sort of thing, you have got people working beyond that and you wouldn't think that you know they are old, do you know what I mean or ready for retirement as they have put it. But urm so I think having that exposure to working with different age groups you just think, you just become accustomed to well yeah age is just a number because people are out here, and they are doing what they are doing. You talk to them and find out their backgrounds and stuff and you kind of realise that actually it's up to you you know, you dictate what you want to do, when you want to do it and how you want to do it. Urm and we dictate whether we let age define you or not. IND 30-40 yrs.PT4*

This re-defining of old age and ageing was further reinforced by participants' exposure to active healthy agers in their personal lives and its impact was observed to be significant in two ways. Firstly, it enabled participants to differentiate between healthy and unhealthy agers as a consequence of the pursuit of healthy lifestyles, which encompassed physical activity, mental stimulation, social interaction and learning new skills. Secondly, it helped to defy participants' preconceptions about what an old person can and cannot do. The following comments were evident in many focus groups:

*....I am working in pharmacy there are some people at the age of 93 they are coming and collecting medicine from the shop. And some people are 70 or 80 and they can't come they aren't able to walk. So, you can see the difference, 93 years old people come and collect the medicine, so he looks after himself. IND focus group 40-55 yrs. PT1*

*I think it's literally age is just a number, because literally you can see 80-year-olds that are still doing yoga and all sorts. And then you can see some at that exact same age and they are nowhere near as active even if it's not by choice it might be that they have had a condition that limits them. But I do think it's like you said lifestyle and diet and things like that and stimulation, interacting with people, learning new skills. Car 18-30 yrs. PT2*

*But he (uncle) keeps himself active I ain't never seen no 65-year-old man other than him with a six pack. He walks, he goes gym, he does stuff, and he says the same thing as what you are saying, he says we have all got to go but he wants to keep going until he can't do it no more. He wants to keep going, even he was like oh XXXXX next week I want to come to your gym and see what goes on at your gym. And I was like wow. But to look at him he does not look like an old man. Car 40-55 yrs.PT2*

Whilst the above comments pertain to physically active older people, participants' exposure and observances of older people who they perceived to be mentally young

and resilient also served to challenge the past societal belief that old age caused an inevitable decline in mental functionality. Instead, the findings suggest that participants were pointing to an individual's mindset as determining how well they aged, so keeping mentally young was attributed as having a positive effect on the body and mind. The following comments are representative of the many comments with respect to this issue across all the focus groups:

*You see some people, some people are already only in their forties, but they act as though they are 18 and people obviously find that weird, don't act your age. But the older they get they will still have the mental state or mental strength of a younger person so they feel like they can do more. And I personally think that way your body tends to follow you. Car 18-30 yrs. PT3*

*In think it's like a mental thing like if you think you are old then you are old. Like for example if you act old, OK there are certain points where you have to act mature in certain, certain situations you have to be mature, but like I am not saying you have to be immature all the time, but you can still be young. Like for example this weekend when I went London I went climbing up the O2 and urm we were in like, you go in groups and there was like this 70-year-old couple who had walked up and they were both like oh it was our birthday present from our son. And he is like you are never too old to climb up, like you are never too old to do something. IND 18-30 yrs.PT3*

*....Because my sister-in-law is in her seventies and her attitude is younger than mine, or even people that are younger, she keeps going. She has been through so much illness in her life and you'd think anyone else in that circumstance would have collapsed and gone. IND Pilot 40-55 yrs.PT1*

Whilst it is difficult to establish a causal relationship, it can be postulated that the media may have played an influence in shaping and influencing the participants' approach to ageing, which could be discerned to function in two ways. Firstly, it promoted exposure to older people who were active agers, achieving success in acting and modelling during their older years. This kind of exposure through the media and Internet technology was thought to be previously unavailable for previous generations. Secondly, the media itself was directly attributed as shaping people's youthful approach to ageing by promoting fashion trends such as dental implants and hair colouring to combat the physical signs of ageing. These comments are illustrative of the views regarding the media's influence:

*....I think it's just because of urm Internet things like that, now we can see people on TV in their eighties that are doing amazing things or in their seventies and doing active things. Whereas before there might not have been the technology for it to be that open so you might have had to actually know someone who is that age who is doing that, if you get what I mean. Now you can turn on the TV and there are actresses and actors who are older, and they are doing incredible things, models*



*that have just started their career and they are seventy. Car 18-30 yrs.PT6*

*I think it's just like fashion trends impact, if you look at people their colouring of hair, um the option of actually having hair transplants, dental implants all of that, is media orientated. You know the influence of what maybe an older actor does then does reel on to what people in the community do go for. And I think there is that media awareness in that sense. And then what information is being um portrayed in the news you know what research comes out and then does go into um a tabloid or a broadsheet does make an impact. What we read on Twitter has an impact on how we think and behave. IND 30-40 yrs.PT3*

*I think they are aspiring a set goal for ourselves as well, um they make it seem that it's achievable as well. IND 30-40 yrs.PT3*

The above overarching theme through a discussion of past and present conceptualisations of old age and ageing has argued that the concept of ageing has changed from one defined by society through chronological age and life course markers to one which is characterised by a more individualised approach to ageing, which places the responsibility of ageing well on individuals. That being said, the question remains how this re-defining of ageing is framed in relation to dementia? This question is addressed below and introduces findings that demonstrate the participants considered the ageing process itself as a risk factor and they addressed risk by pursuing strategies for healthy ageing. They also conveyed their knowledge and understanding of risk factors related to ageing from their interactions and observations of older people in their personal lives and in their wider community.

### **6.8.2 Overarching Theme: Mitigating the ageing process as a risk factor for dementia**

In this theme I introduce the argument that the implication of this generational shift was that participants considered strategies to mitigate the risk posed by the ageing process itself for dementia and other health conditions. Furthermore, some of the participants used their personal experiences as well as their observations of people in their personal lives and the community to describe some of the threats posed by social isolation and stress to healthy ageing and dementia.

### 6.8.2.1 Theme 1: Taking a balanced approach to life to minimise dementia risk

For a minority of participants, the importance of taking a balanced approach to their life was perceived as the way forward to promote good health and minimise their dementia risk, although this concept of balance encompassed different meanings for participants. For example, it entailed consciously promoting a work life balance and minimising stress. Whereas for others it involved addressing the balance between maintaining their physical and mental health by making life changes, as illustrated by the following comment:

*Ageing we can say definitely, you can't stop your age growing but you can improve your health wise mentally and physically so you can put yourself in somewhere..... Certain age you have look after yourself. Say there is a forties but that time you have to balance your life somewhere, not only just working working and making stressful and things like that. Change yourself a little bit, It's individually for everybody how they are going on and they have to take the step. They need to cut down the workload, look after family, if they have children and responsibility there will will change this way that way. If they want to change their work something like a different way, they might not be enjoying work where they are working, they should change their work they might enjoy something different. Sometimes if they go for the music and some different things you know that will help as well. IND 40-55 yrs.PT1*

In the following focus groups, it was also evident how exposure to dementia in the family motivated participants to think about the ways in which the risk of dementia could be mitigated for themselves and parents as they aged. One of the ways in which a participant addressed this risk for herself was by counterbalancing stressful and challenging days by undertaking self-care:

#### **Excerpt: Indian focus group 30-40 yrs.:**

*IND 30-40 yrs. PT1: I think to a certain element absolutely when you see someone go through it you kind of naturally go what can I do to not get this or what can I do to prevent my parents getting to this stage. And you do start to go like what can I do differently and you evaluate that. I think that's just natural.*

*IND 30-40 yrs. PT3: Urm I think there is that urm again I think we are a bit more aware I think even just in other areas of health we are lot more you know we have the forty plus check and you know we want to be healthy, we go to the gym we do activities urm. We try and do a range of different activities outside socially as well to give that work life balance. And even that is just us I think ... in some way we are looking at going well actually I have looked at my mental well-being as well as my physical well-being. We do look at it in a different way, those small changes do make...*

*IND 30-40 yrs. PT1: You have probably hit the nail on the head there, that we do do, we think of actually how has our day been so we go right do you know what I have had a really crap day really stressful I am going to have a bath, I am going to read a*

*book, I am going to have a glass of wine. We automatically go right to I need to look after myself kind of mode.*

### **6.8.2.2 Theme 2: Focusing on mental and brain health**

The findings suggest that some participants emphasised the necessity of keeping their brain health and mental well-being in good condition through, for example, brain training applications to keep the brain in shape, as well as activities such as yoga and meditation.

The following comments are illustrative of this finding:

*One more thing mental exercise means, meditation and yoga will be helpful for that. Because of that your mental power will increase if you encounter any situation you will be better able to handle it. Bring into your routine yoga and breathing and meditation then your mental power can increase, then you can calm down and handle stressful situation. IND 40-55 yrs. PT2*

#### **Excerpt: Caribbean focus group 18-30 yrs.:**

*Car 18-30 yrs. PT6: I imagine being active like when you say about stimulating the brain and even for all generations now you have got apps and brain training games and things like that. And I imagine just like any other muscle if you don't use it it gradually deteriorates, and I just imagine or assume for it to be the same way you keep active and stimulated in different activities hopefully that's the way to decrease that.*

*Car 18-30 yrs. PT3. Learning new skills.*

Another participant specifically focused on the importance of him learning new skills, and his belief was derived from observing his mother who he believed maintained a youthful mind by undertaking stimulating and new activities:

*To me I go training because you have got to keep your mind occupied or you see people in their nineties doing A-levels or doing degrees and stuff like that. Because you have reached a certain age or retired that's when it mostly happens, you sit and vegetate they don't use their brains any more do you know what I mean, you have to keep yourself occupied. Like my mum she does sewing, she does any crafty things she likes to keep her mind, keep her mind active as well. She is really for her age she is really young and so you have to keep keep learning new stuff all the time, keep your brain ticking over. Car 40-55 yrs. PT1*

The importance of keeping motivated and having a positive mental attitude, as well as keeping healthy and active, was discussed by a participant as a way of helping people feeling young beyond the age of 50:

*I think it depends on your mind, I think oh I am going to be old; I am getting to over 50 it's just a number. You have to think young, you have to be positive, the more*

*activities you do and keep yourself motivated. You can sit in front of a television and watch TV all day, why do that when you can go out and do different activities or keep yourself motivated. Go out and meet people of your own age and do things you have not done before. IND 40-55 yrs. PT3*

However, when the brain health is not maintained due to stress or overuse it was suggested to have a negative impact on brain health, affect memory and cause dementia:

***Excerpt: Pil Indian focus group 40-55 yrs.:***

*Pil Indian focus group PT1: I think stress can be a big factor (INT: in what way?) If you are overworking the brain, if you are stressing out and you are not really giving it time to relax and urm you can become forgetful. Urm I have experienced it you know I was going through a really bad time in my life and I was worrying, worrying about funds coming in and how I am going to cope and that pressure I couldn't see any further. Now there were lots of circumstances leading up to that, it wasn't just one thing it wasn't only work it wasn't home it was personal life stuff it was everything. Urm and I was finding that oh I forget peoples name I go into one room and I say ooh I need to do this, by the time I had walked out of that room I am thinking what was it. That's at a younger age. I have come out of that stress period, still got stress, but that part of it, and I didn't notice I didn't notice I was being forgetful.*

*IND Pilot 40-55 yrs. PT2: From what I think is stress plays an important role, if we don't get a break from the stress, we would tend to lose our brains cells. But if you get enough breaks, I think we can start picking up things again.*

***Excerpt: white British focus group 40-55 yrs.:***

*WB 40-55 yrs. PT4: Wasn't there a study that urm ... said that ... the more dementia cases seem to be those in higher educational and urm... more professional ... people where they are using their brains more. In a sense your body is only built for so much and could you be wearing part of your brain out.*

*WB 40-55 yrs. PT1: You have got a point there haven't you.*

*WB 40-55 yrs. PT5: But that means other people won't bother then learning ought.*

*WB 40-55 yrs. PT4 Male: It's only designed to beat so many times surely.*

*WB 40-55 yrs. PT5: There is Terry Pratchett the author.*

*WB 40-55 yrs. Yes, he died, didn't he?*

### **6.8.2.3 Theme 3: Focus on physical health**

The emphasis on maintaining physical health as they aged was evident from a minority of participants either because they were scared about developing a health condition or

simply wanted to maintain good health as they aged. These comments are illustrative of this issue:

*Yes, I am, I guess I am working on that right now because I have seen um people who end up dead or just you know with a health condition and you know it really scares the hell out of me. So, I am like well alright then I have to eat right I have to exercise you know, I have to do this I have to do that. So, I am more aware, I guess. Car 18-30 yrs.PT1*

*I think ever since I was young um I have always wanted to, I have always said to my mum oh I am going to, when I am 70, I am going to be so fit and so that like, and I still have that mind set. But you know um it's just one of those things that you need to get in place, like you said like now. And you know make it a routine and then make it your lifestyle. So that when it comes to that time you are 70-80 years old you are still looking fine like a forty-year-old or a thirty-year-old and stuff like that. So, it's definitely something that I am definitely working on as well. Car 18-30 yrs.PT4*

#### **6.8.2.4 Theme 4: The risk to health and mental well-being posed by giving up on life and social isolation**

The findings also pointed to a minority of participants who suggested the risk for dementia could be attributed to older people giving up and socially isolating themselves. One of these participants reflected on his observance of his grandmother who he felt lost her confidence and failed to make the most of opportunities as she aged. By learning from this experience, he advocated that people had a choice as to how they aged and they needed to continue to confidently strive and push themselves to achieve things as they aged:

*I mean obviously like medical things could affect you and you've got no choice about that, but I think you do have a choice of how you age in a way. Erm my gran before she sort of passed away, she was quite social but then she sort of became quite secluded herself and she didn't, she had a lot of opportunity to do stuff and she still had quite a few people around her that she could have gone and done things with erm, you know, I feel like she could have done a lot more erm just if she had that sort of confidence and things to go and do it. But in a way that still makes me feel a bit, I don't know, more confident about ageing, that there is quite a lot of opportunities out there and you've got to push yourself to do things. I think there's a lot you can sort of achieve and... WB 30-40 PT3*

Whilst others were aware that retirement, particularly for men, can entail them giving up, staying in and being inactive, thus losing their motivation to engage with life. In doing this it can have a negative impact on brain health:

*I would say it's (when a person is deemed to be old) the age that you retire but I think that's when they decide it's time to give it up. WB 18-30 yrs.PT3*

*Possibly they have not been keeping active as well maybe and maybe a lack of exercise and doing things and mental things to keep your brain ticking as well. There are all sorts of things you should be doing at a certain age and stuff just to keep your brain ticking. Because after you quit your job and retire for example a lot of people don't actually fill up their time as well at that age. Indian group 30-40 yrs.*

**Excerpt: Caribbean focus group 40-55 yrs.:**

*Car 40-55 yrs. PT1 Male: I think to me they have worked all their life right; they retire they don't have any hobbies or any social things to do so they just sit there and watch TV or don't have anything to do.*

*[...]*

*Car 40-55 yrs. PT1 Male: To me that's usually the women, for men they just give up they have got nothing, nothing to ... motivate them.*

*Car 40-55 yrs. PT2 Female: Well, I don't know.*

*Car 40-55 yrs. PT1 Male: Because they have worked all their life and that's, their motivation was to keep the family going.*

The importance of maintaining social interaction and avoiding social isolation and loneliness was emphasised by both the Caribbean and Indian focus groups 40-55 years. However, undertaking social interactions was implied to be challenging as opportunities to socialise within the Caribbean community was perceived to be on the decline. The Indian focus group 40-55 years posited the view that the weather prohibited social interaction and engagement and this led to depression, which in turn reinforces the reluctance to socially engage and to pursue an active life.

**Excerpt: Caribbean focus group 40- 55 yrs.:**

*Car 40-55 yrs. PT1: Back in the older, I don't know back in the olden days, everybody knew everybody and said hello talked and conversations.*

*Car 40-55 yrs. PT2: Definitely in our community, I think.*

*Car 40-55 yrs. PT1: Yeah, but not nowadays, do you know what I mean.*

**Excerpt: Indian focus group 40- 55 yrs.:**

*IND 40-55 PT1: I think because of depression cos of the weather here, one illness can lead to another that could be possible. That's the depression and the darkness of the weather, people don't go outside and don't talk and things. If people are working and active and things, they would be fine. Sometimes, they would be lonely, and people are not connecting. Because of depression, people here don't go outside.*

*IND 40-55 yrs. PT5: Yes, stuck in the house.*

The impact of social isolation was suggested to have a detrimental effect on brain health:

*Some people like to do things or people think neh I'm not giving up my precious time or haven't got the ability to do that. Or because they are restricted because they have to care for other people and can't go and do work in the community. There's various reasons but it depends on what you have been exposed to. If you are just somebody who sits at home and lonely you are going to, the brain is going to deteriorate a lot quicker than people who are actively meeting people in a social circle or even other organisations cos the brain is still ticking away. IND Pilot 40-55 PT1*

The above comments encompassed both lifestyle factors that attended to physical and mental health as well as consideration of the impact that psycho-social issues such as a loss of motivation and social isolation have on the risks to dementia and more generally mental well-being.

## **6.9 Summary of chapter findings**

This chapter discussed the idea that possession of knowledge and understanding in this research study sample was characterised by variation. This variation was derived from three discernible factors which include exposure to knowledge, exposure to the media and exposure to higher education. There was little or no variation in knowledge across focus groups about the risk posed by chronic health conditions to the development of dementia and that dementia is an umbrella term.

The findings also suggested that knowledge and understanding is a complex issue shaped by factors such as a perception that minority ethnic groups are less likely to have access to information that is representative of ethnic diversity and is culturally appropriate. In addition, when and where participants access information is also influential in shaping understandings of dementia. This is mainly at the point of need when someone is diagnosed. Until then there is unlikely to be a pro-active search for information and knowledge, because in part dementia is also deemed to affect older people. As such, the intricate relationship between acquisition of information and knowledge to conceptualisations of dementia was exposed.

The findings on conceptualisations of dementia suggest that it was commonly

conceptualised as a mental illness that occurs mainly in older people. Again, the nuanced analysis presents a complex picture of how this conceptualisation was formed, such as through the influence of professional backgrounds, and that categorisation and knowledge of dementia symptoms equated to be reflective of mental illnesses. This conceptualisation was mainly underpinned by the knowledge that participants had gained.

The other common conceptualisation of dementia as a consequence of ageing was driven by beliefs participants held of the declining functionality of the body and mind as it aged. This conceptualisation demonstrated nuances in the overall conceptualisation as some participants believed it occurred randomly, whilst others attributed to as a coping response to the overuse of the brain.

As we can see, knowledge, understanding and conceptualisations of dementia are entwined with concepts of old age and ageing. These concepts were explored in the final section of this chapter and several important findings emerged. Cultural beliefs about age-related deterioration were highlighted to have changed amongst younger Indian generations, by Indian participants. There was a convergence to a belief that functionality in old age was not linked to chronological age markers, but how individuals engaged with their ageing process. Exposure to a raft of societal structural changes, as well as exposure to successful, active and resilient agers in their personal lives and through the media, contributed to the belief that it was up to individuals on how they aged to mitigate the risks posed by the ageing process to the development of dementia and other health conditions.



# **Chapter 7: Findings for a Typology of Help-seeking Approaches and Care Strategies**

## **7.1 Introduction**

In the preceding chapter I discussed some of the linkages that exist between knowledge and understanding, concepts of dementia, and old age and ageing. The inter-relatedness of the issues was also evident in help-seeking approaches and care strategies, defined for the purposes of this chapter as seeking diagnosis as well as professional home care support and care homes. In this chapter, I shall discuss how help-seeking is also shaped by the complexity of interactions between structural influences and factors, as well as cultural values.

In the literature review it was evident that much of the empirical research on help-seeking strategies, including care strategies, is derived from studies conducted with older lay public, older people with dementia and their carers. So presently there is a gap in our understanding about whether these strategies differ in younger generations of people within and across ethnic groups. The presentation of the following findings addresses that gap in knowledge.

My exploration of data commenced initially with an analytic interrogation of findings that pertained to participants' help-seeking strategies. This was followed by a consideration of which of factors and issues influenced these strategies, including ethnicity and generational age.

## 7.2 Overview

The following sections of the chapter will commence firstly by stating the research questions that guided my analysis, and how they were addressed by the formation of a typology which functions as conceptual framework to understand help-seeking within and outside this research sample. The typology consists of four types which are Traditional, Flexible, Constrained and Individualised. Secondly, I shall provide a brief reminder of how and why these types were developed. Thirdly, I shall provide a visual overview of the types in the form of a grid which will followed by a narrative explanation of this grid. Finally, prior to presenting each of the four types, I shall briefly explain the types and the key arguments.

The research questions I shall address in this chapter are:

1. What are help seeking strategies for dementia amongst younger and middle-aged adults from multi-ethnic communities?
  - (a) What factors and issues shape and influence these?

A common feature of the focus group discussions was the positioning taken by the participants in relation to older generations outside of the research sample, as well as idealised and contradictory positions viz a viz other ethnic groups. These positions revealed a typification of behaviours, values and beliefs accredited to older generations and in the process of discussing these, revealed participants' own values and beliefs. These revelations led to the tentative development of categories to capture some of the differences between groups in help-seeking approaches, including the role played by structural factors and culture in the development of these. As these categories evolved, I began to extract key and significant elements which led to constructions of types as way of conceptualising and presenting the findings. Typologies in social sciences are methodological or theoretical concepts which according to McKinney are *patterned expectations which govern and define what is perceived to be roles and appropriate behaviour by individuals, and what is expected of them in typical circumstances* (McKinney, 1969a: 1).

The names of each type capture and signify a key aspect of the typology that orientates the participants' perceptions and experiences of their approach to help-seeking. All four types were initially developed using the findings from the ten focus groups. These were then combined with my analysis of findings from the community workers, each of whom works with families to provide care support, including for dementia. The findings from their interviews provided contextual insights which offered nuanced and detailed explanations for the experiences of families and communities with regard to care strategies.

The following table provides a visual representation of the types, which will be followed by an explanation of each column.

Table 7.1: A Typology of help-seeking approaches and care strategies

| Type           | Attributes  |   | Perspectives pertaining to help-seeking                                    | Focus group and community worker interview/s findings   |
|----------------|---|---|--|---|
|                | Factors & Issues affecting process of seeking diagnosis                                 | Factors and Issues shaping and influencing care strategies                                      |  |   |
| Traditional    | Concealment of dementia   |   |  |   |
|                | Impact of stigma and lack of disclosure on awareness and knowledge of dementia symptoms |   |  | Pilot Indian Focus group 40-55 yrs.; Indian focus group 40-55 yrs.; Indian focus group 30-40 yrs.; Indian focus group 18-30 yrs.; |
|                | Health system failing to convey culturally appropriate dementia knowledge               | Filial piety: conflicted family responses to familial care strategies                           | Related to older generations and some families                             | Caribbean focus group 40-55 yrs.; Caribbean focus group 30-40 yrs.; Caribbean focus group 18-30 yrs.                              |
|                | Impact of generational differences in knowledge and cultural values                     |   |  | Community workers: PT1, PT2, PT3 & PT4  |
|                | Preference for complementary and faith-based approaches                                 |   |  |   |
| Flexible       |   | Filial piety: a matter of culture and individual choice   |  |   |
|                |   | Responding flexibly to the demands of care and careers  |  |   |
|                |   | Responding flexibly to tailor care strategies to the needs of the PWD                           |  | Indian focus group 40-55 yrs.; Indian focus group 30-55 yrs.; Indian focus group 18-30 yrs.                                       |
|                | Acceptance of dementia as an illness & the need to seek diagnosis                       | The structural and cultural influences shaping flexible responses to care                       | Related to their own approaches to diagnosis and care for older relatives. | White British focus groups 30-40 yrs.; White British focus groups 18-30 yrs.  |
|                |   | Impact of occupational and geographical mobility on care  |  | Community workers: PT1, PT2, PT3 & PT4  |
|                | Impact of changing generational values on the commitment to care                        |   |  |   |
| Constrained    |   | Filial piety: a commitment to provide inter-generational care                                   |  |   |
|                | Willingness to see GP for relative with symptoms of dementia                            | Constrained by a lack of information on where to go for help to care                            |  | Caribbean focus group 40-55 yrs.; Caribbean focus group 30-40 yrs.; Caribbean focus group   |
|                | Health system failing to convey culturally appropriate dementia knowledge               | Constrained by a lack of culturally appropriate professional home carers service and care homes | Related to their own approaches to diagnosis and care for older relatives  | 18-30 yrs. Community worker PT2   |
|                |   | Use of care homes as a last resort  |  |   |
| Individualised |   | Individual taking the responsibility for their future care planning                             |  | White British focus group 40-55 yrs.  |
|                | Reluctance to disclose symptoms of dementia to family due to fear of care homes         | The lack of filial piety and the use of care homes  | Related to their own future of dementia diagnosis and care strategies      | Community worker: PT2 & PT5   |

Taking each of these columns in turn, I shall provide an explanation of their function.

The first column conveys the names of the four types, and how these names were

selected is discussed in more detail in the Methods chapter in section 4.11.2.10 They appear to be four neatly bound types but the selection process to assess a focus group's fit for a type uncovered some overlaps on a few issues, for which I had to make a considered judgement with regards to their categorisation. For example, the Indian focus group 40-55 years in the Flexible type shared an allegiance to the more traditional adherence to filial piety but in all other respects conveyed a flexible approach to diagnosis and care strategies, which was in sharp contrast to that of the Traditional type. However, these overlaps were not sufficiently distinct and frequent enough to merit the development of additional types. They did, however, prompt me to take a step back and evaluate them to ensure I made an informed judgement on the overall orientation of each focus group to ascertain the best fit for each type. Also, these types are ideals, which are unlikely to exist in their purest form (Kalberg, 2000; Rosenberg, 2016).

The second column refer to the attributes, that are factors and issues affecting the process of diagnosis, and factors and issues shaping and influencing care strategies. These are the two broad attributes with which the typology was formulated. They speak to the aims of this study which is to explore help-seeking behaviours. I structured the help-seeking into diagnosis and care approaches to facilitate clarity and to make a distinction so as to avoid confusion between the two strands of help-seeking.

The third column refers to the perspectives from which the types were developed through the process of analysis. The Traditional type, as discussed in section 7.4 of the methods chapter, was described as an Existential typology (McKinney, 1969) as it was developed from the typification that Indian and Caribbean focus groups, and community workers who work with these communities, discussed. The Flexible, Constrained and Individualised types were developed and structured from my interpretation of the findings from the focus groups and community worker interviews. As such they are referred to in the theoretical literature as secondary constructs (Kim and Berard, 2009) so, for example, the Individual type was developed from the analysis of findings related to participants' discussions about their own potential diagnosis and care strategies. Whereas the Flexible and Constrained types are discussed from the analysis of findings in which participants discussed their proposed approaches to the diagnosis and care of parents and grandparents.

The fourth column refers to which focus groups and community worker interviews the typology was developed from. I shall now move on to present a narrative overview of the types combined with some key arguments for each of them.

