Caring for the Caregivers:
Exploring the Experiences of South Asian Carers of People with Dementia in Greater Manchester Area: An IPA study

AMBILY SATHISH

A thesis submitted in partial fulfilment of the
requirement of
Manchester Metropolitan University
for the Degree of Doctor of Philosophy

Faculty of Health, Psychology & Social Care
Manchester Metropolitan University

2023

Declaration

I, Ambily Sathish, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Acknowledgements

I would never have been able to finish my final PhD thesis without the proficient guidance of my supervisors, help from my colleagues and unwavering support from my family. First and foremost, I would like to express my sincere gratitude to my current supervisors: Dr. Gayatri Nambiar-Greenwood and Dr. Nigel Cox, who met with me regularly and provided their expert guidance and prompt feedback that enabled me to complete this PhD. My gratitude extends to my previous supervisors Prof. Josey Tetley, Prof. Abebaw Yohannes and Dr. Emma-Reetta Koivunen for sharing their expertise and providing their guidance and support in helping me through the PhD process.

I would also like to thank my advisor, Prof. Iracema Leroi, for her support and motivation to pursue a PhD. My thanks and acknowledgement also go to Manchester Metropolitan University for providing the funding and making it possible for me to complete the research and the South Asian Community centres in Greater Manchester for help with recruitment.

I am indebted to all the participants of this research study for giving their time to participate in my study and for their vital role in personifying this pressing issue; without their valuable input, this research would not have been possible.

I extend my sincere thanks to my ex-colleagues at DeNDRoN and friends for their positive reassurance and support during various stages of my research study. I would also like to thank the IT services and administrative staff at Manchester Metropolitan University for helping me with numerous queries and issues that I have encountered during my research study journey.

I would once again like to thank my husband, children, parents, and extended family for their continuous support and motivation throughout my PhD. My love goes to my husband Sathish and my beautiful children Diya and Ritvik, who inspired and encouraged me during the difficult times, got me through the lows and highs, and steadfastly supported me to achieve this milestone. Finally, I would like to dedicate this thesis to my children.

Abstract

The contribution of South Asian caregivers to dementia care has not received adequate recognition. These caregivers are significantly underrepresented in dementia services, a concern identified by the Department of Health. They often face challenges related to social dynamics, language barriers, limited education, and cultural differences when accessing community services. Given the projected exponential increase in the aging South Asian population, understanding the unique experiences of caregivers from these backgrounds has become increasingly urgent. This study aims to gain a comprehensive understanding of how South Asian caregivers in the Greater Manchester area perceive their role in caring for a family member with dementia, as well as their positive and negative caregiving experiences.

Qualitative methods were employed, involving semi-structured interviews with eight caregivers from Indian and Pakistani backgrounds living in Greater Manchester, UK. The interviews generated rich accounts of their experiences in caring for someone with dementia. Interpretative Phenomenological Analysis (IPA) was utilized to analyse the interview transcripts.

Key findings revealed several significant themes: "Now it's my turn to take care of you," "When it’s family, you can't say no," "It is a norm, a good norm, a very good norm to follow," "It was a constant roller coaster," and "Tell us what it is and what the best way is to deal with it." The first three themes depict caregiving as a positive experience influenced by cultural factors and strong family values. Participants demonstrated strong attachment to their families and a sense of obligation to care for older family members. The fourth theme illustrates the complexity of South Asian caregivers' experiences, which are influenced by

cultural, psychosocial, and physiological factors, leading to various stressors. The final theme highlights the participants' lack of preparedness for the caregiving role and their disappointment with the support services available, including the absence of culturally tailored services and unmet basic needs.

This study strongly supports existing knowledge about the challenges faced by South Asian dementia caregivers and provides a systemic understanding of how caregivers from diverse cultural and socioeconomic backgrounds are differentially affected. It highlights the importance of support for South Asian caregivers and offers insights on how healthcare services can be improved to meet their specific needs. Addressing these issues may alleviate the caregiving burden and significantly enhance the quality of life for both the patients and caregivers involved.

Contents

List of Tables

List of Figures

List of Abbreviations

AD	Alzheimer's Disease
APPG	All Party Parliamentary Group
BAME	Black, Asian, and Minority Ethnic
CPEC	Care Policy and Evaluation Centre
CSF	Cerebrospinal fluid
DoHSC	Department of Health and Social Care
GP	General Practitioner
IPA	Interpretative Phenomenological Analysis
LMIC	Low- and Middle-Income Countries
MCI	Mild Cognitive Impairment
NICE/SCIE	National Institute for Health and Clinical Excellence/Social Care Institute for Excellence
NHS	National Health Service
ONS	Office for National Statistics
PWD	People with Dementia
PET	Positron Emission Tomography
SA	South Asian
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

Chapter 1. Introduction

This overall aim of this thesis is to explore the 'caregiving experience' of South Asian caregivers of people with dementia in the UK. Dementia continues to have a huge socio-economic impact globally due to the rapid increase in the number of people affected by this condition. In the United Kingdom (UK), since the Prime Minister's Dementia Challenge (Department of Health and Social Care, 2012) was launched, dementia has become a public health priority and there has been significant progress made in improving the health and care for people with dementia and their carers (All Party Parliamentary Group on Dementia (APPG), 2013, 2021). At the same time, the dementia experiences of underserved members of the community have also begun to emerge (NIHR, 2020). Underserved in this health context refers to those individuals, communities and parts of society who do not receive equitable access to health and social care services. This is mainly caused by due to socioeconomic, cultural, or geographical isolation from the healthcare system. They can experience either a total lack of services or severe barriers to accessing services (Bantham et al, 2021). However, the social and ethnic disparities in dementia still exist, and there is not adequate evidence to interpret these inequalities (Mayeda et al., 2016). The predicted seven-fold increase in the number of people with dementia from Black, Asian and minority ethnic (BAME) communities, including those of South Asian origin, raises important questions regarding the provision of care in the coming years (Alzheimer Society, 2013; APPG, 2013).

On the other hand, unpaid carers contribute substantially to supporting loved ones with dementia and how they cope and manage dementia care in their everyday lives has not been fully recognised by services (Lance et al.2008; Lankers et al., 2010; Kenning, 2017*).*

These groups of family caregivers, especially women, are under-represented in the provision of dementia services and this has been highlighted as a critical policy issue by the Department of Health and Social Care (Moriarty et al., 2011; Sorensen et al., 2011; Parveen et al., 2013; Jutlla, 2013; Whitlatch et al., 2018). These dementia family caregivers are at significantly higher risk of developing burnout and stress-related health complications compared to adults without a caring role (Shah, 2008; Jutlla, 2013; Alzheimer's Society, 2014a). However, most importantly, people with dementia (PWD) and their families from BAME communities experience perceived stigma associated with diagnosis and access to services (Nolan et al., 2006). They often face social challenges, language and education constraints, and cultural barriers when they attempt to access community services (Moriarty et al., 2011; Alzheimer’s society, 2014). Even those who do manage to seek help might not get suitable services as there is often a lack of appropriate culturally sensitive dementia services available.

In the light of these social and political concerns to bring dementia out of the shadows for South Asian elders, a sensitive approach and a high level of understanding about their diverse cultures are required. Each BAME community such as Africans and Asians have their own unique context, and cultural and linguistic differences; therefore, it is essential to narrow down this study, to a specific, homogenous group of the population. Despite the growing literature on the attitudes, experiences, and needs of family carers of people with dementia in minority ethnic communities, and despite the striking evidence of lower take up of dementia care services in the South Asian community, there is a noticeable paucity of research that explores how minority ethnic carers experience caring for a relative with dementia. Understanding the tailored needs of caregivers, their unique life experiences, and how they are coping with the disease may help to avoid a 'one size fits for all' approach and develop culturally sensitive interventions to meet the needs of the caregivers (Whitlatch et al.,2018).

Against this backdrop, this study aimed to explore the experience of South Asian caregivers of people with dementia in the Greater Manchester area and their perceptions about the impact of dementia care on family caregivers.

1.1 Overview of thesis

Chapter 2 is concerned with the ***background*** of dementia which is the underlying focus of this study. The first section of this chapter gives the reader an overview of dementia, how it can affect all aspects of a person’s life and key risk factors of dementia. This chapter outlines the global, national, and local statistics of dementia and the disparities in dementia prevalence between South Asians in the UK compared to other white majorities. The later section of the chapter delves into the caregiving aspects of dementia, particularly the associated feelings of caregiver burden within the South Asian community, which is the principal focus of this study.

Chapter 3 is the ***narrative literature review*** which was conducted to evaluate the evidence base exploring the experiences of BAME caregivers of people with dementia. To examine the various literature on dementia among BAME communities and especially South Asians, a scoping review was undertaken under the set methodological framework. These methods include fundamental theories contributing to the issues underpinning how South Asians feel about caring for their family members living with dementia. The review is structured around two central themes. The first section explores the challenges faced by the caregivers of PWD from BAME groups, in particular South Asians, who are the largest non-European community in the UK. The second section of the narrative review discusses the impact of dementia on South Asian caregivers. These themes are expanded upon within the thesis. The second half of this chapter then further discusses the cluster of theories and conceptual models which can contribute to understanding the experiences of South Asian caregivers of a family member with dementia.

In Chapter 4, I discuss the ***methodological underpinning*** of the study and the rationale for adopting interpretative phenomenological analysis (IPA) to address the aims and objectives of this thesis. This chapter begins with the importance of qualitative research, then gives a discussion of IPA's intellectual origins emphasising the theoretical underpinnings: phenomenology, hermeneutics, and idiography. The chapter further explores how the ontological and epistemological dimensions of IPA informed the research questions of the study and why other methodological approaches were not utilised. In addition to this, there is a detailed discussion of sampling and recruitment, informed consent, ethical procedures, data collection, and data analysis applied, delving into the rationale as to why this methodology was the most fitting for the defined methodological approach and presenting the quality criteria employed throughout the course of this study.

Chapter 5 presents the ***findings*** of the IPA of the data from eight South Asian caregivers of people with dementia. This chapter offers an analysis and interpretation of the data and an overview of the main themes and sub themes that emerged from the comprehensive IPA. Each theme and its subordinate themes discuss the perceptions of the interviewees regarding each thematic idea, these are illustrated by extracts from the interview transcripts.

Chapter 6 contextualises the findings section and provides a comprehensive ***discussion of findings*** obtained from the research study through specified questions utilising an IPA approach to explore the caregiving experiences of South Asian caregivers of people with dementia. The discussion chapter summarises how the caregivers of people with dementia feel about caring for a family member with dementia as well as what might be interpreted from their interviews about the motives and challenges in caregiving. This is then further investigated to reveal the specific meaning of identified concepts and trends and other experiences shared by the participants. The discussion is based on five main themes that emerged from the data: 1) *"Now it's my turn to take care of you"; 2) "When it's family, you can't say no"; 3) "*It *is a norm, a good norm, a very good norm to follow"; 4)* the impact of caregiving on caregivers*: "It was a constant roller coaster"; and 5). "Tell us what it is and what the best way is to deal with it".*

Chapter 7, the final chapter, provides a ***conclusion*** of the key findings of this thesis and the potential implications for future practice. This chapter outlines how this study can contribute to existing knowledge and provides suggestion on how to effectively support South Asian caregivers to reduce their care burden, thus improve quality of life. Furthermore, this chapter discusses the strengths and limitations of this qualitative study, and makes recommendations for future practice and potential research.

Chapter 2. Background

This chapter begins by explaining the background of dementia, which is an underlying focus of this study, thus giving the reader an overview of dementia, how it can affect the person and their life, and key risk factors. This chapter outlines the global, national, and local statistics of dementia and the disparities in dementia prevalence between South Asians and the white British population majorities in the UK. The later section of the chapter discusses the caregiving aspects of dementia, particularly the associated feelings of caregiver burden within the South Asian community, which is the principal focus of this study.

2.1 What is dementia?

Dementia is a clinical syndrome that affects a person's cognitive abilities due to impaired brain function (WHO, 2015). Dementia affects the brain by causing complete or partial impairment of concentration, the ability to create thoughts, solve problems, memory, and mental capacity (Coleman et al., 2017). Although there are different types of dementia, the most commonly occurring is Alzheimer’s Disease (WHO, 2015). Vascular dementia and Lewy body dementia are the other major classes of dementia (Alzheimer’s Society, 2018).

Dementia affects each person differently depending upon their health condition, lifestyle, and comorbidities. Although decades of research have gone into investigating dementia’s complexities, there is currently no cure for this condition; however, there are drugs available that can aid in alleviating the common symptoms (Livingston et al., 2020). The leading causes of dementia are still unclear to health experts; however, the growing body of evidence suggests that certain genes such as Apolipoprotein E4 (APOE4) can increase the risk of developing dementia (Sienski et al.,2021). This is an increasingly important and emerging therapeutic and diagnostic target of Alzheimer's disease research. As a result of ongoing research using advanced technology, such as amyloid detection with positron emission tomography (PET) and cerebrospinal fluid (CSF) analysis, we have seen over the past decade that dementia aetiology has been constantly evolving, allowing new discoveries to be scoped. One such is mild cognitive impairment (MCI), a new term developed by Peterson and Tangalos (2018) which brought rise to a new perspective in diagnostics in the dementia pathophysiology and early detection of cognitive decline, which may lead to dementia (Tangalos and Petersen, 2018).

There are a number of medical conditions and social factors that contribute to the disease (WHO, 2020). In the Lancet Commission report of 2017, the possible risk factors of dementia are low education in early life, hypertension in middle life, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, and low social contact (Livingston et al., 2020). More recently, in 2020, the Lancet Commission reviewed the 2017 report and added excessive alcohol consumption, traumatic brain injury, and air pollution as further risk factors for dementia based on new supporting evidence (Livingston et al., 2020). In addition to these risk factors, there are few studies showing that Vitamin B12 and folic acid deficiency worsen cognition in people diagnosed with dementia (Mental Health Foundation, 2009; American Academy of Neurology, 2001; Prince et al., 2016).

2.2 Global prevalence of dementia

According to the World Health Organisation (WHO), it is estimated that globally around 50 million people have dementia (WHO, 2020). Statistics show that a person develops dementia every 3.2 seconds. However, the distribution of dementia is quite varied; it is reported that the number of people with dementia is predominantly high in low- and middle-income countries (LMIC). In the East Asian region, around 9.8 million people are living with dementia followed by 7.5 million in Western Europe, 5.1 million in South Asia, and 4.8 million in North America (WHO, 2020). This global prevalence of dementia figure is estimated to increase exponentially to 82 million in 2030 and 152 million by 2050 with 10 million new cases of dementia being diagnosed each year. The majority of these diagnoses are predicted to occur in developing and emerging countries (LMIC), due to these countries' limited infrastructure to provide social services, support, and care which leads to a greater risk factor burden. Currently, 60% of the total number of cases of dementia live in LMIC, which is expected to increase by 70% by 2050 (WHO, 2020) (see Figure: 2.1).

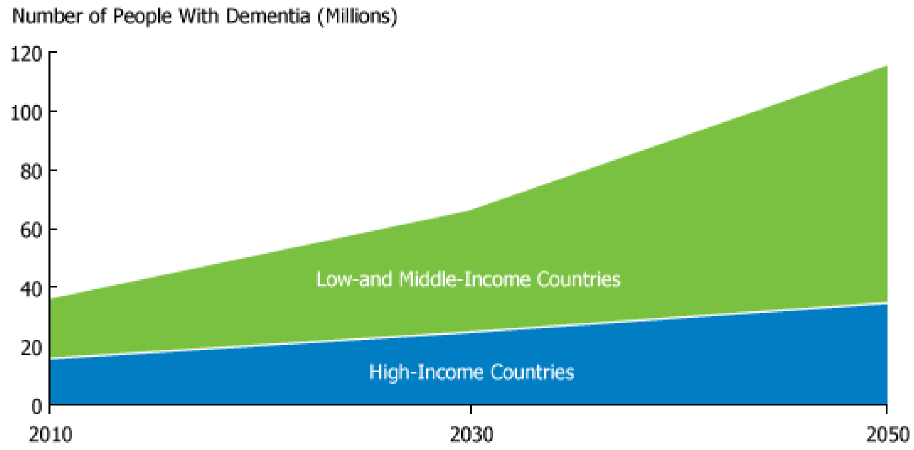


Figure 2.1: Projected Numbers of People with Dementia, by Country Income Level, 2010 to 2050 (Source: Alzheimer's Disease International, World Alzheimer Report 2010)

According to the Alzheimer's disease statistics reported by WHO (2020), currently among all diseases, dementia is the seventh leading cause of death. Furthermore, among older people globally, it is one of the main causes of disability and dependency. Depending on the underlying causes and a person's overall health status and cognitive functioning, dementia affects individuals differently. In particular, the early-stage symptoms such as mild forgetfulness, losing track of the time and appointments, and becoming lost in familiar places, can be easily overlooked as they develop gradually. When dementia progresses into the middle stage, symptoms can be alarming as PWD become more forgetful of recent events and people's names, and become confused frequently even in their own home. They will also have increased difficulty with communication and may need extended help with personal care. Some PWD even experience difficult behaviour changes, including restlessness, wandering, and asking repeated questions. As dementia progresses to an advanced stage, PWD present serious cognitive problems and an increased or complete need for self-care assistance. In the late stages of dementia, PWD suffer with severe physical symptoms and behaviour changes that may escalate and include aggression (WHO, 2020).

Dementia can change many aspects of life as it is associated with the loss of personhood and personal autonomy since it causes changes in the neuropsychiatry, pathological, and mental systems (Livingston et al.2020). Consequently, the affected persons may not recognise the family member caring for them. There is a relationship between the caregiver-care receiver dyad's health and healthcare costs, with caregivers who experience higher caregiver burdens increasing their own use of healthcare (Nichols et al., 2017).These health effects result in increased caregiver burdens and healthcare costs (Nichols et al., 2017). Moreover, impaired brain function and cognitive decline affects social functioning and the person’s ability to carry out the activities of daily living. Therefore, dementia continues to remain a global public health priority as it has a profound socio-economic impact on the affected individual and their families. As the number of people living dementia and the costs associated with diagnosis, treatment, medication, and care increase, this impact extends to the general population putting further strain on healthcare and the economy, with global costs estimated at about US$1.3 trillion annually; these costs are projected to rise to US$ 2.8 trillion by 2030 (WHO, 2019).

2.3 Prevalence of dementia in the UK

Although dementia is a worldwide concern, it is more prevalent in developed countries where the mortality rate is considerably lower (Livingston et al., 2020). The UK falls into the category of such countries where the risk of developing dementia increases with continued population ageing, that is mainly due to the increased life expectancy (Prince, et al., 2014). The UK is currently experiencing a demographic shift towards an elderly population with almost 12 million people aged 65 and over and about 3.2 million people aged 80 and over. The impact is predicted to be significant as a quarter of the 'baby boomer' generation reaches retirement age or gets close to retirement. In 2015, the number of people living with dementia in the UK was estimated to be around 850,000 and as predicted, this number continues to grow steadily year on year (Alzheimer's Society, 2014a). The Alzheimer's Society's latest *Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040* indicate that over 900,000 people are now living with dementia in the UK (Wittenberg et al., 2019). Of this number, 500,000 people have the prevailing cause of dementia – Alzheimer's disease, while 150,000 people have developed the condition due to cases of vascular dementia – dementia's second most common cause. The total number of PWD is expected to surpass 1 million by 2024 and 2.1 million by 2051. This is more than double the current figure, representing 3% of the total population (Alzheimer's Society, 2014).

As a population ages, the prevalence of dementia also increases. Although age is identified as the greatest risk factors for dementia, it is not always associated with aging. Approximately 42,000 of this population in the UK are below the age of 65, with 773,502 having late-onset dementia (Prince et al.,2014). This report was also consistent with the shocking figures predicted by the Alzheimer's Society in 2014, that 600,000 women in the

UK are now living with dementia. Dementia has become one of the leading causes of death for females in the UK (Office for National Statistics, 2019). As part of the reasons dementia related death rates are higher among females is due to the high number of the older female demographic in the UK. Alzheimer's Research UK statistics from their 2nd Edition report (produced by King’s College London and the London School of Economics for the Alzheimer’s Society) highlights, 65% of people living with dementia are women and 35% are men (Prince et al., 2014). In 2019, there were 933,274 females and 548,171 males aged 85 years or above in England and Wales, according to mid-year population estimates.

In the UK (2019), the leading cause of death for women was Alzheimer’s disease and other dementias with 31,850 deaths per year. There are many causes for the increase in the number of deaths from dementia and Alzheimer's disease among females in recent years. The main reason being that the likelihood of dementia and Alzheimer's disease increases significantly as age increases; therefore, as more females live longer and survive other illnesses, this results in more deaths related to ageing. Another underlying reason for this is that women are more susceptible to high levels of stress. Both of these reasons are risk factors associated with dementia. While women are more likely to develop dementia, they are also much more likely to inherit caregiving roles for someone with dementia, due to gender roles, with many female caregivers feeling less supported than their male counterparts. Many carers feel isolated and depressed, which is also a risk factor for developing dementia (Blackmore, 2018).

2.4 Dementia in BAME groups

In Britain, the broad term ‘minority ethnic’ covers all ethnic groups except white British, and includes Asians, people from a black Caribbean background, and white minorities, such as Jewish, Gypsy, Roma, and Irish Traveller groups, among others. As discussed above, the number of people with dementia in the UK is expected to grow rapidly over the next several decades (Lievesley, 2010., Wittenberg et al., 2020). While such a rapid rise in the prevalence of this debilitating disease already presents a considerable challenge for the UK, the magnitude of this challenge is even greater for BAME communities who make up over 14% of the nation's population (Prince et al., 2014).