It's important to note that in the fourth column, the findings for the Traditional type are drawn from Caribbean and Indian focus groups and community workers that work within these communities with older people and families outside of this research sample. In some of those same focus groups, such as the Caribbean and Indian focus groups, the findings also contributed to the development of the Flexible and Constrained types with regards to their own approaches to help-seeking for a member of their families with dementia.

### **7.3 Narrative overview of the types**

In the following section I present a narrative overview of the four types.

The Traditional type is so named because both help-seeking behaviour in relation to diagnosis and care strategies are shaped and influenced by traditional cultural values and beliefs, as well as the conceptualisation of dementia as madness. However, my data shows that whilst these beliefs and conceptualisations are culturally based, they are also formed generationally due to a lack of knowledge and understanding of dementia. This was indicated in the knowledge and understanding theme, in which Indian and Caribbean focus groups discussed their perception that older people within their communities lacked access to culturally appropriate information about dementia. This is unlike younger Indian and Caribbean participants who have exposure to information about dementia through the media and health education. So, whilst traditional approaches to help-seeking are influenced by culture, they are also indicative of the health system's failure to promote accessible information and knowledge about dementia. These failings, together with a traditionally culturally orientated approach to help-seeking, contribute to a self-perpetuating cycle of social stigma. This operates practically through concealment strategies employed by families, which has a negative impact on the generation of knowledge and understanding about dementia within these communities. In turn, this lack of understanding affects a family's ability to recognise symptoms of dementia and gives rise to family conflicts as there are different

generational understandings of dementia when symptoms manifest.

In many respects, the Flexible type is the antithesis of the Traditional type, because its help-seeking strategies in relation to diagnosis and care strategies are influenced by better access to information and knowledge about mental illness in general, through media campaigns and health education. Consequently, participants are likely to use this knowledge and not cultural beliefs to accept dementia as an illness that requires medical diagnosis and not conceal it. However, there are also similarities with the Traditional type within the realm of participants' commitment to filial piety. For example, the Indian participants accept it is their responsibility to care for parents and grandparents, whilst white British participants expressed their commitment to care but as an option they choose to exercise.

The key distinction between the Traditional and Flexible type therefore arises when we look to how filial duty and a family's choice to care is flexibly exercised in response to a number of different issues and factors. These include balancing career demands and tailoring care strategies to consider the use of professional home carers or care homes. However, the social context in which these care options are exercised differ. So for white British participants placing a PWD in care is suggested to be sanctioned by society. In contrast, whilst Indian participants stated that they would use care homes to support a PWD with advanced dementia, they recognised that such a step would be considered taboo by the community. However, we also see how the influences of education, occupational and geographical mobility have changed cultural values, so much so that Indian participants seemed to focus less on what the community thinks, preferring instead to think of themselves and the needs of their immediate family. This approach therefore is in sharp contrast to the Traditional type which adheres to cultural values and beliefs, with help-seeking behaviours underpinned by collectivist norms and values, which is family and community orientated.

The Constrained type is similar to the Flexible type, because they too have access to media campaigns about mental health and recognised dementia as an illness for which they would seek diagnosis on behalf of a relative. However, it differs from the Flexible type in several important respects, as it is constrained by a lack of culturally appropriate

information on how care and support can be given to their relatives with dementia.

In a similar way to the Traditional type there is a strong commitment to provide inter-generational filial care but at the same time their choice to consider other options are constrained by their perception about the unavailability of a culturally appropriate professional home carers service and care homes. In contrast to other types too, the responses to care are also influenced by negative historical experiences with the mental health system and this lack of trust carries over to the care system.

The Individualised type is formulated based on the perspective of white British participant discussions and is framed in the context of their own potential diagnosis of dementia in the future. The justification for using the label of individualised is derived from the participants conveying their personal responsibility for sorting out their own care and financial arrangements if they received a diagnosis. They wanted to plan ahead and for the most part welcomed NHS dementia risk screening as it would enable them to undertake advanced planning. It seemed as if the participants were conflicted, as on the one hand they wanted to be cared for by their families, in a similar way to their perception of other ethnic communities are apt to provide, but at the same time they did not want to burden them with dementia as it progressed. Additionally, unlike other types filial care was not perceived to be traditional practice in white British communities. This was illustrated by their reflections on other cultures around the world and in this country. This led them to think that filial care was not an option they could rely on as their children may not be willing to care for them or could not care due to pressures of work. This individualistic approach contrasted sharply with the Traditional, Flexible and Constrained types in which there were varying degrees of commitment to provide filial care.

This fear about their future care was a key factor in their willingness to conceal dementia symptoms should they arise to avoid diagnosis and the possibility of being placed in a care home.

I shall now move onto providing a discussion of the findings for each of the four types.



## 7.4 Traditional Type

### 7.4.1 Approach to diagnosis

#### 7.4.1.1 Concealment of dementia

The approach to diagnosis in this type was shaped and influenced by a combination of cultural values and beliefs, as well as a lack of knowledge and understanding of dementia. This was evident in the way dementia was conceptualised, which initially, when symptoms of forgetfulness and memory loss are present, are culturally understood as a normal consequence of ageing. However, as the symptoms progress it's conceptualised pejoratively as madness. It is at this point that the cultural value of privacy comes to the fore with both the PWD and their families seeking to conceal the illness, consequently delaying diagnosis. For Caribbean communities this cultural value of privacy was suggested to be something that families were socialised over generations to uphold and applied to dementia because of fears that the PWD could be incarcerated, thus causing a delay to diagnosis:

*So, if they are forgetting stuff, they will laugh it off as due to age and just pass it away as age. Even if they are just forty or thirty or whatever, I am getting old now that's why I am forgetting. (...) So, to me it maybe a cultural thing of how we are passing, talking about dementia or forgetting you know, do we pass it off as oh it's an age thing and that's why Asian people probably think its age related where it may not be. IND Pilot 40-55 PT5*

*It's not like spoken about really, I guess I am sure there is, they know but ... they don't experience or if they actually have that I guess seen as crazy maybe, lost the plot maybe. Car 18-30 PT*

*I think we are a very private community and anything outside of the norm, if anyone is acting differently you assume it's because they are mad. And you don't necessarily want people to know that, so you are not necessarily going out there and talking about your experiences and asking for help because you are scared oh my gosh, they are going to think they are mad, they are going to lock them up. So, its potentially doing ourselves a disadvantage, you know if you are, the ignorance of not knowing and not understanding. Car 30-40 PT1*

#### 7.4.1.2 Impact of stigma and lack of disclosure on awareness and knowledge of dementia symptoms

This conceptualisation of dementia as madness has far reaching effects as it is cited as contributing to social stigma and partly drives the motivation to concealment. It therefore

affects the dynamics of interaction between the PWD and their families with the community. It leads to fear and embarrassment and is indicative of stigma by association (Pryor et al., 2012) which is akin to Goffman's tribal courtesy stigma (Goffman, 2009). This refers to the experience and psychological reactions of family or friends being stigmatised, because they are associated with a PWD. The impact of stigma can be cyclical and self-perpetuating as it limits disclosure of dementia to maintain families' privacy amongst their community. Consequently, this reluctance to disclose contributes to a curtailment of awareness and knowledge of dementia, and this in turn limits families' understanding of dementia and their need to seek diagnosis for symptoms:

*I think we have kind of touched upon it, I think society, as soon as a problem like occurs the first thing that comes to mind is what is everyone else going to think about it, what is everyone else going to think, what are they going to talk about. So, I think everyone in our community is scared of being a talking point for everyone around us. And that's what prevents us from taking action earlier. IND 18-30 PT4*

#### **7.4.1.3 Health system failing to convey culturally appropriate dementia knowledge**

This pejorative conceptualisation of dementia was attributed in part to the health system's failure to tailor and disseminate existing information and knowledge about dementia to older peoples' level of health literacy:

***Excerpt: From interview with community worker PT2***

***INT:*** *And why isn't (information and knowledge) reaching the older people?*

***CWPT2:*** *It's not being done in the right way I don't think maybe.*

***INT:*** *What is the right way?*

***CWPT2:*** *In a way that they understand, campaigns where they urm maybe more visual things more urm... small sort of urm groups being held where information is passed over. And the groups that I hold I find they work really well urm.(....) Yeah, it needs to be done in a way, I don't think the things like literature I think it needs to be more visual things more talks and things, I think they are, that is the route to go down to have a higher impact.*

Older generations' lack of exposure to information and knowledge about dementia was perceived to be further exacerbated. This was attributed to their generational age which entails them missing out on the benefits of receiving and accessing knowledge from information technology such as Google, in addition to medical knowledge and better

healthcare in relation to dementia. These factors were attributed as impacting on their ability to recognise symptoms and seek diagnosis:

*Well, if you look at the elder generation what the education behind dementia is probably not, I don't think it was that developed, medical advances today can tell dementia pretty quickly, technological advances can detect dementia. So, from that angle now because it's talked about, it's on the computer, it's on the Google, if you take an interest the information and all that is there, there is publicity around, you pick up a leaflet and have you got dementia, you read it, that is because people are much more and more educated. PIL IND PT3*

*Purely lack of knowledge urm if.. the information was available for them openly then I think there would be a better understanding about that. And urm I think this is urm we are now on the third generation of Indian people who have been living here so we are looking at children so going forward these things will get better. Community worker PT3*

#### **7.4.1.4 The impact of generational differences in knowledge and cultural values**

The impact of generational differences on knowledge about dementia when combined with older people's cultural values contribute to making family dynamics more problematic during the process of seeking diagnosis, and can cause delays. These issues come to the fore when older people experiencing symptoms of dementia may be unwilling to listen to younger generations when the latter advocate the need to seek diagnosis. Their reluctance to seek diagnosis was cited as stemming from older peoples' cultural belief that their status of 'old age' accorded them with more experience and wisdom than younger people. Consequently, their cultural concept of dementia as normal ageing is likely to clash with a younger person's medicalised understanding of dementia. Hence, when a younger person asks them to seek diagnosis for dementia symptoms, they are unlikely to listen or respect their advice even though younger people may possess an awareness and knowledge about dementia:

*IND 18-30 PT2 : Yes I think in our culture especially if ... if you are trying to bring up a point that you know your parents or your grandparents or someone older than you doesn't solely agree with or think it's true they will come up with a point and ... this is just a saying that my family says, I see older eyes than you or I've seen more Diwalis than you or my hair is greyer than yours it's like I have seen I have lived a longer life I have seen more than you. But that is not always the case. You would have new illnesses appearing up that might not have been true when they were a younger age. I think it's more of accepting that. Because that's how I have seen this it's like in our community its more of I am older than you I have seen more in my lifetime than you have in your short lifetime. So obviously I might have a better view of something.*

*IND 18-30 PT3: Yes, I think when you come across a lot of like elderly Asian people*

*urm... like I think they get quite patronised because you are educated and you know a lot within a particular area, like not just dementia for example, but within a particular area. And ... they because you are younger, they have to be right if that makes sense.*

#### **7.4.1.5 Preference for complementary and faith-based approaches**

Other cultural values and beliefs attributed to delays in diagnosis were cited as a preference to seek complementary medicine as opposed to pharmacological treatment for symptoms, a practice that was said to be promoted on Asian television channels. In addition, within Caribbean communities a preference to rely on faith and spirituality instead of conventional approaches to treatment was cited:

*And to be honest on the Asian Channel for example they probably mention it however they say you can have a cure for it and say if you have this illness take this medicine for example it will cure it and go away. And that's what older generations believe in more, they don't believe in general medicines more, the medicines that may work or may not work. IND 30-40 PT2*

*And they don't want to embrace western culture sometimes which can also be that stigma of I am not going to the doctor because I know my community medicine. IND 30-40 PT3*

*I think a lot of it as well is not just cultural its religious based because a lot of it is Christian based so we tend to pray on things and not being right or wrong its more of a if you are not right, I will pray for you type thing. Car 18-30 PT3*

#### **7.4.2 Approach to care strategies**

##### **7.4.2.1 Filial piety: conflicted family responses to familial care strategies**

The traditional approach to caring is governed by filial piety which is a cultural value that places an obligation on family members to care for their parent or grandparents, as they did for them when they were younger. For many families, traditionally the responsibility for the care of an older person rests with the oldest son.

However, the fulfilment of this cultural value may be impeded by a range of factors influencing family interactions, such as sibling conflicts about who will undertake the main responsibility for caring for the older family member, including day-to-day care management in the face of work demands.

These family interactions can also create an additional layer to the process of seeking diagnosis if siblings hold different understandings and conceptualisations of dementia.

So, for example, one sibling who conceptualises dementia as a disease is likely to seek diagnosis in contrast to another who conceptualises it as a normal consequence of ageing:

*So, like within like the Hindu culture a lot of things, a lot of people still believe that it's the son's responsibility, if there is a son and a daughter it's the son's responsibility to take care of the parents urm. So, I hear still a lot of those kind of issues urm, that again just generally with siblings who is going to do the caring you know, lots of conflicts there. Who is going to take the time out, who is the going to take them to the appointments, who is going to be the main carer? Urm ... and then again with the understanding and the acceptance ... So, like you might have three siblings urm one of them or two of them may get it, what the disease is about, the other one might be still finding it really really difficult, not accepting saying no it can't be, you know just various yeah. Community worker PT2*

Filial piety is very much firmly embedded in both the Caribbean and Indian traditional value system so a failure to uphold filial piety signified by a family seeking care support outside of the family would be likely to stigmatise families. This is because the family would be perceived by the community as failing to live up to their obligation to provide care themselves. This stigma may be compounded by the PWD who themselves feel ashamed of having dementia and experience self-stigmatisation, and so fear that receiving care support is likely to expose the fact that they have dementia. This stigmatisation would apply to seeking care support whether it be in the form of day care centres, professional home carers or a placement in a care/residential home of a PWD. Consequently, stigma contributes to a reluctance to seek care support:

*For families it might be difficult to make it public if a sense if they are struggling to take care of the vulnerable person they might see, they might think that the community will think less of them for putting them in a home do you know what I mean. They might think that people might judge them for taking certain services and think why can't you just look after them yourselves kind of thing. Car 18-30 PT5*

In the event, that families who do wish to place a PWD into a care home with specialist dementia, even if they received culturally appropriate support, it would be challenging do so, because there was a perception that there was a gap in provision. This can deny the opportunity of families to access the appropriate level and type of support for older Asian people with advanced stage dementia:

*....we need something like (culturally appropriate specialist dementia care home support) that for Asian people specifically. I mean we need a home specifically for Asian, a dementia home where they can actually care for people with dementia in their advanced stages. Urm and that's just not there at the moment, maybe something in the future but at the moment there is a lack of urm lack of that facility*

*for them. Community worker PT3*

I now move onto a discussion of findings related to the Flexible type which is framed from the perspectives of participants in relation to diagnosis and care for their parents and grandparents' generations.

## **7.5 Flexible Type**

### **7.5.1 Approach to diagnosis**

#### **7.5.1.1 Acceptance of dementia as an illness & the need to seek diagnosis**

In contrast to the Traditional type, participants' acceptance of dementia non-pejoratively as a mental illness informed their willingness to seek assistance rather than dismiss it as madness and conceal it. This acceptance was attributed to education about dementia being more widely available in the present, as well as the media's role in raising awareness of dementia occurring in older people. These factors were cited as alerting younger members of the family to seek diagnosis for signs and symptoms:

*Yes, I think nowadays as urm XXX as she mentioned in the media it's a lot more alert for like older people. OK maybe I need to go to the like doctors even for like like sons and daughters of that person or even a family member for that matter like to take them and get them checked out. Awareness has risen basically. IND 18-30 PT3*

*I think there is a lot more acceptance in the younger generation of ailments and illnesses, mental illnesses. I think it's a lot easier to spread awareness with the Internet and TV. I think education is better than it was 50 years ago. I think education largely, whatever medium it gets to us is better now than it was. WB 18-30 PT1*

The above comment from the Indian participant is reflective of Indian participants' approach to diagnosis, which would be to pursue the process of diagnosis on behalf of the PWD, reflecting a familial approach to filial responsibility. However, this approach differed to that suggested by white British participants, which was more indicative of an individualistic approach. The white British focus groups argued that they would wait until the PWD approached them to go for diagnosis, rather than making the decision for them. Their approach was based on a number of factors including the need to avoid patronising the PWD, respecting the right of the PWD to determine when they want to go

to the GP and being sensitive to the devastating impact a diagnosis may have on the PWD. In taking such an approach, there was a recognition that dementia may progress to an advanced stage by the time diagnosis is made:

*Do you think it's kind of patronising going to the GP on someone else's behalf or telling someone they need to go to the GP, I think so? WB 18-30 PT1*

*I think that if that person feels that they need help I think you have to give them the time and space and I think you should let them come to you. So, then they will feel like they are ready to go to the GP. Instead of you pushing them to the GP because they might not want to sit there and talk about something like that. Or they might not want to know they have got dementia because it's like a hard situation to think that you are going to forget one of your family members or your grandchildren. It's not easy to live with. WB 18-30 PT2*

*It's difficult to go against someone isn't it that you care about, like it's very difficult to go behind their back sort of thing and I think it's quite tough on, it's quite an advanced point before you think... WB 30-40 PT3*

## **7.5.2 Approach to care strategies**

### **7.5.2.1 Filial piety: a matter of culture and individual choice**

Whilst all the participants expressed their commitment to care for older members of the family with dementia, white British participants stressed that this commitment was driven by individual family choices rather than by cultural values, which may mean some families are likely to place a PWD into a care home:

*I think it's still the case where, even if it's your daughters and your, your daughters' husband or your son and your son's wife, you still have that responsibility even our generation understands that, you still have that responsibility. IND 18-30 PT1*

*I think I think it's like I think we have the same debate (about use of care homes) with each other because there are some families, white British families that like they don't they refuse to put their family in care. And there are families that think that is probably the best place for them. So, I think that's kind of a debate between two white families. WB 18-30 PT4*

### **7.5.2.2 Responding flexibly to the demands of care and careers**

However, unlike the Traditional type in which upholding of filial piety involved families providing care to the PWD come what may and in spite of family conflicts, this type was characterised by participants' flexibility in relation to their care strategies. This flexibility was based on a recognition that they would need to balance the demands of care with their career demands, and this would necessitate the use of professional home carers

as well as the use of care homes. There was an acknowledgement that, for previous generations in their community, such approaches would be considered taboo:

*I think in an ideal world you would want to care for your parents yourself like you wouldn't want to just jump to that step of putting them in a home. But I think it is changing in our generation in terms of we can see what we are capable (aspirations and goals) of a lot more, like we are a bit more realistic um in terms of what we can do to help. And what others can do to help and whether that's better or not. Whereas older generations it would have been like forbidden to even think about putting people into care homes. IND 18-30 PT1*

*People do understand now, people are not talking that they put the person in a home that it's not possible to care for people in their home, not so many people talk as much you do feel a bit shamed, but they get used to it, because people have to go to work that is the situation here. IND 40-55 PT5*

### **7.5.2.3 Responding flexibly to tailor care strategies to the needs of the PWD**

Besides career demands, Indian participants also argued they would prioritise the need for the PWD to access specialist dementia support as their dementia progresses, rather than adhere unquestionably to cultural values of filial piety. So, they would consider the use of professional home carers or care homes:

*Yes, it depends how severe the dementia is as well because if it's really severe then you would need constant probably 24/7 care. But if it's not that severe then you probably can go with having less care but more, paying attention to what they are doing and making sure they are doing something that they should do or something that might affect it or make it worse. IND 18-30 PT2*

*I think that's the defining point there, where um culturally everybody thinks it's right to be at home, but actually medically you get to a point that it's actually not possible and it's not fair on that person. Um and that's a tough barrier because people don't see that barrier, sometimes they don't see that line and they kind of see it as oh and it's cultural mentality. Um but they... you sometimes get to a point where you, you physically it's not the best for them anymore. You can't give them everything that they need. IND 30-40PT1*

*I think that is the biggest problem we try to do it ourselves. IND 30-40 PT4*

Whilst the above comments demonstrate that making the decision to use professional home carers or care homes may not be dictated to by culture, cultural factors do play a role in the selection of the most appropriate care home for relatives with dementia. The search for a culturally appropriate care home requires careful research to ensure that they care homes that not only offer specialist dementia support but also access to culturally appropriate language and dietary services too:



*It's then being selective of where they go and do, as part of a child or grandchild do your research before. It's not a case of actually we are going to put you into a home, we actually did extensive research we made sure that all the carers had you know special dementia care unit. They had erm someone always on shift that spoke her language, her food was provided and what she was comfortable with. And actually when we made those changes we saw a slight improvement in her erm she, she liked the fact that she was around people that had similar things wrong with her, she didn't feel like she was isolated and she was the only person that had this. Urm and I suppose the medical care that we couldn't give her she started to benefit from.*  
IND30-40PT1

#### **7.5.2.4 The structural and cultural influences shaping flexible responses to care**

The above flexible approach to care was suggested to be influenced by structural changes in white British society. These were discussed by white British participants, who shared their perception that there was a decline in family solidarity and cohesiveness that supported and enabled the care of older people within families in the past, amongst families in white British communities. This change was attributed to the preponderance of care homes in this country, and this in turn contributing to the sanctioning and encouragement of some families to make use of care homes rather than take care of PWD within the family home:

*I do think, I think more people erm in other countries, I think they do look after their family more than perhaps over here. There's a lot more care homes, it's just like put them in a home, they'll look after you kind of thing, do you know. WB 30-40 PT5*

*Because them services are there, I think they kind of make use of the service. It sounds awful doesn't it but, you know, make use of the services whereas I don't really know to be honest in other countries whether there's services there like that so you kind of, that's just what they do. Like you look after your family, that's just the way it is, but over here because they're there I think it's somewhere for you to go kind of thing. It sounds awful doesn't it but... WB 30-40 PT5*

#### **7.5.2.5 Impact of occupational and geographical mobility on care**

Indian focus group participants emphasised occupational and geographical mobility as fragmenting family structures, as people tended to live where they find jobs. Furthermore, once younger generations have their own families, it was suggested that it was challenging to travel and provide care as they have commitments to children as well as financial pressures. They also suggested that some parents and grandparents wanted to retain their independence, including having their children and grandchildren live independently of their family home:

*IND 18-30 yrs. PT2: Their children at the same time it's not just the elderly it's their own children, you end up having babysitters for them at some point if the parents can't come home on time while the children are back from school, it's dealing with kids and their elders.*

*IND 18-30 yrs. PT5: Even if they don't have kids or something they have got like responsibilities like a mortgage or something to pay off for a house or something and they can't take time off work.*

*IND 18-30 yrs. PT1: Nowadays where you live isn't necessarily the place where you find a job or where you have your career. Say you are born in Leicester that doesn't necessarily mean you would be able to find what you want in Leicester or what you, even if you don't want it it's something that you might not be able to have in Leicester and you might have to move somewhere else for that job. But having that situation, that geographical difference you can't really do much about it unless you shift everything to that different location. But then the elderly might not want to shift they may, nowadays I think I have seen, even if it's say grandparents, they want their children to move out to make their own living rather than staying in that same house. Because they feel, I don't know if they feel anything that way, but I think it's more giving them that freedom of I have done this much for you I think I want you to move out of this house and make your own living for yourself and secure your future and your children's future.*

#### **7.5.2.6 Impact of changing generational values on the commitment to care**

Whilst structural factors affected the capacity of Indian families to care, it was also evident that changes to cultural values may also explain why there was flexibility in care approaches amongst younger generations. The latter were suggested to hold less of commitment to care for older members of their families as they were focused on living their own lives and materialistic pursuits, which gives rise to the neglect of older people in their families:

*Urm I think people are more into materialistic things now, urm you know they want the best ... cars or best house or best food or you know whatever, the best gadgets whatever is going. I think people definitely are going more ... that side rather than urm say looking after err their loved ones. Urm that's personally I feel that I see that myself all the time. Community worker PT4*

*Yes, and part of its also like the younger generations don't always look after their elders as well, which is how it used to be. So, the thing is a lot of them are too busy in their younger lives and just enjoying themselves and to be honest don't actually go back and look after their families and stuff. Due to they have got jobs or home for example or commitment and stuff therefore the older generation and it's also getting neglected and sort of as well and brushed under the carpet. IND 30-40 PT2*

Changes in cultural values were also characterised by a much more individualistic focus because of geographical distancing from communities. Therefore, their decisions about

seeking care support were not influenced by what the community thinks, instead it was more about the individual family unit and the choices they wished to make for their families:

**Excerpt: Indian focus group 30-40 yrs.:**

*IND 30-40 yrs. PT4: I think urm they (older generations) are more concerned about what people think whereas we are like we don't really care what, I don't care what people think about me. I think the attitude has slightly changed; I don't really care if it (seeking help for care) would be perceived as a weakness urm whereas my parents would be completely like oh we wouldn't ask for help because that would be seen as being a weakness.*

*IND 30-40 yrs. PT3: I think community has a lot to it, we think so individually they still think of community, extended family that sort of thing urm. Whilst I look at my family, me that is it, the five of us is the important bit. But I think for that generation urm what my community thinks because we have always done things together it's like that urm one mindset goes across the breadth of that whole urm generation as such. You know that's what we have always done that's how it works, that's why we need to keep linked to the community you know be in that mindset. But actually, as we have gone away to university and moved away from community not coming into our community to do interactions the way they have, urm we have got that independence to say well actually I am not going to shy away from asking and talking about this.*

I now move on to a discussion of findings related to the Constrained type, which is framed from the perspectives of diagnosis and care for their parents and grandparents' generations.

## **7.6 Constrained Type**

### **7.6.1 Approach to diagnosis**

#### **7.6.1.1 Willingness to see GP for relative with symptoms of dementia**

The approach to diagnosis was similar to the approach in the Flexible type, which would be a willingness to go to the GP when the symptoms of dementia if a close relative went beyond the expectations of forgetfulness associated with normal ageing:

**Excerpt: Caribbean focus group 30-40 yrs:**

*INT: So, do you think it has changed for your generation, are you likely to if you spotted signs and symptoms, say in a parent.*

*Car 30-40 yrs. PT3: In a parent, yes.*

*INT: You would go to a GP?*

*Car 30-40 yrs. PT2: Yes, I think so.*

*Car 30-40 yrs. PT1: Definitely.*

*Car 30-40 yrs. PT4: Yes.*

*Car 30-40 yrs. PT3: ....we went to the GP because we thought OK, she (grandparent) is repeating the same thing again and then she was wandering off and we were like where are you going, and she was like oh work. You stopped working so you can't be going to work.*

Unlike the Traditional type, which was characterised by stigma, the willingness to pursue diagnosis was not hampered by fears of the family being stigmatised. This lack of stigma amongst younger generations of Caribbean people was attributed to them possessing a better understanding of mental health in general in comparison to their elders. This lack of stigma and acceptance of dementia as a condition that necessitates diagnosis was similar to the Flexible type.

The understanding in this type enabled a differentiation between different types of mental illnesses and facilitated an acceptance for themselves and for others that when they are not feeling mentally or physically well to seek help. In contrast, older generations were thought to lump all mental illnesses together and view them as madness, and so unlike younger generations they would not be willing to discuss or disclose a mental illness such as dementia to the wider community. This understanding of mental health may explain why they would be willing to seek diagnosis if a parent or grandparent was experiencing the signs and symptoms of dementia:

***Excerpt: Caribbean focus group 30-40 yrs.:***

*Car 30-40 yrs. PT1: ...because the older people are still you know what I mean, if someone is mad, they are mad. Where I think younger people are a lot more open to there is mental health and that's fine if mentally, I am not feeling very well, I think they are accepting mental health and physical health is something that needs dealing with. And identifying that there is depression or there is post-natal depression, you know separating the different ones. So, I think people are quite open to speaking about it and accepting it and sharing experiences. Where when I obviously hear older generation so and so is mad, it's not oh they are depressed or you know something happened and its they are grieving, its they are mad, its categorised as one thing and that's it. Where I think we are a bit more open like me and my friends we will speak about things, we will speak about health issues oh I have noticed this have you had that before that don't seem right, I am going doctors. But I don't know if my grandparents would have spoke like that.*

*Car 30-40 yrs. PT2: No, I don't think they will.*

*Car 30-40 yrs. PT3: Nor do I.*

### **7.6.1.2 Health system failing to convey culturally appropriate dementia knowledge**

However, the ability of Caribbean communities to seek early diagnosis was suggested to be compromised because the health system was argued to be failing to convey culturally appropriate advice and information about dementia to Caribbean communities across a range of generations, so that they are less equipped to understand and seek diagnosis at an early stage for family members. This finding overlaps to some degree with the Traditional type. To address this issue, there was a suggestion that the need for younger generations to be provided with information was accentuated. This was because the practice of inter-generational care could mean that children being looked after by grandparents after attending school are likely to be more attuned and better placed to detect symptoms of dementia in their grandparents more readily than their parents who might visit their parental homes intermittently or briefly:

#### ***Excerpt: Caribbean focus group 30-40 yrs.:***

*Car 30-40 yrs. PT1: ....where I am young, and I think I am quite in the community and I am on social media but where are these things pumped into our generation for the younger ones to know let alone the older ones. So, if they are not hearing about it, they are not going to be very receptive of accepting anything that they don't fully understand.*

**INT:** *So, what you are saying is your generation needs to know?*

*Car 30-40 yrs. PT1: I think we need to know because if we know then we can help our grandparents or we can understand. But if we are not understanding and our grandparents definitely don't understand because it's not something spoken to then how ... is that...*

*Car 30-40 yrs. PT3: Going to work.*

*All: Yeah.*

*Car 30-40 yrs. PT2: It comes down to our kids as well because if we know we teach our kids about it and their kids teach their kids and that.*

*Car 30-40 yrs. PT3: And everybody will know at one point what needs to be done or what can be done about it. And people will get help earlier.*

*Car 30-40 yrs. PT1: From secondary school up because a lot of kids spend time with their grandparents, you know even when their parents aren't there, so it's from 11 and*

*12 they might be able to say you know what mummy I have noticed da da da da. And because they're aware you know what I mean, you are never too young to learn and I think there just needs to be more understanding from the younger ones. Because as parents we are busy, we do rush around we do nip in and see our parents, but our kids are probably going to their houses after school to be looked after might see a lot more. So, if they know they would probably be key to the early symptoms really.*

## **7.6.2 Approaches to care strategies**

### **7.6.2.1 Filial piety: a commitment to provide inter-generational care**

In a similar way to the Traditional and Flexible types, the cultural value of filial piety was articulated in the form of their commitment to provide inter-generational care to the PWD. Whilst it was acknowledged that family care was under strain due to work and childcare pressures, it was alleviated to some extent by other family members including grandchildren pitching in to assist with caring to ease the pressures of caring. This approach was different to the Flexible type in which participants expressed that their balancing their career demands may prompt them to consider professional carers as well as the use of care homes:

*....because like my family are adamant like we are not putting my grandma (with dementia) in a home or putting her anywhere, we are going to look after her. But then she wouldn't ever tell anybody anything is wrong with her. To her nothing is wrong with her she is normal like what everybody is saying isn't happening so that's normal. You wouldn't put her in a home. Car 30-40 PT3*

*I wouldn't say that its changing (cultural value of inter-generational care). I think there is a hindrance like when, the expectations I would say of going to work coming home stuff like that. There is things that hinder these err lack of care that is needed urm for a family member. But at the same time when .. that person is in need you would come together as much as we can. So, there is hindrance I would say. Car 18-30 PT4*

### **7.6.2.2 Constrained by a lack of information on where to go for help to care**

However, whilst the decision to provide inter-generational care was a positive cultural choice it was also taken in the light of other factors that constrained the ability of Caribbean families to make choices from a variety of options. One of these limiting factors was the lack of information available about where people from their communities can go for help and support. As a consequence of this uncertainty, it was proposed that some families will continue to care in isolation without support until they reach a point when they can no longer care:

*I wouldn't say that its changing (cultural value of inter-generational care). I think there is a hindrance like when, the expectations I would say of going to work coming home stuff like that. There is things that hinder these err lack of care that is needed urm for a family member. But at the same time when ... that person is in need you would come together as much as we can. So, there is hindrance I would say. (...) so, it's like where do you go or what do you need to do, I don't know. That's the bit that, I know every community must suffer with dementia at some point so what do you do, that's the thing. Car 18-30 PT4*

### **7.6.2.3 Constrained by a lack of a culturally appropriate professional home carers service and care homes**

Other factors too played a constraining role in the decision to provide family care rather than seek professional home care support or care home provision. One of these related to the perception that there is a lack of a culturally appropriate professional home care service, which may leave families without access to care workers of a similar cultural background. This contrasts with the Flexible type, in which both Indian and white British focus groups were able to exercise choice in relation to care homes. For the Indian focus groups they could find culturally appropriate care for Indian communities, and the white British communities discussed some families having the ability to choose to place family members with dementia in a care home, because care homes were available. However, such choices were constrained for Caribbean communities because participants placed an importance on having Caribbean care staff who understood and respond to different languages, including body language and food practices. It was argued that the lack of such staff may lead to a PWD having to passively accept inappropriate care practices which, when delivered, fail to respect an individual's cultural beliefs and needs, and thereby diminish their self-hood and quality of life. It may also contribute to misunderstandings arising out of ignorance of the different ways in which Caribbean people express themselves and lead to a misapprehension that the PWD is being aggressive:

*I think it's massive, I think it's a massive thing not just whether you are African, Chinese it doesn't matter where you come from. I think culture plays a massive part in terms of when we look at how we look after our elders. You have to take into account cultural differences in terms of carers as well. It's difficult to have a carer who has no understanding whatsoever of someone's cultural needs to then looking after them 24 hours a day or even a portion of that day, that what kind, I know you have to do the best with what you have but it should at least be an ambition to be able to meet people's cultural needs. Because if you can't do it yourself what kind of quality of life is that. It just feels like you are literally a puppet you can't, do you get what I mean,*

*you can't do anything for yourself, someone has to do it for you, and they are not acknowledging or respecting your cultural beliefs or your religious beliefs. There is nothing you can do about it but complain or sit there and accept it. So, I think culture plays a massive part in how you care for people as well. And how we relate to people. Like for example it's a known fact Africans and Caribbean's we talk with our hands a lot, to other people that comes across as aggressive. I don't see aggressive when I see people flare their hands because I am listening to the tone of their voice and the context of what they say as to are they being aggressive. We are passionate people we talk with our hands that's just how we are. So, I think culture plays a huge part in this. Car 18-30 PT2*

The constraints in options for other care strategies was also based on a perception about the lack of culturally sensitive care home provision. This concern was suggested to be particularly relevant for PWDs from different ethnic backgrounds, such as the Caribbean community, because the regression of their memories may be accompanied by a change of language from English to Patois. Their tastes in food might also revert to their early life diets in the Caribbean. Families would therefore find it difficult to have confidence that their family member with dementia will be cared for appropriately. This is because of their concerns that care homes do not cater for the Caribbean community as a whole, as well as the diversity within this community. This concern also extended to personal hygiene practices:

*And I think especially if you don't see anything around you that, OK I think a lot of the homes that you see like have a predominant ethnicity and as the older generation get older and probably you know regress to more of their roots and everything, putting them somewhere that's going to seem foreign to them, the food that they don't recognise, the personal hygiene standards that they don't recognise, it's like you are going to be traumatising them you know what I mean. When they are asking and Caribbean people are different, Jamaican people don't cook like Antigua people. Antigua people don't cook like Montserrat people it's like if ... they are not going to be somewhere where they are going to have their needs catered to it would be very difficult to say I am going to send my grandmother there. You are going to think she is not going to be happy because they are not going to meet her needs. When they are washing her if they have to start tending to personal care, they are not going to do it how she likes to be done. And that's going to make her feel more uncomfortable, it's going to make, if you feel your loved one is uncomfortable in a situation that's going to make you feel bad. So, you just think forget it I am not going to put anyone through that. Car 30-40 PT1*

#### **7.6.2.4 Use of care homes a last resort**

The complexity of participants' approach to care was accentuated and constrained by African Caribbean communities' negative historical experiences with mental health services, which involved over-representation, sectioning and overuse of medication.



These perceptions fuelled a concern that their elderly relatives with dementia could be overly medicated and sectioned in a care home too, in addition to a failure to provide culturally appropriate care. As a consequence, seeking care home support for a relative with dementia may be undertaken as a last resort, when the family can no longer offer their own care:

*And I think the culture comes in terms of over-representation as well of African Caribbean people in mental health in particular. So, when you are looking at medication there is a lot of fear and stigma around that thinking OK, they are going to get sectioned, no one is going to look after their cultural needs, they are just going to put them somewhere and dose them up with medication. And there is a massive fear around that so that a lot of people won't go there unless its drastic enough where they can't handle it themselves and need help. Car 18-30 PT5*

The commitment to provide care within the family home was also reinforced because of negative stories about care homes in the media:

*When my mum gets to that age, I tell my mum you ain't going in no home. You see too much horror stories on the TV about what goes on in homes and blah blah blah. My family looked after me when I was young regardless to what they got, why am I going to put them in a home. I will look after them, the medical people can come in and do what they want but I am looking after them, so I know what is going on. I ain't doing no home thing. Car 40-55 PT2*

I will now move onto the final type, which is the Individualised type developed from the perspectives of white British focus group 40-55 years about their own future diagnosis and care for dementia.

## **7.7 Individualised Type**

### **7.7.1 Approach to diagnosis**

#### **7.7.1.1 Reluctance to disclose symptoms of dementia to family due to fear of care homes**

There was a palpable sense of fear about being placed into a care home, one that was suggested to be hidden and not widely discussed, and this fear was thought to play a key role in the reluctance of some people to disclose symptoms of dementia to families. This fear of care homes was based on the anticipation of experiencing a loss of control and agency, in addition to being exposed to poor care practices in these homes. This may

explain why, for some white British families, there are delays to diagnosis:

**Excerpt: White British focus group 40-55 yrs.:**

*WB 40-55 yrs. PT6: I think a lot of people hide it, I have got a fear of residential homes and I don't want to end up in one and I haven't got any family or kids. I will, this is why I will probably go and get myself euthanised before I end up in one. But I think a lot of people will hide it because they are scared to end up in a residential home or a nursing home. And they probably want to stay with their family or their loved ones, but they are probably thinking God this is really horrendous and you know then might hide it so that they don't end up in a care home.*

*WB 40-55 yrs. PT3: Because you don't know what you are going to end up either when you go in one of these places.*

*WB 40-55 yrs. PT1: No, my (relative) was in care home and she fell over in the shower and broke her teeth it was awful, she had worse bed sores that social services had ever saw, care homes are disgusting.*

## **7.7.2 Approaches to care strategies**

The approach to care is differentiated from the other types, which are characterised to differing degrees in relation to allegiance to filial piety. In this type, care appeared to be articulated in more individualised terms. This is demonstrated by its focus on independent decision making, in collaboration with their families. Their approach to planning finances and care was driven by the balancing of their future individual needs and desires with those of their family and the need to plan for the future.

*I think it's good for that person that may have that condition be... in the plan of looking forward to what might happen and then have their decisions in, you know set out. If this happens or that happens and this is where I want to go or stay and you know I don't want to be at home I would rather be you know, and have a look out there and see what care is there for them. That will cost thing as well, it's like everybody does things where you plan for your funeral so you take it off your family but what if you could do something like that, so you sort out the cost so when it comes to it you know they have got enough to look after you. Or put you somewhere or whatever. WB 40-55 PT1*

*I think it's good to have a written plan for the family to sit down and have a plan for the future for that person and their decisions are going to be there for the future. Rather than trying to get an answer when you know you are not going to get an answer. Like a contract. WB 40-55 PT2*

### **7.7.2.1 Individuals taking the responsibility for their future care planning**

It was this fear alongside an understanding of the progression of dementia that led the majority of the participants to consider undertaking NHS dementia screening if it was

offered. This was because if they were at risk, it could enable them to have the time to take responsibility and plan whilst they retained the ability to do so, and arrange issues such as their finances as well as care arrangements with their families, during the early stages of their dementia. This advanced knowledge of risk would enable them to articulate the idea that they would be prepared to go into a care home to avoid being a burden on their families and absolving them of guilt if needed:

***Excerpt: White British focus group 40- 55 yrs.:***

*WB 40-55 yrs. PT5 Male: And you don't want to be a burden.*

*WB 40-55 yrs. PT2 Female: Yes.*

*WB 40-55 yrs. PT5 Male: That's how I feel.*

*WB 40-55 yrs. PT6 Female: .... you have got to think of your family.*

*WB 40-55 yrs. PT6 Female: ... then you can set things in motion.*

*WB 40-55 yrs. PT2 Female: And then you have got to live with it then.*

*WB 40-55 yrs. PT6 Female: ... with your family, with getting some form of care in while you are still at a low stage, but it gives your family then time to adjust and get ready for what is going to come. Yes, I would want to know.*

*WB 40-55 yrs. PT2 Female: And then sometimes your family might feel guilty, oh I have got to put them in a home, but if you can sit there beforehand and say look if I get that bad don't feel guilty that's where you have got to put me.*

### **7.7.2.2 The lack of filial piety**

An individualised focus on and responsibility for one's own health and future was also informed by individualised anxiety about dementia. Although it has to be noted that, unlike other types that focused on care strategies for family members with dementia, here participants were referring to their own future with a potential diagnosis of dementia. Their anxiety was palpable, so much so that it led to contemplations of euthanasia and conflicted feelings because of the tension between wanting to receive familial care and not believing they will get it. In addition, there was a general anxiety about where they might end up in old age. Their individualistically focused future care strategies were partly formed in response to these anxieties. These were clearly evident in their discussions the positioning of white British cultures with those in Eastern

countries as well as Asian families in this country with regard to filial piety. The strive for individual responsibility was based on a belief that filial piety was not considered to be traditional cultural practice in white British communities. This was because some families, including grandparents, choose to live independently away from their families and they can often rarely see each other, although it was acknowledged that some families do maintain familial contact. Added to this was their argument about a lack of respect and care of older family members in British families. To support this argument they cited the preponderance of older people placed in care homes and forgotten about, as indicative of the white British community's lack of filial piety:

***Excerpt: White British focus group 40-55 yrs.:***

*WB 40-55 yrs. PT4: In Japan the urm... the pensioners if you like the grandparents when grandparents don't live by themselves, they live with the younger families, so they are looked after by the younger families and it's part of their culture. In this country it doesn't work like that you know it's like your grandparents go and live by themselves somewhere. And the kids could be hundreds of miles away and never see them. Or they could be on their doorstep and do see them.*

*WB 40-55 yrs. PT2: The family across the way they are Muslim, and they have got three generations living in one household and the kids look after the older generation.*

***INT:*** *So why is that different in white British cultures or is it the same, do families still take care of their own?*

*WB 40-55 yrs. PT2: Probably some but I don't know. Its traditions isn't it, it's never been like a traditional way of life in Britain.*

*WB 40-55 yrs. PT4: I don't think we look after our family like other cultures look after ...*

*WB 40-55 yrs. PT3: Its more respectful say in Japan and India, here we have not got that closeness I don't think.*

*WB 40-55 yrs. PT4: You can look at the amount of people who are in care homes or nursing homes and what have you they never see their families; they are put in there and forgot about.*

For them the possibility of care being provided by their children, something that was accepted as a given in all the other types, was not something they could rely on. This was because some younger people were perceived to be unwilling to provide care to older relatives. In the event that they were willing, it was suggested that they would be

able to offer only a limited amount of time to care because of the demands placed on them by employers:

***Excerpt: White British focus group 40-55 yrs.:***

*WB 40-55 yrs. PT2: That younger generation might just go can't be arsed to look after you no more.*

*WB 40-55 yrs. PT5: It is a worry.*

*WB 40-55 yrs. PT4: They (younger people) think they haven't got the time... employers will push them and push them and push them because nobody these days will turn round and say no, I am not doing it. The employers can get away with it.*

Consequently, for this group of participants, it led to responses which were characterised by anxieties about the question of who will care for them. Overall, their responses suggested uncertainty about who was going to care for them, with one participant articulating a conflict between a desire to remain with the family but at the same time not wishing to be a burden to the family, so there was a strong possibility of agreeing to go into a care home. For others, their flippant responses indicate that a lack of filial piety and a lack of family to care for them entailed a consideration of looking after themselves or even euthanasia if residential care was required:

***Excerpt: White British focus group 40-55 yrs.:***

***INT: So who is going to care for yourselves then?***

*WB 40-55 yrs. PT4: Myself.*

*WB 40-55 yrs. PT2: But what about when you can't though?*

*WB 40-55 yrs. PT4: Me dog!*

*WB 40-55 yrs. PT5: Hopefully my family will look after me, my children my wife she is younger than me hopefully them. But you know I said to her forget that just bang me in a home that's what I said as a joke but deep down I don't really want to go I would rather be with my family.*

*WB 40-55 yrs. PT6: I would rather go and euthanasia before I go into a residential home.*

## 7.8 Summary of findings

This chapter discussed approaches to help-seeking using the theoretical concept of typologies to differentiate approaches to help-seeking in this research, as well as older people and some families outside of this research sample. The Traditional type shows that the reluctance to seek diagnosis is shaped by conceptualisations of dementia as a mental illness, which leads to concealment of symptoms to avoid being stigmatised. It's also informed by a lack of culturally appropriate knowledge about dementia symptoms. There is also a reluctance to seek treatment as there is a preference to rely on faith and alternative remedies for the symptoms of dementia. In contrast to the Traditional type, in the Flexible type we find that there is a willingness to seek diagnosis because participants are more accepting of dementia because they have been educated about it from the media and health services. There is also a willingness to seek care support in the form of professional home care workers and care support to assist with the burden of care but also as a way of accessing specialist support for the PWD.

The Constrained type is also characterised by a willingness to seek diagnosis for a family member with dementia, because of the awareness that mental illnesses require diagnosis. The need for diagnosis was recognised even amongst those that conceptualised dementia as a normal consequence of ageing. Nonetheless, there is an acknowledgement that there is a lack of information about dementia to promote early diagnosis across all generations within the Caribbean community. Seeking professional care and care home support, in contrast to the Flexible type, was constrained because of a perception about the lack of culturally appropriate care. In addition, racism in the mental health system contributed to a reluctance to seek care support outside of the family.

In a similar manner to the Traditional type there is a reluctance to seek diagnosis within the Individualised type, but unlike the Traditional type it stemmed from a fear of being placed in a care home. Unlike all the other types, familial approaches to care were not a given. As a consequence, there was a receptiveness to plan ahead for dementia by taking part in dementia screening. This type was marked by tension, uncertainty and conflict as, on

one hand there was a desire to be taken care of by the family, but on the other a wish to not be burden on the family as dementia progresses. In contrast to the other types, filial piety as the driver shaping familial expectations and provision of care was not a given. In addition, for some participants the lack of a family to care for them entailed a fall-back position in relation to their care was to make individualised plans.

These types, which constitute the overall typology, convey a nuanced approach to help-seeking, combining a discussion of values interacting with structural issues and factors that are identified as different within and across ethnic groups and generational ages.

# Chapter 8: Discussion

## 8.1 Introduction

This thesis aimed to explore understandings of dementia and approaches to help-seeking in a multi-ethnic younger and middle-aged study population. The research was designed to respond to and address the paucity of these generational perspectives identified by the literature review of worldwide empirical studies and grey literature.

The study aims and objectives were developed by conducting a preliminary literature review of empirical studies to develop the following research questions. These were:

1. What is the knowledge and understanding of dementia in younger and middle-aged adults in multi-ethnic communities?
  - (a) What factors influence and contribute to this knowledge and understanding?
2. How is dementia conceptualised by younger and middle-aged adults in multi-ethnic communities?
  - (a) What factors and issues shape and influence these conceptualisations?
3. How is old age and ageing conceptualised in younger and middle-aged adults in multi-ethnic communities ?
  - (a) How is old age and ageing framed in relation to dementia?
4. What are help-seeking strategies for dementia within younger and middle-aged adults in multi-ethnic communities?
  - (a) What factors and issues shape and influence these?

These questions were addressed by taking a qualitative approach with the selection of CONGT (Charmaz, 1995) as the methodological framework for the research. This



methodological framework involved the use of focus groups with younger and middle-aged participants. In addition, face to face semi-structured interviews were conducted with community workers and volunteers who work with Indian, Caribbean, and white British communities.

After analysis of the findings was completed, a review of the theoretical literature was undertaken to develop a critical interpretation of the findings. The theoretical review assisted with my understanding of how the both the empirical and grey literature had unproblematically treated some of the categories such as ethnicity, culture, and old age. The following chapter will present the analysis and interpretation of the findings, drawing upon the theoretical, empirical and grey literature.

This chapter is organised and presented in three sections. In Section 1, I shall provide a succinct summary of the key findings of this research, including how these questions were addressed. In Section 2, I shall discuss my interpretation of some of my key research findings, and draw upon findings and commentaries from theoretical, empirical and grey literature with which to make to make comparisons. In Section 3, I will provide a summary of the chapter. The arguments underpinning these sections are as follows.

This research has shown that the assumption that it is mainly BAME or minority ethnic groups that conceptualise dementia as a normal consequence of ageing or as a mental illness, and delay diagnosis is flawed. This is because this research has shown these issues are evident in white British communities too. Thus, there needs to be an emphasis on the necessity of including white British communities in future research because it been has found that both younger and middle-aged white British participants would be likely to delay seeking diagnosis. For younger participants the reasons given include the need to allow time for the person with symptoms to come to terms with the possibility of diagnosis. For middle-aged participants, it was due to them being afraid that it will eventually lead them to being placed in a care home. Unless the same level of research scrutiny that is applied to BAME communities is applied across the board to all ethnic communities, research will perpetuate the pathologising of BAME cultures. It needs to be recognised that even white British communities interpret this experience through a cultural lens. As this research has shown, this cultural lens is one that values autonomy and agency. These

findings add weight to Hashmi's point (2009), which is that dementia assaults those in Western societies and stigmatises people for no longer being productive members of the community (Hashmi, 2009). This might explain why white British younger participants found approaching the subject of seeking diagnosis with a family member experiencing symptoms as patronising, and wanting to allow time for the person to come to terms with a loss of self.

This research has demonstrated that participants conceptualised dementia as a mental illness and/or as a consequence of the ageing process. Therefore, it might need a two-pronged approach to raising awareness of dementia symptoms, which includes mental health and dementia awareness campaigns. These approaches can address the diversity of conceptualisations that currently exist. These campaigns need to be diversified in their content and delivery to appeal to all generations, not just older people. This is because, as we have seen, both adult children and grandchildren undertake care and support of family members with dementia. These campaigns should also attend to the representation of ethnic diversity. This needs to be urgently addressed, as the discussion within the Introduction chapter has shown that the prevalence of dementia is projected to increase due to the ageing of white British, Indian and Caribbean communities. Also, BAME communities in particular are at higher risk of developing dementia due to a higher prevalence of chronic health conditions such as diabetes and hypertension. This research has demonstrated that an awareness of these risk factors in the majority of focus groups was lacking. This is further substantiated through my own extensive professional experience and voluntary work in community education about diabetes. Yet, research efforts are focused on gauging dementia knowledge when it's quite evident that groundwork to disseminate the knowledge of dementia and its risk factors has not been undertaken. This means that research on dementia aetiology becomes an exercise in stating the obvious i.e., there is an absence of knowledge about risk factors rather than solutions focused on how we can raise knowledge and understanding to help with prevention. It would be advisable only after the groundwork has been laid to undertake research evaluations of knowledge.

I also argue that dementia awareness and mental health campaigns should focus on

supporting the identification and detection of symptoms of dementia and target all generations within all ethnic communities. This research has shown that family members, including younger people such as grandchildren, are involved in the diagnosis and care of parents and grandparents with dementia. However, as we have seen, participants' information-seeking behaviours are characterised by waiting until the need arises to familiarise themselves with dementia to provide support to family members, by which time symptoms will have become severe and possibly too late to ameliorate its progression. Whilst arguing this point, I take on board that dementia symptoms are difficult to separate from normal age-related declines of the body and mind. Although a quick scan of the Alzheimer's UK website demonstrates that advice about this is available, it needs to be disseminated more widely to all generations within families to raise awareness in advance of the need.

Research on the impact of the media in the dissemination and creation of cultural scripts about bio-medical understandings of dementia is still in its infancy. Nevertheless I would argue that these findings support the need to research the impact of soap dramas. The reason for this is because they reach a mass audience from different socio-economic and ethnic backgrounds. I found it challenging to find any empirical evidence to support my findings about the impact of dementia storylines within soaps and programmes. Of course, there are films such as *Still Alice* and films similar to those mentioned in this thesis' literature review, but these may not be well known to 'ordinary people' on the street. This research has demonstrated some degree of evidence about the positive influence of soaps, such as generating understanding about symptoms of dementia as well as empathy for the person with dementia. As such, they may play a role in de-stigmatising dementia but we don't know as yet to what extent, nor do we know how these impact on approaches to seek diagnosis. In addition, I would strongly argue for conducting studies similar to that conducted on mainstream print and news media, on the media that caters for BAME audiences, such as *The VOICE*, *Asian Voice* and *Garavi Gujarat*, to explore the impact of disseminating dementia information on BAME audiences.

I contend too that the findings on individualised responsibility for ageing and its framing

in relation to dementia raise a number of concerns that need to be addressed. Firstly, in a multi-ethnic study population there is a shared societal discourse about individualised responsibility for ageing that transcends ethnic differences. Secondly, it has the potential to add another layer of stigma and discrimination for people with dementia for failing to age successfully. This is not a new argument, but it is disturbing nonetheless that here is an empirical substantiation of the theoretical discussions highlighted in the literature review (Higgs et al., 2009; Innes, 2009; Hulko, 2004; McParland et al., 2016). For some BAME and working class white British communities that experience socio-economic disadvantage over a life course, it does not auger well for societal support and acceptance of people diagnosed with dementia. Finally, these findings signal a need for society-wide understandings of socio-economic and political measures on how people from diverse ethnic socio-economic backgrounds can be supported to age well, as well as to raise awareness of any prevention strategies for dementia that are accessible. These should take into account health literacy and cultural appropriateness. The urgency of this is underscored given the projected increases in dementia prevalence in the UK and globally.