The acronym BAME stands for Black, Asian, and minority ethnic and is defined as all ethnic groups except White ethnic groups. BAME is an umbrella term, common in the United Kingdom, used to describe non-white ethnicities. There has been increasing opposition to the use of the term BAME for the way it groups people and numerous ethnicities together, thereby stripping them of their individual identities. The UK Government recently adopted the term ‘ethnic minorities’ due to the increasing objections (Commission on Race and Ethnic Disparities report, 2021). However, the acronym BAME is used in this thesis as the statistical data available has categorised most of the ethnic minorities under the term BAME rather than ethnic minorities (Law Society UK, 2022).

BAME populations in the UK continue growing in size, diversity, geographical dispersion, and population share (Office for National Statistics, 2021). The existing research identifies the main reasons for this as net immigration and high fertility rates, combined with declining mortality rates for settled immigrant groups and the birth of children of mixed race (Wohland et al., 2010). Projections show the total UK population growing from around 59 million in 2001 to 78 million by 2051. Within these totals, the share of white British majority groups is projected to decline from 89% from 2019 to 79%, while that of non-white ethnic groups is expected to increase from 8 to 21% (Office for National Statistics, 2016; Wohland et al., 2010). Results from the 2011 Census indicate an increasingly diversifying community in England and Wales, that has changed greatly since the 1991 census (Office for National Statistics, 2016). These communities include individuals belonging to ethnic groups and born in the UK (i.e., 2nd generation migrants and onwards) as well those who immigrated to the UK (i.e., 1st generation migrants). In 2011, 87% of the population (48.5 million individuals) were born within the UK whereas, 13% (7.5 million people) were born in other countries and then immigrated to the UK (Office of National Statistics, 2016). Figure 2.2 shows the composition of ethnic minorities in England and Wales.

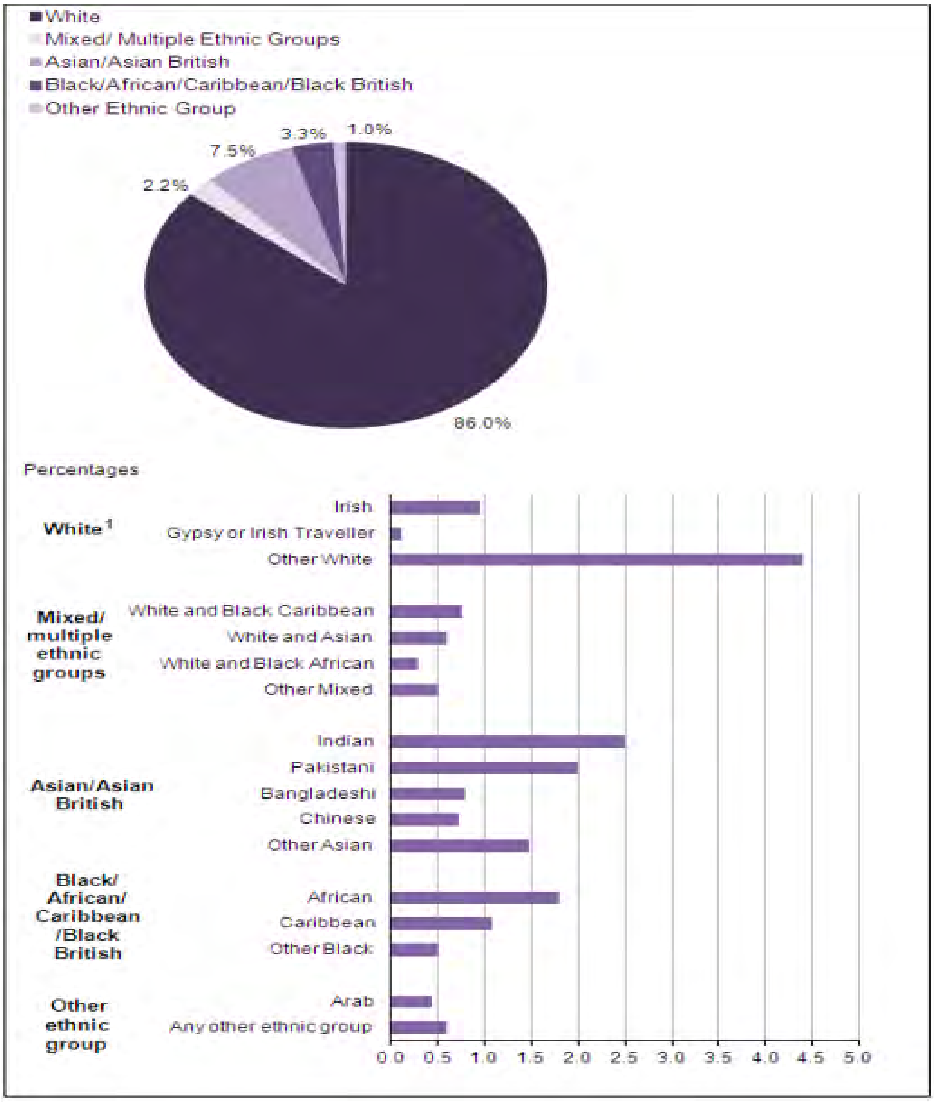


Figure 2.2: Ethnic Minority Groups in England and Wales, 2011 (Office for National Statistics, 2012)

The above statistics give a clear indication of the increasing ethnic diversity in the UK and ageing of that population; however, it is crucial to remember that dementia does not discriminate and ‘one size’ does not ‘fit all’.

Dementia continues to be a growing challenge among the BAME communities (Alzheimer’s Society, 2021). Surprisingly, the correlation between the total BAME population in the UK and exact figures on the prevalence of dementia is not linked. According to the APPG 2013 report on dementia, between 2011 and 2051 the number of ethnic minority people living with dementia in the UK is projected to increase from just 25,000 to about 172,000, and their share in the total number living with dementia is expected to steeply rise from approximately 3% to around 10% over the next 40 years (APPG, 2013). This represents a huge seven-fold increase in the prevalence of dementia among ethnic minorities, which is significantly higher than the growth projected for the UK population (Jones et al., 2020).

Furthermore, this consists of a substantial proportion of people under 65 years affected by young-onset dementia in minority ethnic communities (6%) compared to the white British population (2%) (Knapp et al., 2007). A study conducted by Pham and colleagues at University College London in 2018 compared the incidence of dementia diagnosis rates in UK ethnic groups. The findings of this study are consistent with APPG’s (2013) report on dementia that highlighted that older people with South Asian and Black African-Caribbean backgrounds are more likely to develop dementia compared to other BAME groups and white majorities (Pham et al., 2018). This increased risk is due to the higher prevalence of vascular risk factors for dementia such as cardiovascular disease, hypertension, and diabetes (Justin et al., 2013; Diabetes UK, 2012; Singh et al., 2018).

2.5 Dementia in South Asians in the UK

The term ‘Asians’ refers to people from East Asia, South Asia, and Southeast Asia. In the UK, the term South Asian is a collective term used to refer to people from the Indian subcontinent, Pakistanis, Bangladeshis, and other Asians from the south Asian region (Katbamna et al., 2004). According to Office for National Statistics, 2021 South Asians account for 50% of all ethnic minorities and make them the largest ethnic minority group. Although they may appear similar, they differ in terms of their culture, religion, language, and diet, so it is always important to use terms that accurately reflect how they feel as individuals.

It is estimated that about 25,000 people from BAME communities in the UK are affected by dementia, but these figures are underestimated and expected to grow exponentially over the next few decades (APPG, 2013). A large proportion are from South Asia, who make up over 5.3% of the total UK population (Blackmore, 2018). As such, the collective term ‘South Asians’ refers to people of Indian subcontinent origin and in the UK, Indians, Pakistanis, and Bangladeshis are the biggest minority ethnic group (Lawrence et al., 2008). Although, South Asians are one of the fastest growing ethnic groups in the UK, South Asian people with dementia are a substantially marginalised group who face prejudice from both the general population and the South Asian community itself. They are a demographic who remain excluded from literature and studies documenting the experience of living with dementia and effectiveness of services (Wilkinson, 2012; Hossain, 2020). It is questionable whether the above estimated numbers adequately represent the extent of people living with dementia among the UK South Asian community (Blackmore et al.2018). Yet, it is clear that as the prevalence of dementia increases in the UK, it will also steeply increase among South Asian people in the UK. This is because many first wave South Asians who migrated to the

UK between 1950 and 1970 for employment are now ageing and becoming susceptible to the most crucial risk factor of dementia: age (Knapp et al., 2007; Lievesley, 2010; Hossain, 2020).

Bhattacharyya et al. (2012) have argued that the South Asian population is at higher risk of developing dementia. In addition to age, this is because of diabetes, heart disease, stroke, depression, and low education which are major risk factors for dementia, as indicated by the Lancet Commission 2017, leaving people from South Asia more vulnerable to dementia. Diabetes UK warns that people in the UK from the South Asian diaspora are six times more likely to develop type 2 diabetes (Diabetes UK, 2012). The high prevalence of diabetes and heart disease among older South Asians in the UK predisposes this population to cognitive deterioration, as diabetes mellitus and heart disease also have a role as prominent risk factors for cognitive decline in later life (American Academy of Neurology, 2001; Prince et al., 2016). Bhattacharyya et al. (2012) have argued that this is because the South Asian population is at a much higher risk of developing dementia. This increase in the prevalence of cases of dementia will most certainly add to the burden on healthcare services. With little specific research to evidence needs and wants around care, those caring for PWD will be under even greater pressure to understand the presentation of the disease in the UK South Asian community in order to diagnose and treat the population (Livingstone et al.,2020). Additionally, there is a lack of awareness and understanding on how some South Asians may conceptualise dementia not as an illness but as a spiritual or psychological issue, which can hinder help seeking (Mukadam, Cooper & Livingston et al., 2011). Despite all the risk factors mentioned above, there has been little discussion on how to improve the likelihood of families seeking support to promote an early diagnosis of dementia in South Asians groups (Mukadam et al., 2011).

2.6 Prevalence of dementia in Greater Manchester

This doctoral study was conducted in Greater Manchester metropolitan county in North West England, my local area. Greater Manchester is a county with an increasingly ethnically diverse population. It consists of 10 metropolitan boroughs: Bolton, Bury, Manchester, Oldham, Rochdale, Salford, Stockport, Tameside, Trafford, and Wigan. At the time of the last National Census with publicised data, conducted in 2011 (Office of National Statistics,2011) Greater Manchester's population was given as 2,685,400, and of this, ethnic minorities made up approximately 33% of the total population; that is an 80% increase since the previous Census in 2001 (Figure 2.3 below presents data in a figure from the Census data, 2011). In the January 2020 population data from the Office for National Statistics (Office of National Statistics,2020) Greater Manchester's total population growth rate was 6.7% in 2011, a steady increase from 2,685,400 to 2,858,823. At the time of the 2021 Census, the ethnic makeup of Manchester is expected to diversify further with an estimated 40% increase in BAME groups, particularly within the biggest ethnic groups of Pakistani, Black African, and Arab.

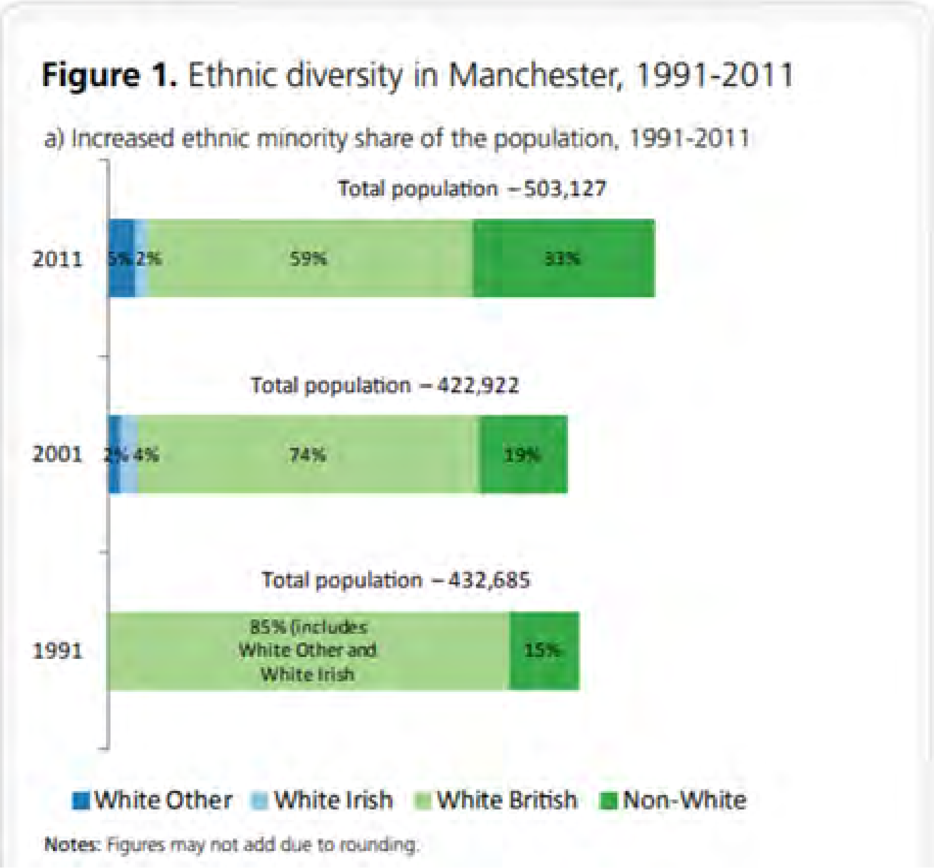


Figure 2.3: Ethnic Minority Groups in England and Wales, 2011 (Office for National Statistics, 2012)

The South Asian population in Greater Manchester is diverse, dispersed, and forms a higher percentage than in the average demographic in England. They make up the second highest ethnic group in Greater Manchester (Office for National Statistics, 2011). Among Asians, the largest ethnic minority group in Manchester, accounting for 9% of the population, is Pakistani. From the 1950s, during the industrial economic boom, many workers from South Asian countries (India, Pakistan, and Bangladesh) came to Manchester to work in the cotton mills (Ballard, 2002). Some of the ethnic groups settled in Longsight and Rusholme and continue to be clustered in these small pockets. However, most other ethnic minority groups are evenly spread across Manchester and the rest of Greater Manchester. Despite the 2021 Census data not yet being released, a huge shift in population patterns has been predicated when compared with the 2011 census, mainly due to the increasing migration of many foreign students and healthcare workers to the Greater Manchester area over the last decade. As a population ages, the demands of the demographic shift and new implementations to address these requirements must be put in place. This will most certainly be the case with current South Asian groups in Greater Manchester who migrated in the first and second wave of migration after World War II.

The figures obtained from Alzheimer's Research UK statistics show that Greater Manchester has more than 33,000 people living with dementia and there are no doubts about the rise in this number considering the ageing population in Manchester (Alzheimer Research UK, 2017). According to the report published by Public Health England (2020) it is expected that 34,973 people will live with dementia in Greater Manchester by 2025. This figure includes the South Asian population. Currently, to treat and care for people with dementia, Greater Manchester is spending around £270 million a year and has a vision to make Greater Manchester the best place to live for people living with dementia. To this end, social care partners aligned with Dementia United (2017) are committed to working together over the next five years. Manchester has a culturally diverse and ageing population. A recent report funded by the Manchester Statistical Society Champion Fund highlighted that currently 9.4% of the BAME Community, which includes South Asians, are over 65 years of age. Due to cultural differences, these ethnic group will have different expectations from the generated needs of the British majority population, which must be considered while planning the healthcare services for the elderly. Therefore, it is important to uncover the real-life experiences of people with dementia and their caregivers from South Asian communities in Manchester.

The above statistics provide an overview of dementia and the growing prevalence rate at the local, national, and global levels, revealing a global concern. The European Union and UK have demonstrated growing agreement in dementia care through the development of policies across countries. As the UK is leading in these efforts with policy development, the next section will focus on policy development on dementia in the UK.

2.7 Policy developments on dementia in the UK

This section provides an overview of the national political developments surrounding dementia. In recent years, dementia has been a prominent focus on the political agenda and has received increased recognition as a national priority in the UK. While the government continues to increase social care funding and resources, the Alzheimer's Research UK's policy team work to ensure dementia stays as a priority on the political agenda and that research funding better reflects the impact that dementia has on individuals, families, and our economy (Alzheimer's Research UK, 2021). Several policy areas raised by Alzheimer's policy experts in England's National Dementia strategy seek to improve diagnosis, access to treatment, and care coordination.

Living well with dementia (2009) was the first National Dementia Strategy in the UK which outlined the government's key strategies to raise awareness of dementia and remove the stigma associated with the condition, and to increase access to dementia diagnosis and improve diagnosis rates and quality of life for PWD and their carers. Subsequently, in 2012, the Prime Minister's ground-breaking *Dementia 2012: A National Challenge* was launched to deliver significant improvements in dementia care and research by 2015. One of the key areas of this initiative, along with other pivotal areas of change, was to improve support for carers and families by increasing awareness among the public thus creating a dementia-friendly community. The government published the successor to this in 2015 which summarised the noteworthy progress and achievements of the 2012 objectives. Some of the crucial successes of this challenge were its role in increasing awareness of dementia by creating one million Dementia Friends and the number of people with a dementia diagnosis was greatly amplified, most significantly, by hosting the G8 summit in 2013. The initiative was also vitally important in enabling improvements to health and social care by highlighting the issue of research and efforts to bring together government, charities, and other organisations. This summit also had an integral role in kick starting the vision to tackle dementia globally by highlighting the need for further initiatives. Despite the significant improvements in the field of dementia between 2012 to 2015, the government wanted dementia to remain a top political priority and therefore set out a new initiative called *The Challenge on Dementia 2020* with further areas where sustained action was to be taken.

The Equality Act 2010 came in force in the UK to legally protects people from discrimination, harassment, and unfair treatment in the workplace and in wider society. Under The Equality Act 2010, all people in Britain including PWD are protected against discrimination and unfair treatment regardless their age, disability, gender, race, religion, culture or belief. Despite the introduction of The Equality Act (2010), it was shocking to see the 'Dementia does not discriminate Report' (APPG, 2013) that, PWD including South Asians and their carers continue to experience health care inequalities, discrimination, and treatment. In many cases, discrimination is embedded in the design and delivery of care and support services (Alzheimer's society Dementia UK, 2014). People from BAME groups including South Asians face significant challenges when accessing support. There is a lack of culturally sensitive dementia services and families can be reluctant to use services that do not meet their cultural or religious needs. As a result, people with dementia from South Asian communities are less likely to receive a diagnosis or post-diagnosis support compared to white British carers. In order to dispel the stigma of dementia to challenge this inequality, Alzheimer’s Society calls for increased awareness, better focus on preventative services, local community action and improved access to services for people from BAME communities (Alzheimer’s society Dementia UK, 2014).

As the proportion of people diagnosed with dementia is increasing, the number of carers will also continue to increase. Along with other key strategies, supporting carers and their feelings, and an ambition to have more employers who support carers to remain in employment were key priorities in the Prime Minister’s challenge on dementia 2020 (Department of Health and Social Care, 2015). The Care Act (2014), the biggest piece of legislation ever to affect adult social care in England, came into force in 2015 after The Equality Act in 2010. This was a turning point in support to recognise the needs of family carers in England. While The Equality Act (2010) aimed to protect individuals from discrimination and promote equality, The Care Act 2014 intended to have a positive impact across the various communities, including South Asians in the UK. However, for South Asians this impact may not have seen as significant due to several reasons. Factors such as cultural beliefs, language barriers, lack of culturally sensitive information and communication channels have contributed to this limited impact (Fernandez, 2020). Additionally, the knowledge gap among the older generations, historical experiences of discrimination and mistrust also contributed to the limited impact (Fernandez, 2020).

Through the NHS *Long Term Plan* (2019), a recent policy development, the NHS is committed to greatly improving the quality of care provided to PWD and their caregivers. To further extend the policy support for PWD and carers, the Alzheimer's Society published, *Fix Dementia Care*, which supports people with dementia to access affordable and high-quality care.

In the UK, since the Prime Minister's Dementia Challenge (Department of Health and Social Care, 2012) was launched, dementia has become a public health priority and there has been considerable progress made in improving health and care for people with dementia and carers. Building on the National Dementia Strategy, the APPG in collaboration with the Alzheimer's Society UK acted as a beacon for legislation and policy making on some of the aspects of dementia that have been overlooked by policy makers. The APPG is a cross party group made up of MPs and peers with an interest in dementia (All Party Parliamentary Group, 2021). The APPG investigated the dementia experiences of underserved members of community and raised important questions regarding the provision of care for the increasing number of PWD from ethnic minority communities, with a predicted seven-fold increase by 2051 (Alzheimer Society, 2013; All-Party Parliamentary Report, 2013). The APPG report has established that there is an urgent need to increase awareness of dementia among BAME communities and highlighted that the 'one service fits all' approach does not work due to cultural differences among the BAME communities.

Comparatively, the Scottish government envisions access to skilled, well-coordinated support for those with dementia and their caregivers. This is seen through the publishing of three national dementia strategies: the first in 2010, which was aimed at enhancing timely diagnosis, treatment, and care; the second sought to improve and strengthen post-diagnostic support; and this was further emphasised in the third strategy enacted in 2017. The plan is now set to enhance the quality of care for people with dementia and their families through further coordinated works in diagnosis, post-diagnostic support, and care coordination (McKenzie et al., 2019).

In North Ireland, various recommendations aimed at improving services for PWD were put forward in a report called *Listening Well* in 2009 by the Alzheimer's Society (2009), which has been factored into the regional strategy on improving dementia services in Northern Ireland. This includes raising awareness on dementia, improving access to information and support after diagnosis, and facilitating further research.

The main challenges posed by dementia have been recognised across all the above-mentioned policy documents. The main themes developed by global policy documents summarises the need to raise awareness and actions to reduce stigma around dementia; for further research, education, and training for workforces; for early diagnosis and preventative, person-centred approaches with integrated care; financial investment; increased support for people living with dementia; and care close to home (Wright and O'Connor, 2018). Although the UK has been the backbone of developing and implementing policies to improve dementia care, the current policy documents show gaps in dementia care with little specific government policy on caring for those with dementia from BAME backgrounds (Wright and O'Connor, 2018). The following sections will explore dementia care in the UK and further focus on caregiving in the South Asian population.

2.8 Dementia care in the UK

The UK exemplifies the worldwide trend of increasing numbers of people with dementia and has demonstrated the growing impact of dementia care which includes the significant financial burden associated with the increasing costs for family members to provide care for their relative with dementia while simultaneously fulfilling other familial needs. Concerns over the growing number of people with dementia, dementia care, and the impact on the economy have been raised by many researchers and policy makers in the UK (Wittenberg et al., 2020). The estimated global societal cost of dementia was US$ 1.3 trillion, and these costs are predicted to increase to US$ 2.8 trillion by 2030 as the number of people with dementia is also predicted to increase (WHO, 2020). As the number of people with dementia increases, dementia care has become a growing challenge not only in the UK but also around the world. According to the Care Policy and Evaluation Centre (CPEC) report commissioned by the Alzheimer’s Society in 2019, the total cost of dementia every year is £34.7 billion per year in the UK. Of this cost, the NHS only fund £4.3, while social care and local authorities’ social services contribute up to £15.7 billion and £5.2 billion, respectively. This leaves a massive deficit of £8.3 billion to be covered by the people with dementia and their families (Wittenberg et al., 2020).

Dementia is already having a crippling effect on the NHS as the cost of care has doubled in the past decade and continues to have a huge implication (Alzheimer's Research UK, 2020). While the government debate continues about the best strategies for managing dementia care, this already high cost is expected to increase rapidly over the next two decades to £94.1 billion in 2040. These costs will continue to rapidly inflate if the system continues to fail at supporting PWD and their caregivers. It is therefore essential that the national government builds progress and introduces strategies for adequately resourced dementia services in the UK.

In the UK, other than the NHS, the social care system is the other supporting stream for people with dementia and their family members. Although NHS covers a proportion of the associated cost free of charge, social services costs on the contrary are supplemented by the family of the person with dementia, a cost which cannot always be met. While in recent years, the funding for social care has increased, demand for said services has risen exponentially, thus resulting in a high level of unmet need. A recent report issued by the UK government on social care funding and workforce (2021), highlighted that in the past decade alone, the cost of adult social care has increased by £8.5 billion while total funding has only increased by £2.4 billion. This therefore, only accounts for approximately one third of the pressures leading to a £6.1 billion deficit. This report also highlighted the vital role that approximately 700,000 unpaid carers play in supporting people with dementia. As per Personal Social Services Survey of Adult Carers in England, 2016-17; It is estimated that 36% caregivers have each spent over 100 hours caring for dementia patients (Alzheimer's Research UK, 2020). However, despite their upmost efforts, these caregivers are still very much in need of the support and critical care services they deserve.

Although the number of people from BAME communities living with dementia in the UK is still relatively small, the projected rapid increase in their number in the coming decades raises important questions regarding the provision of care. In 2013, the APPG produced a comprehensive report on the experiences of BAME communities with dementia (APPG, 2013). This report notes that people who migrated to the UK during the period from the 1950s to the 1970s are now reaching their seventies and eighties and their health needs are also increasing (Jutlla, 2013). Since age is a primary risk factor and dementia does not discriminate, BAME elders are equally susceptible to developing dementia. Moreover, other vascular factors such as type 2 diabetes, hypertension, and stroke also contribute to this high prevalence rate.

One would expect that the disproportionate increase in the number of older people with dementia in the UK from BAME communities would have led to a rise in their demand for dementia services, but this is not reflected in the data. Compared to the high-risk factors and prevalence of dementia, the 2013 report of the APPG on dementia found that people from ethnic minority backgrounds are hugely under-represented when policy makers consider dementia care provision and services. This leads PWD in these communities to be much less likely to receive a timely diagnosis or access appropriate, accessible support than people from the white majority population (Parveen, 2018; Pham et al., 2018). Due to this under-representation, members of BAME communities are thought to be cared for by members of their families in their own homes.

A research study carried out in London by Lawrence et al. (2008) among African-Caribbean and South Asian populations, published in the British Journal of Psychiatry indicates that caregivers in minority groups often possess traditional caregiver ideologies (Lawrence et al., 2018). Strong religious and cultural values are also known to inform this point of view. A good proportion of minority carers who have experience in the nursing profession suggested a natural inclination towards the caregiving role. Caregiving in minority communities can also portray the intrinsic value of their cultural collective identity. This is reflected in the number of South Asians in the NHS and caregiving professions and can also be viewed as the virtue of 'serving', which is seen as fundamental in Hinduism, Christianity, and Islam, the larger primary religious affiliations among the BAME groups in the UK (Lawrence et al.,2008). According to NHS Workforce Statistics (2020), Asian people make up 10.7% of NHS staff.

2.9 Dementia caregiving in South Asians

A study conducted in the UK compared the incidence of dementia diagnosis rates among different ethnic groups and found that people from British Asian ethnic groups were less likely to receive a dementia diagnosis compared to the white majority population (Pham at al., 2018). They further highlighted the limited availability of demographic and epidemiological data on the South Asian population in the UK to inform the actual state of dementia specifically among the BAME groups. The diagnosis rate and help seeking among South Asians are delayed due to multiple reasons, highlighted by many researchers (Bowes and Wilkinson, 2003; Mukadam et al., 2013; Mukadam et al., 2015; Kenning, 2017; Blackmore et al., 2018). The main difficulties in early diagnosis and delayed help seeking were cultural factors and stigma linked with lack of awareness about dementia (Giebel et al., 2014; Moriarty et al.,2011; Werner et al., 2014). The elderly population of South Asian origin who are more susceptible to dementia is predominantly made up of an immigrant population from the 1960s and 1950s. There is a tendency within the South Asian community to look after their elders within the family, which hinders diagnosis and access to medical services (Sagbakken et al., 2018).

Though the number and specific characteristics of the South Asian population caring for their relative with dementia is not clear, an interesting finding from a Carers UK (2011) report suggests that at least 10% of all caregivers from a minority ethnic background are most likely a family member. South Asians are predominantly the heavily populated group of minority ethnic caregivers making up to 2.2% of the total BAME population, with most of these caregivers being responsible for their full-time caring needs (Parveen & Oyebode, 2018). The difficulty in pointing out the individual carers within the minority ethnic population is attributable to the cultural beliefs of the people (Jutlla, 2015). Katbamna et al. highlighted in their research that South Asian participants found it difficult to define the term ‘carer’ (Katbamna et al., 2004). According to their belief system, family members ought to provide support and care to their own. These moral-religious-cultural obligations are referred to ‘seva’ or selfless service. Discussed within Hindu Veda (scriptures), seva is seen as the highest form of dharma or righteousness. The literature around seva, in relation to caring is both, viewed positively (Pagani, 2013) and negatively, often, but not exclusively through the lens of old-age certainty in being cared for (Lamb, 2013) and gendered roles (Snell-Rood, 2015), but not from the experiences of the carer’s perspective.

In the UK for example, carers of South Asian ethnic descent tend to feel more culturally obligated to care for their ageing family than their white British carer counterparts. Lawrence et al. (2008) and Parveen & Oyebode (2018) are of the view that South Asian carers of the ageing population with dementia, tend to hold a more traditional caregiver ideology deeply rooted in their culture as compared to white British carers. The former view caring for their elderly as natural and expected. In this thesis, therefore, the term ‘carer’ and ‘caregiver’ refers to family members who take care of their relatives with dementia either through providing emotional support or nursing them.

The belief of caring for elderly parents is also visible in other communities around the world, such as the African American minority in the USA. Knight and colleagues (2010) in their findings state that African Americans and South Asians tend to feel more culturally obligated to care for their family member with dementia compared to their white American colleagues. Sluder (2020) further explored this and pointed out the frequent misconceptions regarding BAME communities, that the family members are under cultural obligation to take care of their elders and that they can do so with the support of their large extended families. To support this stereotypical misconception, evidence has shown that this assumption has led to the carers not being offered the services they need (Carey et al., 2017). This is most likely due to the clashing ideologies of collectivism and individualism.

In a traditional minority society, a collective approach may be undertaken during caregiving, with care tasks being distributed within a community (Hanssen and Tran, 2018). In contrast, the Western society usually adopts an individualistic approach for caregiving, with care mainly given by main caregivers. Thus, when ethnic minorities migrate to the UK and adopt Western ideologies, collectivism within caregiving evolves, and the previous networks of support disappear, causing care tasks to fall on only immediate family members, while services assume minority caregivers have the support of the wider community (Mackenzie, 2016). This clash of ideologies then results in increased burden for minority caregivers, due to the perceived lack of need of service support (Parveen et al., 2017).

There is a growing body of research about the willingness of South Asian communities in the UK to take care of their elderly parents with dementia (Katbamna et al., 2014; Parveen & Oyebode, 2018). There are number of assumptions about factors attributed to their willingness to care for their own family members, which is deeply rooted in their social and kinship network. The ethnic minority family, especially voiced by South Asians, appear to have a strong cultural stereotype belief in its obligation to provide care for elders. Even though the obligation to care for a family member with dementia is deep rooted culturally, it is important to consider the significant changes to the dynamics of family structure in the British Asian community. The family structure of South Asian families in the UK has been shifting due to the influence of modern individualism; hence, the large extended family support they had is no longer valid. In addition, the 1992 Immigration Act has made it difficult for families of immigrant minorities to unite and support each other. Therefore, the ageing population of the BAME communities may be left on their own in the UK, while their family who would have usually taken care of them are unable to enter the UK due to strict immigration laws passed in 1992 (Parveen & Oyebode, 2017).

Similarly, those fortunate enough to be with their family in the UK are affected by economic changes which increase pressure on working-age adults to move away from their family to find work. In turn, this has influenced a culture change in the way we live and to the ideas of collective communities. The affected members tend to exit and adopt urban cultures' notion of individualism, thus absorbing the cultural way of living in the UK, causing the interconnected nature of South Asian extended families to erode and dissolve at a practical level. With the notions of Western individualism being adopted by the South Asian population, it is essential to understand that individuals may not be willing to care for their elderly due to practical, social, or previously held cultural obligations. When it comes to readiness to perform care duties related to dementia, it has been noted by some sources that the South Asian carers feel no different to their white British counterparts, even though they feel culturally responsible.

While it is evident that a majority of minority ethnic families care for their elderly, the structure of family care among the South Asian communities is difficult to ascertain. However, there are a handful of studies suggesting that while most white British caregivers are the spouse of the person with dementia, South Asian carers are significantly younger and mostly are the adult children of the affected elderly person (Lawrence et al., 2008; Brodaty, 2019; Parveen & Oyebode, 2018). These caregivers often have other dependants; a heavy burden since they must balance between caring for elderly parents, their children, and their employment. Common practice propounds that the designated carer is mostly the appointed next of kin to the older adult. In the majority of cases the next of kin is a male, being either the son or spouse, who accompanies the relative to clinical appointments and speaks on their behalf. However, these persons may not have the required information on the needs of their relative suffering from dementia since they do little of their daily care. The burden of everyday care of dementia patients in the South Asian household often falls on the daughters or daughters-in-law who dedicate long hours of their time to this responsibility. They are often 'hidden carers' who go unrecognised and without support (Knowles et al., 2016). This unprecedented absence of a single identifiable carer in these minority communities makes it hard for the UK government to determine the number of carers who ought to receive support from the UK government.

Under-representation of minority ethnic communities in dementia services is a contemporary issue in the battle against the disease. There is substantial evidence alluding to the fact that minority ethnic communities are under-represented in services pertaining to dementia (Raghavan, 2016). There are multiple attributing factors that undermine the importance of dementia care in minority ethnic groups, including misconceptions by some community members who do not consider dementia an illness and stigmatisation of people living with the disease. Additionally, South Asian communities may encounter several hurdles which further hinder the already low access to services such as lack of care sharing and appreciation of intersectional experience (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Jutlla, 2015; Sagbakken et al., 2018); negative experiences of services in the past (Bowes & Wilkinson, 2003; Jutlla, 2011); lack of culturally appropriate services and language barriers (Bowes & Wilkinson, 2003; Mackenzie, 2006; Mukadam et al., 2011); and not being aware of the existing services offered regarding dementia (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Jutlla, 2011).

Most of these barriers are caused by high levels of illiteracy as well as language barriers. In the South Asian community, only a third of older people above the age of 65 can speak English (Giebel et al., 2016). Of this population, only 21% can further read and write in the English language. Most of this population solely rely on their first language in communicating. Such circumstances make the completion of diagnostic tests particularly challenging. In addition to these low literacy levels and language barriers, there is a lack of awareness about the disease dementia. Many people from the South Asian community link memory loss to old age. Hence, while an individual may show apparent symptoms of dementia, family members may disregard these symptoms as signs of natural ageing. Other symptoms of dementia may also be linked to several Asian religious and cultural beliefs. For example, there is a resounding belief in the Muslim diaspora that neurological conditions are often associated with Djinns or spirits, therefore leading to the dismissal of dementia-like symptoms due to the assumption of possession which leads to a delay in seeking support for the person with dementia (Lim et al., 2018). Overall, such misinformation and ignorance results in the reduced seeking of help from professionals by the affected elderly who are entirely dependent on their caregivers.

The stigma and prejudice associated with the minority Asian caregivers is often two-fold and intersectional (Sagbakken et al., 2018); however, despite the unique caregiving experiences that this minority group face, it is striking to acknowledge that there is a paucity of research delving into the role that South Asian migration in the UK and intersectionality play in caregiving outcomes. Even though the South Asian carers may experience some of the obstacles that their white majority counterparts face, they are subjected to additional challenges such as language difficulties, community barriers, and institutionalised prejudice (Greenwood et al., 2015; Parveen, 2018). Reasons for migration, such as the type of work the majority of South Asian migrants were 'coming over' for, such as employment in cotton mills, and the collective living within their communities in an alien land, perpetuated misinformation and superstitions. As Sagbakken (2017) found, issues such as social class influenced reasons for migration.

Furthermore, the caregivers also go through additional stigma within their community as they take care of their relatives. This is attributed to long-held community view that dementia is a curse, a consequence of bad behaviours from a previous life and there is a shame accompanied by it. Overall, not only do caregivers experience stigma from their community due to the negative connotations of dementia, but also fall subject to the prejudice associated with a minority ethnic status and low socio-economic status attributed to being migrants, overall leaving them prone to discrimination and stigmatisation from all sectors of society (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Jutlla, 2015; Sagbakken et al., 2018). In light of this double jeopardy experienced by South Asian minority families, many caregivers of this ethnic descent experience less successful outcomes as compared to their white British colleagues.

The BAME community and other minorities tend to experience increased risks of ill health, poverty, social exclusion, and unemployment. In surveys carried out by Carers UK, the profession of giving care among the minorities is associated with curtailed opportunities to get an education, employment, and promotions in their employment places (Carers U.K, 2011; Carer UK, 2019 a; Carers UK, 2019b). These factors seem to provide a greater benefit to white caregivers, putting the minorities at higher risk of facing increasing poverty, marginalisation, and discrimination from health and welfare systems. This takes place even though there is no evidence to suggest white British outcomes of caregiving are better than those of their minority ethnic counterparts. The added personal strains minority caregivers go through, however, seems greater than their white British counterparts. This pressure is thus attributed to the South Asian caregivers experiencing more anxiety and depression (Broady, 2009; Parveen et al., 2018).

Therefore, if we are to motivate the South Asian and BAME populations in general to seek help earlier and improve the national ability to provide suitable healthcare on dementia, there is a need to provide them with a joined-up, health and social care culturally appropriate services (Berwarld et al., 2016). At the given moment, there exists no framework for culturally relevant services and precisely translated neuropsychological assessments for BAME communities that would improve the need of dementia services in the BAME population. However, with the increasingly diversifying population of the UK, there is a need for such services to be implemented as soon as possible to avoid a crisis.

In their study, Lawrence et al. (2008) reported that caregivers, when classified according to two significant attitudes, consisted of those who hold a traditional caregiver ideology, akin to sewa, which mainly included the minority ethnic groups, and those that hold a non-traditional caregiver ideology, which comprised mostly white British children. However, Parveen and Oyebode's (2018) research further explored this but found very little evidence supporting this broadly held- ideology and suggested the need for further exploration of the link between cultural obligation and willingness to care amongst minority ethnic communities.

Among those holding traditional caregiver ideology, caring for the elderly with dementia is perceived more as a chance to reciprocate parental support hence bringing about a sense of contentment and reward to the caregiver. Carers holding a more non-traditional caregiver ideology saw taking care of the elderly with dementia as an unprecedented event, which lacked virtue and was a burden, where an absence of reward, loss of personal agency, and increased conflict resulted from the caregiving role generating stress. Stakeholders, including the people with dementia, their families, and carers have, on the other hand, put forward guiding values and principles to be considered when designing and developing services for people with dementia (Dening et al., 2019). These include autonomy in decision making, dignity, respect, justice and equity, safe, effective personal centred care, care for carers, and skills for staff. About two-thirds of the older population in the UK have the community and family members as their primary caregivers; this is more prominent in the minority groups, among them the south Asian population, due to limited access to specialist healthcare or social care services. Data on dementia care has also shown the limited availability in acknowledging the nature of the family carers, their ethnic diversity, and needs that are culturally appropriate and in keeping with their attitudes and beliefs.

2.10 Starting point for the research

I started as a researcher in the area of dementia in 2009 without any previous experience in the field of clinical research. As a novice researcher, I entered this field of research and quickly learnt that the subjective experience of dementia was in its infancy and there were only a handful of people working in the area of clinical research that focused on carers and ethnic minorities. My interest in the area of dementia research evolved over the years along with my professional experience which also gave me the opportunity to work closely with PWD and their carers. From 2009, I was a part of multiple research projects and was surprised to find no representation of people from the South Asian population within it. As part of the National Dementia Strategy, raising awareness about dementia by facilitating dementia awareness campaigns across Greater Manchester, I had the opportunity to engage in many conversations with participants from South Asian communities and saw their eagerness to know more about the condition and frustration about managing care of their family member with dementia on their own. Having worked on multiple dementia projects involving people from the South Asian community and interacting with their caregivers, I identified the crucial need to explore how South Asian caregivers feel about caring for a family member with dementia and understand more about their challenges.

2.11 Chapter summary

Chapter 2 summarised the area for the research topic and the political and socio-economic rationale for choosing this topic for research. This chapter also delved into how this topic has been studied to date and the gaps in existing knowledge. There has been a paucity of research into the caregiving aspects of South Asians looking after a family member with dementia, especially their motives and perception of caregiving. Chapter 3 will now further explore the current understanding of the perspectives of caregivers of dementia especially within the South Asian community and gaps in the existing research to explain the scope of this study.

Chapter 3. Narrative Literature Review

3.1 Introduction and background to the review

This chapter examines the results of a literature search conducted as part of this study to gather evidence to support the scope of the current topic. The review was mainly focused on the research question, and the aim was to provide a rationale for the problem I was investigating, justify the need for further research on this topic, why I chose my research framework, and how I developed my interview guide.

In qualitative studies, especially in interpretative phenomenological analysis (IPA), there are arguments and disputes about the type of literature review, and whether or when a literature review should be conducted due to the inductive nature of IPA (Smith & Osborn, 2003). Traditional literature reviews are done before the primary data collection and are considered as the central components of any inquiry. However, this has been challenged by scholars such as Dunne (2011), Thornberg (2012), Thistol, Hooper and Pauleen (2016), and Thornberg and Dunne (2019). The contentious issue regarding qualitative studies such as IPA, is the methodological recommendation to review theoretical literature and explore empirical evidence after the data analysis to avoid preconceptions affecting data. At an academic level, doctoral-level students are required to exhibit strong knowledge of the research process and to present a compelling justification for the chosen methodology. As such, an initial literature review was conducted in this study prior to data collection as I felt it was important to establish whether the topic being researched had been studied before or not, and if so, by whom, where, when, in what way and for what reasons (Polgar & Thomas, 2013). Having considered the various review approaches, the concept of the narrative literature review emerged as the one that would most suit my research as the selected topic area requires the wider scope of a narrative review, in which less explicit methods are the trade-off for broad coverage and situational choices about inclusion of evidence is a means of gaining an initial impression of a topic area (Green et al., 2006). The narrative literature review approach was mainly utilised as it gives space to the many voices that need to be heard in the context of this research and allows for a concise review of the state of knowledge of this subject and its interconnections. This provided me with the rationale for choosing this approach over a systematic review.

The choice of literature review of this study has followed advice put forward by Smith and Osborn (2003), Thornberg (2012), and Dunne (2011). As a first step, a preliminary literature search was conducted in 2016 prior to the primary data collection. The purpose was to identify existing published work that examined the experiences, attitudes, and needs of people from South Asians, who provide care for a family member with dementia. This search helped to determine the scope of this study, refine the research topic, and provide rationale for conducting an IPA study in this area. This initial literature search helped me to become familiar with the topic broadly, without developing any bias towards any specific theoretical mast. The literature search was repeated during the discussion write-up stage, which enabled me to establish the relationship between the most current study findings and the data, as well as allowing a hermeneutic revisit to the relevant literature around the topic, and a comparison of the research with theoretical concepts and empirical findings (Smith and Nizza, 2022; Gyollai, 2020).