My final argument is derived from the findings related to the typology. This is that help-seeking, including care strategies, should not be based on de-contextualised understandings of cultural values, but on a recognition that there is dynamic inter-play between culture and structure. These may operate in different ways in all ethnic communities, and differ in response to inter-sectional characteristics such as age, socio-economic status, migration history and status, as well as gender.

## **8.2 Section 1: Summary of findings and overview of how research questions have been addressed**

The empirical and grey literature review highlighted that ethnic minority groups on a worldwide basis possess lower levels of knowledge and understanding of the bio-medical model of dementia, which is commonly termed dementia literacy. In light of this finding, I aimed to explore the knowledge and understanding of dementia possessed by participants in this research sample, including the factors that are involved in shaping

this.

This research demonstrated that there was variation in participants' possession of knowledge within and across focus groups. This variation could not be explained with respect to its mediation by ethnicity or generational age. It was though explained by three factors: exposure to caring for relatives with dementia and through social networks; exposure to the media, and; exposure to knowledge about dementia through higher education. The latter factor was only found amongst Indian participants in the 18-30 years focus group, who were the most dementia literate.

There were, however, two areas in which there was a lack of variation in the possession of knowledge. One of which related to an absence of knowledge about the role of chronic health conditions as risk factors for dementia. The other being a lack of awareness that dementia is an umbrella term that encompasses Alzheimer's.

This research did not find ethnicity as a mediating factor to explain differences in the possession of knowledge within this research sample of participants. However, ethnicity was attributed as playing a role in restricting access to culturally appropriate information and knowledge for BAME communities. This was a perception articulated by the Caribbean focus groups. When ethnicity is combined with generational age, all BAME focus groups and community workers that support these communities perceived that access to information and knowledge for older people outside of this research sample was limited.

It was also evident that participants' own information seeking behaviour and attitudes can play a role in influencing their dementia literacy. This is because they were unlikely to search for information and knowledge about dementia until the point of need i.e., when a family member was diagnosed. This unwillingness to seek information and knowledge was partly influenced by conceptualisations of dementia as only affecting older people. This motivation to acquire information and knowledge about dementia when it was on their 'doorstep' was found across the focus groups irrespective of ethnicity and generational age.

The conceptualisations of dementia were explored in more depth in this research,

including the factors and issues that shaped them. The analysis demonstrated two main forms of conceptualisation. First, dementia as a mental illness and for some as a mental illness in old age. These conceptualisations were most commonly found in all focus groups irrespective of generational age.

The other conceptualisation of dementia in this research was as a normal consequence of ageing, and not as disease or an illness. This conceptualisation, unlike that covering mental illness, was not developed on the basis of knowledge gained through avenues such as the media or professional training but beliefs participants held about the functionality of the ageing body and mind. These beliefs were derived, in part, in a similar way to the conceptualisation of a mental illness, from caring for a PWD.

It is evident from the discussions on the conceptualisations of dementia that concepts of ageing and old age were inextricably linked to dementia. Old age was associated with physical and mental deterioration, even amongst those that conceptualised dementia as a mental illness. However, when an individual is considered to be old was not clear, particularly as the focus groups spoke about 'age being just a number'. The exploration of this statement led to an iterative exploration with all focus groups to understand how ageing was framed in relation to old age and dementia. The analysis of the findings led to the identification of a perception held by all focus groups, that there has been a shift in generational attitude and beliefs about ageing and old age. The latter was no longer defined chronologically but perceived to the end stage of the continuum of ageing when ill health, including dementia, is expected to occur. However, focus group participants discussed the idea that ageing in this way was not inevitable and there was a perception that people have control and responsibility over how they age. In addition to this, how they mediate their risk of dementia as they age.

In this research, the influence of knowledge and understanding of dementia and conceptualisations of dementia could be seen to influence help-seeking strategies, including diagnosis and care. The analysis of help-seeking strategies discerned there to be some distinct differences between focus groups, in part determined mediated by ethnicity but also by generational positioning. These characteristics interacted with structural factors and the values the focus groups held, to influence different responses

within help-seeking behaviours. The influence of filial piety was also explored in help-seeking approaches and I was able to show how it was adapted and negotiated in light of structural factors and issues. To further understand these differences within the research sample, the analysis also drew upon the perspectives of community workers in the development of types named to capture the core features and differences in help-seeking. The analysis of findings related to help-seeking culminated in the development of four types to categorise four different approaches. The Traditional type was developed to capture the views, experiences and perceptions arising out of the contrasting positions Indian and Caribbean focus group participants had taken with respect to older people in their communities. As such they were postulated to characterise older people outside of this research sample's help seeking-approaches. However, the analysis of interviews with community workers who work with Indian and Caribbean communities, whilst supporting the relevance of the Traditional type for older people, also extended its applicability to the approach taken to help-seeking amongst many of the families they worked with.

The Flexible type was developed from the perspectives of white British focus group participants (18-30 years & 30-40 years), in addition to Indian focus groups (18-30 years, 30-40 years & 40-55 years), with reference to their own help-seeking approaches for relatives with dementia.

The Constrained type was derived from the analysis of findings from the Caribbean focus groups (18-30 years, 30-40 years & 40-55 years) and similar to the Flexible type was developed from the perspectives of their own help-seeking approaches for a relative with dementia. Finally, the Individualised type was formed on the basis of findings from the white British focus group (40-55 years) who discussed help-seeking in the context of their own future should they develop dementia. My interpretation of the significant aspects of all the four types will be discussed in the following section, including a comparison with the existing literature.

## **8.3 Section 2: Interpretations and comparisons with existing literature**

In the following section I shall extrapolate some of the significant findings from this research to share my own interpretations and undertake comparisons with existing empirical, grey and theoretical literature.

### **8.3.1 Systemic barriers to dementia literacy**

In the literature review, as stated previously in the summary of findings, existing studies commonly utilise ethnicity as a mediating factor to understand its influence on understandings and conceptualisations of dementia, as well as approaches to help-seeking. In these discussions, a key issue that was consistently highlighted is that dementia literacy is lower in ethnic minority groups than majority populations such as white British and Anglo Americans, (Ayalon and Arean 2004; Berwald et al., 2016; Heese, 2015; Jolley et al., 2009). Despite the plethora of studies that support this association, this was challenged by Roche (2020) who argued that lower levels of dementia knowledge are not confined to ethnic minority groups but can also be found in majority ethnic populations in countries such as Australia (Bettens et al., 2014) and France (Breining et al., 2014). These inconsistencies raise questions about the merits of undertaking comparisons based on ethnicity. Indeed, this research found little or no variation by ethnicity. However my analysis of the findings of both the Indian and Caribbean samples did identify a perception that dementia literacy varies within their communities by generational age. This would suggest that research that focuses on intra-ethnic differences may be more meaningful and may help to understand the factors and issues that disadvantage certain groups of people within an ethnic group.

This approach was taken in Lee's (2010) study conducted with Korean immigrants in America, which found acculturated participants i.e., those who use more *American media and have more American friends, and have a more American lifestyle, were more likely to have greater access to sources of mainstream information, including Western biomedical knowledge, and can acquire more accurate information about AD* (Lee al.,



2010: 71). Lee's findings (2010) suggest that information about dementia is less likely to reach people that are less connected to mainstream sources of information, which concurs with the All Party Parliamentary (APPG) report (2013) based on research with older multi-ethnic participants. This report stated *obviously for people who do not read or write in English, they do not watch the main terrestrial channels, they do not read the main newspapers. So obviously a lot of stuff there about people like Terry Pratchett and Iris Murdoch does not go out to them* (All Party Parliamentary Group on Dementia 2012: 27). Other research has also suggested that older members of ethnic minority groups have limited access to sources of information (Roberts et al., 2003), and that factors such as level of education and years of speaking English (Ayalon, 2013) may also shape their knowledge of dementia.

Whilst these studies draw attention to the barriers to dementia literacy due to language differences and lack of acculturation, I would argue the scrutiny of barriers should not end there. This is because there is a danger that certain groups, such as BAME older people or those who do not speak English, are likely to be blamed for their failure to access bio-medical understandings of dementia. This research argues for the need to identify and address systemic barriers that exist within health services and the media that lead to a failure to recognise and address these intra-ethnic group differences in dementia literacy. This is because Indian and Caribbean participants, including community workers, drew attention to the failure of health services and the media to provide culturally appropriate bio-medical understandings of dementia that cater for different levels of health literacy. They suggested that BAME older people are more likely to turn to BAME media because it caters for their language and cultural needs, but may not necessarily give them access to credible information about dementia. In contrast, younger generations from BAME communities were better positioned to access this information through their education, use of technology, familiarity with mainstream soap dramas, reality shows and health organisation leaflets.

Thus, this research advocates a need for future studies to explore how dementia literacy can be promoted equitably, both within and across ethnic groups. This should include intersecting ethnicity with other characteristics such as generational age and

socio-economic status. This is a point made by Hulko (2004), who from a social science perspective argued that an intersectional approach can be used to point to the ways in *which multiple and complex identity categories such ethnicity, class, age, interact to shape individual life experiences* (Hulko, 2004: 232). Therefore, in relation to dementia literacy, my research advocates the need to move away from the homogenisation and categorisation of people through single characteristics such ethnicity to a recognition of how a combination of characteristics shape our understandings of dementia. Unless this occurs, minority ethnic groups will continue to be problematised for their failure to understand bio-medical understandings of dementia due to cultural and language differences, at the neglect of a focus on systemic failures to equitably promote dementia literacy within and across ethnic groups.

Another systemic barrier identified by one of the Caribbean focus groups was the lack of ethnic representation in health information resources and the media. This can challenge the acquisition of dementia literacy amongst minority ethnic groups because, for example, images depicting white older people on dementia leaflets or media campaigns are unlikely to facilitate a recognition that the information being conveyed is of relevance to them and their experiences. This finding is supported by other studies in which participants believed that they had a low risk of developing dementia (Roche et al., 2020), perceiving it to be to be a white man's disease (Berwald et al., 2016), and one that *Asian Americans don't get [AD], or... not as much as white Americans, and blacks don't really get it either* (Jones et al., 2006). Roche et al. (2020) argued this lack of resonance and identification is because *people ascribe racial and ethnic attributes to illnesses based on how they are represented and whether they are encountered in their surroundings* (Roche et al., 2020: 16). They also highlighted the fact that this inequity in representation of black communities in dementia dissemination strategies is in contrast to the over-representation of black, African and Caribbean *in other chronic condition such as HIV where portrayal of African Americans prevails over other ethnic groups* (Roche et al., 2020: 9). My research findings concur with these and emphasise the need for future empirical research to evaluate dementia knowledge campaigns to assess whether they are inclusive of ethnic diversity, both in terms of representation and

experiences of ethnic minority communities.

### **8.3.2 Information-seeking behaviour as a barrier to dementia literacy**

This research identified a significant barrier to dementia literacy that stemmed from participants' own information-seeking behaviour prior to diagnosis, and which was found to exist across and within the majority of ethnic and generational groups. This is an under-explored issue in empirical studies, which primarily focus on information-seeking behaviours amongst carers and PWD *after* diagnosis (Forbes et al., 2012; Rutkowski, et al., 2021; Soong et al., 2020). This research identified that, irrespective of ethnicity and generational age, participants were reluctant to proactively seek information and knowledge about dementia unless and until it affected someone in their family. One reason identified for this was that dementia was a *specific illness*, in contrast to general health and well-being information that they considered they would be likely to access on an ad hoc basis. In part, this reluctance also stemmed from apathy as participants conceptualised dementia as affecting mainly older people, and information about the illness was therefore perceived to be irrelevant to them. This significant finding contributes to our understanding of why the lay public may not be able to detect and differentiate between normal age-related forgetfulness and dementia symptoms until the condition progresses. It was difficult to identify comparable findings in the existing empirical literature. Parveen's (2016) multi-ethnic study of lay participants in the UK mentioned their unwillingness to know about dementia until it affected them personally, but in this case the reluctance stemmed from an unwillingness to discuss dementia within their communities due to perceptions of stigma.

This research contributes new knowledge and suggests the need to identify factors that influence information-seeking behaviours prior to diagnosis. This may help to address the factors that contribute to delays in diagnosis that have been identified in many studies across a range of ethnic groups (Bond et al., 2005; Clark et al., 2005; Schrauf and Iris, 2012; Hossain and Khan, 2019a; Czapka et al., 2020a). Otherwise, undue emphasis is likely to be given to ethnic minority groups' culture, in particular their conceptualisations of dementia as normal ageing as a cause for delays. This research instead draws attention to how information-seeking behaviours are shaped by an interaction between dementia

attitudes and conceptualisations that can be found in a range of ethnic groups, including white British communities.

Dementia literacy also involves awareness of the aetiology of dementia to assist with addressing risk factors. However, in this research, a significant finding across almost all ethnic and generational focus groups was a lack of knowledge about the risks posed by chronic health conditions such as diabetes and hypertension to the development of dementia. In part, this lack of knowledge was linked to participants' conceptualisation of dementia as a mental illness or the belief that it occurs randomly in old age. These findings are of particular concern, as there is evidence that some BAME communities, such as the Indian and Caribbean communities, have a higher risk of developing dementia (Adelman et al., 2011; Mayeda et al., 2016) due to risk factors such as diabetes and hypertension.

The findings from this research concur with cross-sectional studies highlighting the paucity of knowledge of the link between dementia and high blood pressure (Cations et al., 2018; Devine, 2016; Schrauf and Iris, 2012), and diabetes and high blood pressure (Yang et al., 2015). Qualitative studies conducted with minority ethnic groups also found poor awareness of the link between diabetes and dementia (Farina et al., 2019; Fontaine, et al., 2007). The APPG report (2013) drew attention to the importance of BAME communities having knowledge about the role played by chronic health conditions in the development of dementia because it may facilitate the opportunity for younger generations to mediate their risk of developing dementia. Despite this important and concerning finding, there is little UK empirical research, particularly with BAME communities, about the knowledge about the risks these chronic conditions pose to the development of dementia. My research strongly advocates that this issue needs to be prioritised in future research and within dementia knowledge-raising campaigns targeted to BAME communities.

Whilst the above discussion highlights the barriers to dementia literacy, this research also found that a key factor that contributed to both knowledge and understanding of dementia symptoms and its progressiveness was participants' exposure to caring for relatives with dementia and hearing about dementia symptoms through their social networks. For many younger and middle-aged participants, including white British, exposure to dementia in

these ways facilitated their ability to differentiate between age-related forgetfulness and memory loss in dementia and behavioural and personality changes in a PWD. This finding of an association between exposure to caring and knowledge concurs with a range of studies (Adamson and Donovan, 2005; Carpenter et al., 2011; Laditka et al., 2012; Ahmed et al., 2014a; McParland et al., 2012; Seo et al., 2015). Ecclestone's study (2019a), which evaluated the impact of an educational intervention for the lay public, found that prior to participation in their study *the lived experience of dementia through family and work settings, and/or to education about dementia, were associated with higher baseline knowledge of dementia* (Eccleston et al., 2019b: 4). In addition, Glynn's (2017a) study with an Irish population also found that *those who knew or had previously known someone living with dementia were over twice as likely as those without this experience to report confidence in telling the difference between the signs of early dementia and normal ageing* (Glynn et al., 2017b: 866).

In relation to this research, Indian and Caribbean focus group participants' exposure to dementia through caring and social networks may be greater than those of their parents and grandparents. This is because these participants' parents and grandparents may have left their countries of origin at a younger age to migrate to the UK, and consequently did not have the same level of exposure to dementia and/or caring responsibilities for older relatives with dementia as younger generations in the UK do. Moreover, in BAME younger generations in the UK, exposure to dementia may be enhanced because life expectancy is greater amongst their first-generation migrant relatives, such as grandparents or parents. However, these factors are not articulated in the literature, largely because generational perspectives are under-researched and predominantly involve a focus on older carers and PWD. These findings point to the need to promote dementia literacy not just to older people but across generations within ethnic groups, so they can be equipped to identify symptoms of dementia and be supported in their help-seeking strategies.

### **8.3.3 Areas of media influence**

In the discussions within the theoretical review in Section 2.5.4 it was argued that research about the broader role of the media and dementia is relatively new (Peel, 2014; Ratnakaran et al., 2018). Where it does exist, it is often framed in relation to the media's

informational role. For example, it is commonly attributed as a source of information alongside friends and family (Gray et al., 2009, Sun, et al., 2014, Friedman et al., 2009). In this research too, there were some examples of the media's informational role. These included some participants accrediting the Angela Rippon documentary and the news as fostering their awareness that it is possible for younger people to develop dementia. In addition, soap dramas were attributed by participants in generating their awareness of symptoms such as a loss of recognition of faces and money. The role of the media in contributing to dementia literacy in this way is an issue highlighted in the theoretical review with specific reference to the informational role played by the media in the absence of direct interactions with healthcare professionals (Lawless and Augoustinos, 2016).

In relation to attitudes and beliefs about dementia and PWD, there was an assertion within the theoretical review that exposure to the media, particularly news on television and in print, can have an adverse impact on the lay public attitudes towards dementia as well as PWD (Grigorovich, 2020; Kirkman, 2006; Peel, 2014; Zeilig, 2014). The media was identified as generating fear and revulsion of PWD, with depictions of them as empty shells, zombies, or the living dead (Hillman and Latimer, 2017a; Peel, 2014; Zeilig, 2015). In this research, some participants discussed the media with reference to their anxieties about dementia and fears about poor standards of care within care homes. However, in these examples it is difficult to explicate the media's influence in the creation of their anxieties and fears because there were other influences at play too. These included first-hand experiences of participants whose relatives with dementia had been in receipt of negligent care in care homes, as well the sharing of information about dementia symptoms in participants' social networks. In this instance therefore, it might be more judicious to consider whether the media may have acted as a trigger for their anxieties and concerns, and/ or they were using it as touchstone in discussions with others about these issues. It may also be worth considering that the media coverage may itself be 'downstream' or reflective of participants' wider social and cultural milieu's discourse about dementia, help-seeking and care strategies. This discourse may also be indirectly informed by critical reports about standards of care in the media by the Care Quality Commission, which is

an independent regulator of health and social care services. Therefore, these findings cannot be treated unproblematically and be used to attribute a causal role to the media in shaping participants' attitudes and beliefs about dementia, as well as their care strategies. To do so would require a different research design to that undertaken in this research study. Nevertheless, the contribution of this research is that it has highlighted some limited knowledge about potential areas of media influence such as care strategies that can be explored in future research.

An additional area for future research has also been identified in this study. This involves going beyond the informational role played by soaps such as *Emmerdale* to a focus on the impact soaps have on attitudes and beliefs about dementia and people with dementia. There is clearly a gap in knowledge about the media's role in this area. However, the need to explore this further is particularly salient given the viewing figures for the *Emmerdale* episodes in which the storyline about dementia was presented and attracted such high viewing figures, in the region of 6.2 million viewers (BBC, 2016). In the absence of such evidence with which to draw comparisons, it might be helpful to direct our attention to the evidence about the impact of dramatic portrayals of dementia that currently exist, such as films including *Iris* (1968), *Robert and Frank* (2013) and *Still Alice* (2015) (Hillman and Latimer, 2017). These, Hillman suggested (2017b), may assist with provoking an exploration of a range of issues, as *they facilitate the opportunity to reflect and confront our fears generated by dementia such as losing ourselves, as well as facilitate the opportunity to explore inter-related issues such as identity, memory and our humanity* (Hillman and Latimer, 2017a: 2). In this research too, in a similar way to these films, participants shared the view that soap dramas made them reflect on dementia, its symptoms and the impact on the PWD.

The opportunity to be reflective and experience a range of emotions, as well as increase dementia literacy through soap operas and films, was perceived to be unavailable to all sections of the UK's population, according to the Indian focus group (30-40 years). They argued that the opportunity for Indian communities to learn about dementia through Indian soap dramas was not possible to the same degree (as with British soap dramas), as the quality of their storylines and information may be compromised by plots and

music. Therefore, they suggested one way to generate understandings of dementia amongst non-English speaking Indian audiences was for the Indian media, including Bollywood movies, to address dementia in a similar way to the British mainstream media. Their suggestion is congruent with the point made by the APPG report (2013), which recommended that the media that caters for BAME communities could play a greater role in dispelling myths and promoting dementia literacy, as some members of the BAME communities do not watch the main terrestrial channels and lack access to the discussions of dementia in the generalist UK media which has increased in the last ten years (All-Party Parliamentary Group on Dementia, 2013: 27). Fei Sun's study (2014), conducted with Chinese Americans, also highlighted the importance of media messages about dementia tackling not only information about dementia but also cultural beliefs. However, the role and contribution of the media that caters for BAME communities in the dissemination and portrayal of dementia continues to be under-researched.

Whilst the theoretical review of the literature discussed that the media creates negative stereotypes of ageing (Kirkman, 2006), my research suggests that it may also have a positive influence too. The findings suggest that the media, alongside other factors in their personal lives, may have prompted participants to be reflective and view the ageing process in a better light. The latter was helped somewhat by media portrayals of successful older celebrities, proving to them that old age does not have to be a barrier to achievement. Furthermore, the media was cited by participants as promoting advertisements of products that counteract the effects of ageing. In this respect, my research countervails some of the existing premises about negative stereotyping of ageing and people with dementia in the media by presenting a more balanced commentary in relation to the influence of the media. These findings also add weight to the observation that the marketing industry, through the media, plays a key role in supporting the growing trend of anti-ageing medicine which positions ageing as an illness which can be treated or slowed down by the consumption of products and lifestyles (Cardona, 2008: 477). Whilst this research has highlighted areas of influence on attitudes and beliefs about ageing, again one cannot attribute to the media a casual



role as that too would require a different study design to determine its causality amongst a range of other influential factors.

### 8.3.4 Conceptualisations of dementia

The following figure visually depicts the nuanced findings that explain the two most commonly found conceptualisations of dementia in this research, which include it being viewed as a mental illness and as a normal consequence of ageing. I shall thereafter discuss each of these conceptualisations in turn, referring to the most significant aspects only for the purposes of this chapter.

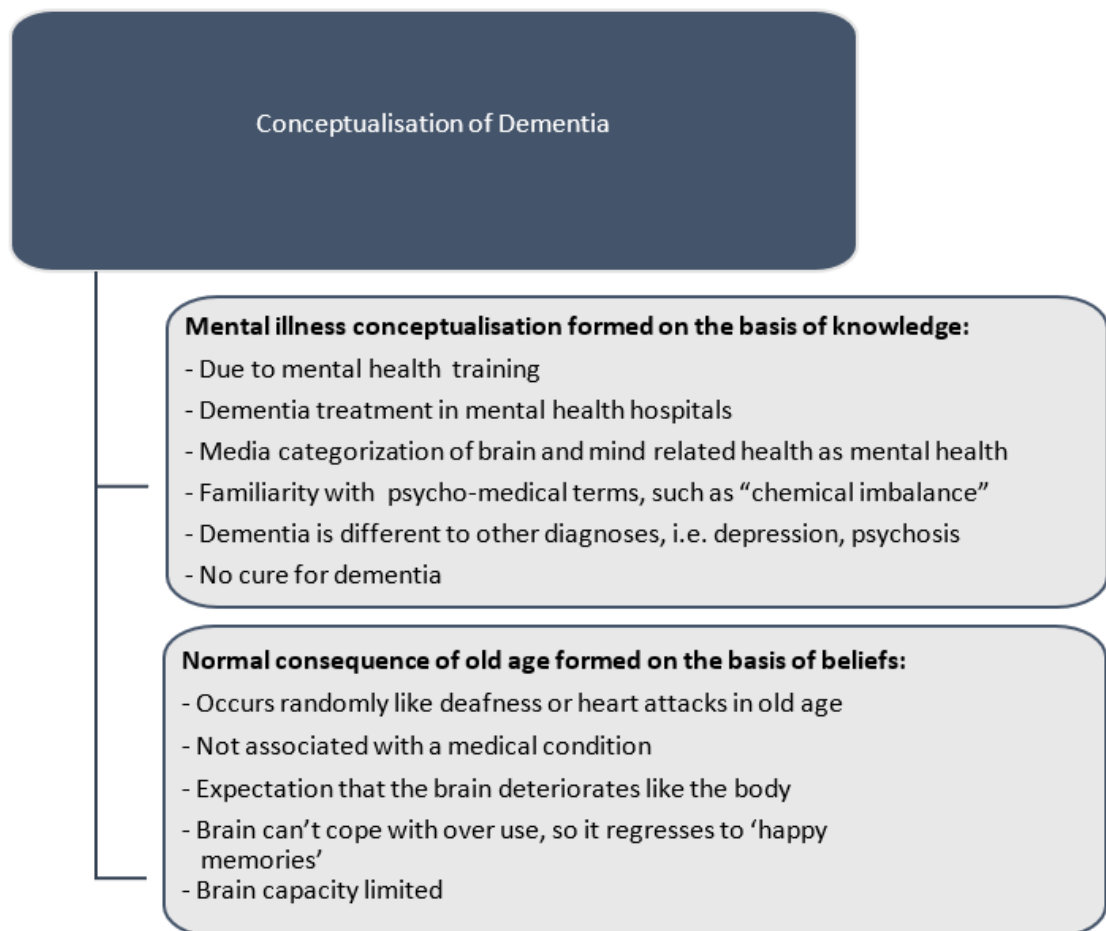


Figure 8.1: Different conceptualisations of dementia

#### 8.3.4.1 Conceptualisations of dementia as a mental illness

The descriptive language used to convey the mental illness conceptualisation of dementia in my research reflected the use of bio-psycho-social language such as

behavioural symptoms, memory loss and chemical imbalances. This language was in stark contrast to the derogatory and pejorative descriptions found in other studies, such as Adebisi's (2016) study conducted with Nigerian lay participants. These included descriptions of dementia and those with dementia as *mentally subnormal*, and the mind becoming stale (Adebisi et al. 2016: 271). Other studies also discussed participants using derogatory language to describe how dementia is viewed as craziness (Berisic and Nesvadba, 2008; Clutterbuck and Mahoney, 2003; Jett, 2006; Liu et al., 2008; Mahoney et al., 2005; Neary and Mahoney, 2005) by people in their communities. One of the reasons to account for the absence of pejorative descriptions in this research may be related to the personal and professional backgrounds of participants. These enabled access to training in mental health and exposure to knowledge after diagnosis of a family member. Although comparable findings relating to the background of participants are not evident in the wider research, the Alzheimer's Europe (2018) report discussed the view that it was not uncommon for health and social care professionals to consider dementia as a mental disorder. This is because diagnosis, treatment and support for people with dementia are organised in some countries under the umbrella of mental health services (Alzheimer's Europe, 2018: 6).