I also searched for previous literature reviews related to this topic area which summarised various aspects of dementia caregiving among the ethnic minority population. A systematic review conducted by Milne and Chryssanthopoulou (2005) presented the significances of dementia caregiving experiences in Black and South Asian communities compared to the experiences of white caregivers in the UK. This review highlighted the consequences of incorporating the findings from USA based studies to investigate the attitudes, experiences, and needs of BAME carers of PWD in the UK. The review also highlighted the pragmatic aspects of generalising the findings from BAME communities in the USA to the UK, due to the differences in culture, cultural characteristics, and the functionality of the healthcare systems in both countries. Later, Johl and colleagues (2016) carried out another literature review to update these findings. This review included studies that explored the caregiving experience of carers from all BAME communities in the UK. Johl et al.'s (2016) review highlighted several complex and cultural factors in relation to BAME caregiver's attitudes and experiences of caring for a family member with dementia. This review not only presented the complexities in conducting research with BAME groups but also provided a few implications for future research such as exploring the experiences of male caregivers and exploring the in-depth experiences of caregiving in a range of geographical locations across the UK.

The current understanding of the perspectives of caregivers of PWD belonging to a particular ethnic minority community in the UK is minimal and reliant upon a small number of studies (Blackmore et al., 2018). The following narrative review, therefore, aimed to summarise findings from the available body of research and drew conclusions from what is known so far about the real-life experiences of South Asian caregivers of PWD.

3.2 Research question

The narrative review question is: ***"What are the experiences of South Asians caring for a family member with dementia?"***

To facilitate an effective literature search, a SPIO framework (Study design, Population, Interventions, Outcomes) search strategy was adopted from Richardson et al., 1995 and are detailed in Table 3.1. This framework involved breaking down the components of research question into keywords, allowing for a systematic and targeted literature search (Richardson et al., 1995). This adapted version of PICOs allowed me to formulate quantitative, qualitative, and mixed method research search terms where the traditional PICO/PEO framework retrieves only quantitative or qualitative research papers to answer the question of the review and achieve an effective literature search.

The main keywords used are listed in Table 3.1 below:

Table 3.1: SPIO Framework

Study Design	Quantitative, qualitative, and mixed methods
Population	Family caregivers of people with any type of Dementia from South Asian cultural background i.e. India and Pakistan
Interventions	Experience of caring for family with dementia, motives of caregiving, willingness of caregiving
Outcomes	Factors affecting taking the caregiver responsibility

3.3 Identifying of the search terms

To understand the literature search strategy process, different textbooks were referred (Benton and Cormack, 2000; Sackett, et al., 2000; Bettany-Saltikov, 2012). I found the librarian- led session on literature search strategies was informative. Initially, web-based databases were searched through the Manchester Metropolitan Library page. The following electronic databases were searched to retrieve relevant journals on the topic: Academic Search Complete, MEDLINE, CINAHL, PsychARTICLES, PsychINFO, PubMed, and Google Scholar. These databases were initially searched with exact phrase ‘experience of

South Asian dementia caregivers’ which only generated a limited number of non-relevant articles. The components of the research question were used to generate the keywords for the search. As outlined in Table 3.2, a comprehensive search continued using the keywords combined with subject heading, free texts and index term of MeSH terms. However, the search generated too many non-relevant results due to the controlled terms of vocabulary. The search was widened with search strategies such as Truncation (*), and Boolean search (AND, OR) which resulted in more relevant results. The search string was further developed with additional combination strategy of a thesaurus of keywords, free text words, and broad text words generated several numbers of studies. The search was then refined using limits to retrieve articles relevant to the research topic. Limiting the search effectively with mapping by the use of “AND” and (OR) restricted it to specific documents containing the two keywords.

Table 3.2: Database and Search Terms

Academic Search Complete (EBSCO) MEDLINE, CINAHL, PsychARTICLES, PsychINFO, PubMed, and Google Scholar	Dementia **OR** Alzheimer’s disease **OR** Vascular dementia **OR** Frontotemporal dementia **OR** Lewy body disease **OR** Young onset dementia **OR** Cognitive impairment **OR** ‘Memory problems’ **OR** ‘Forgetfulness’ **OR** ‘Memory* **OR** *Cognitive* **OR** Forget* **AND** ‘South Asian’ **OR** ‘South Asian in the UK’ OR ‘Indian’ **OR** ‘Pakistani’ **OR** ‘Ethnic Minorities’ **OR** Ethnic* **OR** Minority **OR** ‘South*’ **OR** ‘Asia* OR ‘United Kingdom’ **AND** ‘Experience’ **OR** ‘Motivation’ **OR** ‘Perspective* **OR** ‘Beliefs’ **OR** ‘Attitudes ‘**OR** ‘Understanding’ **OR** ‘Reason’ **OR** ‘Feel’ **OR** ‘Views’ **AND** ‘Caregiving’ **OR** ‘Caregiver’ **OR** ‘Care* **OR** ‘Carer **OR** ‘Family Carer’ **OR** ‘Looking after’ **OR** ‘Taking care’ **OR ‘**Elderly parents’ **OR** ‘Patient, **OR** ‘person’ **OR** ‘Family member’ **OR** ‘Family* Limit to English, between 2000-2019

3.4 Hand searchers and Internet sources

Hand searches were conducted by examining the contents pages, abstracts and reference citation in journals such as The Journal of Neurology, Journal of Geriatrics, and British Journal of Medicine and Geriatrics that specifically focused on dementia care and South Asians in the UK. Hand searching was valuable in supplementing web searches, particularly some of the articles where full text wasn't available electronically. Additional papers have been included after hand searching the list of references in the previous systematic reviews (Milne and Chryssanthopoulou, 2005; Johl et al., 2016) and a scoping review (Blackmore, 2018).

General internet searches in Google and Google Scholar were also effective. In addition to the above, an internet search was conducted on various organisation websites including DoHSC, NICE, GOV.UK, NIHR portal, INVOLVE , Trials.net Alzheimer's Society to locate grey literatures. Web portals were accessed for obtaining healthcare policy documents along with the WHO and National Statistics databases for the statistics required for the study.

3.5 Inclusion and exclusion criteria

An inclusion and exclusion criteria based on the research question was also developed to establish the scope and validity of the review (Meline, 2006; Green, 2006; Torgerson, 2003). The inclusion and exclusion criteria employed in this study helped me to select papers based on their relevance to the topic thus reducing selection bias. However, due to the studies inclusivity of the specific South Asian ethnic group, it was expected that there would be a limited number of empirical studies that strongly matched the selection criteria. Therefore, when delving into previous literature, a broad inclusion criterion was employed to establish rich and high-quality results. As outlined in Table 3:3, the primary selection criteria were:

Table 3.3: Inclusion/Exclusion Criteria

Inclusion criteria	**Exclusion criteria**
Caregivers of people with dementia from South Asians including Indian, Pakistani, Bangladeshi, Sri-Lanka and others classified as South Asians	Non-South Asian studies i.e. other Black and Ethnic minorities
Papers explored family caregivers' experience of caring a South Asian PWD	Papers explored the healthcare providers and paid caregivers experience of caring South Asian PWD
All type of dementia	Stroke, Parkinson's disease or any other condition other than dementia
Published in English	Non-English studies
All primary and secondary studies All research designs and methodologies	PhD Thesis, Policy Reports, Newspaper blogs
Adult caregivers above 18 years of age	Caregiver under 18 years of age
Caregiver and PWD lives in the UK	Family members live abroad
Articles published from 2000 onwards	Articles published before 2000
Research studies conducted in the UK	Research studies conducted outside the UK

The time frame of the data search was initially set to include studies published within the last 10 years to keep the focus on current knowledge. As the search did not yield enough studies, I extended the time frame set for this search from year 2000 onwards. Non-English studies were excluded due to the limited time and the expense involved in translating the data. Setting a language limit in the selection criteria may introduce publication bias; however, this will be acknowledged as a limitation of the study. Research studies from countries outside the UK were also excluded as the focus of this review was within the context of UK dementia care and there are considerable variations within diversified cultural, linguistic, and religious populations.

3.6 Results of the study search

The initial literature search across 7 databases yielded in a pool of 3301 papers. Following the removal of duplicates and applying limit filters based on abstracts, titles and full texts, a total of 77 studies were selected to establish the specific inclusion and exclusion criteria. 17 studies were excluded due to non-South Asian samples, 15 excluded due to other exclusion criteria such as language, timeframe, and type of articles. 21 studies were conducted outside the UK thus were excluded from the final list due to the cultural differences and variations in healthcare system in the UK compared to other countries such as USA, India and Pakistan and the difficulties in generalising the findings from BAME communities in other countries and attributing these to the UK. The reference lists of the studies were also reviewed to identify additional articles which were not found in the initial database search. In total, 11 studies were included in the final review according to their relevance to the aims and objectives of the review.

The PRISMA flowchart has been utilised to illustrate the various stages of the literature search process, as detailed in Figure 3.1. Although the PRISMA 2009 flow diagram is primarily employed as a selection parameter for the systematic review of studies that evaluate the effects of health interventions, as recommended by Baethge et al. (2019), I have chosen to integrate this feature of systematic reviews in my narrative review process to enhance transparency and rigor. Table 3.4 provides an outline of the forms of review I eventually settled on.

.

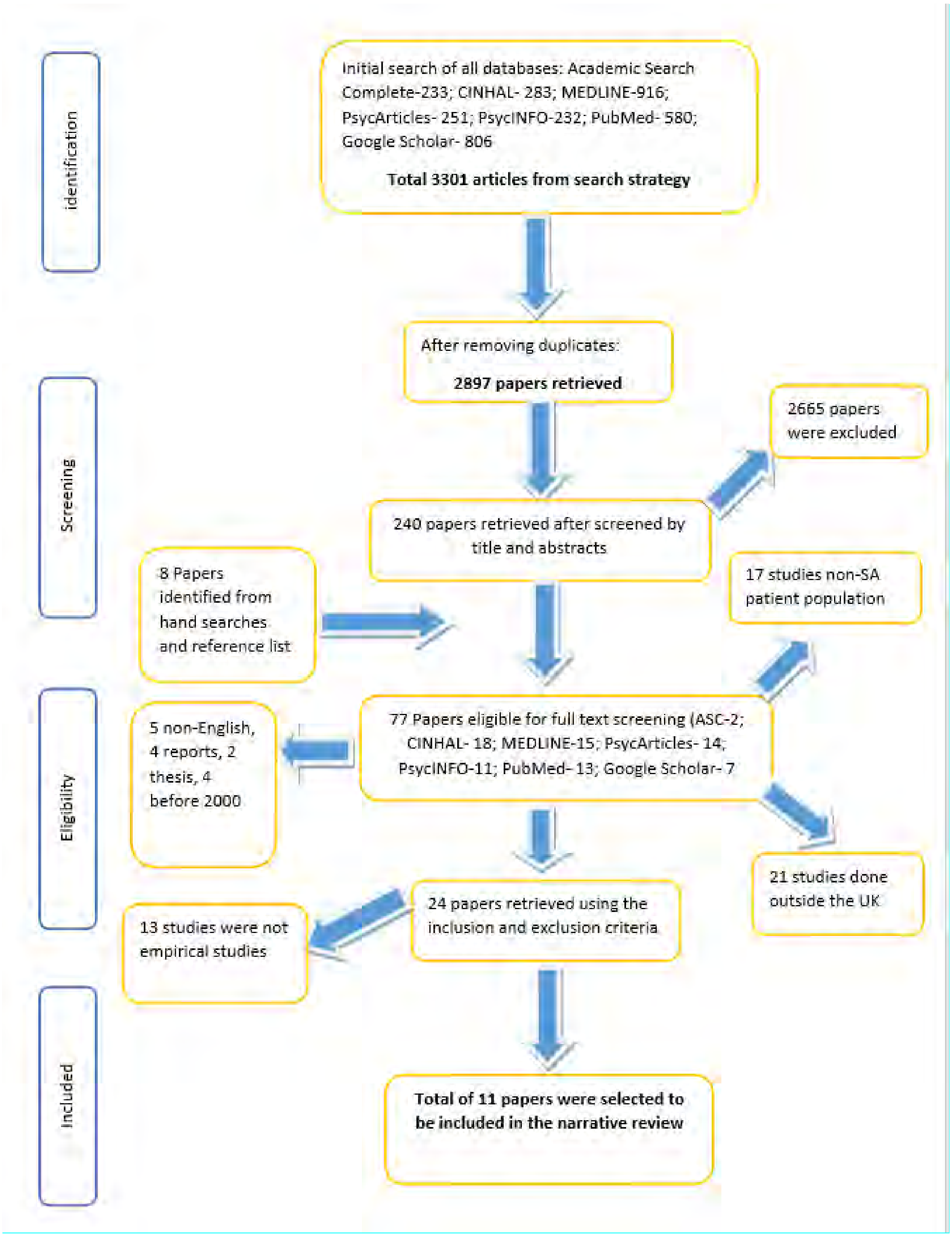


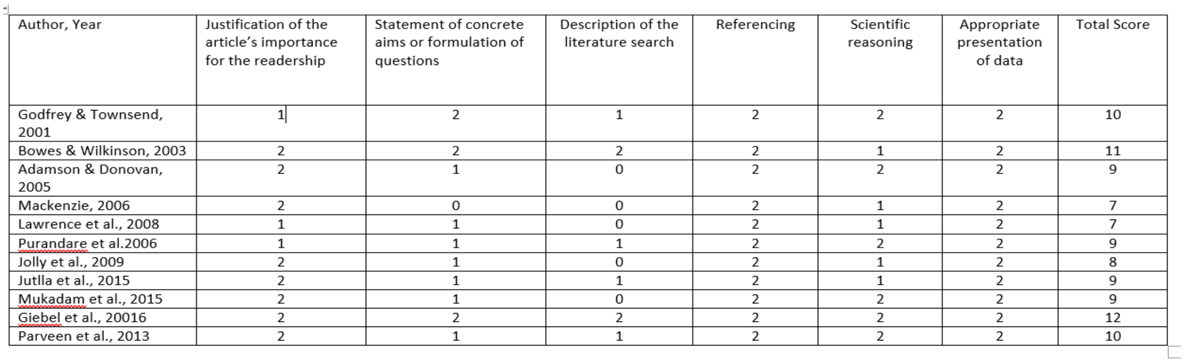
Figure 3.1: Flow Chart of the Literature Selection Process for the Present Study

3.7 Appraising the papers

Most studies shortlisted for this review were conducted based on a qualitative methodology and used semi-structured interview as the data collection method. The participants in the literature review had a range of demographic data, age ranged from 18 to 83 years. Eight studies adopted qualitative methodology, while three studies used a mixed method approach. All studies were conducted in a community setting with a sample population including family carers of PWD from South Asia communities in the UK. All studies explored the South Asian family caregivers' views on dementia and caregiving.

The traditional systematic review style would involve adhering to stricter parameters on the type of research I could use, and this could have limited the type of literature I intended to access. Although different approaches and quality appraisal tools are available for systematic reviews, there are not many tools available for appraisal and evaluation of narrative reviews. In this literature review, I have used SANRA—a scale for the quality assessment of narrative review articles. SANRA is a simple and brief quality assessment instrument (Appendix: 1) developed by Baethge et al., 2017 to assist authors in writing narrative reviews. The quality of the narrative review articles was assessed based on the three scoring options, 0, 1, 2 against six questions (see Table 3.4 for a summary of SANRA score for each paper). SANRA quality assessment intended to provide a swift and pragmatic sum score for quality of narrative review articles (Baethge et al., 2017). Table 3.5 provides a list of paper selected for inclusion in the narrative review.

Table 3.4: Quality Assessment Results According to SANRA Scale



Author, Year	Justification of the article's importance for the readership	Statement of concrete aims or formulation of questions	Description of the literature search	Referencing	Scientific reasoning	Appropriate presentation of data	Total Score
Godfrey & Townsend, 2001	1	2	1	2	2	2	10
Bowes & Wilkinson, 2003	2	2	2	2	1	2	11
Adamson & Donovan, 2005	2	1	0	2	2	2	9
Mackenzie, 2006	2	0	0	2	1	2	7
Lawrence et al., 2008	1	1	0	2	1	2	7
Purandare et al.2006	1	1	1	2	2	2	9
Jolly et al., 2009	2	1	0	2	1	2	8
Jutlla et al., 2015	2	1	1	2	1	2	9
Mukadam et al., 2015	2	1	0	2	2	2	9
Giebel et al., 20016	2	2	2	2	2	2	12
Parveen et al., 2013	2	1	1	2	2	2	10

Table 3.5: Study Overview

Author	Year/ country	Study design	Sample size	Sample and Settings	Data collection	Main findings
Godfrey & Townsend	2001 UK	Qualitative	25	Community N=12 carers; Pakistani 7, Indian 3, Bangladeshi 1 & East-African Asian	Exploratory; in-depth interviews, individual and focus group interviews	Understanding of the barriers to respite care services experienced by SA families caring for a relative with dementia
Bowes & Wilkinson	2003 UK	Qualitative case studies	11	Community 11 interviews with carers 4 case studies of South Asian patients	Semi-structured interviews	-Need for culturally sensitive response from support services -Lack of awareness about the dementia -Negative experience about the service provision -Additional responsibilities -Isolation from wider contacts -Caring role is obligatory
Adamson & Donovan	2005 UK	Qualitative grounded theory	36	Community n=15 (42%) South Asian carers of people with dementia	In-depth interviews	South Asian participants talked about caring for family as a cultural norm and wider families were more likely to live together to facilitate this.
Mackenzie	2006 UK	Qualitative study	21	Community n=11 Pakistani and 5 Indian caregivers of PWD	Semi-structured interview	Stigma-Caring identified as religious obligation to the family and faith. Dementia as a mental illness. Religious and spiritual influence. Hiding the dementia diagnosis and person Isolation to avoid rejection Mechanism to protect family reputation
Lawrence et al.	2008 UK	Qualitative study Grounded theory	32	Community n=10 (31%) South Asian carers of people with dementia	In-depth interviews	South Asian carers possessed a traditional caregiver ideology, conceptualising caregiving as natural, expected and virtuous. This informed their attitudes towards formal healthcare services.

Purandare et al.	2007 UK	Cross-sectional study	246	Community n=191 (78%) South Asians	Questionnaires Semi-structured interview	Lack of knowledge and understanding about dementia and awareness of service provision is still ongoing among South Asians
Jolly et al.	2009 UK	Qualitative study	24	Community and Health Care Provider n=2 focus groups of family caregivers of PWD 8= health care provider	Semi-structured interview	Lack of knowledge and understanding of dementia Stigma, Mistaking symptoms with old age Carers remaining isolated Service provision Lack knowledge of dementia among GPs Lack of cultural awareness, including language barriers
Jutlla	2015 UK	Qualitative study	12	Community South Asian Sikhs caring for someone with dementia and living in Wolverhampton, UK Community	Semi-structured interview	Understandings participant's migration experiences and identities is important for understanding family carers experience of services when caring for someone with dementia
Mukadam et al.	2015 UK	Qualitative study	53	Community South Asians aged 18–83 years	Semi-structured interview	Stigma around dementia was linked to ideas of 'madness' a lack of physical explanations and a lack of treatment. Barriers to help-seeking were that memory problems were an inevitable part of ageing. Denial of symptoms was evident in order to maintain position in the family and community, and due to fear of institutionalisation.
Giebel et al.	2016 UK	Mixed methods	35	Community n=Three groups—South Asian, over 60 years: without memory problems; memory problems not consulted GP; memory problems had consulted GP	Questionnaire Semi-structured interview	Those who had not consulted a GP often considered memory problems to be given by God and did not identify medical support as appropriate for them. Those who had attended a consultation with GP identified forgetfulness and loss of social meaning as symptoms of dementia.
Parveen et al.	2013 UK	Cross-sectional survey	235	Community n=235 162-White British 73-British South Asian	Survey	Socio-cultural stress model Coping associated with anxiety and depression Motivational factors Implication of culturally specified interventions to reduce caregiver stress

3.8 Synthesis of the Literature findings

After the selection of primary research papers and appraisal, the next stage of this narrative review is to summarise the findings of the selected studies by interpreting the findings of individual studies and identifying the differences and similarities of the outcomes. The goal of this narrative review is to bring together all the existing primary research studies focused on caregiving experience of South Asian dementia caregivers and address the topic in a wider way and provide a conceptual description of the research topic (Harden, 2010). Although there is a range of methods that are available to synthesis such as a narrative summary, thematic analysis, meta synthesis for different types of evidence, I have utilised a thematic analysis in bringing together the literature findings as outlined in a theme matrix, Appendix 2. The research findings in relation to each of these themes will now be presented.

3.8.1 Cultural factors affecting caregiving

On review of the literatures, it was identified that caring for a family member with dementia places huge psychological, physiological, and emotional strain on the family members. There are a handful of studies highlighting that the caregiving experience is different between the ethnic minority groups due to traditional ideologies associated with the role. A study conducted by Bowes and Wilkinson (2003) examined the views and experiences of dementia among older South Asians. This study conducted an in-depth exploration of four case studies of South Asian PWD as well as their families and carers (Bowers & Wilkinson, 2003). This study aimed to explore the central issues of service support; family carers in this study highlighted that caregiving was considered as a natural obligation. Families portrayed a strong sense that they wanted to look after their family member with dementia in their own home.

These findings were further explored by Adamson and Donovan (2005) who examined the experiences of ethnic minority caregivers of PWD. This study investigated the cultural norms associated with the caregiving role within the South Asian communities using a grounded theory approach. Semi-structured interviews with 36 BAME caregivers including 15 South Asian caregivers, found that most of the carers indicated that the caregiving role is ‘normal’ and an extension of their existing role. While this study highlighted the existing concepts of traditional caregiver ideologies, this topic was further expanded by Lawrence et al. (2008) who investigated the cultural attitudes and beliefs surrounding the caregiving role. This was the first study in the UK to identify the patterns of caregiving in dementia across the ethnic group. Lawrence and her team interviewed 32 carers of people with dementia using a qualitative grounded theory approach. This study revealed that many South Asian carers held strong traditional ideologies as part of their identity, and they prioritised the care recipient needs over their own needs.