The implications of conceptualising dementia as a mental illness and its focus on behavioural symptoms of dementia is that it can entail people viewing it as sign of abnormality (Knifton and Yates, 2019) and can lead to stigma. The stigmatisation of mental illness and its impact on people with the condition has been well documented and evidenced (Crisp et al., 2000; Mak et al., 2007; Sartorius and Schulze, 2005). The evidence also suggests that stigmatisation of mental illness is greater in comparison to physical illnesses (Crisp et al., 2000; Rüsck et al., 2005). Indeed, the empirical research on dementia is replete with accounts of dementia-related stigma because its symptoms are construed as being synonymous with mental illness (Adebisi et al., 2016; All-Party Parliamentary Group on Dementia, 2013; Berwald et al., 2016; Devine, 2016; Fontaine et al., 2007; Liu et al., 2008b). However, in my research, stigma related to mental illness conceptualisations was not evident as an influential factor in shaping their conceptualisations and understandings of dementia. The lack of this can not only be

attributed to their personal and professional backgrounds, but also to the influence of the media and mental health campaigns. Although a direct reference to the media was not made, it was implied as the media is primarily the conduit for mental health campaigns. This may have led participants to frame their dementia as a mental illness by focusing on the similarity of symptoms such as behavioural changes and memory loss, in common with other mental illnesses. In addition, articulating their conceptualisations in less pejorative terms than those described in empirical studies.

These mental health campaigns are designed to raise awareness of mental health and de-stigmatise it. The most prolific and lengthy campaign was the Time to Change social marketing campaign launched in 2009 on a nationwide basis in England and implemented until 2015 (Evans-Lacko et al., 2014). The evaluation at the end of the campaign similarly found attitudes related to prejudice and exclusion and showed a greater positive change (Evans-Lacko et al., 2014, Sampogna et al., 2017). An evaluation of a similar campaign in New Zealand (Thornicroft et al., 2014) targeted to the general public also noted that participants had observed and experienced a reduction in stigma and discrimination in relation to mental illness. However, little is known about how these campaigns penetrate non-English speaking diverse ethnic communities in the UK. There is evidence from a study conducted in Scotland with BAME community groups about mental health campaigns to tackle stigma that the lack of diverse ethnic representation is a cause for concern, alongside inappropriate use of language and a lack of high-profile BAME people discussing mental illness (Knifton, 2012).

My research advances knowledge of the impact of mental health campaigns in a multi-ethnic English study population, with findings suggesting that an unforeseen outcome of these campaigns is that illnesses related to brain and the mind are categorised as mental illnesses. This results in the bio-medical disease framing of dementia in terms of brain cell pathology (Knifton and Yates, 2019: 11). I would argue being circumvented by the cultural script of mental illness within campaigns. There are indications in this research that mental health campaigns have contributed in this research sample to not only de-stigmatise dementia but also in raising knowledge about different mental illnesses, so much so that participants in this research engaged in

informed discussions about treatment and cure.

When it came to diagnosis, the impact of these campaigns is not so consistent in my research, as on the one hand Caribbean focus groups discussed their willingness to seek diagnosis for a relative and this was attributed to their greater awareness and understanding of mental health. On the other hand, the analysis of younger generational focus groups with white British participants (18-30 & 30-40 years) appeared to indicate a reluctance to seek diagnosis on behalf of family member with symptoms of dementia. They articulated they would not like the family member to feel patronised, and they wanted give them time to come to terms with the impact of a diagnosis. There was an acknowledgement that this approach may lead to delays in diagnosis. These findings raise an issue which has been identified by other studies, which is that media campaigns on mental health do not necessarily translate to help-seeking (Demyan and Anderson, 2012; Mukadam et al., 2015; Henderson et al., 2013). In part, this is due to the challenges of designing evaluations of campaigns with a control group of study participants who may not have experienced a campaign and those that are targeted with a media campaign (Henderson et al., 2013).

#### **8.3.4.2 Conceptualisations of dementia as normal ageing**

The other conceptualisation found in this research was viewing dementia as a normal consequence of ageing, which was significantly found to exist within the white British focus group (40-55 years) alongside the Pilot Indian and Caribbean focus groups (40-55 years) The presence of this conceptualisation with white British participants challenges a commonly held perception that it is predominantly found amongst ethnic minority groups (Connell et al., 2009; Giebel et al., 2019; Lawrence et al., 2008). This perception was also supported by a study conducted by Turner (2005) in the UK with older lay public participants from South Asian and white British communities. Turner (2005) found the South Asian participants conceptualised dementia as a normal consequence of old age but white British participants discussed physical disease and organic causes, such as deterioration of brain cells in keeping with bio-medical understandings of dementia. They used this knowledge to help them understand why it affected younger people too.

In contrast, the research findings from the white British focus group (40-55 years) are

consistent with Clare's study (2006) conducted with white British participants with dementia. In the latter study, participants also associated dementia with normal ageing. White British carers in Quinn's study (2017) conceptualised dementia as a result of normal ageing. The contradictory evidence presented here suggests that assumptions about ethnicity's association with conceptualisations of dementia as normalised ageing cannot be taken as a given. This may be because white British/European communities have not received the same level of research scrutiny that ethnic minority groups with regards to their conceptualisations. It may also be due to the paucity of studies exploring conceptualisations of dementia with lay multi-ethnic samples involving white British/European participants in the UK across a range of generational groups.

The evidence that resonates with the views expressed by the white British focus group (40-55 years) about memory loss and regression of memories to happier times was difficult to locate in the wider literature. Nevertheless, these views seem to reflect and respond to the recognition called for by Katz (2013) in the theoretical literature review for an integrated approach to memory, one which recognised its physiological and emotional function (Katz, 2013) at a societal level. During the diagnostic process this integrated approach to memory is taken account, according to the ethnographic observations of Latimer and Hillman (2019).

The beliefs about age-related deterioration of brain health in this conceptualisation continue to challenge bio-medical conceptualisations of dementia and not just in minority ethnic communities. The symptoms of cognitive decline as conveyed by my research participants are actually in keeping with the current database of evidence gained through cross-sectional studies (Fletcher, 2020). Consequently, it may be that it is not minority ethnic groups', as well as other ethnic groups', conceptualisations that are wrong, but concepts of dementia as a separate organic disease that are not widely shared.

### **8.3.5 How is old age and ageing framed in relation to dementia?**

The framing of dementia as the end stage of the ageing continuum, as indicated by conceptualisations of dementia as a mental illness and as a normal consequence of ageing, indicate the entwining of the concepts of old age and ageing with dementia. It

therefore leads, as we can see, to not only dementia being problematised but old age too (Knifton and Yates, 2019), so to be an older person is to be a typical 'kind' of person that will succumb to an eventual mental deterioration (Knifton and Yates, 2019: 10). Other studies confirm this perspective of the problematisation of old age (Kim et al., 2015; Liu et al., 2008b).

However, where this research makes a significant contribution to knowledge with a clarification of what 'old age' and 'ageing' mean to study participants. This research found that old age or the later stage of life is no longer viewed in terms of chronological age and socially mandated markers, but viewed by participants as dependent on how they address and take responsibility for their ageing process. Therefore, the boundaries between normal ageing and old age have become more malleable (Jones and Higgs, 2010). The malleability of these boundaries has arisen not only because of the structural changes highlighted by participants but also because of their exposure to healthy, active and resilient agers, who have challenged their conventional meanings of old age as a period of functional decline. Furthermore, the malleability of this boundary is also supported and reinforced by concepts at the macro level of society, such as healthy ageing, active ageing, independent living and successful ageing, as well as notions of 'agelessness' (Jones and Higgs, 2010). Micro-level evidence of an alignment to these concepts was reflected in all focus group accounts of successful and healthy agers, which were characterised by their awe and respect.

These older people were positioned as role models for ageing well. All focus groups discussed how these role models encouraged them to focus on their own ageing process to age well by making lifestyle changes which involve undertaking physical activity, addressing mental well-being and seeking a work life balance. These concepts in the theoretical literature are associated with third agers (Laslett, 1994), or people who have retired and free from familial duties and obligations to pursue healthy and active lifestyles (Higgs et al., 2009b). In this research these concepts were evidenced to be supported and articulated in both younger and middle-aged focus groups as recognition of the need to pursue healthy lifestyles to mitigate risk of ill health and dementia in old age.

These concepts of successful and active ageing are also supported by consumerist approaches in society, which are demonstrated by the proliferation of *self help books and an expanding array of anti-ageing products, nutraceuticals and cosmeceuticals "designed" to ward off the signs of old age* (Gilleard and Higgs, 2007: 18). In this research the participants identified these consumerist approaches to marketing being targeted to older people through the media.

The significance of my research findings is that they map very closely to the theoretical literature on critiques of concepts of successful (Rowe and Kahn, 1997) and active (Havighurst, 1963) ageing as discussed in the theoretical literature review, in particular the shift to individualised responsibility for ageing (Latimer, 2018). This is posited to have occurred in response to a complex inter-play of societal changes that have occurred during the past fifty years (Higgs et al., 2009b). Some of these are a consequence of neo-liberal ideas and policies which have resulted in a change in the commitment of the government in the UK in the post-war years to care for people in their old age. This commitment was previously articulated through a discourse of social citizenship based on collective responsibility. However, post-war, this commitment became dismantled as a consequence of political and ideological responses to the rising life expectancy and the concomitant increased drawing on public health resources to meet the needs of increasing numbers of older people (Westerhof and Tulle, 2007: 240). Thus, the state's neo-liberal ideologies are now characterised by an enabling and facilitative role (Higgs et al., 2009a: 691), and part of the drive to push active healthy lifestyles amongst older people is to reduce their demand on public resources. The articulation of this neo-liberal paradigm takes place by a range of institutions including the media, socio-technical devices and scientific/cultural intermediaries, which also includes the anti-ageing movement (Cardona, 2008: 8). Ageing and growing older therefore become key fields in which the reflexive self is expected to act agentically in pursuit of making the right choices (Jones and Higgs, 2010: 516).

The changing discourse on the individual responsabilisation of ageing includes a focus on lifestyle choices and a consumerism approach to ageing. It is argued to have led to a fusion of fashion, health and identity for both young and old people (Higgs et al., 2009a).

In this context, normal ageing has now become connected to an increasing emphasis on self-care aimed at delaying or denying bodily decline and where the image of dependency is banished to the margins (Jones and Higgs 2010: 1561). This approach to ageing was clearly mirrored and articulated in the findings, which indicated all focus groups, irrespective of ethnicity and generational age, stated that it was 'up to you how you age'. People who had aged well were perceived to have achieved this through dint of self care such as physical activity and having mental resilience, which at times was attributed to be greater than that of younger people.

In this research the findings relating to old age as a time of physical and mental decline, such as dementia at the end of the ageing continuum, resonated with the concept of the 'failed fourth age' (McParland et al., 2016) as discussed in the literature review in this thesis.

This is the final stage of life characterised by *frailty, decline, disability and ultimately death* (Katz and Peters, 2008: 689). The findings correspond to this concept because participants' discourses about various strategies they advocated for others as well as themselves to address dementia risk was characterised by a moral undertone that placed the responsibility to address dementia risk on individuals, even amongst participants who believed that dementia occurs randomly in old age. The failure to address this risk led some of them to attribute blame or a predisposition to develop dementia amongst people in their personal lives as well as certain groups of people. These included people such as retired men and women who had given up on life, failed to keep socially, mentally and physically active and those who had lost their purpose. Similar findings were evident in Fontaine's study (2007) of English, Hindi and Punjabi speaking British South Asians, aged 17–61 years, in which participants blamed older people for their failure to address their social isolation and loneliness, and the lack of support by relatives to facilitate this. Such moralising was evident too in Liu's study (2008) conducted with Vietnamese and Chinese family caregivers in the US, in which distinctions were made between older people that aged well, and those who had not such as people with dementia (Liu al., 2008b). This is despite the fact that beliefs about normalised ageing consisted of an expectation that there would be cognitive decline



amongst older people. The findings from studies such as Fontaine's (2007) and Liu's (2008), along with this research, imply that the emphasis on individualised responsibility for ageing can result in people with dementia being stigmatised for 'ageing poorly' (Liu et al., 2008b: 11). However, these perspectives can ignore wider socio-economic determinants of health and the challenges they pose to individualised responsibility in old age (Latimer, 2018). This view resonates with that articulated in a recent Commission (Draper and Fenton, 2014a) held to review health inequalities in the older population, in which one of its speakers stated *there seems to be a gap between the dialogue of individual autonomy, decision-making and control, and community cohesion and support for health and positive ageing* (Draper and Fenton, 2014b:1).

### **8.3.6 A typology of help-seeking approaches and care strategies**

The findings on dementia literacy, media and the concepts of ageing and dementia informed help-seeking approaches. To better understand these help-seeking approaches I developed a typology consisting of four types as theoretical concepts to convey the complexity and interaction of these factors, and other issues within and across ethnic and generational focus groups. The process of developing these types involved drawing upon the findings from the interviews from the community workers and volunteers.

In the following section of the chapter, I shall interpret the significance of these types as well as compare aspects of each with existing literature, beginning with the Traditional type.

The above discussion about conceptualisations of dementia as normal ageing were strongly reflected in this research within the Traditional type. This type was developed from the analysis of findings derived from the contrasting positions taken by Indian and Caribbean participants with older generations, outside of this research sample in their respective communities. The findings concurred with existing dementia research utilising a socio-cultural perspectives. The commonality between my research and existing research was demonstrated in several ways. Firstly, it included the conceptualisation of dementia as a consequence of normal ageing and the concealment of dementia symptoms to avoid being socially stigmatised as mad (Adebiyi et al., 2016;

Uppal et al., 2014; Lee et al., 2010; Liu et al., 2008).

Secondly, with reference to families being socially stigmatised for help-seeking outside the family and for failing to uphold filial piety. Social stigma associated with help-seeking is well documented in studies conducted with a range of ethnic minority populations on a worldwide basis (All-Party Parliamentary Group on Dementia, 2013; Chee and Levkoff, 2001; Czapka et al., 2020b; Haralambous et al., 2014; Mackenzie, 2006; NÆSS and MOEN, 2015; Nielsen et al., 2011). Thus, drawing attention to the need for research conducted with BAME communities needs to incorporate an exploration of multiple stigmas. These go beyond those associated behavioural symptoms being indicative of madness, and the physical impact of dementia such as incontinence (Narayan et al., 2015) and failing to age well (Liu et al. 2008c).

The Traditional type typifies the cultural approach to understanding help-seeking in BAME communities. In this research it was also conveyed as a cultural approach by Indian and Caribbean participants. The upholding of filial piety remains a motivating factor of caring strategies, as demonstrated by a recent study conducted with older carers of Bangladeshi and Indian participants in the UK (Herat-Gunaratne et al., 2020). This study found family carers discussed that their approach to caring for their family member with dementia was motivated by filial piety (Herat-Gunaratne et al., 2020).

Whilst these accounts are helpful in generating understandings of cultural norms and values, they are de-contextualised accounts, even when presented by participants themselves. As a consequence, they can mask the diversity of understandings and experiences of dementia, including-help seeking, arising out different social locations such as generational age, social class and gender (Hillman and Latimer, 2017b). Moreover, de-contextualised cultural explanations for help-seeking can fail to recognise that culture may also be shaped by communities' responses to structural influences (Gans, 2012). Cultural values may be rooted in historical socio-economic contexts and experiences so, for example, amongst older generations from a range of ethnic minority groups around the world the cultural value of filial piety may not only be a spiritual and religious belief but also a response to *resource-deprived lives* (Dutta and Basu, 2008). This is because it supports, mandates and directs people to address the health of their

families collectively, supported in communal settings in contexts characterised by a lack of access to healthcare and the ability to pay for it (Dutta and Basu, 2008: 566). Therefore, the cultural value of filial piety may have evolved in socio-economic contexts that BAME older generations will have migrated from, to the UK and elsewhere in the Western world (Dutta and Basu, 2008). Given this, it is not surprising to find that filial piety is still considered to be influential in many countries' cultures, particularly in societies where state support for elder care is financially prohibitive or lacking (Levande et al., 2000).

The point being made here, that cultural framings of dementia stress the spiritual and religious elements dimensions of filial piety, omits the historical socio-economic context in which this value was formed and may continue to be upheld as people migrated to Western countries. This research supports the view that structure contains culture in dynamic relations and intersections that are impossible to ontologically parse or disentangle (Krupnick 2012: 650). This has been aptly illustrated with reference to conceptualisations of old age and ageing, in which attitudes and approaches in all focus groups towards ageing has changed generationally in response to a complex interaction of structural changes, the media's influence and socio-political changes. To accept this entanglement helps to avoid reductionist cultural explanations and instead offers more nuanced perspectives for help-seeking in BAME communities and other ethnic groups. This was the rationale for developing the Flexible, Constrained and Individualised Types to explain help-seeking in this research, as they enabled a focus on the complex interplay between cultural values and structural influences, which are dynamic. This interplay is discussed in the following section with particular reference to filial piety.

The Flexible type consisted of both Indian focus group participants (18-30 years, 30-40 years & 40-55 years), and white British participants (18-30 years & 30-40 years) For the Indian participants we see an acknowledgement and commitment to uphold the cultural value of filial piety but it was clearly being adapted in response to external factors and pressures, and for some participants prior knowledge and experience gained from caring for a PWD in the family. One of these external factors was occupational mobility, which entailed younger Indian participants going to live where the jobs are, and accepting this

may entail them living in a different geographical location to their family home, either in this country or abroad. This has led to changes to the family structure so that Indian families traditionally associated with multi-generational households are changing to nuclear family units. These changes to family units were evidenced in a study conducted by Burholt (2004), who noted in her study of settlement patterns and residential patterns that Indian and Punjabi families were more likely to be living in nuclear family structures. These changing family structures clearly impact on the proximity of family carers to be available to provide care to a person with dementia.

Younger Indian focus group participants also expressed their desire to pursue their career aspirations, whilst middle-aged Indian participants within this type stated their need to go out to work. These career and job demands were attributed as creating pressures on participants' ability to balance the demands of their careers/jobs, the needs of their own families and the care needs of older family members with dementia. These conflicting demands are acknowledged in other ethnic groups, such as Native Indian communities in the US (Lanting et al., 2011). These competing pressures were cited as creating an acceptance to seek professional home care support to enable them to respond flexibly to care through the use of professional home carers and care home support for a family member with dementia. The important factor to note here was it was not only motivated by a need to relieve the burden of care but also to gain access to the most appropriate form of care for the PWD. These approaches were acknowledged to be considered as culturally taboo or frowned upon by the wider community. Nevertheless, community judgement did not appear to matter as much to younger focus group members, as they said their ties and affiliation with their communities were weaker through geographical distancing that occurred as a consequence of their university education and post-university careers. Community judgement about their care strategies would not deter them as their priority was what was best for themselves and their families, including the PWD. Their approach suggests that the pressures to conform to Indian cultural expectations about filial piety seem to be narrowed in scope away from communal gaze and towards family interests and priorities. There was a recognition too that values amongst their parents and grandparents had changed, so they preferred to retain their independence and not have their adult

children returning home to live with them. These values in older generations were also found in a study conducted in Goa, India (Patel and Prince, 2001) and suggests these changes to values amongst older generations are trans-global. As consequence, the Flexible type challenges the assumption that seeking care support outside the family is universally subjected to social stigma but that the experience of social stigma can be shaped by generational positioning and a complex range of factors, including availability of care support. Koehn (2016) aptly clarified this issue by arguing, based on findings from a study conducted with multi-ethnic carers and people with dementia in Canada, *that structural factors relating to the availability of family members to care in the midst of conflicting demands may in fact be more important than ethnicity or filial piety in the navigation of care support* (Koehn et al., 2016: 51).

It is challenging to undertake comparisons with the wider literature with regards to filial piety amongst younger generations in BAME communities as it has been acknowledged that there is a paucity of research in the UK regarding its influence in caring more generally within South Asian communities (Harper and Levin, 2005), and much less so with regard to dementia (Hossain and Khan, 2019b). However, from the few reports and studies that have been conducted with Indian communities, their findings concur with some aspects of this study's findings. They confirm that filial piety, whilst recognised, valued and upheld amongst some families, is not a given. This is because a range of intersecting issues, including changing values and family structures, geographical distancing between family members and work pressures for younger generations, have resulted in some people from older generations being unable to rely on care support from younger generations (All-Party Parliamentary Group on Dementia, 2013; Ahmed et al., 2014b; Nijjar, 2012; Seabrooke and Milne, 2004) for dementia. This has led to older people themselves having to adapt their approach to care by accessing professional home carers (Nijjar, 2012). It has to be noted, however, that unlike my research these studies have been conducted with lay older people, carers and people with dementia, and the perspective of lay younger generations such as those in this study is noticeable by its absence and does not take into account their perspectives to the changing socio-economic context they live in.

The Flexible type also included younger white British participants (18-30 years & 30-40

years) and their approach to caregiving was similar to that of Indian participants, in that they took a flexible approach to caring strategies to take account of career demands and to ensure the PWD accessed the most appropriate care. However, whilst they acknowledged cultural influences in shaping care strategies, these were made with reference to past generations in their community. In the present, their willingness to care was not driven by cultural values but by individual and family choices. This finding was reflected in Willis' UK (2008) study on cultural values governing caregiving with multi-ethnic participants consisting of White Irish, White British, South Asian, Mauritian and Black British aged between 60-90 years. Willis' study (2008) found that white British participants did not give cultural explanations such as filial piety for their care strategies but individual choices and motivations. Nevertheless, it does not deny the existence of a culture, which may be based on individual familial cultures and choices that are exercised. These are enabled because of the availability of care home support. This is unlike Caribbean participants in the Constrained type, in which care decisions were predicated on availability of care home provision, enabling that choice to be exercised.

The approach to filial piety and care strategies within the Constrained type, encompassing Caribbean focus group participants and community worker perspectives, highlighted how filial piety expressed in the form of inter-generational care was still strongly valued and upheld. This finding has been well documented in a number of studies conducted with African American and African Caribbean study care participants (Berwald et al., 2016; Clutterbuck and Mahoney, 2003; Jett, 2006; Lawrence et al., 2008). However, the argument that this research advances is how this commitment to care was also formed in response to a range of other structural factors and influences, one of which included a lack of information about where to go for support. This finding is reflective of the experiences and perceptions of African-Caribbean participants in Ahmed's UK study (2014b) conducted with multi-ethnic lay participants in Salford, Manchester. Participants in Ahmed's study (2014b) discussed that information about services available to support people with dementia and carers in their communities were unavailable due to a disconnect between their communities and service providers (Ahmed et al., 2014b).

Another constraining factor identified in this research relates to previous negative experiences, including the experiences of racism experienced by African Caribbean people, in addition to perceptions of being over-medicated in the mental health system. These also shaped the willingness to access formal care support. There was a fear amongst the participants in this research that a family member with dementia might be likely to be over-medicated in care homes too. These constraining influences on the decision to access care have been echoed in a number of studies conducted with African American and African Caribbean participants in the UK and US too (Ahmed et al., 2014c; Baghirathan, et al., 2020; Cheston et al., 2017; Daker-White et al., 2002; Lampley-Dallas et al., 2001; Jett 2006; Mahoney et al., 2005a). How these factors 'play out' is aptly captured by the following US study (Lindauer et al., 2016) conducted with African American caregivers. It is explained how the experience of slavery and racism in the past informed family caregiving rather than seeking care outside of the home: *Way back when...even in the struggles, and slavery, all we had is each other. So that's why we hang on to each other. This caregiver explained that the history of enslavement and oppression shaped these AA caregivers' values. Specifically, the caregivers in our study placed high value on keeping the family together and hanging on to the elder with dementia for as long as possible.*

The final factor that contributed to constraining care strategies in this research included a lack of culturally appropriate professional homecare services and care homes. This finding was echoed in Cheston's (2017) study conducted with multi-ethnic participants in Bristol, UK, and Bangladeshi carers of people with dementia in London, UK (Herat-Gunaratne et al., 2020).

The Individualised type was developed from the perspective of the white British focus group participants (40-55 years) about their own care in the future should they develop dementia. The Individualised type, unlike the Traditional, Flexible and Constrained types, was not based on familial approaches to care underpinned by filial piety. It was driven by individualised approaches to their future care support needs, in recognition that their children and spouse may not be able to provide care due to work or an unwillingness to provide care. Their approach therefore was influenced by the need to

plan for themselves, including financial and care support plans. In the discussions of other types, familial responsibility to care was strongly articulated, but in this type the perception that this could not be relied upon created anxiety and stress about their futures. At the same time, there was a conflict which arose from the aspiration of wanting to be cared for by the family and yet not wanting to be a burden. This approach was echoed in Corner's qualitative study (2004) with lay white British older people, who positioned families as the real victims of dementia because of the burden of providing care. This positioning contrasts with studies conducted with BAME communities in which providing care to a parent or grandparent was perceived to be a way of fulfilling filial piety or a moral obligation that was met in a spirit of reciprocity (Baghirathan et al., 2020; Cheston, et al., 2017; Hossain and Khan, 2019a; Jett 2006, Mahoney et al., 2005b) and not a burden. Cahill's (2009) study involving multi-ethnic older participants, aged 65 years and over in the US, found that viewing oneself as a burden to family was more likely amongst white participants than black participants. This was suggested to be linked to feelings of inequality or loss of *independence* (Cahill et al., 2009: 11). I would argue that the need to avoid being a burden speaks to and is indicative of wider Western societal values, highlighted by Hashmi (2009), which include autonomy, independence and cognition. A diagnosis of dementia may be perceived as assaulting these values and this might explain why white British participants in my research did not want to burden their families. Consequently, in a similar way to white British participants in other studies (Lawrence et al., 2008; Turner et al., 2005), white British participants in this research were prepared to go into a care home to alleviate the burden of care on their families.

The above four types have demonstrated that care approaches in both younger and middle-aged groups cannot be understood through cultural perspectives only but rather through a complex interplay between culture, structural issues and influences which shape responses to diagnosis and care strategies.



## 8.4 Summary

This chapter commenced with a summary of the key findings from an analysis of the ten focus groups and five interviews with community workers. It then went on to a discussion of some of these key findings to highlight the contribution of this research to knowledge in relation to several issues. One of these involves the role of ethnicity as a marker of discrimination, inequitable access and disadvantage in relation to dementia literacy and the availability of culturally appropriate care support for some ethnic minority groups. An important finding relating to information-seeking behaviours of participants suggests that this behaviour prior to diagnosis needs to be the subject of future research to address delayed diagnosis. I have also discussed the implications of the two most commonly found conceptualisations of dementia in this research, namely it being viewed as a mental illness and as a normal consequence of ageing. I have also challenged the view that the conceptualisation of dementia as normal ageing is primarily confined to ethnic minority groups but argued it can be found amongst white British communities too. This research has also drawn attention to the pervasive influence of the media on help-seeking and concepts of ageing, which to the best of my knowledge is the first time it has been undertaken in a multi-ethnic UK study population. However, more research is needed to identify causal relationships on the direct impact of the media on these issues in multi-ethnic communities. The inter-twining of the concepts of ageing and dementia have been explored and I have contributed new knowledge to the literature by drawing attention to how and why individualised responsibility about ageing has emerged, as well as assessed its implications. Finally, a significant contribution to the literature through the formation of a typology has been discussed. This helps to explicate help-seeking approaches within and across ethnic groups, and highlight how help-seeking is shaped and influenced by a complex interaction of dementia literacy, conceptualisations of dementia, media influence and structural issues and factors.

# Chapter 9: Conclusion

## 9.1 Introduction

In the preceding Discussion chapter, I shared my interpretations of the findings from this research, in addition to undertaking comparisons with existing theoretical, empirical and grey literature. As part of this process, I drew attention to some key areas in which this research has made a contribution, or where it has challenged or concurred with existing knowledge.

## 9.2 Overview of the chapter

In this chapter, I shall engage in a discussion of why and how this research has contributed to existing knowledge from a broader perspective. I further highlight the implications of this research for future research, to healthcare commissioners and providers of healthcare services. The limitations of this research are also discussed and how they were addressed or need to be heeded in future research.

I will draw upon the criteria from CONGT (1995) to evaluate the credibility, resonance and originality of this research. This will be followed by my reflections, including the role my positionality played throughout the process of this research. I shall conclude this chapter with an aspiration that future research in the UK promotes a dynamic and intersectional account of dementia understandings and approaches to help-seeking in ethnic communities that is inclusive of the white British lay public.

## 9.3 Contribution to knowledge

This research has challenged cultural reductionist approaches in the existing empirical research by contributing an awareness of a range of factors, other than culture, that act

as facilitators or barriers to understandings and help-seeking approaches to dementia. These include, for example, information-seeking behaviours, exposure to caring and knowledge of dementia in social networks, in addition to the role played by the media in generating understandings of dementia.

I have also contributed to the literature by focusing attention on the other dimension to ethnicity, away from its predominant association with culture so commonly found in empirical studies. This other dimension consists of its role as a marker of discrimination, disadvantage and inequity, that operates on several different levels. Firstly, the inequitable access to culturally appropriate information, particularly for BAME older people. Secondly, how this inequitable access to information may play a role in conceptualisations of dementia as normal ageing and delayed diagnosis amongst BAME older people. Thirdly, by contributing findings that draw attention to inequitable access to culturally appropriate care for some BAME communities and constrained choices of care strategies, as demonstrated by the Constrained type. Lastly, I have also discussed how perceptions and experiences of racism within the mental health system also play a role in reinforcing the need to care for older people at home by the family, amongst Caribbean participants in the Constrained type. Together, these findings contribute more nuanced understandings of approaches to dementia literacy, and highlight approaches to help-seeking that go beyond culture.

To the best of my knowledge, this is the first study conducted in the UK that involves an exploration of the media's influence on understandings and help-seeking approaches in a multi-ethnic study population. As a consequence, I have been able to uniquely demonstrate some positive aspects of the influence of the media through the discussion of films and soap dramas. The latter is hitherto an under-researched area of the media's role. This research has also challenged the view expressed in the theoretical literature about the media shaping stereotypes of ageing (Kirkman, 2006) but at the same time this research does reinforce the idea that people need to treat the ageing process as something that needs to be addressed through anti-medicine products and treatments (Cardona, 2008). I have also contributed new knowledge on how the media may play a role in shaping conceptualisations of dementia as a mental illness and help-seeking

through mental health media campaigns. Again, this is an under-researched area in current empirical research on dementia.

To the best of my knowledge, the contribution of this research with respect to discussions on the concepts of old age and ageing in relation to dementia are unique in empirical research with a multi-ethnic study population. This is because the meanings of these concepts were not taken for granted in my research but interrogated and explicated. As a consequence, this research has been able to show how changes in concepts of old age and ageing, and their framings in relation to dementia, have converged in all the generational groups, irrespective of ethnicity. I have demonstrated how they have overridden pre-existing cultural beliefs about age-associated brain deterioration in Indian communities. Again, in a similar way to help-seeking, these changes can be seen to be derived from a complex interaction of micro-level and macro-level factors and issues, leading to an acceptance that individuals should bear the responsibility for how they age. Moreover, I have been able to empirically substantiate the theoretical discussions about individualised responsibility for ageing (Latimer, 2018) and dementia being perceived as 'failed ageing' including the potential for social stigma that this may ensue (McParland et al., 2016) in a multi-ethnic study population.

It is acknowledged that the types of help-seeking and care strategies were developed from discussions with many participants who have never sought help or cared for a PWD. Thus, discussions from these 'naive' group of participants are theoretical, i.e., what if the need arises for help-seeking and care, and how they propose to address these needs. It was not based on their experiences. Nonetheless, the types developed from these naive participants are a valuable and informative aspect of this research because they highlight key issues that shape and influence help-seeking and care strategies. In doing so, they assist with identifying factors to consider as starting points in research, healthcare and support. These include, firstly, assisting with differentiating help-seeking approaches across generations within ethnic communities, and in doing so helping to avoid homogenising ethnic groups in relation to help-seeking. Secondly, the typology has also contributed to an understanding of the interaction of micro-level and macro-level factors, such as familial choice, cultural values, dementia literacy,

prioritisation of the needs of the PWD, availability of culturally appropriate care, and geographical and occupational mobility. Overall, this typology has created an opportunity to apply these theoretical concepts in future research to assess whether they exhibit a fit, and whether they are likely to have utility for subsequent analysis (McKinney, 1969) to other study populations. They lend themselves to be used for making comparative analyses, and help to avoid making simplistic assumptions about culture. They instead encompass the inclusion of a range of factors and processes (McKinney, 1969) involved in help-seeking approaches that go beyond culture. The following list captures the contribution to knowledge by this research:

- Importance of taking inter-sectional approaches to the design of research to encompass factors such generational age and socio-economic status
  - Highlighted generational changes to attitudes and beliefs to ageing, social stigma about dementia and help-seeking approaches, in particular amongst Indian and Caribbean participants
- Importance of including white British communities in multi-ethnic research to highlight the commonalities of understandings of dementia and approaches to help-seeking. In addition to understanding white British cultures using an inter-sectional approach
- Highlighted the role of and contribution of information-seeking behaviours to help-seeking and how they act as barriers to early diagnosis
- Identified that the majority of all ethnic and generational groups were unaware of the risks posed by chronic health conditions to the development of dementia
- Factors other than culture play a role in facilitating understandings of dementia and include exposure to caring, to dementia in social networks and higher education
- Nuanced understandings of mental illness and normal consequences of ageing
  - Demonstrated that a range of personal and professional factors, as well as understandings of mental illness affect conceptualisations - going beyond culture

- Importance of ethnic representation and diversity in health service education and the media
- Impact of soap dramas on generating understanding of dementia and empathy for the PWD
- Influence of the media on attitudes and beliefs about ageing
- The need to research systemic barriers to dementia literacy
- Clarified meanings of old age and ageing and the framing of these to dementia
- Insights on multi-ethnic generational perspectives that highlight a moral undertone to beliefs about individualised responsibility for ageing
- Types of help-seeking approaches and care strategies provide intersectional understandings of the dynamics between culture and structural influences and issues, including racism.

## **9.4 Implications for future research**

One of the first things that came to my mind when writing this section of the chapter was the phrase ‘can we move it along now’ because there is enough evidence to prove that people, irrespective of ethnicity, conceptualise dementia differently to the bio-medical model. Indeed, studies conducted in the UK (Clare et al., 2006; Quinn et al., 2017), including this research, have shown white British communities also conceptualise dementia differently, as a mental illness and a normal consequence of ageing. In the light of such evidence, it is time to focus research efforts on how we can support all ethnic communities to be equipped to differentiate between normal age-related deterioration and dementia. This will entail addressing gaps in knowledge, such as being able to differentiate between forgetfulness and memory loss and being equipped to identify behavioural and psychological symptoms of dementia. It will also require promoting an awareness of young onset dementia, in addition to addressing the discernible gap in knowledge about chronic health conditions (including lifestyles) as potential risk factors for dementia as well as the difference between Alzheimer’s and dementia. It makes sense for researchers to move the research along to encompass the

design and evaluation of strategies that support people to identify dementia symptoms so they seek early diagnosis. In order to do this, as this research has demonstrated, focus needs to be re-directed to addressing a range of factors, such as information-seeking behaviours prior to diagnosis, systemic barriers to dementia literacy and how the media can facilitate this endeavour. Otherwise, there is a risk that this constant focus on conceptualisations and measuring dementia literacy across minority ethnic groups can lead to research fatigue.

In moving the research agenda along, future avenues of research should consider developing the most effective methods of dissemination of information and knowledge about dementia symptoms across and within all ethnic groups, taking into account factors such as age, health literacy, socio-economic status and language needs.

This research has also highlighted the need to move away from the simplistic association of ethnicity with culture, but to encompass the multidimensionality of ethnicity such as how it operates as a marker for discrimination and disadvantage. This is to ensure the *intersection of structural lines of oppressions/subordination such as sexism, racism, and ageism that affect individual and communities positioning* is explored in relation to dementia (Chaouni et al., 2021: 2). The need to do so is clearly articulated in the Constrained type in which care strategies are not only driven by the cultural value of filial piety but are also a response to experiences and perceptions of racism in mental health systems. Care strategies were also a response to a lack of access to culturally appropriate care. Unless this multi-dimensionality is incorporated in research, it will continue to perpetuate the pathologisation and blaming (Zubair and Norris, 2015) of minority ethnic groups for their cultural failure to seek care outside of the family.

Future research should also interrogate meanings of old age and ageing, and how they are framed in relation to dementia. These issues have been highlighted in the theoretical research (McParland et al., 2016) but more empirical research in multi-ethnic communities in the UK is needed, particularly with regards to their implications for social stigma relating to failed ageing.

The findings of this research also highlight the importance of using ethnicity as a category of differentiation that should be intersected in future qualitative research, for example, with gender/social class/generational age and migration history to promote nuanced understandings of the heterogeneity and diversity of experience and approaches to dementia within and across ethnic groups. This can assist in providing dynamic portrayals of cultural changes, as evidenced in my research, with regards to the upholding of filial piety. Otherwise, reified and static portrayals of culture (Torres, 2015; Zubair and Norris, 2015) that are currently applied on a wholesale basis to minority ethnic groups on the basis of research predominantly conducted with older people will continue to dominate dementia research. These do not take into account the generational diversity within ethnic groups nor the socio-economic status as highlighted by this research.

This multi-ethnic research study involving white British, Indian and Caribbean study participants has highlighted commonalities across all ethnic groups with regards to conceptualisation of dementia as a normal process of ageing, re-defining ageing and help-seeking. More research is needed with multi-ethnic samples to identify commonalities and differences to facilitate nuanced explanations of understandings and approaches to dementia that go beyond essentialist culturalist approaches. However, it should also take on board the point made by Sin (2006) who argued *such comparative research should avoid a perspective which uses White British samples as a yardstick against which other groups are compared as this can lead to pathologisation of non-White groups. Instead, all groups under study should be equally subjected to empirical scrutiny* (Sin, 2006: 223). When this empirical scrutiny was equally undertaken with white British focus groups in my research, I was able to highlight that they too experience challenges and issues with not only delays to diagnosis but also with care. Whilst the causes of these may be different to other ethnic groups, they are nevertheless important to highlight as they have implications for care strategies.

A key message to inform future research is that the influence of the media is vitally important to explore, but with due attention paid to its various formats and their impact on shaping attitudes and beliefs about dementia, towards people with dementia, as well



as with help-seeking. The research on the media within dementia studies is in an embryonic stage of development, and the gap in knowledge about the impact of the various forms of media that cater for BAME communities needs to be the subject of a future research focus. The need for such research is particularly salient with those sections of BAME communities that do not access mainstream media.

Finally, the gap highlighted by this research on information-seeking behaviours of multi-ethnic communities prior to diagnosis, as well as after diagnosis, needs to be addressed by future research. My research has illustrated that it is a complex issue that encompasses a range of factors but merits further exploration to identify enablers and barriers to dementia literacy prior to diagnosis.

## **9.5 Implications for commissioners and providers of health and social care services**

It is recommended that health services and their use of media campaigns must consider dementia information strategies promoting awareness and de-stigmatisation of dementia that respond to and is inclusive of the UK's diverse ethnic communities. The implications of this study's findings echo those made by an Europe's report (2018) which highlighted the needs for all multi-ethnic communities to be provided with culturally appropriate information that caters for different levels of health literacy. In addition, even if understandings of dementia differ to the bio-medical model of dementia, access to support and care should be provided equitably. This research has highlighted strongly held perceptions and experiences that suggest this is clearly not happening at present.

This research has also emphasised the need for health and social care commissioners to address gaps in the provision of culturally appropriate provisions to meet the projected increase in numbers of Indian and Caribbean older people with dementia. The analysis has demonstrated that inequitable access to culturally appropriate professional home carers and care homes played a role in the Caribbean focus group's unwillingness to access formal care support. The consequence of this is that it can create additional pressures on carers, and place them in a position where they have little or no choice but

to care in the absence of such support. It also denies the opportunities for people with dementia from these communities to have access to specialised dementia support. This research has also highlighted the challenge and anxieties faced by participants, particularly white British participants, who may have little or no family support should they develop dementia. It is therefore important to take into account that, irrespective of ethnic group, it should not be assumed that everyone has access to family carers.

A concerning finding in this research was the lack of knowledge about the risks posed by chronic health conditions to the development of dementia amongst the majority of focus group participants. These risks are raised in Indian and Caribbean communities, and healthcare commissioners and providers should be doing more to raise awareness of these factors, particularly in these two communities.

## **9.6 Limitations of this research**

One of the limitations of this research is that it was undertaken with a heterogeneous sample of participants both within and across ethnic and generational groups. This heterogeneity stemmed from some participants having been former family carers and others who had received training in dementia in a professional capacity in previously held job roles. Nevertheless, this heterogeneity served to illuminate factors that may well explain the contributory factors to differential knowledge and understandings amongst the lay public, other than culture. This heterogeneity also helped to ensure that homogenised accounts of ethnicity have not been portrayed, but instead illuminated the impact of professional and educational backgrounds on understandings and approaches to dementia help-seeking. At the same time, it has to be acknowledged that professional and higher educational backgrounds of some of the participants could have been a potential limitation and led to bias in the findings. This is because these backgrounds could have had the potential to adversely affect and limit the engagement of less-educated participants in the focus group discussions. However, I did not observe this in any of the focus groups, including, for example, in the Indian focus group 30-40 years. In this focus group, a participant's professional healthcare background informed her use of medical terms such as 'co-morbidities' during the discussions. However, the

use of medicalised knowledge and terms did not deter interactions within this focus group as all the participants were highly educated and were confident to engage in lively challenging discussions. In other focus groups too, I observed that the participants were confident and willing to challenge and/or seek clarification from other participants. Therefore, in this research the heterogeneity, whilst having the potential to be a limitation, was actually a strength because it enhanced the opportunity to elicit different perspectives from a range of experiences and backgrounds.

Another important aspect to note is that the findings related to the theme of 'dementia on my doorstep' identified the fact that participants were unlikely to seek information until someone had developed dementia in their circle. This may have contributed to their lack of realisation that dementia is a disease. Despite this lack of realisation it was evident that there was an awareness of the social impediments and indignities suffered by a PWD, so much so that some participants expressed a fear of care homes and voiced the preference for assisted suicide.

One of the exclusion criteria for the focus groups was caring for a PWD, so this criteria precluded current exposure to dementia knowledge through caring experiences. Instead, the majority of focus group participants were the lay public who had no prior exposure to dementia knowledge through caring for a PWD. The impact of this exclusion criteria is that it limits the generalisability of this research study's findings.

Both the Caribbean and Indian participants in Leicester were drawn from communities that span four to five generations of living in Leicester. Many of the Indian focus group participants were born and educated in this country, and some had received a British education curriculum in colonised African countries. There were a number of participants who, by virtue of the university education in this country, held professional managerial and healthcare roles. Hence this research has indicated a further inter-sectioning characteristic that was influential in participants' care strategies, which was social class. As a consequence, these findings may not be generalisable to other South Asian sub-groups that are characterised by younger ethnic group age profiles, differences in migration history, socio-economic positioning and non-English speaking communities. The ability to generalise these findings may also be limited on the basis of

geographical location of other South Asian communities in the UK. Some of these communities elsewhere in the UK may have little or limited access to culturally appropriate care, unlike in Leicester, which due to the size of its South Asian population has access to a choice of culturally care-appropriate professional home carers and care home support. Such provision may not exist elsewhere in the country where there are smaller numbers of South Asian communities, so care strategies maybe constrained.

A smaller number of people took part in the Caribbean focus groups, so the same breadth of perspectives I was able to access in the white British and Indian focus groups was not possible in the Caribbean focus groups. Nonetheless, the smaller number of participants in the Caribbean focus groups enabled more in-depth discussions to take place. Similarly, there was a paucity of male participants across and within all focus groups, and possibly gendered issues and approaches to care may have been omitted in the focus group discussions. Despite these limitations, this research has contributed to addressing the paucity of research with Caribbean communities and shown the diversity of understandings and experiences generationally in this community, including changing attitudes and beliefs about mental illness.

The social constructionist approach to the process of conducting focus groups entailed discussions that were less guided and directed, particularly with the older focus groups by participants because of their positive rapport with each other. The limitation to this approach is that it challenges consistent and uniform discussions of topics across all the focus groups. What also complicated matters was the fact that I wanted to ensure I balanced the goals of my research with those of the participants' interests. I therefore decided to iteratively explore only a few issues, such as the influence of the media, concepts of old age and ageing, and differences in generational approaches to the acquisition of information and knowledge with all focus groups. Nevertheless, these in-depth explorations have illuminated new avenues for future research. In particular, the meanings of old age and ageing and the positive influence of the media, particularly with regards to creating empathy for the PWD.

## **9.7 Ensuring credibility, resonance and originality**

### **9.7.1 Credibility**

Charmaz (2008) advocated evaluating credibility with reference to a set of criteria that pertain to the rigour and robustness of the analysis process. This has been attended to in this research, firstly by clearly articulating how the research questions were developed from the literature review and my positionality as a second generation migrant.

Secondly, I have explicated the analysis process for both the thematic and typological analysis to illustrate how it was grounded in the data. An example of the logical link between the gathered data, my argument and analysis (Charmaz 2008: 337), is demonstrated in the iterative exploration of 'age is just a number'. The typological analysis too involved clarification and transparency about how the types initially emerged through an inductive process of analysis. This was subsequently followed by a deductive process of analysis to assess fit for the typological analysis I proposed and subsequently fully developed.

Charmaz (2008) also asked whether the data is sufficient to make the claims I have made in this research. This was addressed by the iterative and concurrent data collection process between focus groups and community workers that promoted the gathering of rich and dense data. This enabled me to not only identify how and where factors such as ethnicity and generational age made a difference, but also, from the copious amount of data, make robust claims about how other factors such as exposure to caring and the role of the media influenced understandings of dementia.

Charmaz (2008) advocated probing whether grounded theory makes sense to the study participants or people that share similar circumstances. This was one of the more challenging aspects of this research as I was unable to return to the focus group participants to clarify and check my interpretation of the findings. Nevertheless, I was able to utilise the community worker interviews, for example, to explore changes to cultural values such as filial piety, help-seeking amongst younger Indian people and individual family choices to care. The interviews with the community enabled me to

establish whether the findings that emerged from the focus groups reflected the experiences of community workers who work in the communities from which the study population was drawn from.

### **9.7.2 Resonance**

Charmaz (2008) also drew attention to the assessment of resonance, which involves drawing a link between institutions and individuals, and assessing when they are indicated. These links were identified in many ways in this research, for example, how a lack of culturally appropriate professional care service and homes, perceptions of institutional racism constrained the ability of Caribbean participants to make safe choices about care in congruence with their values and needs. In addition, I have demonstrated perceptions of how the media and health services fail to connect and address inclusivity of ethnic diversity in their dissemination of dementia information and knowledge.

### **9.7.3 Originality**

Finally, Charmaz (2008) also included 'originality of contribution' as a key factor in social constructionist grounded theory. This is highly relevant to a PhD research project in relation to whether it offers new insights or extends existing knowledge (Charmaz 2006). To the best of my knowledge, this research is unique in the UK, intersecting ethnicity with generational age using life stages, to select three ethnic communities. Consequently, it has highlighted commonalities in conceptualisations and understandings of dementia and ageing across and within ethnic and generational groups. It has also introduced fresh insights by demonstrating how exposure to the media and Internet technology influences understandings of dementia and approaches to caring. So much so, that assumptions about the pervasiveness of social stigma as a barrier to help-seeking are challenged. In particular, in relation to help-seeking and filial piety amongst younger Indian generations, this research has uniquely identified that both younger generations and middle-aged participants, because of their increased knowledge and experience of dementia, are also likely to prioritise the needs of the PWD as dementia progresses, rather than being constrained by community judgement

of their actions to seek professional care.

The typological approach derived from the findings on help-seeking represents a unique approach to generate an understanding of the interaction of culture and structural influences to help-seeking and care strategies. Furthermore, to the best of my knowledge this is the first time in the UK that help-seeking for dementia has been researched with a younger lay public from three ethnic communities.

By not taking for granted the meanings of old age and ageing articulated in conceptualisations of dementia during the process of data collection and analysis, I have explicated and interrogated meanings of old age and ageing. By doing this I have provided an insight into how these concepts are framed in relation to dementia in a multi-ethnic younger and middle-aged adult population. To the best of my knowledge, this presents a unique approach to the exploration of understandings of dementia and ageing in a generational multi-ethnic sample of participants in the UK.

#### **9.7.4 Reflexivity**

In this section, I highlight my reflections on some key aspects of the research process, and these are organised under sub-headings.

The researcher's positionality within CONGT (2008) performs an integral role, as its subjective epistemology emphasises that neither the participants nor the researcher come to the research as a 'tabular rasa' (Mills et al., 2006). Both have values, knowledge, and preconceptions about what constitutes reality. In addition, their professional roles, the researcher's social characteristics such as age, gender, and ethnicity, as well as social roles, confer perspectives and assumptions about the world and actions in relation to them. Therefore, argued Charmaz (2008), it behoves researchers to be *reflexive about the issues that they bring to the research, to be essentially upfront about what we do and how we see it* (Charmaz 2008: 27).

##### **9.7.4.1 Starting the research journey through a kaleidoscope of identities and lenses**

My research journey commenced as an academically naive student of dementia but I did bring to the research over 30 years of professional experience of working within BAME

communities in various professional capacities. One of the most pertinent to this research was my previous role as a qualitative researcher in applied health research.

On a personal level, I possess many identities which offered unique vantage points which served to inform and help me during my PhD journey. These multiple and intersecting identities, with their concomitant experiences, include being a second generation migrant from East Africa, a bi-cultural middle aged Indian woman, a mother to two young adult sons, and a carer for two elderly parents. Charmaz's (2008) version of grounded theory does not deny these identities and experiences, instead it acknowledges and recognises their presence and the impact they have on the research process. Nonetheless, for me, this process of recognising and acknowledging their impact was gradual, not an overt process, but with the passage of time these identities began to shape and inform a 'kaleidoscope' (Chacko, 2004) of lenses, which continue to illuminate and inspire my research journey.

From the vantage point of a second generation middle-aged woman, I could readily grasp and relate to some of the cultural conceptualisations of dementia, filial piety and ageing. The majority of which are conveyed in studies conducted with older participants from a range of different ethnicities, including those with dementia, carers and older people living in the community.

At the same time, as a woman 'sandwiched' between two generations, I have borne witness to and experienced many dynamic changes to cultural values and norms within the Indian Hindu-Gujarati community. These have occurred on a range of issues such as inter-caste and mixed-race marriages. As well as changes to the different ways in which filial piety is upheld or not upheld due to changing values, changes to family structures, geographical and occupational mobility; my own family members live outside and around the UK.

#### **9.7.4.2 Rueful reflections on the approach to reviewing the literature**

When the initial exploration and review of literature was undertaken for institutional requirements and to identify the research questions, I was daunted by my inexperience and lack of knowledge about dementia. Yet, at the same time there was a certain



amount of excitement about undertaking this PhD with 'a blank slate', without being 'sullied' by prior research experience in this area of research. The process of scrutinising the literature inevitably entailed the use of a kaleidoscope of lenses from my personal and professional past lives, and these were pushed to the forefront and highlighted the need for me to pursue this research from a generational perspective.

However, it soon became apparent at quite an advanced stage of this PhD that there were disadvantages to using a grounded theory approach (Charmaz, 2008) to the literature review. This is because it advocates a cautious use of the literature prior to data collection. This was counter productive as the empirical and grey literature treated concepts such as culture, ageing, ethnicity and dementia unproblematically. It was only after the data analysis phase was completed that I accessed the theoretical literature and found it had dissected and critiqued all these concepts. Consequently, my assumptions about the bio-medical diagnostic and conceptual category of dementia were challenged. Whilst these critical perspectives helped with my Discussion chapter, it would have been helpful to access these at the beginning of the research in the design of my study. If I had read and understood these at the commencement of my PhD journey, I would have undertaken interviews with dementia healthcare providers and commissioners to explore with them issues such as health system barriers to addressing dementia in a multi-ethnic city such as Leicester. I also would have explored lay participants' views and perceptions of dementia on how and why they label health conditions such as dementia. I would have undertaken a more critical and in-depth exploration of the role of the media about its contribution to understandings of dementia and old age than I was able to do in this research. Finally, attitudes about screening for dementia would have been interesting to explore with all the focus groups.

#### **9.7.4.3 Data collection process**

During the process of data collection I managed and reflected on my identity as an 'insider' researcher with the Indian focus groups. This status was recognised by a focus group (Indian focus group 40-55 years) to the extent that they started communicating with me in Gujarati during the discussions. It assisted with engaging effectively with this group, as I recognised that some of the participants felt more comfortable conversing in Gujarati

than in English, although all were fluent in both languages. My insider status also alerted me to differentiate between the Pilot Indian focus group (40-55 years) and the Indian focus group (40-55 years) in relation to their migratory history and how it might affect their perspectives. An outsider to this ethnic group may not have been able to understand this difference and consequently may not have retained the data from the Pilot Indian focus group (40-55 years) for the full analysis.

I was aware, though, when I conducted the focus group with the white British groups that I would be an 'outsider' on many counts, not just because of my ethnicity but also because of my educational background and gender. I addressed this at the start of the focus groups by briefly discussing my professional background, including being a mature student. During the break, I spoke about my family and where I live, and this sharing of commonalities of experience at a human level helped with rapport and engagement during subsequent discussions. This included, for example, a lengthy discussion after the break about what it meant to live in Braunstone, the pride and prejudice participants experienced and felt. It also led to some very honest discussions about ethnicity and the changing demographic profile of Braunstone by the participants. This experience enabled me to feel comfortable about disclosing my professional and personal background, such as during conversations within the short refreshment breaks. I found that by doing so, I was reciprocating the openness of dialogue with which participants contributed to the discussions. It resulted in a much more balanced approach to the focus group discussions than if I had adopted a dispassionate stance of a privileged researcher (Chacko, 2004). It is this spirit of reciprocity and mutuality of benefit that assisted with developing rapport during the discussions, so much so that two of the community workers relayed to me that participants had spoken to them about how they enjoyed taking part in the focus group and that they had learnt so much. I realise that this learning and enjoyment was a consequence of the group interaction as much as the information they received from me. As a researcher that left me feeling that the process of data collection was not a process of me 'taking' but a balanced interaction: one which fostered the empowerment of individuals during the research process and has been at the heart of my previous diabetes research for over a decade.