3.8.2 Lack of awareness about dementia and services on offer

Lack of awareness about dementia among South Asians in the UK has received considerable research attention over the years as one of the main barriers in tackling dementia. There appears to be generally lower levels of knowledge and understanding about the nature of dementia and available treatment options among South Asian communities compared to the white population in the UK. Bowes et al.’s (2003) study highlighted that due to a lack of knowledge about dementia they were isolated from services, community, and family life.

To explore this topic further, Purandare et al. (2007) captured the results from a survey which examined the knowledge of dementia among South Asian older people in Manchester. The survey was conducted among 246 older Caucasian and Indian people without dementia who were users of day care services for seniors in Manchester. The study found that older Indian people were significantly less knowledgeable about dementia than their Caucasian counterparts. The authors of this study concluded that lack of knowledge about dementia among older Indian people in Manchester may be one of the reasons for their relative absence in the local dementia treatment clinics.

Similar observations have been made in a two-year research project carried out with the carers of older people with dementia from South Asians background in Wolverhampton by Jolley et al. (2009). The main findings from this study reported that lack of knowledge and understanding about dementia and awareness of service provision is still ongoing among South Asians. However, this study shows variability in knowledge between South Asian families and between generations. To summarise the up-to-date findings, a review article published by Giebel et al. (2014) extracted information from 18 studies published from 1984 through to 2012 on South Asian older adults in the UK with mental illness or dementia and their family carers. The authors were particularly interested to document understandings of mental illness and dementia, and patterns of services used by this ethnic minority group. This study further supported the previous findings regarding lack of knowledge of dementia and mental illness, lack of awareness of local services on offer, stigma, culturally preferred coping strategies, and difficulties with communication as the main barriers to obtaining culturally appropriate mental healthcare for older South Asians suffering from dementia.

Mukadam et al. (2015) conducted another qualitative study on a larger population utilising IPA. Although this study's findings reported an improvement in recognising memory problems among South Asians, there were many barriers reported when trying to access services. The findings from another study conducted by Parveen et al. (2017), reported parallel findings that support the previous results. Due to the limited awareness about dementia, many older people with dementia have remained hidden from health and social care services. Recently Blackmore et al. (2018) conducted a scoping review to identify the gaps in the evidence around the priority areas of dementia in the UK South Asian population; this highlighted that lack of awareness is still an ongoing issue among South Asian communities in the UK.

3.8.3 Stigma of dementia among South Asian caregiving

Another distinct perception noted in many studies was the influence of stigma associated with diagnosis and decisions about accessing support services. Often this is not due to societal attitudes but is internal to the community itself. Many family carers from ethnic minorities are more concerned that a formal diagnosis of dementia will bring shame upon the family (Mackenzie, 2006). In this study Mackenzie explored the experience 11 Pakistani and 5 Indian caregivers of people with dementia and found religious and cultural stigma associated with causes of dementia. Findings from Mukadam, Cooper & Livingston (2011) study was also correlated to Mackenzie's study conclusion. This includes "not conceptualising dementia as an illness, believing dementia is a normal consequence of ageing, feeling that caring for a person with dementia is a personal or family responsibility and stigma attached to acknowledging dementia" (Mukadam et al., 2011). This study had a small sample of 18 family carers of people with dementia, 64from the minority ethnic groups in the UK, which included five South Asians. This study compared the impact of culture and ethnicity of BAME groups with the white UK-born population in help-seeking for dementia symptoms.

Later, Mukadam et al. (2015) conducted a follow-up study with a larger sample of 53 South Asian family caregivers to further explore their interpretation of dementia symptoms and the barriers behind seeking medical help for these symptoms (Mukadam et al., 2015). This study concluded that South Asians in the study were unable to define dementia and they related the symptoms of the condition to madness. Although Jutlla's study (2015) expected a change in South Asian groups' awareness about dementia diagnoses, the findings from the experience of 12 Sikh dementia caregivers in Wolverhampton were similar to Mckenzie's (2006) and Mukadam et al.'s (2015) conclusions. Giebel et al.'s (2016) study aimed to implement a specific dementia tool, The Barts Explanatory Model Inventory for Dementia (BEMI-D), for use with people with dementia in the South Asian population highlighted that the cultural or religious appropriateness of the services on offer were unique to people belonging to ethnic minorities.

Using a socio-cultural model of stress and coping, Parveen et al. (2017) found that "British South-Asian caregivers were younger, had significantly higher levels of familism (need of the family is more important), used significantly more behavioural disengagement and religious coping, and reported having significantly less support than White British caregivers". This same study (2016) noted that in South Asian communities there was no word for dementia. It is often considered just a normal part of ageing and no help is sought until symptoms become severe. Indian participants in group discussions sponsored by the University of Bradford mentioned family, religion, cultural stigma (shame), and language barriers as explanations for why families with members living with dementia do not seek help from community services that are available to support them.

All the studies mentioned above highlighted the high degree of stigma associated with dementia among South Asians in the UK, and the possible factors that constitute notions of stigma: language barriers, migration, and ethnicity, societal perception about dementia, ageing, and socio-cultural and religious factors.

3.8.4 South Asian caregivers' experiences of dementia

Studies that have examined South Asian caregivers' experience of dementia have highlighted the increased burden associated with caregiving on family members. Evidence from studies shows that the extent of the caregiving burden is experienced quite differently by carers in the South Asian population compared to those in the white population of the UK (Godfrey & Townsend, 2001; Bowes & Wilkinson, 2003; Adamson & Donovan, 2005; Lawrence et al., 2008). In interviews with 10 caregivers, Bowes and Wilkinson (2003) found that South Asian caregivers experienced intense psychological and physical challenges, consistent with findings from a previous study conducted by Godfrey and Townsend (2001) where 11 South Asian family carers described their stress associated with caregiving, and how it had a negative impact on their family relationships. South Asian caregivers in this study also had to deal with PWD behaviour and sleep disturbances. Multiple demands of caregiving led to social isolation and increased burden on the immediate family and other informal carers in this study. Because of this, ethnic minority carers are at a particularly high risk of developing depression and stress-related health complications. Women carers, especially daughter-in-law carers, expressed their concerns about the lack of appreciation and lack of support from their husband and other family members. Godfrey and Townsend (2001) further explored the concerns of daughter-in-law carers and point out their "invisible" status in the family. When Jutlla re-investigated this concern (2015), the author hoped to see a change in the ideology of traditional gender roles, but the results were consistent with previous studies.

Chapter 4. Theoretical and Conceptual Framework for this Study

While reviewing the existing literature on this topic, questions naturally emerged requiring an understanding of how South Asian caregivers experience the phenomena of caring for an immediate family member with dementia. As pointed out at the beginning of this chapter, due to the inductive nature of IPA, conclusions of an IPA study are based on the data rather than developing a new theory or testing an existing theory. Although it is recommended that the IPA researcher approach the research topic without being aware of the existing theories and concepts, it is not always possible for the researcher to approach the area in question without predetermined beliefs and presumptions (Smith & Nizza, 2021) but a pragmatic approach to theories and concepts shape data collection and analysis of the data (Charmaz, 2008). The suggested approach is that the researcher enters the research setting with an open-minded approach to the data but not influenced by any prior knowledge of theories.

For many, theories are a fundamental means of describing, forecasting, and understanding a certain phenomenon. Theoretical frameworks present and indicate particular theories that expound why the research problem under study exists. It is also a firm structure that provides a foundation and support to a theory within a research study. Therefore, the theories and concepts relevant to the topic have been used to expand the understanding of the chosen phenomenon in this study. The theories that are the base findings from this study will be looked at in depth during the discussion chapter. Using theoretical/conceptual frameworks are validating methods for enhancing transferability and adding rigour to particular research because theories tend be incredible versatile allowing them to be easily applied to several settings, even beyond the researcher’s specific research field. Secondly, a theoretical framework can also aid in the researcher’s thought process during significant decisions and help ‘make sense’ of data, by explaining the explicit and implicit linkages in the perspectives of study participants.

A consistent theme evident from the narrative review was that South Asian family caregivers experience a significant burden in providing care to family member with dementia. Although there is an abundance of research exploring the caregiver burden of family caregivers providing care to patients with mental health illness and terminal cancer, there is a dearth of findings relating to South Asian caregiver burden when caring for a family member with dementia. The predicted sharply increasing rate of older adults with dementia from South Asian communities presents the UK with a pressing need to deepen its understanding about how caregivers from distinct cultural backgrounds are differentially affected by caregiving. There are a number of studies that highlight that those older adults with dementia from ethnic minority groups will have a greater functional limitation compared with the white majority (Sinclair & Gomez, 2006). The next section discusses clusters of theories and conceptual models which can contribute to understanding the experience of South Asian caregivers of family member with dementia. The burden of dementia care was explored within the framework of the general stress theories.

4.1 Stress, Appraisal, and Coping Theory – Lazarus and Folkman (1984)

The concept of caregiver burden was first proposed as subjective and objective burden by Hoenig and Hamilton in 1966 cited by Lue et al. (2020). Later, Lazarus and Folkman (1984) extended this concept to a theoretical framework and the current evidence base on caregiver burden has mainly been developed on stress research by Lazarus and Folkman (1984). The historical evolution of the concept of caregiver stress theories is the stress and coping paradigm espoused by American psychologists Richard S. Lazarus and Susan

Folkman (1984). In their theory of Stress, Appraisal, and Coping, Lazarus and Folkman presented the theory of stress by emphasising its psychological dimension and possible predictors of caregiver burden.

In their findings, Lazarus and Folkman (1984) emphasised that an integral part of the human stress response is perception and cognitive appraisal. Lazarus and Folkman argued that an event must first be appraised as threatening in order for it to be truly perceived as stressful for an individual (Lazarus & Folkman, 1984). Lazarus and Folkman’s (1984) Stress, Appraisal, and Coping Model is one of the first transactional models that explored caregiver stress and explained the possible predictors of caregiver burden in dementia and their influence. Figure 3.2 illustrates the key features of the appraisal model: the transaction between how a person cognitively appraises and reappraises a situation and their resultant cognitive, emotional, or behavioural response (coping) and experience presented in this model. Lazarus and Folkman extensively explained that stress or distress occur when there is a perceived mismatch between the perceived or actual demands of the situation, interpreted by an individual, and the coping resources available to the individual to deal with the situation. Despite three decades passing since the creation of this theory, the influence of Lazarus and Folkman’s (1984) transactional theory of stress and coping is still perceived as crucial and thus, it remains a pillar of psychological stress and coping research across multiple fields.

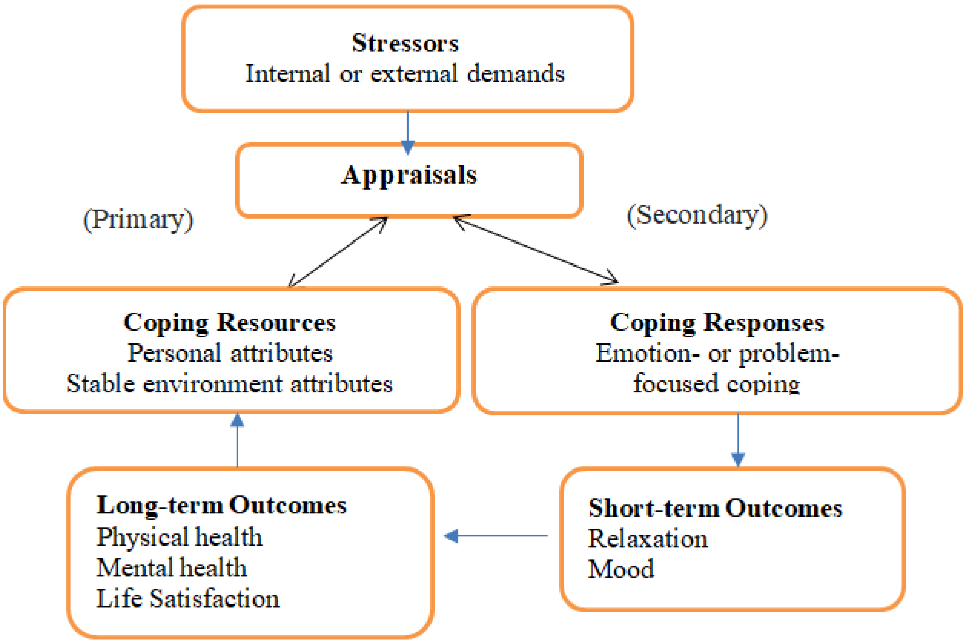


Figure 4.1: Transactional Model of Stress and Coping (Lazarus & Folkman, 1984)

4.2 Caregiving Stress Model, Pearlin et al., 1990

Another framework by Pearlin et al. (1990) notably utilised a specific application of the stress-coping model of Lazarus and Folkman (1984) in which they extensively analysed the concept of caregiver stress, by incorporating the difficulties associated with care into a model of care for patients with Alzheimer's disease. Pearlin and his colleagues (1990) implied that caregiver stress is often attributed to the unequal exchange of assistance among people with close familial ties, which in turn results in caregiver feelings of tension, guilt, and fatigue. Pearlin et al. (1990) outlined that the Caregiving Stress Model is a multidimensional phenomenon, citing the four main domains that contribute to carer stress. The framework of care-background and context of the stress process, includes firstly, characteristics of caregiver and their family, support, and the impact of the life events. All other steps in the process are influenced by these key characteristics of the carer and caring context. Second, Stress situations – Primary or first-degree stresses relate directly to the illness. Indicators of the primary stressors are the cognitive status of the persons with dementia, their problematic behaviours and precautions and supervision required to deal with them, and the extent of their dependency on the carer for ADLs and IADLs. Next, Secondary roles – strains that include family dynamics and conflict and stress from the carer's life outside the caregiving role including their employment and recreational. These are not secondary in the sense that they are less potent, but because conditions surrounding the primary stressors are productive of secondary stressors. Finally, Intrapsychic strains are the carer's self-concept and psychological state. (Pearlin et al., 1990)

Coping skills and social support may help at various stages of the stress response. According to Pearlin et al. (1990), primary stresses are difficulties and challenges related to caring. Secondary stressors are divided into two types: external stressors, which include duties and activities outside of caring, and intrapsychic stressors, which include self-concept erosion (Pearlin et al., 1990). Coping skills and social support may help at various stages of the stress response.

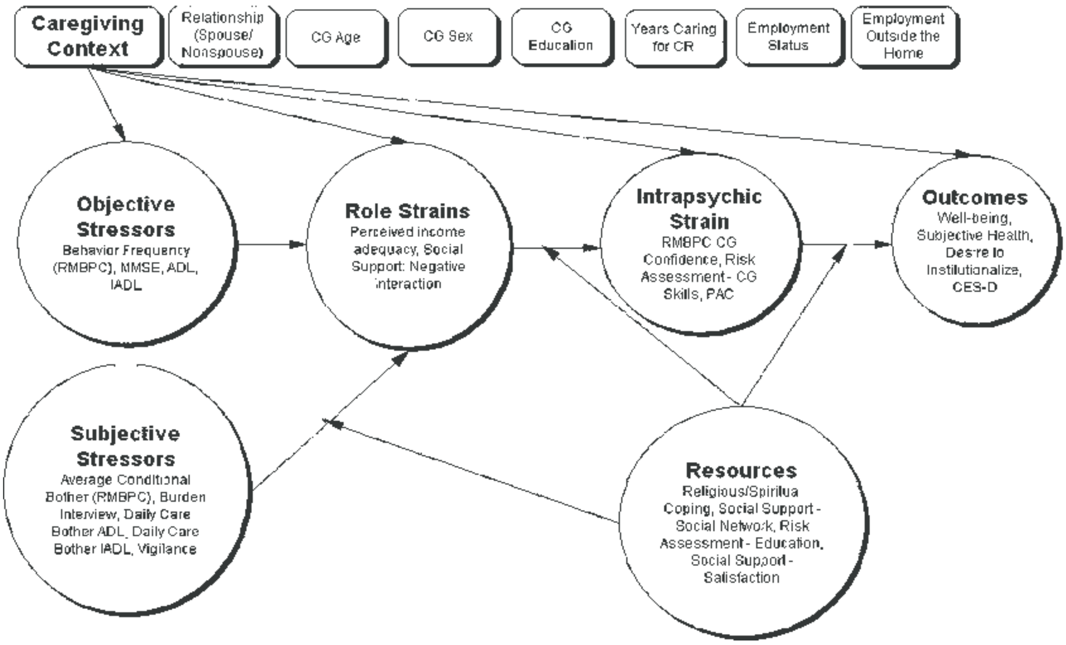


Figure 4.2: Stress Process Model based on Pearlin et al.'s (1990) original conceptualisation

4.3 Sociocultural Stress and Coping Model – Knight and Aranda (1997); Knight and Sayegh (2010)

In order to tackle the unique challenges experienced by ethnic minority caregivers, Knight and Aranda (1997) developed the sociocultural stress and coping model which provides a framework for understanding how ethnicity and culture play a role in caregiver stress and coping processes across diverse cultural groups. These authors employed the Stress, Appraisal, and Coping Model by Lazarus and Folkman (1984) which holds variables such as appraisals, social support, and coping style to account for the consequences of stressors on people, as the basis for this newly introduced model. Although initially Aranda and Knight (1997) framed their framework on the dimensions of familism and individualism (concepts which are deeply rooted within immigrant communities) as the focus to measure cultural values and test that their influence has increased, the multidimensional nature has become a more complex appraisal.

The predicted rapid increase in older adults with dementia from South Asian communities presents the UK with a pressing need to deepen its understanding about how caregivers from distinct cultural backgrounds are differently affected by caregiving. Knight and Sayegh (2010) argued about the urgent need to deepen our understanding on culturally diverse caregiving based on a theoretical and conceptual framework. It was felt that South Asians in the UK very much fall under this category as the urgent demand associated with dementia caregiving is expected to grow rapidly in the next decade. Therefore, expanding comprehension and understanding of such a phenomenon based on the principles of a theoretical and conceptual framework on how South Asian caregivers are differently affected by caregiving demands, and the extent of variation of caregiving across diverse ethnic and cultural groups, will help to inform the specific interventions and services aimed at reducing caregiver distress among individuals from different cultural backgrounds.

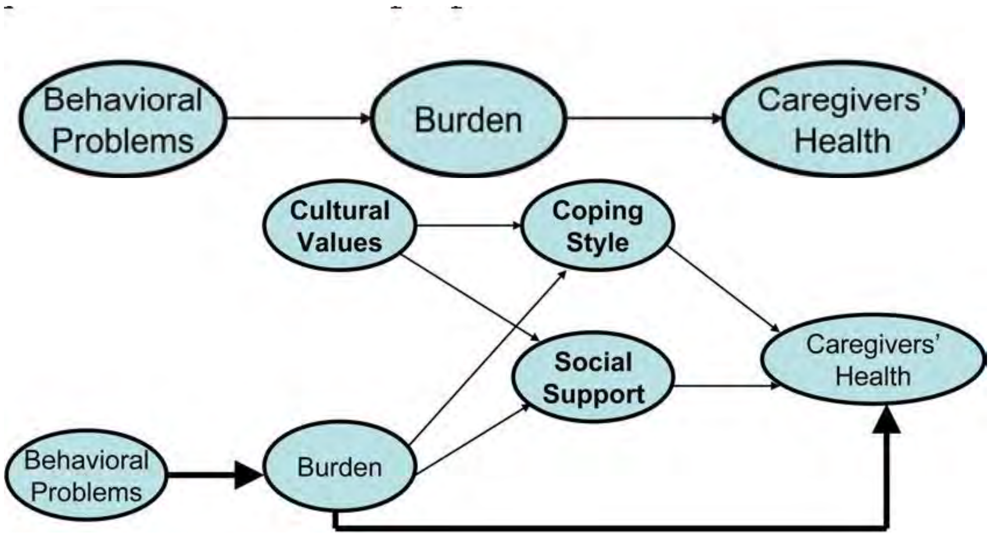


Figure 4.3: The Revised Sociocultural Stress and Coping Model for Caregivers based on Knight and Sayegh (2010)

This chapter is a summary of the findings from a range of studies that have explored factors affecting the experience of South Asian caregivers of PWD. It is obvious with this literature review that there remains a lack of research exploring the experience of South Asian caregivers with dementia. It is therefore imperative that this type of research is carried out to add greater knowledge to what is known about the holistic care of PWD. As a consequence, the research question for this thesis is:

"How do South Asian Caregivers perceive their experience of caring for a family member with dementia?"

Chapter 5. Methodology

5.1 Introduction

In the previous chapter, the narrative review highlighted the knowledge gaps in the topic concerning the experiences of South Asian caregivers of PWD. The purpose of this chapter is to discuss the rationale for adopting IPA as the most appropriate methodology in relation to the aims and objectives of my thesis as well as my role as a researcher. This chapter gives an outline of the importance of qualitative research and the other methodological approaches that were considered and the reason why they were not utilised for this study. This chapter further explores how the ontological and epistemological dimensions of IPA informed the research questions of the study, then progresses to discuss IPA's intellectual origins emphasising the theoretical underpinnings: phenomenology, hermeneutics, idiography and the ways in which IPA draws on these theoretical approaches to inform its distinctive epistemological framework. This chapter also provides details of ethics, recruitment, data collection, interview process, and data analysis methods employed in this study.

5.2 Rationale for the qualitative research methodology

In this thesis, I have chosen the qualitative framework as the research methodology. Although there is growing interest in studies exploring the experiences of South Asian caregivers of PWD, there is still a clear gap in the current findings within the context of South Asians' perspectives, knowledge, and attitudes to dementia. Most of the existing studies are conducted on this topic place the caregivers under the broad BAME category. When researching real life experience, placing BAME as a wider collective group does not acknowledge the specific diversities within the South Asian community (Roche et al., 2020). Moreover, this thesis aims to provide a richly descriptive account of caregiving experiences, not to quantify those experiences (Pietkiewicz & Smith, 2014). In this study, the meaning of this experience is central, and the focus is to explore the details and complexity of those meanings.