#### **9.7.4.4 Making sense of the data and concepts**

The data analysis process was fraught and complex simply due to the rich amount of data I had to process. It took three stages of analysis to interrogate the data. I continually challenged myself about why my findings were different in so many respects to the existing empirical literature. It was only after the data analysis process and reading, examining the critiques of ethnicity as a category of differentiation and ageing that I felt confident that I had new insights to contribute. As a consequence of undertaking this PhD, I have radically transformed the way I interpret categories of differentiation such as ethnicity and old age, including the diagnostic and conceptual category of dementia. This PhD journey was an illuminating journey because I was able to critically assess the bio-medical model of dementia through sociological and anthropological perspectives.

### **9.8 Conclusion**

In this research I have, through the theoretical literature, highlighted that the bio-medical concept and diagnostic category of dementia as an organic brain disease is contested. In order to provide a balanced discussion about the diagnostic category of dementia I have provided insights about the complexity of the diagnosis process and addressed some of the critiques expressed about dementia within the theoretical literature. The literature explores ethnic minority group concepts and understandings of dementia, with a view to determining how and why these understandings diverge from bio-medical understandings of dementia. In doing so, it has a tendency to pathologise ethnic minorities' perspectives of age-related brain deterioration by generally attributing differences in understandings and concepts of dementia to culture. My research has challenged these cultural reductionist approaches within the wider research by intersecting ethnicity with generational perspectives, including those of the white British participants, to offer more nuanced understandings. As a consequence, the outcomes of this research will contribute to a gap in qualitative empirical research with regards to multi-ethnic generational perspectives. These can assist in producing dynamic and nuanced accounts of lay public perspectives that reflect the diversity of experiences within ethnic groups as well as across ethnic groups. I have been able to identify a

range of factors implicated in understandings of dementia, such as exposure to caring, hearing about dementia through social networks, the media and the participants' own information-seeking behaviours. I have also highlighted the pervasive influence of the media, not only with respect to its informational role but in shaping concepts of ageing and dementia, as well as help-seeking.

I have not negated the influence of culture in help-seeking but instead have drawn attention to micro/macro influences that interact with cultural beliefs and values such as filial piety. Thus, highlighting how culture cannot be considered in isolation but has to be contextualised generationally and by socio-economic status to reflect the diversity of help-seeking approaches within and across ethnic groups. This research has illustrated this complex relationship and interaction between structure and cultural values with respect to help-seeking approaches through a typological analysis. The four types have been developed to reflect this interaction and relationship, and also demonstrate that more sophisticated approaches to understanding help-seeking are required. There is potential for this typology to be tested and further developed to offer more nuanced understandings of help-seeking in future research for different ethnic groups.

Finally, the exploration of concepts of ageing, old age and their relationship to dementia presents a unique insight of how micro and macro influences, including the media, challenged conventional understandings of frailty in old age as an expected outcome of chronological ageing. Instead I have shown that ageing is viewed as a continuum with dementia and other illnesses expected to occur towards the end of life. I have also uniquely demonstrated that the advocacy of individualised responsibility for ageing well emotionally, mentally and physically is shared across generational and ethnic groups. The fresh insights generated by this research offer an exciting opportunity to explore understandings and approaches to dementia, ageing and help-seeking that go beyond culturally deterministic approaches in future research. Also, this research strongly suggests that future research needs to be inclusive of multi-ethnic perspectives, including those of white British communities, to highlight commonalities as well as differences.

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# Appendix A: Search strategy for literature review

## A.1 Methods

### A.1.1 Information sources and search strategy for empirical studies (peer reviewed studies)

From February 2016 to September 2016, a systematic search of eight databases was undertaken. These included Academic Search Science Premier, CINAHL Plus with Full Text, Medline, Science Direct, CPA/Age Info, Web of Science, Scopus and Pub Med. Assistance was sought from the Faculty librarian for the initial searches.

### A.1.2 The following search terms were used

Concepts\* AND Dementia or Alzheimer's AND Dementia Diagnosis, Concepts\* AND (Dementia or Alzheimer's) AND (ethnicity, race or culture), Attitudes or perceptions or opinions or thoughts or feelings or beliefs AND (Dementia or Alzheimer's) AND (ethnicity, race or culture), Cultural construction AND ethnicity, race or culture, Concept\* AND ethnicity or race or culture OR multi-ethnic OR black and minority OR BME AND Dementia or Alzheimer's, Conceptualisation OR attitude\* OR perception\* OR opinion\* OR belief AND (Dementia or Alzheimer's) OR Lewy Bodies OR Korsakoff syndrome or vascular dementia, Ethnicity and dementia, Conceptualisation of dementia by ethnicity, multi-ethnic and black and minority.

The search terms 'concept' or 'conceptualisation' yielded very few papers and many of those retrieved pertained to the clinical dimensions of dementia as well as conceptual papers about theoretical approaches to dementia. In the light of this, the search terms were broadened to include knowledge, beliefs, opinions and attitudes. To retrieve papers relating to black and minority ethnic groups as well as white European, white American and white British, the term multi-ethnic was used. The search was conducted for papers from 2000 to 2016, with 'alerts' set up on several databases, and having subscribed to Mendeley, alerts to relevant articles in the area of interest were also sourced periodically.

These alerts continued to be used until the completion of this thesis to ensure I received



notification of newly published studies until March 2021.

### **A.1.3 Process for selection of papers to review**

The purpose of this review was to include studies pertaining to conceptualisations of dementia in multi-ethnic communities. The eligibility criteria for screening of peer reviewed studies pertaining to conceptualisations of dementia, knowledge and understanding, and help seeking is discussed below.

### **A.1.4 Inclusion criteria**

Peer reviewed publications of studies written in English from 2000 to 2020. This time period was selected as both international and national UK policies were addressing the issue of dementia in relation to raising awareness of the condition, issuing updated diagnostic guidance and tackling stigma about the condition. In this respect, the restriction of the time period can facilitate an understanding of the impact of these on conceptualisations of dementia. The criteria were as follows:

- Quantitative/ Qualitative studies
- English language
- Worldwide
- Between 2000-2020

### **A.1.5 Exclusion criteria**

Papers relating to discussions about the clinical management of dementia were excluded. Any review articles and opinion pieces not providing any primary data were also excluded but sourced for references to peer reviewed empirical studies. Books on dementia were excluded as were conference papers, commentaries and dissertations until the second stage of the literature review. The criteria were as follows:

- Not in English
- Over 16 years old
- Before 2000

### **A.1.6 Screening papers**

The process of screening involved reading abstracts, and in some instances when the abstracts did not provide enough detail for screening, full texts were reviewed for their eligibility. All retrieved papers screened deemed as eligible for inclusion were saved in RefWorks, the bibliography and database manager.

### **A.1.7 Other sources**

To take an inclusionary approach to the literature and to address the paucity of qualitative research conducted with BAME groups in the UK in particular, grey literature in the form of research reports were also retrieved by undertaking a google search, using search terms such as ethnicity, beliefs and dementia.

## **A.2 Conceptual and theoretical papers**

The search strategy for peer reviewed journal articles did yield theoretical papers which were sourced but were not reviewed alongside the empirical peer reviewed studies between February 2016 to September 2016. Instead they were downloaded into NVivo software programme and descriptively analysed after data analysis was completed in September 2020.

# Appendix B: Table of studies

Table B.1: Table of studies

| Title  | Author/s  | Year of Publication | Country | Study design                  | Total sample size (n=), study population and age (yrs).   | Recruitment strategies/ Study Setting   | Ethnicity of participants                          |
|--|---|---------------------|---------|-------------------------------|---|---|--|
| Awareness and understanding of dementia in African/Caribbean and South Asian families  | Adamson   | 2001                | UK      | Qualitative                   | n=30<br>Carers:<br>ages ≤ 40 years,<br>>40 years  | Carer support services, day centres, community psychiatric nurses and general practitioners | African Caribbean, South Asians                    |
| Enacted and implied stigma for dementia in a community in south-west Nigeria   | Adebisi, Fagbola, Olakehinde, Ogunniyi            | 2016                | Nigeria | Qualitative & Cross-sectional | n=20<br>Total sample for qualitative study: 48<br>Lay public: ages 20–39, 40–59, >60                            | Recruited from community setting  | Nigerian   |
| Prevalence of dementia in African–Caribbean compared with UK-born White older people: two-stage cross-sectional study  | Adelman   | 2011                | UK      | Cross-sectional               | White UK born n= 218<br>African-Caribbean n=218<br><br>Lay public: ages >60                                     | Recruited from community settings or in 24-hour residential care                            | African-Caribbean white British                    |
| Promoting diversity and inclusiveness in dementia services in Salford  | Ahmed, Yates-Bolton, Collier                      | 2014                | UK      | Qualitative                   | n=47<br>Community participants and stakeholders<br>No age stated  | Recruited from community settings   | Diverse BAME communities                           |
| House of Commons All Party Parliamentary Group on Dementia   | All Party Parliamentary Group                     | 2013                | UK      | Qualitative                   | n= not stated<br>Community participants and stakeholders<br>No age stated                                       | Oral evidence sessions and community settings   | Irish, Indian, Pakistani, Black Caribbean, Chinese |
| Frankly, None of Us Know What Dementia Is: Dementia Caregiving Among Iranian Immigrants Living in Sweden   | Antelius and Kiwi                                 | 2015                | Sweden  | Qualitative                   | n= 66<br>Residential care home residents, PWD, family and professional carers<br>No age stated                  | Residential care facility, family homes and home help care service                          | Arabic, Persian, Kurdish, Russian                  |
| Knowledge of Alzheimer's disease in four ethnic groups of older adults   | Ayalon and Arian                                  | 2004                | USA     | Quantitative                  | n=193<br>Patients of primary care clinic: aged >60  | Primary care clinics  | Anglo-Americans, African-Americans, Asian, Latino  |
| Re-examining ethnic differences in concerns, knowledge, and beliefs about Alzheimer's disease: results from a national sample  | Ayalon  | 2013                | USA     | Quantitative                  | n= 1230<br>Representative national sample of US residents over the age of 50 years and their spouse of any age. | The study is based on the 2010 wave of the Health and Retirement Study                      | White, Latino, Black                               |
| A grounded theory analysis of the experiences of carers for people living with dementia from three BME communities: balancing the need for support against fears of being diminished | Baghirathan, Cheston, Hui, Chacon, Shears, Currie | 2020                | UK      | Qualitative                   | n=102<br>Carers, Community workers & volunteers<br>age not stated.  | Recruited from community organisations  | African-Caribbean, Chinese, South Asian            |

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| Assessing accuracy of knowledge of cognitive effects of normal ageing and mild stage of Alzheimer's disease                     | Bettens, Ownsworth, Hohaus, McKendry              | 2013 | Australia | Combination of dementia knowledge scales used in survey  | General community, n=251<br>Aged care professionals, n= 59<br><br>Community sample: aged 18-69<br>Aged care professional: aged 23-65                         | Recruited through: email, clinic, conference              | None stated  |
| 'They don't quite fit the way we organise our services' —results from a UK field study of marginalised groups and dementia care | Beattie, Daker-White, Gilliard, Means             | 2005 | UK        | Qualitative  | n= 61<br>Rural/urban:Service Managers, care staff in care homes, nursing homes, social services, specialist dementia services<br>No age stated               | In service and provider settings                          | Black and minority ethnic  |
| Perceptions of dementia in ethnic communities   | Berisic, Nesvadba                                 | 2008 | Australia | Qualitative, questionnaires                              | n= not stated<br>Lay public, Ethno-specific agencies: Greek, Russian, Vietnamese<br>No age stated  | Recruited from community settings                         | Arabic, Croatian, Chinese, Greek, Italian, Macedonian, Polish, Russian, Spanish, Serbian, Turkish and Vietnamese |
| Black African and Caribbean British Communities' Perceptions of Memory Problems: "We Don't Do Dementia"                         | Berwald, Roche, Adelman, Mukadam, Livingston      | 2016 | UK        | Qualitative  | n= 50<br>Community groups members aged >18   | Community setting   | Black African and British Caribbean  |
| Alzheimer's disease and related neurological disorders: stigma in developing countries  | Bhandari, Joshi                                   | 2010 | Nepal     | Questionnaire  | n=159<br>PWD, caregivers, in rural urban settings<br>No age stated   | Primary care  | Indian   |
| Inequalities in dementia care across Europe: key findings of the Facing Dementia Survey   | Bond, Stave, Sganga, Vincenzino, Connell, Stanley | 2005 | Europe    | Quantitative   | n= 2500<br>caregivers, lay public, physicians, people with Alzheimer's, influencers of health policy   | Recruited by Millward Brown                               | France, Germany, Italy, Poland, Spain, UK  |
| Being at risk of dementia: Fears and anxieties of older adults  | Corner, Bond                                      | 2004 | UK        | Qualitative  | n=15<br>Local day center users: aged 62-93   | Local day centres   | White  |
| Dementia and relationships: experiences of partners in minority ethnic communities  | Botsford, Clarke, Gibb                            | 2011 | UK        | Qualitative  | n=43<br>Partners of PWD: age: mid 60s - late 80s   | Recruited through Mental Health Services for Older People | Greek-Cypriot, African-Caribbean   |
| 'We didn't know it would get that bad': South Asian experiences of dementia and the service response                            | Bowes, Wilkinson                                  | 2003 | Scotland  | Qualitative  | Healthcare Professionals n=11,<br>No details about sample size for PWD, families and carers of PWD<br><br>Healthcare Profs., PWD, families and carers of PWD | Recruited through healthcare services, community groups   | South Asian  |
| Appropriation and Dementia in India   | Brijanth, Manderson                               | 2011 | India     | Critical ethnography: interviews participant observation | n= 20<br>Family caregivers mean age: 52.65<br>Service providers  | Recruited from clinics                                    | Indian   |
| To what extent does diagnosis matter? Dementia diagnosis, trouble interpretation and caregiving network dynamics                | Brossard, Carpentier                              | 2016 | Canada    | Survey, Qualitative                                      | n=60<br>Caregivers of PWD>65   | Recruited from clinics                                    | Francophone, Anglophone, Migrants  |

|   |  |      |                   |  |   |  |   |
|---|--|------|-------------------|--|---|--|---|
| Demographic and Contextual Factors Related to Knowledge About Alzheimer's Disease   | Carpenter, Zoller, Balsis, Otilingham, Gatz                      | 2011 | USA               | Quantitative: Alzheimer's Disease Knowledge Scale (ADKS) | n=794<br>Adults: w/out cognitive impairment, involved in dementia research, senior center staff, carers of people with Alzheimer's Disease, undergraduate students: aged 18 - 93                        | Recruited from Social service agencies, healthcare facilities, research centres, universities                          | Asian/Pacific Islander, Black, Native American, White, Multiracial/ other |
| Culture and dementia: Accounts by family caregivers and health professionals for dementia-affected elders in South Korea  | Chee, Levkoff  | 2001 | South Korea       | Qualitative  | n= 15<br>Caregivers, researchers, service providers: ages 32 - 58   | Recruited from Health and Social care, Association for Family Caring for the Demented, Elderly Persons in Seoul, Korea | Korean  |
| The effects of exposure to scenarios about dementia on stigma and attitudes toward dementia care in a Chinese community   | Cheng, Lam, Chan, Law, Fung, Chan, Tam, Chan                     | 2011 | Hong Kong         | Quantitative   | n=494<br>Lay public: aged 55-58   | Recruited from Colleges, vocational training centres, community centres, social and health centres for older people    | Hong Kong-Chinese   |
| Managing threats to self: awareness in early stage Alzheimer's disease  | Clare  | 2003 | UK                | Qualitative  | n=12<br>PWD: ages 57 - 83   | Recruited from Memory clinic, Clinical Psychology team, Alzheimer's Society  | White-European  |
| Illness representations in early-stage dementia: a preliminary investigation  | Clare, Goater, Woods   | 2006 | UK                | Qualitative  | n= 22<br>PWD: ages 57 - 87  | Recruited from 2 urban/rural memory clinics  | White-European  |
| Impediments to Timely Diagnosis of Alzheimer's Disease in African Americans   | Clark, Kutner, Goldstein, Peterson-Hazen, Garner, Zhang, Bowles, | 2005 | USA               | Qualitative & Quantitative                               | n=79<br>People with Alzheimer's Disease and caregivers mean age: 75   | Recruited from Urban/suburban Memory Clinics   | African-American  |
| African American dementia caregivers  | Cloutterbuck, Mahoney  | 2003 | USA               | Qualitative  | n= 7<br>Caregivers: ages 53 - 71  | Alzheimer's Association African American Support Group   | African-American  |
| Screening for Dementia: First Signs and Symptoms Reported by Family Caregivers  | Concoran   | 2009 | USA               | Qualitative  | n= 68<br>Caregivers no age stated   | Recruited from community settings  | White, Black  |
| "It is always me against the Norwegian system." barriers and facilitators in accessing and using dementia care by minority ethnic groups in Norway: a qualitative study | Czapaka, Sagbakken   | 2020 | Norway            | Qualitative  | No details of sample not provided to protect anonymity<br><br>Ethnic minority family members of PWD, representatives of immigrant communities, representatives of healthcare personnel working with PWD | Healthcare professionals, from primary and secondary care, community health centres                                    | Somalis, Pakistanis, Turks, Polish  |
| Family Caregiver's Perception of Alzheimer's Disease and Caregiving in Chinese Culture  | Dai, Mao, Wu, Mei, Levkoff, Wang                                 | 2015 | China             | Qualitative  | n=21<br>Family carers of people with Alzheimer's Disease and mild cognitive impairment: ages 54-85  | Memory clinics   | Chinese   |
| Public attitudes and knowledge of dementia: Northern Ireland, Republic of Ireland and Scotland  | Devine   | 2016 | NI, ROI, Scotland | Surveys conducted face to face                           | n=: 10,240<br>Lay public: ages >18 in NI, Scotland and ages >15 in Republic of Ireland  | Recruited from community settings  | Northern Irish, Irish, Scottish   |
| Understanding dementia amongst people in minority ethnic and cultural groups  | Fontaine   | 2007 | UK                | Qualitative  | n=49<br>Lay public: 17-60   | Recruited from cultural centres, arts and leisure centres, Gurdwaras', women's groups, colleges                        | Indian or Indian origin,  |

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|---|--|------|-----------|--|--|--|--|
| The Pathway to Diagnosis of Dementia for Francophones Living in a Minority Situation  | Garcia, McCleary, Emerson, Leopoldoff, Dalziel, Drummond, Cohen, Koehn, Silvius                | 2013 | Canada    | Qualitative  | n= 14<br>PWD/Alzheimer's Disease patients and carers: ages >60   | Recruited from Memory Disorder Clinic  | Francophones   |
| Making sense of dementia: understanding amongst Indigenous Australians  | Garvey   | 2010 | Australia | Cross-sectional survey using modified ADKS                 | n=174<br>Lay public: >18   | Recruited from Indigenous festival   | Indigenous Australians   |
| Learning from Recruitment Challenges: Barriers to Diagnosis, Treatment, and Research Participation for Latinos with Symptoms of Alzheimer's Disease | Gelman   | 2010 | USA       | Qualitative  | n=29<br>Carers of PWD and Alzheimer's Disease  | Recruited from study promotion flyers  | Latino: Puerto Rico, Dom. Republic, Sth. America, Mexico, Cuba                         |
| Ethnic Differences in Beliefs Regarding Alzheimer Disease Among Dementia Family Caregivers  | Gray, Jimenez, Cucciare, Tong, Gallagher-Thompson  | 2009 | USA       | Quantitative   | n=215<br>Carers of people with Alzheimer's Disease: aged <21   | Recruited by healthcare professionals, self-referrals (mainly whites)  | White, Hispanic, Chinese-American  |
| Cognitive impairment in the U.S.: Lifetime risk, age at onset, and years impaired   | Hale, Schneider, Mehta, Myrskylä   | 2020 | USA       | Quantitative   | n= 29, 304<br>Lay people who participate in the two waves of the Retirement Study who had a cognition score or proxy score | Utilised findings from 16 yr Health and Retirement Study: aged>50  | Non-Hispanic-White, African-American/ Black Hispanic, Non-Black Hispanic, and "Other." |
| Help seeking in older Asian people with dementia in Melbourne: Using the Cultural Exchange Model to explore barriers and enablers                   | Haralambous, Dow, Tinney, Lin, Blackberry, Rayner, Lee, Vrantisidis, Lautenschlager, LoGiudice | 2014 | Australia | Qualitative  | n= 39<br>Carers: aged >39<br>Healthcare professionals, community workers   | Carers recruited from Dementia clinics, Aged Care Assessment Services, Community Workers recruited from informal contacts & service provider organisations | Chinese, Vietnamese  |
| Cultural construction of disease: A "supernormal" construct of dementia in an American Indian tribe   | Henderson, Henderson   | 2002 | USA       | Qualitative  | One Case Study with PWD  | Recruited from community settings  | Native American  |
| Conceptions of Dementia in a Multiethnic Sample of Family Caregivers  | Hinton, Franz, Yeo, Levkoff  | 2005 | USA       | Data from two qualitative studies conducted from 1994-1997 | n= 92<br>Family carers for PWD >55   | Convenience sample from Primary care, home health program, caregiver support groups, adult day centres, nursing homes                                      | African-American, Anglo-European-American, Asian-American, Latino                      |
| African American caregivers   | Hughes, Tyler, Danner, Carter  | 2009 | USA       | Qualitative  | n=17<br>Family carers for people with Alzheimer's Disease: ages 42 - 80  | Recruited from African-American Outreach Partnership   | African-American   |
| Knowledge of Alzheimer's Disease, Feelings of Shame, and Awareness of Services Among Korean American Elders   | Jang, Kim, Chiriboga   | 2010 | USA       | Quantitative   | n= 675<br>Lay public: aged >60   | Recruited from: Korean churches, other religious groups, senior centres, senior housing, and elder associations  | Korean-American  |
| Mind-loss in the African American community: Dementia as a normal part of ageing  | Jett   | 2005 | USA       | Qualitative  | n= 14<br>Lay persons connected to PWD but not carers aged 45-84  | Recruited from community settings  | African-American   |

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|--|--|------|-----------|-------------|---|---|--|
| The 'Twice a Child' projects: learning about dementia and related disorders within the black and minority ethnic population of an English city and improving relevant services | Jolley, Moreland, Read, Kaur, Jutla, Clark   | 2009 | UK        | Qualitative | n=38<br>Community representatives, carers, health and social service managers   | Recruited from community settings   | African-Caribbean, Asian   |
| Asian Americans and Alzheimer's disease: Assimilation, culture, and beliefs  | Jones, Chow, Gatz  | 2006 | USA       | Qualitative | n=62<br>Lay participants of 1st & 2nd generations ages 23 - 82  | Lay participants from contacts of medical students focus group leaders, community organisations             | Japanese-American, Korean-American, Chinese-American   |
| The impact of migration experiences and migration identities on the experiences of services and caring for a family member with dementia for Sikhs living in Wolverhampton, UK | Jutla  | 2015 | UK        | Qualitative | n=12<br>Family carers for PWD: ages 44 - 83   | Recruited from community settings   | Sikhs  |
| A qualitative study of older and middle aged adults' perception and attitudes towards dementia and dementia risk reduction   | Kim  | 2015 | Australia | Qualitative | n= 34<br>Lay public aged 52-90  | Convenience sample of lay participants recruited from an advertisement in community newspaper               | White Australians  |
| Aboriginal experiences of ageing and dementia in a context of socio-cultural change: qualitative analysis of key informant group interviews with Aboriginal Seniors            | Lanting  | 2011 | Canada    | Qualitative | n= 3<br>Caregivers aged 59-73   | Recruited from the Saskatoon Community Clinic and mothers Group   | Aboriginal   |
| How do older people describe others with cognitive impairment? A multi-ethnic study in the United States   | Latidka  | 2013 | USA       | Qualitative | n=396<br>Lay public<br>Mean ages:<br>African-American -70.0<br>American Indians -69.6<br>Latinos-61.3<br>Chinese-69.0<br>Vietnamese-60.6<br>White other than Latinos-74.4 | Recruited from senior centers, tribal & community orgs., local conference, churches,                        | African-Americans, American Indians, Latinos, Chinese, Vietnamese, Whites other than Latinos |
| Threat to valued elements of life: the experience of dementia across three ethnic groups   | Lawrence, Samsi, Banerjee, Morgan, Murray  | 2010 | UK        | Qualitative | n= 30<br>PWD<br>Mean ages:<br>Black Caribbean-76<br>South Asian-77<br>White British-82  | Community Mental Health Teams for Older Adults, Memory clinics, day centres, community mental health progs. | Black Caribbean, South Asian, White British  |
| Pathways to diagnosis: exploring the experiences of problem recognition and obtaining a dementia diagnosis among Anglo-Canadians   | Leung, Finlay, Silvius, Koehn, McCleary, Cohen, Hum, Garcia, Dalziel, Emerson, Pimlott, Persaud, Kozak, Drummond | 2011 | Canada    | Qualitative | n=13<br>PWD, people with Alzheimer's Disease and their carers: ages 30s - 70s   | Alzheimer's Society   | Anglo-Canadians  |

|  |   |      |           |  |  |   |  |
|--|---|------|-----------|--|--|---|--|
| Re-examining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers                                   | Liu, Hinton, Tran, Hinton, Barker   | 2008 | USA       | Qualitative  | n=32<br>Family carers of PWD aged: >55   | Primary Care Physicians, home health program, Alzheimer support groups, home health agencies, day centres, nursing homes                      | Chinese-American, Vietnamese-American  |
| Older adults are less accurate than younger adults at identifying cardiovascular disease as a cause of dementia in the Chinese American community        | Liu   | 2013 | USA       | Quantitative   | n=208<br>Lay public aged >65   | Recruited through ageing seminar  | Chinese Americans  |
| Mental health of migrant elders- the Islington Study   | Livingston, Leavy, Manela, Sembhi, Katona   | 2001 | UK        | Quantitative   | n= 1085<br>Lay public<br>Aged: 65-104  | Recruited from community, residential homes (no information about whether PWD)  | Black British, Black Caribbean, Black British, Irish, Turkish Cypriot, Greek Cypriot, Black others, white others, Indian, Asian, Chinese, Bangladeshis |
| Dementia literacy: recognition and beliefs on dementia of the Australian public  | Low and Anstey  | 2009 | Australia | Quantitative   | n=1,701<br>Community dwelling public. Mean age (standard deviation) 46 (16)  | Telephone recruitment via national Australian electronic pages  | No information   |
| Stigma and dementia: East European and South Asian family carers negotiating stigma in the UK  | Mackenzie   | 2006 | UK        | Qualitative  | n= 22<br>Family carers of PWD<br>No age stated   | Using health & social care orgs. religious & community orgs. to recruit   | Pakistani, Polish, Ukrainian, Indian   |
| African American, Chinese, and Latino Family Caregivers' Impressions of the Onset and Diagnosis of Dementia: Cross-Cultural Similarities and Differences | Mahoney, Cloutterbuck, Neary, Zhan  | 2005 | USA       | Qualitative  | n=22<br>Family carers of people with Alzheimer's Disease<br>Mean ages:<br>African-American-60<br>Chinese-48<br>Latino-52 | Alzheimer's Association staff recruited from African-American & Latina communities, researcher from Chinese community used community contacts | African Americans, Latinos, Chinese  |
| Inequalities in dementia incidence between six racial and ethnic groups over 14 years  | Mayeda, Glymour, Quesenberry, Whitmer   | 2016 | USA       | Quantitative   | n=274, 925<br>Kaiser Permanente Northern California members: ages >59 as of 1/1/1996                                     | Recruited from Kaiser Permanente Northern California electronic records   | African-American, American Indian/ Alaska Natives, Latino, Pacific Islander, White, Asian-American   |
| Experiences of living with dementia in Iran: qualitative content analysis of semi-structured interviews  | Mazaheri, Eriksson, Heikkila, Nasrabadi, Ekman, Sunvisson                                       | 2014 | Iran      | Cross-sectional design with qualitative content analysis | n=15<br>PWD:<br>ages 60 - 87   | Recruited from Iran Alzheimer's Ass.  | Iranian  |
| Pathways to dementia diagnosis among South Asian Canadians   | McLeary, Persaud, Hum, Pimlott, Cohen, Leung, Dalziel, Kozak, Emerson, Silviu, Garcia, Drummond | 2012 | Canada    | Qualitative  | n=11<br>PWD:<br>ages >70   | Recruited from Adult Day Care Program, flyers in community & social orgs, regional community care agencies, religious & community leaders     | South Asian Canadians  |