Over the last two decades, there has been an increased use of qualitative methods in healthcare research (Greenwood et al., 2019). Traditionally, healthcare research and experimental psychology mainly relied on quantitative studies testing the hypotheses of a treatment outcome and quantifying the situation. Quantitative research evidence strengthens our understanding of the cause and nature of certain disease condition. It also provides information about the safety and efficacy of interventions. However, quantitative studies are inadequate to take the researcher to the heart of the patient’s real-life experiences. For this study, the role of qualitative approaches is more relevant because it is concerned about the quality of experiences rather than the causal relationships. The qualitative health research enhances health professionals and policy makers’ understanding of health, disease, and well-being experiences and how health services are provided, received, and experienced (Luciani et al., 2019).

5.3 Choice of interpretative phenomenological analysis

IPA is the methodology used in this study. IPA was first coined in the UK by Jonathan Smith during the 1990s as a more established qualitative approach in the psychology field as an alternative but complementary approach (Smith, 1996). The IPA approach is well established and increasingly popular in the UK health psychology disciplines due to its distinctive nature (Eatough & Smith,2017). According to Smith, Flowers, and Larkin (2009), IPA is defined as “committed to the examination of how people make sense of their major life experiences and to give a detailed interpretation of that account to understand the experiences”. Initially, this method was considered a simply descriptive methodology that did not attract much attention from researchers and university supervisors (Madill et al., 2005). However, novice qualitative researchers preferred IPA due to its accessibility, flexibility, and applicability (Tuffour, 2017). Over the years, Smith and others developed and defined this approach's philosophical and theoretical underpinnings (Eatough & Smith, 2008; Larkin, Watts & Clifton et al., 2006; Smith, 2004; Smith & Osborne, 2007; Smith, Flowers & Larkin, 2009).

The IPA concepts are largely advanced on findings from various philosophers, including Ricoeur, Gadamer, Schleiermacher, and Heidegger (Smith, Flowers & Larkins, 2009). IPA is now an established approach and stands out as a reliable qualitative methodological approach (Love et al., 2020). This method is usually based on idiography to provide a more precise understanding of the particular issue in the participant's life. In different contexts, IPA creates an opportunity to make more sense of various personal experiences. The viability of IPA is further advanced by the combination of different approaches like the interpretative, psychological, and idiographic elements (Gill, 2014). Data, in this case, is usually collected qualitatively without the aim of doing a test on any given hypothesis. For example, in the phenomenology approach, the researcher is interested in real-life situations. The aim is to understand how the participant is making sense of their real-life situations through their interpretation. In recent years phenomenology has attracted greater interest in public and professional practice, including nursing, education, psychology, and social work.

Grounded theory was also considered as the potential choice of methodological approach for this study. However, grounded theory focuses on developing an explanatory account of people's experiences based on all data sources that might contribute to theory development. Disclosure analysis and conceptional analysis, are the other types of qualitative methods considered when describing the use of written or spoken language in real life situation. One of the main reasons why IPA was the main preferred method for this study is because of its epistemological and ontological characteristics that significantly differentiate the concept of my research: South Asian caregivers' experience of dementia from alternative methodologies including discourse analysis, grounded theory, and narrative analysis (Cuthbertson et al., 2020). This next section sets out my ontological and epistemological stance in critical realist terms.

5.4 Epistemological positioning

As discussed at the beginning of this chapter, the IPA framework is based on idiography, hermeneutics, and phenomenology, which are considered reliable principles when conducting qualitative research because of its reliability to investigate, describe, interpret, and situate the participants' sense-making of their real-life experiences (Pietkiewicz & Smith, 2014, Tuffour, 2017). The social constructivist epistemology complements IPA by acknowledging the subjective relationship between the researcher and participants. These attributes qualify IPA as a suitable means of exploring and comprehensively understanding different individual experiences by conducting a very close examination that presents more details and information about the larger population. This approach used in IPA places high value and importance on people and further understanding them using a holistic approach.

IPA's epistemological stance depends on the person's subjective account of experience. In qualitative methodology, epistemology refers mainly to theoretical knowledge of the scope, validity, and justification of a particular opinion. In IPA analysis, epistemology often aligns with constructivist or interpretive perspectives. As a researcher from South Asian background, exploring views of South Asian caregivers of PWD, my epistemological stance in this study is deeply root in constructivism and interpretivism. Constructivism is a belief that knowledge and reality is socially constructed where the researcher has an active role in co-constructing and interpreting the reality of experience. This personal viewpoint stem from my belief that knowledge is subjective and socially constructed through the interpretations and experience of individuals. I adopted a subjective approach to interpret participants' knowledge, reality, thoughts, feelings, and intuitions about their experience of caring for their family member with dementia. My aim was to create a space where caregivers feel comfortable sharing their stories, challenges, and triumphs in their caregiving journey. One of the main reasons why IPA was the main preferred method for my study is because it facilitated a deeper understanding of the caregiving experience of South Asian caregivers regarding how they perceive the concept of caregiving and provided rich interpretation of their experiences, thus enabling an in-depth analysis while paying close attention to context and process (Smith, Flowers & Larkin,2009 cited by Cuthbertson et al., 2020).

By adopting an interpretivist stance, I value the subjective nature of knowledge and seek to understand the nuanced and diverse experience of South Asian caregivers through their interpretations, cultural backgrounds, and personal narratives. I actively listened to their caregiving experiences, play close attention to the cultural norms, traditions, family dynamics that influence their caregiving phenomenon.

5.5 Ontological positioning

IPA adopts an interpretive ontological stance. Ontology is the study of being; it means the study of existence, knowledge, and reality (Crotty, 2003). Ontology in qualitative research is a form of scientific concept that focuses on specific individual understanding concerning what is actually present in the world and reality (Cuthbertson et al., 2020). Based on the rational evaluation of IPA, epistemology is subsumed by ontology, and how to access that knowledge. Therefore, given that there is a non-radical as well as a soft-realistic approach in IPA, there is an open chance of comprehending new meanings and practical understanding of experiences, hence making it a suitable research methodology. On the other hand, the phenomenological assessment provides the liveable and realistic situations of the external world setting. In this case, there is more focus on creating knowledge or understanding through the means of interpretation. Also, considering the idiographic emphasis of IPA it cannot be radically relative in its ontology. If this were the case, researchers would have nothing general to say about their analysis, hence no legitimacy for findings. The 'reduction' and interpretations of participants' accounts are thus idiographic generalisations.

As a researcher from South Asian community my ontological position shaped my understanding on the nature of reality and knowledge. I adopted a social constructionist stance in this study as I believe that reality is socially constructed and shaped by language, culture, and social interactions. And thus, I can only understand the experiences of South Asian caregivers as socially and culturally constructed phenomena. The ontological position adopted, which guided me in this thesis is that there is no external reality. Instead, reality is an 79interaction between the inner world of the individuals and their beliefs and understandings and the outer social world they inhabit.

The epistemology and ontology significantly influenced the decision to use an IPA methodology. They significantly help in understanding the viability, reliability, and applicability of the IPA method in qualitative studies. My ontological and epistemological position helped me in comprehending how IPA could help in framing the current research and attain the desired and viable findings. These concepts were highly reliable in exploring the possible value that IPA could add in this study. Through the guiding framework of ontology and epistemology, it was evident that IPA would be effective for framing and undertaking the phenomenological research work required for this study. My own position and assumption would then help make the interpretations in this study (Smith, Flowers & Larkin, 2011). The similarity of my own ethnic and cultural background to those of the participants in the study was of significant importance. Using an interpretative approach, the current study acknowledges that other interpretations are also possible. Both these concepts link to the congruence of utilising qualitative research for this study and I go on to clarify the compatibility of IPA with these discussions and the methodology for this study.

5.6 Theoretical underpinning of IPA

Aside from ontology and epistemology, IPA has three primary theoretical underpinnings: phenomenology, hermeneutics, idiography, all considered as the foundation of IPA (Smith et al., 2009).

5.6.1 Phenomenology

The main theoretical basis of IPA stems from phenomenology, which describes human experiences and navigates researchers with a rich source of ideas about how to study and understand lived experiences (Sokolowski, 2000). Phenomenology is designed to identify the essential components of phenomena' or 'experiences' of an individual that make them unique or distinct from others. Phenomenological studies thus focus on the way people perceive and talk about objects and events that matter to them rather than describing the phenomena according to a predetermined categorical system, or conceptual and scientific criteria. (Pietkiewicz & Smith, 2014). Edmund Husserl (1859-1938) is considered the founder of modern phenomenology (cited in Smith & Osborn, 2008). Although several researchers referred to the term phenomenology before Husserl, it was Husserl who formulated a systematic and philosophical method to identify the essential components of phenomena or experiences that make them unique (Smith, 2008; Biggerstaff & Thompson, 2008).

Husserl attempted to formulate phenomenology in three different steps. The first one is transcendental phenomenology which is described as one's natural or taken for granted attitude where the individual makes assumptions about how things and events are seen in everyday life. The second step is moving away from the habitual attitude through reflexivity, which is also known as phenomenological attitude, to understand experiences about how things are (Finlay, 2011). The third step is the process of bracketing where the individual carefully describes the essence that has been described. Bracketing is a concept in IPA that refers to a method of demonstrating the validity of the collected data by the researcher putting aside their own assumptions and existing knowledge, beliefs, values, and previous experiences in order to accurately describe participants' life experiences (Smith, Flower, & Larkin, 2009). Husserl argued that it was necessary to bracket off one's natural attitude to distinguish the essence of the things in their appearing. Thorough planning of bracketing will minimise the influence of the researcher in the process of interpretation (Tuffour, 2017).

Husserl's descriptive phenomenological concept has been criticised by many researchers for being too philosophical and difficult to interpret (Tuffour, 2017, Smith, Flower & Larkin, 2009). Many argue that the best understanding of a phenomenon is only possible through interpretation. In most qualitative studies, bracketing concepts is usually considered as a means of indicating the scientific rigorousness of the study mainly using the phenomenological technique. However, there is no clarity regarding how this methodology can be effectively achieved in a study. Hence, in a research project like this one, it is highly challenging for the researcher to understand the effective means of applying this method.

The concept of bracketing has been cited as being incongruent with interpretative phenomenology philosophical orientations (LeVasseur, 2003). In most scenarios, interpretative phenomenologists usually believe that reliance on already existing knowledge on the topic under assessment is a crucial aspect in assessing the subject matter. Prior knowledge from different experts is seen as a reliable and open resource for researchers to advance their work. Therefore, in this study, there are substantial contradictions and uncertainties surrounding the use of bracketing. There is no clarity on whether the researcher should rely on prior knowledge regarding the study subject to draw relevant conclusions or not.

Given that the present study is phenomenological research, there is a likelihood of similar challenges associated with bracketing being evident. I explored the dynamics involved in effective implementation of bracketing and, in turn formulated a reliable response in such a way that the viability of the outcomes or findings has not been compromised. I needed to establish an effective framework to overcome the potential presumptions and biases which can lower the credibility of a study. Currently, there is no reliable explanation on the explicit concept of applying bracketing, and all the approach mechanisms are based on the researcher's consciousness. Given that this study wanted to explore the experiences of participants comprehensively, the effective application of bracketing concepts remains highly sensitive.

However, Heidegger (1927), a student of Husserl, moved away from bracketing (Langdridge, 2008) and argued that achieving bracketing was not a simple task and we cannot put all our experience and understanding of the world to one side and see the phenomenon as if for the first time. Finlay and Gough (2008) also expressed their concerns about the bracketing process. I was becoming aware, however, that I would need to clearly show, as I carried out my research, how I went from what the participants had said about their experiences and my interpretation of how they make sense of it to others.

5.6.2 Hermeneutics theory

Martin Heidegger (1962), a student of Husserl's, further articulated Husserl's work and shifted the emphasis of identifying the components of phenomena to a more descriptive and interpretive process (Smith, Flower & Larkin, 2009). While Husserl's focus was on understanding how we know as humans, Heidegger, in contrast, was more concerned with the ontological question of the mode of what it means to be human (Smith, 2003). Heidegger moved away from Husserl's phenomenology due to it being too theoretical, and he even questioned the possibility of any interpretation in such cases (Smith, Flowers & Larkin, 2009). Heidegger further extended the concept of hermeneutics, which is the second main important theoretical underpinning of IPA. Hermeneutics is the theory of explicit interpretation where IPA researchers attempt to understand what an experience is like from the participant's point of view (Eatough & Smith,2017). The original conception of hermeneutics can be traced back to the interpretation of the Bible but soon after it was developed to the established foundation of the general theory of philosophical interpretation.

Through this dynamic process, IPA researchers try to place themselves in participants' shoes and influence the sense-making of any experiences through a subjective interpretation (Smith & Pietkiewicz, 2012). This is also known as the dual hermeneutic cycle, where first, the participants richly describe anecdotal experience to enabling self-awareness of their reality. Subsequently, the researcher then interprets these accounts based on their beliefs of the anecdotal meaning. According to Heidegger (1962), the essence of interpretation is already contextualised in previous experience in a given context. The researcher has a significant role here by exploring such phenomenon which is already out there. The researcher's prior experience, assumptions, or preconceptions aid them to make sense of the participant's accounts.

Gadamer (1976) was another philosopher who was influenced by Heidegger's work and further extended hermeneutics into a more practical application. According to Gadamer, the understanding procedure occurs in the interpretation of the concept and interpretation is a fusion of horizons in which language is a universal means of better interpretation. He further wrote that the process of questioning helps to open up, and make new horizons and understanding possible; therefore, it is considered as an essential aspect of the interpretive process. For me, returning to the literature review after the interviews felt like a hermeneutic process, as I wanted to ensure that what I had learnt from the horizons of the participants would add to the interpretive nature of my discussions and any other new literature I may had missed previously.

5.6.3 Idiography

The third major and distinctive nature of IPA strongly relies in idiography. This refers to the detailed examination of each case, analysing each study participant's experience and perspectives in their unique contexts (Eatough & Smith, 2008; Smith, Flowers & Larkin, 2009). In psychology, the term 'idiography' refers to the study of individuals, specific situations, or events. Idiography is committed to a case-by-case analysis, where the researcher tries to have a detailed understanding of one case in his own context before moving on to the next. The narrative of individual cases can be compared to several cases to identify patterns in different cases. The idiographic approach of IPA is ideal to collect detailed experiences from participants. Smith et al.'s further advise researchers to explore participants' detailed accounts of a particular phenomenon, extract the in-depth meaning of their experience, and make sense of participants' sense-making by an interpretive analytical process.

5.7 Bracketing

In the hermeneutic phenomenological approach, the technique of bracketing is found to be inconsistent and problematic (LeVasseur, 2003). It is acknowledged that pre-understanding cannot be eliminated or 'bracketed' (Koch, 1995). There is also no single set of methods for undertaking bracketing (Gearing, 2004; Wall et al., 2004). Giorgi (2011) further argued that IPA provides no steps in executing bracketing.

There are many dynamics regarding the use of bracketing techniques, and a critical guide is crucial for implementing this particular method in research. After the initiation of particular phenomenological research, bracketing can be utilised to showcase its validity. Although bracketing is a reliable technique for proving the validity of various processes in a study, including data collection and analysis, there is no comprehensive guide on how it is practically used in most research. It is important to apply the bracketing technique after formulating the research proposal and not necessarily at the data collection stage or in the course of doing analysis. In order to apply bracketing effectively, the available research evidence posits that the reviewing of literature in the research work should be conducted after the collection of data and analysis. This technique will be very reliable in ensuring that the researchers do not formulate their research questions based on the existing prompts from previous studies (Hamill & Sinclair, 2010). Based on a theoretical view, the technique of delaying the reviewing of literature prevents the situation whereby the researcher pre-understands the main question of research. Hence, there is clear evidence and demonstration that there were no attempts to influence the processes of collecting and analysing data.

However, if the literature review is considered the last option when implementing the bracketing concept, the action plan can lead to a disconnect between the broad research background and the current study. Also, it can be challenging to organise the research work and make it complicated to undertake. The researcher can highly question the overall study plan and its justification. Given these challenging and underlying dynamics when using the bracketing approach, it is crucial to figure out the best means of applying its concepts in research work and obtain the required outcomes (Chan, Fung & Chien, 2013).

The main and effective strategy in approaching bracketing involves keeping this concept in the mind of the researcher throughout every given step of the study. In an ideal situation, bracketing is not necessarily limited to certain steps of research like data collection and data analysis as well as any other given stage. However, it is crucial to begin bracketing before even conducting the literature review. This is the case because reviewing literature and other processes, including collecting data and the analysis process, are related sequentially. The undertaking of bracketing should be done based on reflexivity. Specifically, reflexivity is a credible approach to identifying or understanding the possible influences in the course of conduction research work under different processes. According to Primeau (2003), reflexivity specifically entails conducting a comprehensive and honest assessment of the researcher's interests and values that can have a direct impact on the research work. Hence, in qualitative research work it is possible to note the potential bias and, in turn, counter their effects through the technique of bracketing.

Developing and applying the skills of bracketing usually requires specialised skills and competencies. For instance, during a phenomenological research process, it is crucial to have a diary specifically for reflexive purposes (Chan, Fung & Chien, 2013). This undertaking is crucial for facilitating the actualisation of bracketing by guiding the process of decision making. The diary facilitates the researcher in re-evaluating their different thoughts, perceptions, and feelings and, in turn, understand how different issues can influence the study. Therefore, these bracketing concepts were used for this research work purposely during the decision making.

5.8 Reflexivity and positionality

At the beginning of this chapter, it was discussed that reflexivity is key to minimising problems of interpretation in IPA research. In IPA, the participants are trying to make sense of their world; the researcher is attempting to make sense of the participant's sense-making (Smith & Osborn, 2008). In order to do this, the researcher's engagement with the interpretation of the participant's account is an integral aspect of IPA research (Smith et al., 2009). Thus, IPA researchers have an active role in influencing the sense-making process. Therefore, the researchers must be aware and make clear their assumptions, prejudices, and positions on the area in question through reflexive techniques (Caleli, 2001).

In IPA self-reflection it is essential to enhance the meaning and interpretation so reflexivity reduces the biases that the researcher may possibly bring to the research. In addition, reflexivity encourages researchers to think about and make explicit ways in which their values, experiences, interests, beliefs, thoughts, and feelings are involved in research (Willig, 2008). This is from Heidegger's 'being in the world' concept, where he discusses the researcher's prior experiences, assumptions, and preconceptions. However, it may not be possible to know all the assumptions and preconceptions prior to the analysis, and as per Gadamer, these conceptions may constantly change during the interpretation process (Smith, 2007).

As a researcher from South Asian community exploring the experiences of South Asian caregivers of people with dementia, my reflexivity and positionality played significant role in shaping my understanding of the participants' experiences and the research methodology, data collection, and analysis.

Reflexivity was central to my research practice. It involved critically examining my own South Asian Indian background, religious beliefs, biases, and experiences that may influence the research. As a South Asian researcher, I am aware of the cultural nuances and social dynamics within the South Asian community. However, I also acknowledge that my own experiences may not fully capture the diversity and complexities of the caregivers' lives. Therefore, I remained open to learning, constantly reflecting on my assumptions and potential biases, and engaging in ongoing self-evaluation throughout the research journey.

My positionality as a South Asian researcher studying South Asian caregivers provided me with a unique perspective. Being a South Asian, the cultural identity and language I shared with the participants enhanced rapport and trust. It enabled me to understand their experiences within the broader context of our shared culture. However, I was aware that each caregiver's experience is unique and influenced by various intersecting factors such as gender, class, religion, and regional differences. I recognised the need to be cautious about assuming homogeneity so, I stayed open to learning and avoid assuming that each participant is the same within the South Asian community and acknowledge that my experiences may differ from those of the participants. I embraced the gender, language, religious and regional diversity of both Indian and Pakistani caregivers as it was essential in this research to capture the full range of caregiving experiences.

Furthermore, I navigate the power dynamics inherent in the researcher-participant relationship. As a researcher, I hold a position of authority and influence. To address potential power imbalances, I strive to create an inclusive and empowering research environment. This involved establishing collaborative relationships with participants, valuing their expertise as caregivers, and actively involving them in the research process. I aimed to amplify their voices, allowing their lived experiences to shape the findings and recommendations. I made notes during each interview as well as maintained a reflexive log after each interview. In addition, I joined the Northwest IPA Network Group, which conducted face-to-face sessions with researchers using the same methodology and subsequently virtual meetings and forum discussions during the COVID-19 Pandemic. This variety of platforms allowed me to carefully adapt my methodology and enabled self-assessment in conjunction with peer assessment of my preconceptions of dementia care and beliefs as an individual from the South Asian community, throughout the course of my interpretation of data. Several aspects were identified that might have influenced what participants shared with me, how they spoke about their experience, the knowledge produced, and their interpretations. Moreover, throughout the study, I was more conscious and mindful. In making these visible, I hoped to become more conscious and mindful of them throughout the study.

By actively engaging with my reflexivity and acknowledging my positionality, I aim to conduct research that is culturally sensitive, respectful, and representative of the rich tapestry of South Asian caregiving experiences. This self-awareness informs my methodology, data interpretation, and dissemination of findings, ultimately contributing to a more comprehensive understanding of the challenges and strengths of South Asian caregivers of people with dementia.

5.9 Insider and outsider concepts: The role of the researcher

The understanding of both insider and outsider concepts in the research context can be explained based on the level of knowledge. In this case, the insider has knowledge which the outsider may not possess. The insider usually relates to the existing order of things more than their outsider counterpart. According to Hellawell (2006), insiders are usually integral members of a specific community in a specified way, where the research work is being done or conducted. On the other hand, outsiders are usually seen by the participants as external members of the specific group under study.

5.9.1 Insider

Being an insider in research is usually crucial given that it is easy to comprehend and understand various practices and norms. As an insider researcher, it is easy to establish close links and advance trust among the participants. It is also easy to know the specific issues or ideas which are suitable or unwelcome for them. Berger (2013) confirms that there are high chances of the insider researcher being more accepted or welcomed by the respondents. Also, the participants will have high confidence and trust in sharing their opinions, stories, and information with the researcher regarding the topic being studied. Under such circumstances, the insider researcher is usually better placed to advance knowledge in the specific field of study and directly apply the study’s findings in their personal lives. Being an insider in any study enabled me to attain high acceptance by the respondents as well as establish more rapport. The main advantage of being the insider is that there is greater opportunity to gather more in-depth data because of the open and interactive relationship with the participants. My position as a British South Asian and researcher familiar with dementia placed me as an insider for some of the aspects of the study, giving me advantages during the design of the interview schedule and recruitment stages of the study. However, during the interviews I ensured that my insider understanding did not influence the participants' accounts. Although I did not have experience of looking after a family member with dementia, I was able to empathise with participants due to being a South Asian, understanding the experience.

5.9.2 Outsider

Being an outsider in research has various strengths and weaknesses which significantly dictate the research work outcomes. In this case, the researcher usually views the participants from an expert point of view. Under such circumstances, the researcher is more willing to hear about the experiences and views of the respondents about the topical issue being studied and, in turn, share the outcomes. However, the main challenge of being an outsider is that the participants may fail to be open to the researcher. Therefore, in this study, the main approach was to undertake the research work as an outsider.

5.10 Relevance to the study

IPA was chosen for this study for various reasons. Firstly, it was in keeping with my ontological and epistemological position and my need to explore the qualitative nature of this research. IPA enabled me to comprehensively understand the South Asian caregivers' perceptions about caring for a family member with dementia by directly capturing their lived experiences. Compared to other methodologies in qualitative research, IPA is more exploratory in nature. Hence, in this study IPA was a suitable method for understanding the dynamics of caregiving. Another reason why IPA was the preferred method in this study is because it enabled me to explore the personal accounts of each caregiver and allowed them to narrate their lived experiences. Furthermore, rather than the findings being dictated by pre-existing theoretical conceptions, IPA was suitable in this context to produce findings on its own terms. Moreover, the idiographic commitment when examining the personal experiences of participants before adopting a more generalised point of view was beneficial. Therefore, IPA contained all the facilitating attributes for effectively conducting phenomenological assessment of this nature. IPA is reliable for examining the complicated topics which are challenging to explore and dominated by emotions (Smith & Osborn, 2015).

There are different aspects that confirm the legibility and validity of IPA in qualitative data analysis. These aspects qualified it to be the suitable form data analysis for this study. For instance, IPA is an interesting approach that enabled me, the researcher, to be closer to and ensure effective interaction with the data collected. Furthermore, IPA enabled me to move from formulating themes effectively to coding the actual collected data, focusing on all the participants' outstanding characteristics and traits collectively and individually. Overall, IPA was a reliable data analysis method that provided more comprehensive insights about the study subjects and facilitated easy understanding.

5.11 Research method

So far, this chapter has focused on the rationale for adopting IPA as the most appropriate methodology. The following sections will detail the research methods, from ethics, sampling, recruitment, data collection, and interview process to the data analysis methods utilised to explore this research.

5.11.1 Ethics approval

An ethics application for this study was submitted to Manchester Metropolitan University Ethics Committee. The University guidelines were followed throughout the application process which involved the completion of a number of documents such as a study protocol, participate information sheet (PIS), informed consent form (ICF), study advertisement template, interview schedule, caregiver demographic information collection tool, insurance checklist, and health and safety risk assessment. Questions were asked about the involvement of the people with dementia in the study, minor changes were requested by the Ethics Committee on the consent form. Ethical approval from the NHS was not sought for this study as participants were not recruited from any NHS services. Full ethical approval was granted by the Manchester Metropolitan University Ethics Committee to conduct the proposed research. Ethics approval and related documents are included in the Appendices.

Further ethical considerations specific to data collection within the study will be discussed in section 5.13, Ethical consideration.

5.11.2 Sampling strategy

The main aim in IPA analysis is to produce a comprehensive and in-depth examination of each participant's 'horizon of understanding', or how they represent their situation and experiences (Creswell, 2012; Nizza et al., 2021). Several researchers have attempted to explain this; due to the idiographic nature of IPA, analysis is detailed and time-consuming, so IPA studies are usually conducted with small, homogeneous samples (Smith, 2008; Sandelowski,1995; Morse, 2000). This allows the researcher to investigate in idiographic detail the horizonal perspectives of one case before moving on to the next. According to Smith and Osborne (2008) there is no specific rule about the number of participants that should be included in a study but it depends on many factors such as the in-depth case study level of analysis and reporting, the richness of the individual cases, whether the researcher wants to compare or contrast single cases, and the pragmatic constraints the researcher is working under such as time and access to the potential participants (Smith & Pietkiewicz, 2012).

Smith and Osborne (2008) have provided an excellent discussion about the principles of sampling in IPA. Smith recommends that a sample size of 6-8 is appropriate for a doctoral programme which gives the researchers an opportunity to examine similarities and differences between the individual cases but at the same time ensure the qualitative data gathered is not overwhelming. Smith, Flowers, and Larkin (2004) have made a strong case for researchers and PhD students to conduct IPA analysis on single case studies. Smith and colleagues have argued that from a detailed analysis of a single case study, one can learn a great deal about an individual and his/her responses to a specific situation. However, most IPA studies are conducted on a small sample with more useable data rather than a single case study (Morse, 2000).

Although the aim of IPA studies is not generalisation, the richness of data and level of interpretation is crucial (Smith et al., 2007). The researcher should decide on a sample that can provide a sufficient perspective given adequate contextualisation (Smith & Osborn, 2003). IPA researchers normally aim for a small homogenous sample to obtain rich and in-depth descriptions of their lived experience. The rule of a ‘representative’ sample is not applicable in IPA studies; therefore, the participants are mainly selected purposively from a closely defined group for whom the research problem has relevance and significance. When selecting the participants for IPA studies it is recommended to choose a homogeneous sample from one community with a similar culture, demographic profile, and socio-economic status. As with the above recommendation, a homogenous sample of eight caregivers with knowledge about dementia and experience of caring for a family member with dementia were drawn from South Asian communities which was acceptable in this context. As this research aimed to explore the experience of South Asian caregivers of people with dementia, it was most important to include individuals with real-life experience of the same phenomenon i.e., caring for a close family member with dementia.

A purposive sample of South Asian participants with experience of caring for a family member with dementia were selected for this study. Considering the aim of the research, purposive sampling helped the researcher to find a more closely defined sampling group for the study from South Asian communities in Greater Manchester who had experience caring for a family member with dementia. In addition to selecting the sample purposively, a snowball strategy was also applied in the later stage of this study to recruit more participants with similar lived experience of the phenomenon. To ensure that the participants in the study contributed rich and in-depth data by sharing their lived experience, an inclusion and exclusion criteria was created to include participants with adequate caregiving experience. The rationale for the inclusion and exclusion criteria and selecting South Asian family caregivers of PWD was set out in the initial literature review.

5.11.3 Inclusion and exclusion criteria

In this study the participants were recruited from South Asian community centres and the selection was based on an inclusion and exclusion criteria as follows:

- Identifies him/herself/themselves as a South Asian from Pakistani and Indian communities living in Greater Manchester,
- Has or recently had a family member with dementia,
- Aged 18 years and above
- The care-receiver has a formal diagnosis of any form of dementia,
- Have/had provided informal care to a family member with dementia for at least six months,
- Identifies him/herself as one of the primary caregivers, although other family members may be involved in sharing caregiving responsibilities.

As the focus of the research was to identify and recruit individuals with adequate caregiving experience, family caregivers with less than six months caregiving experience were excluded in order to get rich data. Carers who were non-relatives were also excluded as they might not have the same level of duty-bound commitment or have any stigma issues as a relative.

5.11.4 Recruitment

The participants in this study were initially to be recruited from the NHS and GP surgeries. However, from researchers' previous experience in conducting research among South Asian groups, recruiting people from NHS memory clinics has been a major challenge. This was mainly due to the South Asian population remaining under-represented in specialist dementia services in the NHS and primary care, such as memory clinics and post-diagnostic support services. In contrast to this, community centres and religious institutions are found to be the trusted effective way to access this hard-to-recruit population. Many South Asians do not wish to come to hospital for a post-diagnostic dementia assessment and often do not present to their GP when dementia get worse. From previous experience of recruiting dementia patients for clinical trials, it was identified that the South Asian population are more likely to draw on community-based services from these centres and religious institutions. Hence, it was decided to follow the recruitment strategy that has been already proved to be effective in previous research projects.

The Indian participants in this study were recruited from the Indian Senior Citizens Centre and local Hindu temples. The Indian Senior Citizens Centre is a voluntary organisation that provides culturally sensitive day care services for elderly Indian origin people in the Greater Manchester area. This community centre was well attended by 100–120 Indian senior citizen and their family caregivers. Contact was also made with the trustees of two Hindu temples in Manchester and some leads were generated by these referrals.

Three Pakistani participants were recruited from a Pakistani community organisation located in the North part of Greater Manchester that works in partnership with a wide range of community organisations to promote the health and welfare of the South Asian population. This centre runs regular sessions for South Asian PWD and their families and helps to improve their awareness and understanding of dementia, reduce stigma, and build confidence and capacity. In addition to this, the centre has even launched a memory café for the South Asian PWD in collaboration with the Alzheimer's Society. Initially three Pakistani community organisations in Greater Manchester were contacted and they expressed their willingness to support the study. Although, the researcher attended regular carer sessions to discuss the study with all three organisations, the three Pakistani participants were recruited from another community centre in North Manchester.

Information about the study was provided in a number of ways. The researcher attended the routine carer session at the centres to talk about the study and answer any questions during these sessions. The study was advertised verbally at community gatherings and through study flyers distributed through community organisations and groups in the community centres and religious institutions. Conversations with attendees in these community centres and religious institutions helped in getting the request for participants into the community by word of mouth. Some referrals for participants were provided by the visitors of these centres and religious Institutions. The PIS version 1.0 dated 25 March 2016 was provided to participants along with invitation letters produced in simple English. The PIS had all the information about the project, detailing the purpose and study methods and what participation in the study entailed. Participants were encouraged to put forward any questions and queries they may have and to openly raise any concerns in relation to the specific procedures of the study.

Potential participants were contacted after giving them enough time to read the PIS and consider their willingness to participate in the study. A time and place to conduct the interviews was arranged at the participant's convenience. An invitation letter explaining the purpose and procedure of the study and how the collected data would be used along with the PIS was sent to the participants. Interviews only began after receiving their verbal and written consent for their involvement in the study and audio recording the interview. Before interview, participants were informed that their participation was entirely voluntary and during and after the interview they were reminded that they could withdraw from the study at any time. Demographic information was collected from each participant about them and the family member with dementia, such as age, duration since diagnosis, and caregiving, migration history, and use of services. The names are pseudonyms; the real identity of the participants has been anonymised to protect confidentiality.

The recruitment took place over a 13-month period from November 2017 to December 2018. The researcher interviewed eight South Asian caregivers during this period. The researcher was able to establish rapport with the participant before each interview which helped in conducting intense and productive discussions about their experience of caring for a family member with dementia. The researcher's rapport and previous experience with interviewing enabled the participants to narrate their story and experiences in detail, contributing to the richness of data. The data generated from eight participants were incredibly powerful and enough to support the small sample of participants in this study.

As the data collection and analysis was performed concurrently for each case, the researcher was able to determine the quality and richness of data after each interview, based on the IPA principles that the sample aims to achieve a degree of internal coherency and gain a rich data about participants' experience (Smith, 2003a; Nizza et al., 2021). I conducted a follow-up interview with one participant who was not forthcoming during the interview, and therefore it did not yield good data. This was due to the presence of the person with dementia in the room and in this case a second interview was viable. There was better rapport during the second interview and the participant was able to share their in-depth experience. A detailed account of the participants is provided below.

Demographically, a total of five Indian and three Pakistani caregivers took part in this study, six of whom were women and two were men, with ages ranging from 21 to 83 years. All the participants had cared for their family member with dementia for a minimum duration of 1–4 years. Four participants shared their retrospective experience and four were still caring at the point of interview. All the participant caregivers were family member relatives to the person with dementia. The sample also reflected different kin relationships; out of the six women caregivers one was a daughter, one was a spouse, two were daughters-in-law, and two were granddaughters. One male participant was a spouse, and the other was the eldest son in the family. Both daughters-in-law had migrated to the UK after their marriage, and both the granddaughters were British born. All the participants spoke the English language well. From a professional standpoint, three participants were retired, two were students, two were unemployed, and one worked part time.

- Six out of eight participants lived within the extended family set up.
- Six out of eight participants were living with their family member with dementia during the time of interview.
- Two participants shared their experience retrospectively.
- Three participants had received support from paid carers on a daily basis.
- Six care recipients were under the care of memory clinics.
- One caregiver attended post-diagnostic caregivers’ groups

- Out of five Indian care recipients, two had attended Indian community groups for older people, while all Pakistani care recipients attended the Pakistani community group.

Table 5.1: Demographic Information of Interview Participants

Name	Relationship with PWD	Religion	Gender	Age	Marital Status	Migrant status	Duration of Caring
Chawla	Husband	Hindu	Male	86	Married	Indian	3 years
Maya	DIL	Hindu	Female	40	Married	Indian	8 months
Poonam	Daughter	Hindu	Female	48	Married	Indian	1 ½ years
Kamal	Son	Hindu	Male	45	Single	Indian	7 years
Pooja	Wife	Sikh	Female	56	Married	Indian	2 years
Rahana	GD	Muslim	Female	23	Single	Pakistani	3 years
Fatima	GD	Muslim	Female	22	Single	Pakistani	2 years
Sabina	DIL	Muslim	Female	31	Married	Pakistani	11 months

Key: DIL-Daughter-In-Law; GD-Granddaughter

5.11.5 Semi-structured interviews

A semi-structured interview design was employed in this study to gather rich and in-depth experience of South Asian caregivers of people with dementia. In IPA, face-to-face, in-depth, semi-structured interviews are considered as the ideal method of data collection where the participants are provided with more flexibility to share their experience (Smith & Osborn, 2003). As recommended by Smith, Flowers, and Larkin (2009) key features of the IPA analytical process include a detailed examination of a participant’s sense-making; therefore, a flexible data collection tool was required. Semi-structured interviews allow a flexible way of engagement between the researcher and participants (Smith & Osborne, 2008). Furthermore, semi-structured interviews enable the dialogue between the researcher and participants. This method of data collection is considered as the best way to ensure that specific research questions are answered to unfold the meaning of peoples’ experiences, attitudes, perceptions, and beliefs related to the topic of interest. Face-to-face, semi-structured interviews are considered the best method of data collection in IPA.

Semi-structured interviews was the chosen data collection tool in this study, as it enabled the researcher to engage in a collaborative discussion with caregivers as well as to establish rapport with participants. Before the interviews, the researcher did this by discussing their cultural and ethnic background with the participants and then ensured the participants were comfortable to discuss their sensitive experiences and did not have any confidentiality concerns. The interviews were semi-structured allowing streamline, natural conversation with questions focusing on their real experiences and how the interviewees felt about supporting a family member with dementia.

In IPA interviews it is recommended that the silence during the conversation with the participants is not filled immediately. I was mindful about this and was able to navigate such non-verbal cues due to my extensive professional and academic experience in conducting qualitative interviews. However, when the participants had difficulty answering the questions I was able to employ prompts. There were occasions when the participants wandered away from the topic and I was able to direct them back to the interview by asking appropriate questions to encourage them to continue sharing their specific and concrete experiences on caring for a family member with dementia. I was able to be immersed in the deep conversations with the participants as IPA involves in-depth interviews in order to capture the participants' insights through their own eyes, to understand their experience in giving care to their family member.

5.11.6 Interview schedule

An interview guide, considered as the backbone of the interview was developed to facilitate the semi-structured interviews for this study (Appendix 4). The structure and content of the interview guide were developed on the basis of an initial literature review that established the overall geography of the topic and helped me to familiarise myself with the topic at a broad level. The interview guide consisted of open-ended questions, which facilitated the participant's ability to tell their own story in their own words without any leading questions. In IPA it is paramount not to lead the participant and to let them freely talk about their experiences (Smith et al., 2014; Creswell, 2005). This was an integral process as it was necessary for participants to be able to express their stories in their own words. In line with Smith's (2014) IPA recommendation, the interview schedule was developed based on the findings and issues that emerged from the narrative review. The questions were neutral, open ended, with no jargon or technical terms, and organised thematically to allows the interviewer to ask questions in a convenient order in which they are likely to proceed (Pi'tkiewicz & Smith, 2012). As suggested by Smith and Osborn (2003), prompt questions were also kept to a minimum which allowed me to take the lead role during the interview.

In discussion with my research supervisors and following Smith and Osborn (2008) and Smith, Flowers, and Larkin (2009), the recommended guidelines for developing the interview guide were beneficial. The University guidelines were also taken into consideration while devising the topic guide. My previous experience in developing interview schedules and conducting interviews with participants from the same context were additional factors that aided the development of a final version which can be found in Appendix 4.

The interview schedule was practised with one of the supervisors before conducting the pilot interview to see how they interpreted the questions. Initially, a pilot interview was conducted with an undergraduate student who had similar overlapping experience in caring for a family member with dementia. The interview practice with the supervisor and pilot interview helped me to ascertain whether the interview schedule covered the topic well and the associated probes sufficiently encouraged the pilot interview participant to share what I was interested in in my research thus validating the schedule. This also added rigor to the data collection process. The pilot interview participant in this study had experience of caring for their family member with dementia and met the inclusion criteria; therefore, based on the richness of the data collected, it was then decided to use the data generated from this interview. Although the researcher is experienced in conducting semi-structured interviews with PWD and South Asian caregivers, the interview schedule practice with the supervisor and pilot interview helped to identify any gaps between questions in the interview schedule. The pilot interview transcript was reviewed by the supervisor and minor amendments were highlighted but the quality of the interview and richness of the data generated was agreed.

Another rationale for including the data from the pilot interview in the body of analysis was due to the idiographic nature of IPA. Smith et al. (1995) and most recently Smith and Nizza (2022) suggest that the researcher consider each participant case individually one at a time. Using the pilot interview data in the thesis was also discussed in the Northwest IPA group network meeting and I was advised to use the pilot data by the experts in the group.

The data collected in the pilot interview helped to test the interpretation of the questions and added rigor in the interview process. The duration of the interviews was 45–190 minutes. During the interview the participants were encouraged to talk freely about the topic and at the end, they were asked to reflect on how they felt about the interview and were reminded that if they had any questions regarding the study, they could contact the researcher via the details on the information sheet they were given.

5.11.7 Additional data collection tools

A demographic form was created to capture basic profile information about the participants in the study. A copy of the template can be found in Appendix 5. Collecting the demographic data of the participants in this study provided further understanding of the South Asian caregivers interviewed in this study.

Field notes and reflective notes were collected during and after the interviews, detailing my thoughts and feelings about the interview; this is also a vital contribution to the analytical process. Field notes helped me to document my observations of the participants' body language, their environment, and reflections on whether the interview questions were working well. This helped to build connections between the ideas that participants shared, and they formed the first draft of the data analysis. Due to the characteristics of the participants and nature of the topic, I was mindful of any non-verbal cues, sighs, pauses, and laughs. All the interviews conducted were audio taped, then transcribed verbatim by me, producing word-for-word transcripts, before engaging with the case-by-case analysis. The transcription detailed the complete interview including the questions asked by me, pauses, and laughs. After obtaining permission from the participants, the interviews were recorded using a voice recorder provided by the University; following this the next process in the data analysis was the transcription.

During the transcription process, I followed a series of procedures to enable a high-quality, effective, and data-sensitive analysis. Firstly, I ensured that I self-transcribed the interviews instead of using digital transcription software or an external transcriber in order to maintain the integrity, confidentiality, and accuracy of the data. Unlike other methodologies, such as conversation analysis, which involve detailed codified transcription, IPA's primary focus is the contents of the interview; therefore, there is not a requirement for additional content to be added to the transcription. However, no speech can be omitted in a transcription and any notable non-verbal cues such as laughter or pausing needs to be added to the transcription, as filler words and mumbles with no intended significance can build on the subtext of the interview. Following this, I formatted the transcript by adding the participant number for the interviewer and interviewee as well as any abbreviations frequently utilised. In order to facilitate annotation of the text, the right and left margins were also left blank. Through this process, I was able to familiarise myself with the data prior to the coding and in-depth analysis, and additionally enabled me to iteratively review any mistakes.