|  |  |      |            |              |   |   |   |
|--|--|------|------------|--------------|---|---|---|
| Seeking a Diagnosis for Memory Problems: The Experiences of Caregivers and Families in Five Limited English Proficiency Communities                      | Morhardt, Pereyra, Iris  | 2010 | USA        | Qualitative  | n= 50<br>Family carers of people with a history of memory problems<br>No age stated   | Recruited from Cognitive, Neurology and Alzheimer's Disease Center  | Arab, Assyrian, Bosnian, Hindi, Urdu communities              |
| What would encourage help-seeking for memory problems among UK based South Asians? A qualitative study   | Mukadam  | 2015 | UK         | Qualitative  | n=53<br>Lay public<br>Mean age (range)<br>Number percentage<br>Bangladeshi - 32(60.4)<br>Indian - 17(32.1)<br>Pakistani - 2 (3.8)<br><br>Other- 2(3.8)  | Recruited via community contacts  | Bangladeshi, Indian, Pakistani                                |
| Dementia and migration: Pakistani immigrants in the Norwegian welfare state  | Naess, Moen  | 2015 | Norway     | Qualitative  | n= 22<br>Families with relatives undergoing diagnosis for dementia<br>No age stated   | Recruited from Polyclinic and community settings  | Pakistani   |
| Caregiving Experiences of Family Members of Persons With Dementia in South India   | Narayan, Varghese, Hepburn, Lewis, Paul, Bhimani                           | 2015 | USA, India | Qualitative  | n=30<br>Family carers for PWD and PWD:<br>mean ages 51, 70 respectively   | Recruited from Geropsychiatry Clinic  | Indian  |
| West African older people in the UK with dementia  | Ndoro, Marimirofa  | 2004 | UK         | Qualitative  | n=1<br>Person with cognitive impairment<br>79   | Mental Health Care for Older People Clinic  | West African  |
| Dementia Caregiving: The Experiences of Hispanic/Latino Caregivers   | Neary, Mahoney   | 2005 | USA        | Qualitative  | n=11<br>Carers of people with Alzheimer's Disease<br>Mean age: 50   | Recruited by trusted community consultant & Alzheimer's Ass.  | Latino/ Hispanic  |
| Perceptions of dementia and use of services in minority ethnic communities: a scoping exercise   | Parveen, Peltier, Oyebode  | 2016 | UK         | Qualitative  | n=175<br>PWD, carers of PWD, lay public<br>No age stated  | Recruited in cultural specific dementia awareness roadshows   | British Indian, African/ Caribbean, East and Central European |
| Ageing and mental health in a developing country: who cares? Qualitative studies from Goa, India   | Patel, Prince  | 2001 | India      | Qualitative  | n=92<br>Older persons in the community/ old age homes, key informants from the community: councillors, multi-purpose health workers, primary care doctors, family care-givers of elderly persons with disability or dementia: ages 50 - 89 (older person group) | Community settings & key informants from village govt. health & community workers, primary care doctors, family care givers of PWD & disability | Indian  |
| Prevalence of dementia in urban and regional Aboriginal Australians  | Radford, Mack, Draper, Chalkey, Daylight, Cumming, Bennett, Delbaere, Broe | 2014 | Australia  | Quantitative | n= 336<br>Lay public:<br>ages >60   | Recruited from community settings   | Aboriginal, Torres Strait Islanders                           |
| The association between vascular risk factor-mediating medications and cognition and dementia diagnosis in a community based sample of African-Americans | Richards, Emsley, Roberts, Murray, Hall, Gao, Hendrie                      | 2000 | USA        | Quantitative | n= 2212<br>Lay public<br>ages>60  | Recruited from residential addresses in Indianapolis Water Company  | African-Americans   |

|  |  |      |        |   |   |   |   |
|--|--|------|--------|---|---|---|---|
| Implications of the Facing Dementia Survey for the general population, patients and caregivers across Europe   | Rimmer, Wojciechowska, Stave, Sganga, O'Connell    | 2005 | USA    | Quantitative & Qualitative                | n=896<br>Lay public: ages >18<br>People with Alzheimer's Disease: ages 50 - 92<br>Caregivers  | Recruited randomly from Facing Dementia Survey & referrals from AD Assocs., pharmacists, physicians                               | Countries: France, Germany, Italy, Poland, Spain, UK<br>No info on ethnicity  |
| Differences Between African Americans and Whites in Their Perceptions of Alzheimer Disease   | Roberts, Connell, Cisewski, Hipps, Demissie, Green | 2003 | USA    | Quantitative                              | n= 452<br>Lay public: mean age of 47  | Recruitment via volunteers in caregiver & gerontology conferences support groups, health fairs, community, civic orgs. & churches | White, African-American   |
| Knowledge about aging and Alzheimer Disease: a comparison of professional caregivers and noncaregivers   | Rust, See  | 2007 | Canada | Alzheimer's Disease Knowledge Test (ADKT) | n= 105<br>Carers of people with Alzheimer's Disease: ages 19 - 64<br>Students: ages 18 - 43   | Caregivers from Alzheimer care centers, student from Universities   | No ethnicity staged   |
| Causal Attributions of Dementia Among Korean American Immigrants   | Lee, Diwan, Yeo                                    | 2010 | USA    | Quantitative                              | n= 209<br>Lay public: ages 40 -79   | Korean orientated organisations   | Korean-American   |
| A Direct Comparison of Popular Models of Normal Memory Loss and Alzheimer's Disease in Samples of African Americans, Mexican Americans, and Refugees and Immigrants from the Former Soviet Union | Schrauf, Iris                                      | 2011 | USA    | Quantitative                              | n=108<br>Lay public: mean age 63  | Senior centers, caregiver support groups, adult day care centers, caregiver information days, newspaper and radio announcements   | African Americans, Mexican Americans, refugees and immigrants from the former Soviet Union  |
| Why is it that elderly Asian people are not accessing dementia services despite evident need?  | Seabrooke, Milne                                   | 2004 | UK     | Qualitative/ Quantitative                 | Qualitative study n= 249<br>Quantitative n= 21 nursing & residential home staff<br><br>Healthcare professionals, independent service providers, carers, lay public<br>No age stated | Alzheimer's and Dementia Support Service Organisation   | Asian   |
| Caregivers of people with Alzheimer's disease: a qualitative study from the Indian 10/66 Dementia Research Network   | Shaji, Smitha, Lal, Prince                         | 2003 | India  | Qualitative                               | n= 17<br>Caregivers of people with Alzheimer's Disease<br>No age stated   | Recruited from community settings   | Indian  |
| Dementia in a Black and minority ethnic population: characteristics of presentation to an inner London memory service  | Tuerk, Sauer                                       | 2015 | UK     | Quantitative                              | n=460<br>People with mild to moderate memory problems:<br>Mean ages: BME-77.19<br>White British- 80.23  |   | White: British, Black or Black British: Caribbean, White: any other white background, White: Irish, Black or Black British: African, Asian or Asian British: Indian, All other BME groups |
| South Asian and white older people and dementia: a qualitative study of knowledge and attitudes  | Turner, Christie, Haworth                          | 2005 | UK     | Qualitative                               | n=192<br>Lay Public age:58-85   | Recruited from community settings   | White British, South Asian  |

|  |  |      |             |             |  |  |                                      |
|--|--|------|-------------|-------------|--|--|--------------------------------------|
| Understanding and awareness of dementia in the Sikh community  | Uppal, Bonas, Philpott                             | 2014 | UK          | Qualitative | n=28<br>Lay Public<br>age: 18-56+  | Recruited from community settings  | Sikh                                 |
| Explanatory models and openness about dementia in migrant communities:<br>A qualitative study among female family carers | Van Wezel, Francke, Acun, Deville, Grondelle, Blom | 2016 | Netherlands | Qualitative | n= 28<br>Family carers for PWD:<br>ages 20 - 84  | Recruited by nursing staff, case managers, key figures from ethnic communities, dementia educators | Turkish, Moroccan, Surinamese-Creole |
| Families and caring amongst older people in South Asian communities in the UK: a pilot study                             | Victor, Martin, Zubair                             | 2012 | UK          | Qualitative | n= 20<br>Total sample:<br>Lay public<br>ages: 50+  | Recruited from community settings  | Bangladeshi, Pakistani               |
| Pathways to Care for Alzheimer's Disease Among Korean Americans  | Watari, Gatz                                       | 2004 | USA         | USA         | n=321<br>PWD who had sought care:<br>mean age of 77<br>lay public:<br>ages 18 - 73   | Recruited from Christian Korean Churches   | Korean-American,                     |
| Caring for Family Members With Alzheimer's Disease Perspectives From Chinese American Caregivers                         | Zhan   | 2004 | USA         | Qualitative | n=4<br>Family carers of people with Alzheimer's Disease:<br>ages 36 - 62<br>People with Alzheimer's Disease:<br>ages 80 - 90 | Recruited from care agencies   | Chinese-Americans                    |

# Appendix C



## Conceptualisation of dementia and timely diagnosis in multi-ethnic communities (specifically: Caribbean, white British, Indian Hindu Gujarati)

### Community Focus Group Participation Information Sheet

**Name of Investigators:** Naina Patel, Professor Raghu Raghavan, Dr Latha Velayudhan and Dr Paula Wray.

#### Introduction

We would like invite you to take part in a focus group discussion so that we can find out about the various ways in which dementia is viewed and understood in multi-ethnic communities. You do not need to know someone who has dementia to take part in the focus group. We would also like to discuss what you think about how, and where people are likely to go for help to diagnose dementia, if they or a relative/friend were experiencing problems with their memory and the types of support that may be required.

If you think you may be interested in taking part in this focus group, please read this information leaflet and talk to a family or friend about it.

If you would like more information, you can also ask the PhD student who is leading this research study. Her contact details are at the bottom of this leaflet.

#### What will taking part in the focus group involve?

It will be an opportunity to take part in a discussion led by the researcher and for you to:

- share your experiences and views about ageing and culture
- discuss what you understand and think about dementia
- to listen to other people's ideas, views and experiences
- for you to suggest ways in which care and support should be provided to people with dementia and their carers.

#### Why are we doing this research project?

This research study forms part of a PhD and will help with raising awareness of what people from multi-ethnic communities understand about dementia; and what help and support is required by people obtain timely diagnosis of the condition.

#### Why have you been chosen?

We have invited you to take part in the focus group because it's important for the research team to find out about the general level of awareness in different ethnic communities about dementia and how it's understood. In addition, it will help us to find out whether understanding and knowledge of dementia is similar or different across a range of ethnic groups, for example, in relation to seeking help and support for someone with dementia.



### **Do I have to take part?**

You can choose:

To say yes  
Or to say no.

If you say yes to take part in this research project. We will ask you to sign a piece of paper called a consent form at the start of the focus group discussion.

This form says you are happy to take part in the research study.

It is okay to change your mind about taking part.

You can say no

If you say no to taking part in the research project:

- Your rights will not change
- Your health care will not change

### **How long will the Focus Group discussion take?**

The group discussion will take up to two hours, with a break for tea and coffee.

### **I am interested in taking part, what do I do next?**

If you are interested in taking part, please let your community worker/volunteer know and he/she will give you details of when and where the focus group will take place.

### **What are the possible benefits of taking part?**

Taking part in the group discussion will help to identify how people in multi-ethnic communities understand and know about dementia. There is no direct benefit to you for taking part but we would like to give you a store voucher (£20) as our token of appreciation of your contribution.

### **What are the possible disadvantages and risks of taking part?**

As this study just involves taking part in discussion within a focus group it is highly unlikely to be disadvantageous or carry any degree of risk.

### **What if something goes wrong? / Who can I complain to?**

If you have any concerns or complaints about the way you have been approached or treated in connection with the study, you should ask to speak to the researcher who will do her best to answer your questions: Naina Patel on ..... If you remain unhappy and wish to address your concerns or complaints on a formal basis, you should then contact the Administrator for the Faculty Research Ethics Committee, Research & Commercial Office, Faculty of Health & Life Sciences, 1.25 Edith Murphy House, De Montfort University, The Gateway, Leicester, LE1 9BH or [hlsfro@dmu.ac.uk](mailto:hlsfro@dmu.ac.uk)



**Will my information be kept private?**

We will keep your information private (confidential).

Any personal information such as your name will only be seen by the researcher and research team and staff from De Montfort University who are responsible for checking research projects to make sure they are carried out properly.

Any information that you give us such as your age group and language/s you speak are recorded without your name on it. We use a number code instead of a name so you cannot be identified from it.

We will record the things we talk about during the group discussions. This is so we can write things down later.

We would like to use information we have found out about during the group discussions in the research project. This could be in, for example:

- Reports
- Presentations

We will not use your name.

**Who has reviewed the study?**

Before we carry out a research study, it has to be reviewed and approved by De Montfort University, Faculty of Health and Life Sciences Research Ethics Committee.

A Research Ethics Committee is a group of people who make sure:

- It is ok to do a research study
- The research study is being carried out in a way that respects people's rights, dignity and confidentiality

**Who is organising and funding the research?**

This study which forms a part of a PhD that is funded by Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East Midlands and organised by De Montfort University.

**Contact for further information**

For further information or details about this study please contact: Naina Patel on

.....

**THANK YOU FOR TAKING THE TIME TO READ THIS PARTICIPANT INFORMATION SHEET**

# Appendix D



## Conceptualisation of dementia and timely diagnosis in multi-ethnic communities (specifically: Caribbean, white British, Indian Hindu Gujarati)

### Community Workers and Volunteers Interview Participation Information Sheet

**Name of Investigators:** Naina Patel, Professor Raghu Raghavan, Dr Latha Velayudhan and Dr Paula Wray.

*You have been invited to take part in a research study which forms part of a PhD. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part or not. Thank you for reading this.*

#### **What is the study about?**

We want to explore community workers and volunteers' conceptualisations of dementia and how they perceive people from multi-ethnic communities conceptualise dementia. The study also aims to explore some of the issues that may arise during patient journeys to diagnosis. As your work involves supporting people in the community, we would also like to hear about your views and experiences of some of the barriers and facilitators to timely diagnosis within the communities that you work with.

#### **What does the study involve?**

You are being invited to take part in a 'one off' face to face interview with the researcher and it will be approximately up to 30 minutes in duration. The interview can take place at your place of work or De Montfort University. The interview will be digitally audio recorded.

We would like as many people as possible to offer to take part in the interview so that we can select a range of community workers and volunteers. It is possible that we may not need to use everyone who offers to take part in the interview, and if we find that we don't need you, we will let you know.

#### **Why have I been chosen?**

We have invited you to take part in the study because of your role in supporting people in community settings. It's really important to include your views and experiences as this will help us to gain an informed understanding of patient journeys and factors that can contribute to timely diagnosis.

#### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

#### **I am interested in taking part, what do I do next?**

If you are interested in taking part, please email the researcher and she will contact you to arrange a mutually convenient time and place to conduct the interview.

#### **What if I agree to take part and then change my mind?**

You can withdraw from the study at any time, without giving a reason.



**What are the possible disadvantages and risks of taking part?**

As this study just involves taking part in an interview, it is highly unlikely that will be disadvantages associated with taking part in this research study.

**What are the possible benefits of taking part?**

Taking part in the interview may not be of direct benefit to yourself but your participation will play a valuable role in helping to highlight your experiences and knowledge gained from working in communities. This may be of benefit to future research and published research evidence in this area.

**What if something goes wrong? / Who can I complain to?**

If you have any concerns or complaints about the way you have been approached or treated in connection with the study, you should ask to speak to the researcher who will do her best to answer your questions: Naina Patel on ..... If you remain unhappy and wish to address your concerns or complaints on a formal basis, you should then contact the Administrator for the Faculty Research Ethics Committee, Research & Commercial Office, Faculty of Health & Life Sciences, 1.25 Edith Murphy House, De Montfort University, The Gateway, Leicester, LE1 9BH or [hlsfro@dmu.ac.uk](mailto:hlsfro@dmu.ac.uk)

**Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept on a password protected database and in a locked filing cabinet to ensure strict confidentiality. You will be given an ID code which will be used instead of your name. Any identifiable information obtained during the interview will be removed and anonymised. The digital audio-recording will be destroyed at the end of the research study.

**What will happen to the results of the research study?**

The results of this research may be published in a medical journal or presented at research meetings or conferences.

**Who is organising and funding the research?**

This study forms a part of a PhD that is funded by Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East Midlands and organised by De Montfort University.

**Who has reviewed the study?**

This study has been reviewed and approved by De Montfort University, Faculty of Health and Life Sciences Research Ethics Committee and NHS Research and Governance.

**Contact for further Information**

For further information or details about this study please contact: Naina Patel on .....

**THANK YOU FOR TAKING THE TIME TO READ THIS PARTICIPANT INFORMATION SHEET**



# Appendix E



## Conceptualisation of dementia and timely diagnosis in multi-ethnic communities (specifically: Caribbean, white British, Indian Hindu Gujarati)

### Community Focus Group Participant Consent form

Name of Investigators: Naina Patel, Professor Raghu Raghavan, Dr Latha Velayudhan and Dr Paula Wray.

This form is a way for us to make sure that you are happy to take part in the focus group discussions

Please write your initials in each box

1. The researcher has explained what will happen during the Focus Group discussions.
2. I have asked all the questions I want.
3. My questions were answered.
4. It is my choice to take part.
5. I know its ok to say no. Saying no won't affect my rights, services or support.
6. If I say yes, I know I can still change my mind later on.
7. I understand and that the focus Group discussion will be audio-recorded but that all the information collected will be strictly confidential.
8. I understand and agree that any information collected as part of th is research study will be kept private. My information will only be seen by:
  - The researcher and the research team
  - Staff from De Montfort University who check the study is carried out properly
9. I understand and agree that the researcher can use small parts of what I say without mentioning my name in reports and presentation when the results of the research are reported.
10. I give permission for my contact details to be used to send me a letter with a summary of findings from the research study. (This is optional)



11. I give permission for the researcher to contact me to give details of a feedback event so I can find out about the key findings from the research study. (This is optional) 11

12. I agree to take part in the research study. 12

**To be completed by person consenting to participate in this research study:**

| Name (Print) | Signature | Date |
|--------------|-----------|------|
| _____        | _____     |      |
| _____        |           |      |

**To be completed by person taking consent:**

I can confirm that it is my opinion that the participant has understood what is involved in taking part in this research study.

| Name of researcher (Print) | Signature | Date |
|----------------------------|-----------|------|
| _____                      | _____     |      |
| _____                      |           |      |

# Appendix F



## Conceptualisation of dementia and timely diagnosis in multi-ethnic communities (specifically: Caribbean, white British, Indian Hindu Gujarati)

### Community Workers and Volunteers Consent form for interview

Name of Investigators: Naina Patel, Professor Raghu Raghavan, Dr Latha Velayudhan and Dr Paula Wray.

This form is a way for us to make sure that you are happy to take part in the interview.

Please write your initials in each box

1. The researcher has explained what will happen during the interview.
2. I have asked all the questions I want.
3. My questions were answered.
4. It is my choice to take part.
5. I know its ok to say no. Saying no won't affect my rights, services or support.
6. If I say yes, I know I can still change my mind later on.
7. I understand that the interview will be audio-recorded but that all the information collected will be strictly confidential.
8. I understand and agree that any information collected as part of this research study will be kept private. My information will only be seen by:
  - The researcher and the research team
  - Staff from De Montfort University who check the study is carried out properly
9. I understand and agree that the researcher can use small parts of what I say without mentioning my name in reports and presentation when the results of the research are reported.
10. I give permission for my contact details to be used to send me a letter with a summary of findings from the research study. (This is optional)



11. I give permission for the researcher to contact me to give details of a feedback event so I can find out about the key findings from the research study.  
(This is optional)

11

12. I agree to take part in the research study.

12

**To be completed by person consenting to participate in this research study:**

| Name (Print) | Signature | Date  |
|--------------|-----------|-------|
| _____        | _____     | _____ |

**To be completed by person taking consent:**

I can confirm that it is my opinion that the participant has understood what is involved in taking part in this research study.

| Name of researcher (Print) | Signature | Date  |
|----------------------------|-----------|-------|
| _____                      | _____     | _____ |

# Appendix G



Participant number:

**Conceptualisation of dementia and timely diagnosis in multi-ethnic communities (specifically: Caribbean, white British, Indian Hindu Gujarati)**

## COMMUNITY FOCUS GROUP INFORMATION ABOUT PARTICIPANT SHEET

**Name of Investigators:** Naina Patel, Professor Raghu Raghavan, Dr Latha Velayudhan and Dr Paula Wray.

**We are asking each participant for some brief information about themselves as it's really helpful for us to know about the types of people who took part in the focus group. As you can see below we are not asking for your name as each sheet will be given an anonymised identifier number as stated above.**

.....  
.....

### 1. Information about you: (please tick relevant box)

a. Which age group are you in? Under  35  35 to  60 Over 60

b. How would you describe your ethnicity? (Please write below)

.....  
.....

c. How would you describe your gender? (please tick) Male ..... Female.....

d. What is your country of birth? (Please write here).....

e. If you were born outside of the UK, what year did you first arrive to the UK? (Please write here).....

f. What are the highest level of qualifications either in this country or abroad? (Please write here)

.....  
.....

**THANK YOU FOR TAKING THE TIME TO COMPLETE THIS THIS INFORMATION ABOUT PARTICIPANT FORM**

Community Focus Group Information about Participant Sheet V1, 04/12/16

# Appendix H



Participant number:

**Conceptualisation of dementia and timely diagnosis in multi-ethnic communities (specifically: Caribbean, white British, Indian Hindu Gujarati)**

## INFORMATION ABOUT COMMUNITY WORKER AND VOLUNTEER PARTICIPANT FORM

**Name of Investigators:** Naina Patel, Professor Raghu Raghavan, Dr Latha Velayudhan and Dr Paula Wray.

**We are asking each participant for some brief information about themselves as its really helpful for us to know about the types of people who took part in the interviews. As you can see below we are not asking for your name as each sheet will be given an anonymised identifier number as stated above.**

**Please write your responses on the dotted line below each question.**

.....  
.....

### 1. Information about you: (please tick relevant box)

a. Which age group are you in? Under  35  35 to  60  Over 60

b. How would you describe your ethnicity?  
.....

c. How would you describe your gender? (please tick) Male ..... Female.....

d. How long have you worked in your current role?  
.....

**THANK YOU FOR TAKING THE TIME TO COMPLETE THIS THIS INFORMATION ABOUT PARTICIPANT FORM**

# Appendix I



## TOPIC GUIDE FOR FOCUS GROUPS

**A. Before we start, I'd like to ask you to consider some ground rules.** These are:

- Speaking one at a time, particularly as the discussion is being recorded
- Respecting each other's views and experiences and listening to them respectfully
- Respecting confidentiality of these discussions, essentially not sharing details of the discussion outside of this group in a way that can identify people who are taking part today.
- Please know, this focus group is to invite discussion of the topics, there are no right or wrong answers so please feel comfortable to share your experiences and views.

**B. Conceptualisation of dementia: knowledge, beliefs, and awareness**

**I'd really like to explore your perceptions and knowledge about dementia. A gentle reminder just to say I'm not testing you.**

The following two questions will be placed on flipcharts to elicit discussions.

1. I understand dementia to be
2. Other people may understand dementia to be:

- Family
- Friends
- Communities/public

1. Do you think the understanding, beliefs and knowledge of dementia changes by generation or not?
2. Is everybody who gets old likely to have dementia?
3. What do you think causes dementia?
4. What increases the risk of someone having dementia?
5. What decreases the risk of someone having dementia?
7. What do you think are some of the signs and symptoms of dementia?
8. How should care and support be given?
11. Where does your understanding of dementia come from?

**C. Views and beliefs about ageing**

1. Is there a specific age at which you define a person as old?

**Break: 10 minutes**



#### **D. Exploring stigma**

1. Some of the research suggests that dementia is a health condition that people may be ashamed of or hide. What do you think?
2. Do you think stigma is something that differs by culture and over generations or likely to be the same?

#### **E. Ethnic identity**

**We often get asked on forms or when we fill out the census form for example, what ethnic group you belong to. I'd like to explore your views about these terms.**

1. How would you describe your ethnic identity?
2. How would you describe your ethnic group? I have called this group today based on.....

THANK YOU FOR TAKING TIME OUT TO COME HERE



# Appendix J



## TOPIC GUIDE FOR INTERVIEWS WITH COMMUNITY WORKERS

1. **Introduction to interview:** The researcher will reassure the participants taking part in the interview that:
  - The research team is interested in finding out about their views, experiences and understanding of dementia and journey to diagnosis of people from multi-ethnic communities
  - There is no intention of 'testing' participants
  - Participants are free to say as much or as little as they wish in response to any line of questioning
2. Can you tell a little bit about your job role and responsibilities?
3. What do you understand about dementia?
4. What do you believe causes it?
4. To explore professional stakeholders perceptions and experiences of how dementia is conceptualised within multi-ethnic communities:
  - What do you think are the ways in which people within the (Caribbean\white British\Indian community) conceptualise dementia)?
  - Is it changing or not? Explore why.
  - Do you think that ways in which dementia is conceptualised remains the same or is different across generations within the (Caribbean\white British\Indian community)? Probe: why?
  - What factors influence whether conceptualisations change over generations?
5. Explore understanding of their ethnicity and the role it plays in their lives of people with dementia
  - How does culture affect the experience of caring for people with dementia amongst (Caribbean\white British\Indian people) with dementia and their carers?
  - What aspects of culture are different or the same for (Caribbean\white British\Indian people) with dementia and their carers?
  - Do these differ by generations in these communities?
  - What factors influence changes or prevent changes to the experience of caring across generations?
6. Also wanted to explore whether the educational background of families and individuals conceptualise dementia and seek help for dementia?
8. Is the same true of the above for help with caring OR not?
9. Do you think that dementia is a condition that results in people feeling stigmatised?



- Who is stigmatised and why?
- By whom? Probe community, family, healthcare professionals?

THANK YOU FOR YOUR TIME –IS THERE ANYTHING THAT YOU WOULD LIKE TO ADD?