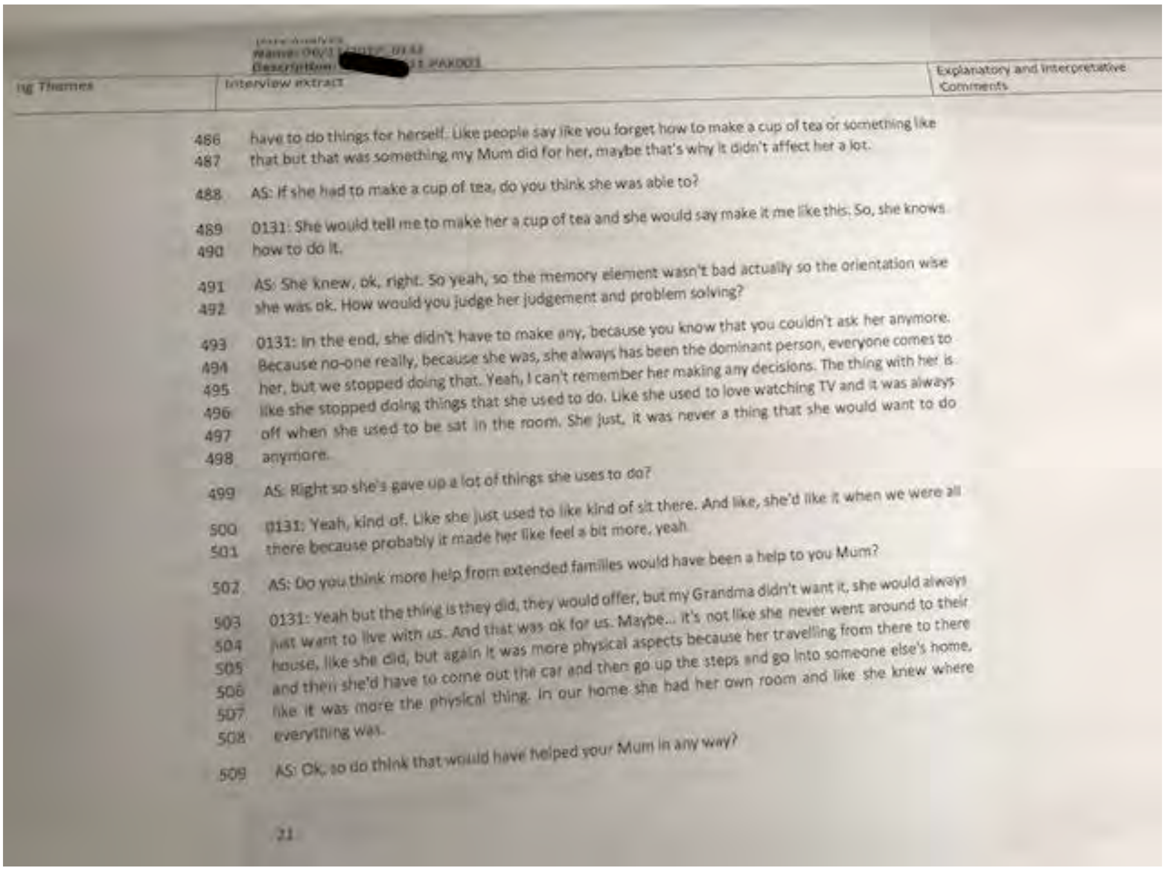
5.11.8 Data analysis

Data analysis was done in accordance with the principles of IPA by Smith, Flowers, and Larkin, (2009) and Smith and Osborne (2008). As the current principles of IPA do not explicitly suggest one particular method for working with the data, researchers are thus encouraged to use innovative approaches for data analysis (Pietkiewicz & Smith 2012). However, the guidance offered by Smith et al. (2009) is still widely used by researchers. The data analysis of IPA studies is complex and time consuming due to the comprehensive interpretative process whereby the researcher tries to step into the participants shoes as far as possible to understand the content and complexity of the sense-making phenomena where the meaning is central. The researcher examines the collected data through his/her psychological lens and then psychological concepts and theories are applied during the interpretation process.

After each interview, I made reflective notes on my thoughts and feelings about the interview, which were taken into consideration during the analysis process. Each interview transcript was then systematically analysed using step-by-step IPA data analysis, including reading and re-reading, initial noting, identifying and developing emergent themes, searching for connections across emergent themes, moving to the next case and examining the patterns across the cases (Smith et al., 2011). As stated above, all the interviews were audio taped, then transcribed using Nvivo 11, a computer assisted qualitative data analysis tool. Nvivo is a useful tool for coding and theme extraction. I used Nvivo for transcribing the interviews and line-by-line coding. The scripts were then exported to Microsoft Word, and thus step 2 to step 5 of the IPA analysis were completed. This research study explored the views and experiences of South Asian caregivers in the Greater Manchester area who were supporting a family member with dementia. IPA analysis is not complete until the researcher writes up the findings. According to Smith et al. (2009) the researcher continues the interpretative engagement with the participants' experiences during the writing-up process, which helps the researcher to make further sense of the data, themes, and sub themes.

Step 1: Reading and re-reading

As noted in the methodology section, in IPA 'meaning' is central; therefore, my aim was to understand the content and complexity of those meanings. In the initial stage of the analysis process, I listened to the interview recordings a number of times which helped me become familiar with the participants' accounts and recollect the entire interview atmosphere, where the interview was conducted, and also to get as close to the data as possible. I prepared a verbatim for each interview as shown in the central column of Figure 5.1. The right and left margins are left blank at this stage. Then the transcripts were read repeatedly. This is called the researcher's active engagement with the data (Smith and Nizza, 2021). Each reading and re-reading of the transcripts and listening to the recordings allowed me to immerse myself in the participants' world.



[redacted]

ng Themes	Interview extract	Explanatory and Interpretative Comments

have to do things for herself. Like people say like you forget how to make a cup of tea or something like that but that was something my Mum did for her, maybe that's why it didn't affect her a lot.

AS: If she had to make a cup of tea, do you think she was able to?

0131: She would tell me to make her a cup of tea and she would say make it me like this. So, she knows how to do it.

AS: She knew, ok, right. So yeah, so the memory element wasn't bad actually so the orientation wise she was ok. How would you judge her judgement and problem solving?

0131: In the end, she didn't have to make any, because you know that you couldn't ask her anymore. Because no-one really, because she was, she always has been the dominant person, everyone comes to her, but we stopped doing that. Yeah, I can't remember her making any decisions. The thing with her is like she stopped doing things that she used to do. Like she used to love watching TV and it was always off when she used to be sat in the room. She just, it was never a thing that she would want to do anymore.

AS: Right so she's gave up a lot of things she uses to do?

0131: Yeah, kind of. Like she just used to like kind of sit there. And like, she'd like it when we were all there because probably it made her like feel a bit more, yeah

AS: Do you think more help from extended families would have been a help to you Mum?

0131: Yeah but the thing is they did, they would offer, but my Grandma didn't want it, she would always just want to live with us. And that was ok for us. Maybe... it's not like she never went around to their house, like she did, but again it was more physical aspects because her travelling from there to there and then she'd have to come out the car and then go up the steps and go into someone else's home, like it was more the physical thing. In our home she had her own room and like she knew where everything was.

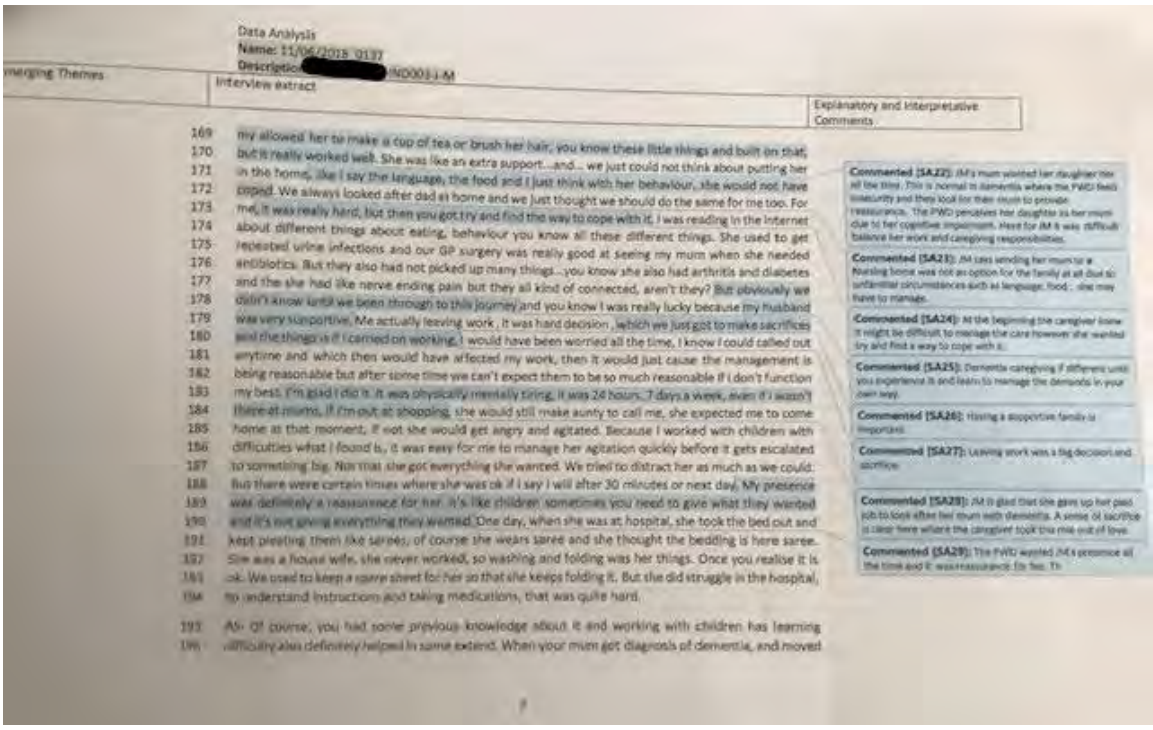
AS: Ok, so do think that would have helped your Mum in any way?

21

Figure 5.1: One Page Transcript with Empty Margins to be Used Later for Analysis

Step 2: Initial noting

While reading and re-reading the transcripts slowly, I started making initial notes in the margin of the transcripts as shown in Figure 5.2.



Data Analysis
Name: 11/06/2018_0137
Description [redacted]

merging Themes | Interview extract | Explanatory and Interpretative Comments

my allowed her to make a cup of tea or brush her hair, you know these little things and built on that, but it really worked well. She was like an extra support…and… we just could not think about putting her in the home, like I say the language, the food and I just think with her behaviour, she would not have coped. We always looked after dad at home and we just thought we should do the same for me too. For me, it was really hard, but then you got try and find the way to cope with it. I was reading in the internet about different things about eating, behaviour you know all these different things. She used to get repeated urine infections and our GP surgery was really good at seeing my mum when she needed antibiotics. But they also had not picked up many things…you know she also had arthritis and diabetes and the she had like nerve ending pain but they all kind of connected, aren't they? But obviously we didn't know until we been through to this journey and you know I was really lucky because my husband was very supportive. Me actually leaving work , it was hard decision , which we just got to make sacrifices and the things is if I carried on working, I would have been worried all the time, I know I could called out anytime and which then would have affected my work, then it would just cause the management is being reasonable but after some time we can't expect them to be so much reasonable if I don't function my best. I'm glad I did it. It was physically mentally tiring, it was 24 hours, 7 days a week, even if I wasn't there at mums, if I'm out at shopping, she would still make aunty to call me, she expected me to come home at that moment. If not she would get angry and agitated. Because I worked with children with difficulties what I found is., it was easy for me to manage her agitation quickly before it gets escalated to something big. Not that she got everything she wanted. We tried to distract her as much as we could. But there were certain times where she was ok if I say I will after 30 minutes or next day. My presence was definitely a reassurance for her. It's like children sometimes you need to give what they wanted and it's not giving everything they wanted. One day, when she was at hospital, she took the bed out and kept pleating them like sarees, of course she wears saree and she thought the bedding is here saree. She was a house wife, she never worked, so washing and folding was her things. Once you realise it is ok. We used to keep a spare sheet for her so that she keeps folding it. But she did struggle in the hospital, to understand instructions and taking medications, that was quite hard.

AN- Of course, you had some previous knowledge about it and working with children has learning difficulty also definitely helped in some extend. When your mum got diagnosis of dementia, and moved

Commented [SA22]: JM's mum wanted her daughter her all the time. This is normal in dementia where the PWD feels insecurity and they look for their mum to provide reassurance. The PWD perceives her daughter as her mum due to her cognitive impairment. Here for JM it was difficult balance her work and caregiving responsibilities.

Commented [SA23]: JM says sending her mum to a Nursing home was not an option for the family at all due to unfamiliar circumstances such as language, food… she may have to manage.

Commented [SA24]: At the beginning the caregiver knew it might be difficult to manage the care however she wanted try and find a way to cope with it.

Commented [SA25]: Dementia caregiving if different until you experience it and learn to manage the demands in your own way.

Commented [SA26]: Having a supportive family is important.

Commented [SA27]: Leaving work was a big decision and sacrifice.

Commented [SA28]: JM is glad that she gave up her paid job to look after her mum with dementia. A sense of sacrifice is clear here where the caregiver took this role out of love.

Commented [SA29]: The PWD wanted JM's presence all the time and it was reassurance for her. Th

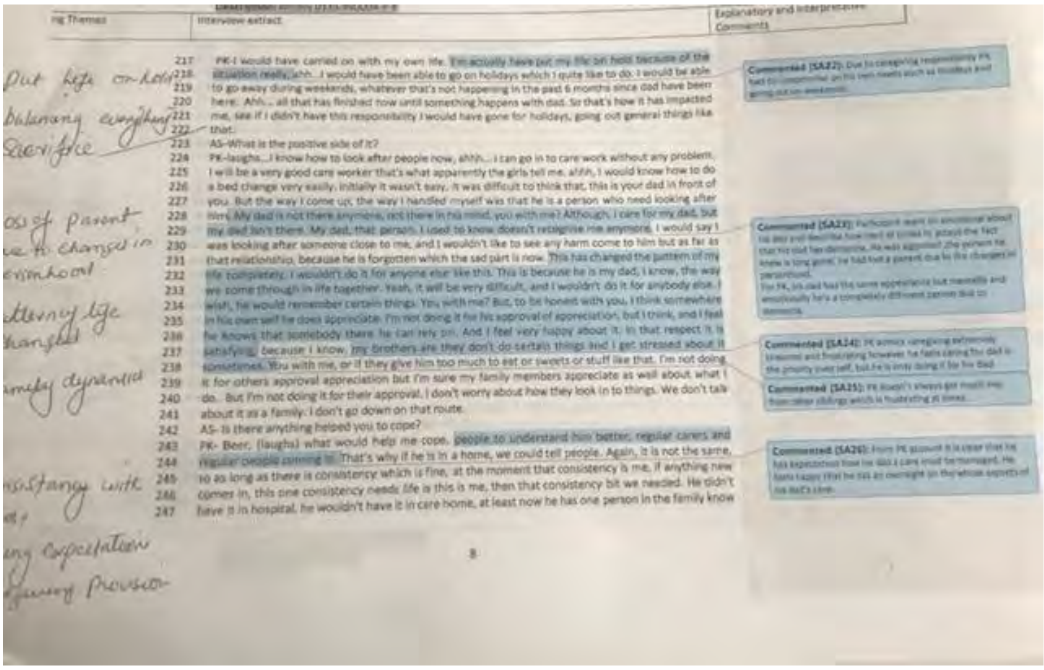
Figure 5.2: Initial Notes in the Margin

I followed Smith et al.'s (2009) IPA process and remained open minded and recorded whatever thoughts came to mind when reading the text. At the first stage, the transcripts were closely examined to understand the content, language, and context. I also started making notes in the right-hand margin to annotate the significant facts that participants provided. Observational notes and reflective logs were also made during the interview which was potentially highly significant at the preliminary interpretation stage. Again, the right-hand margin was used to make comments about summarising, paraphrasing, similarities, differences, use of connecting language, and echoes in the participant's account. Some words and phrases in the transcript that stood out were also underlined.

Step 3: Identifying and developing emergent themes

During the next stage of the IPA analysis, the initial notes were transformed into emerging themes. This process continued through the whole transcript. All themes generated from each section were summarised in the left-hand margin as shown in Figures 5.3. and 5.4.

This was the interpretation stage, where the detailed transcripts and initial notes were turned into concise phrases, and I used psychological concepts and terms (Willig, 2001).



…ng Themes | Interview extract | Explanatory and Interpretative Comments

Put life on hold

Balancing everything

Sacrifice

…oss of parent
…e to changes in
…ersonhood

…ltering life
…hanged

…mily dynamics

…nsistency with
…

…ng expectation

PK-I would have carried on with my own life. I'm actually have put my life on hold because of the situation really, ahh… I would have been able to go on holidays which I quite like to do. I would be able to go away during weekends, whatever that's not happening in the past 6 months since dad have been here. Ahh… all that has finished now until something happens with dad. So that's how it has impacted me, see if I didn't have this responsibility I would have gone for holidays, going out general things like that.

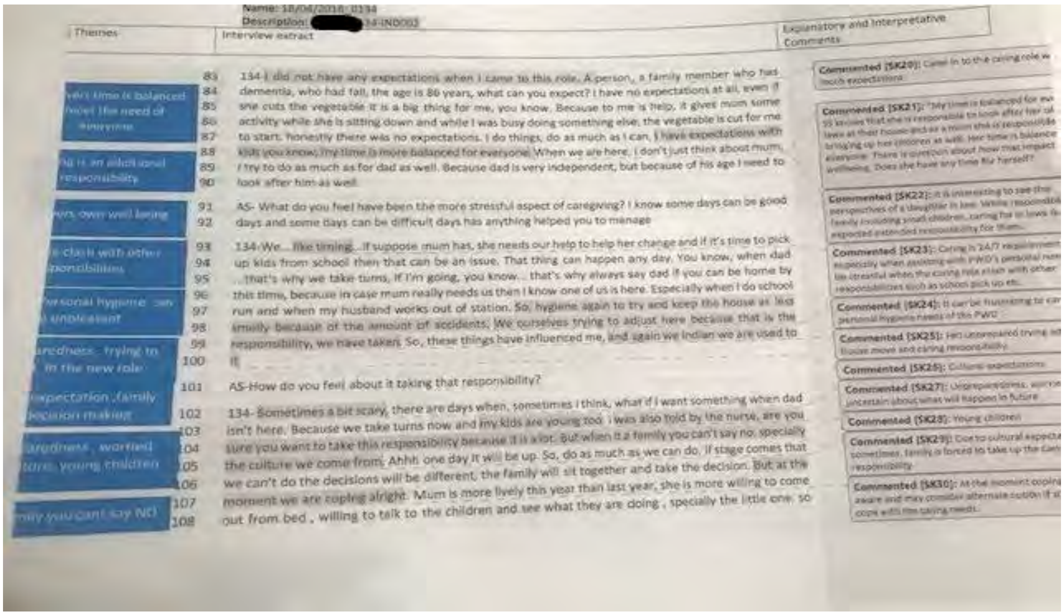
AS-What is the positive side of it?

PK-laughs…I know how to look after people now, ahhh… I can go in to care work without any problem. I will be a very good care worker that's what apparently the girls tell me. ahhh, I would know how to do a bed change very easily. Initially it wasn't easy. It was difficult to think that, this is your dad in front of you. But the way I come up, the way I handled myself was that he is a person who need looking after him. My dad is not there anymore, not there in his mind, you with me? Although, I care for my dad, but my dad isn't there. My dad, that person, I used to know doesn't recognise me anymore. I would say I was looking after someone close to me, and I wouldn't like to see any harm come to him but as far as that relationship, because he is forgotten which the sad part is now. This has changed the pattern of my life completely. I wouldn't do it for anyone else like this. This is because he is my dad, I know, the way we come through in life together. Yeah, it will be very difficult, and I wouldn't do it for anybody else. I wish, he would remember certain things. You with me? But, to be honest with you, I think somewhere in his own self he does appreciate. I'm not doing it for his approval of appreciation, but I think, and I feel he knows that somebody there he can rely on. And I feel very happy about it. In that respect it is satisfying, because I know, my brothers are they don't do certain things and I get stressed about it sometimes. You with me, or if they give him too much to eat or sweets or stuff like that. I'm not doing it for others approval appreciation but I'm sure my family members appreciate as well about what I do. But I'm not doing it for their approval. I don't worry about how they look in to things. We don't talk about it as a family. I don't go down on that route.

AS- Is there anything helped you to cope?

PK- Beer, (laughs) what would help me cope, people to understand him better, regular carers and regular people coming in. That's why if he is in a home, we could tell people. Again, it is not the same, so as long as there is consistency which is fine, at the moment that consistency is me, if anything new comes in, this one consistency needs life is this is me, then that consistency bit we needed. He didn't have it in hospital, he wouldn't have it in care home, at least now he has one person in the family know

Figure 5.3: Adding Emergent Themes in the Left Hand Side Margin



Name: 18/04/2016 0134
Description: [redacted] 34-IND003

Themes | Interview extract | Explanatory and Interpretative Comments

…ver time is balanced
…meet the need of
everyone

…is an additional
responsibility

…vers own well being

…clash with other
…ponsibilities

…ersonal hygiene can
…unpleasant

…aredness, trying to
in the new role

…expectation, family
decision making

…aredness, worried
…tore, young children

…mily you can't say NO

134-I did not have any expectations when I came to this role. A person, a family member who has dementia, who had fall, the age is 86 years, what can you expect? I have no expectations at all, even if she cuts the vegetable it is a big thing for me, you know. Because to me is help, it gives mum some activity while she is sitting down and while I was busy doing something else, the vegetable is cut for me to start. honestly there was no expectations. I do things, do as much as I can, I have expectations with kids you know, my time is more balanced for everyone. When we are here, I don't just think about mum, I try to do as much as for dad as well. Because dad is very independent, but because of his age I need to look after him as well.

AS- What do you feel have been the more stressful aspect of caregiving? I know some days can be good days and some days can be difficult days has anything helped you to manage

134-We… like timing…If suppose mum has, she needs our help to help her change and if it's time to pick up kids from school then that can be an issue. That thing can happen any day. You know, when dad …that's why we take turns, if I'm going, you know… that's why always say dad if you can be home by this time, because in case mum really needs us then I know one of us is here. Especially when I do school run and when my husband works out of station. So, hygiene again to try and keep the house as less smelly because of the amount of accidents. We ourselves trying to adjust here because that is the responsibility, we have taken. So, these things have influenced me, and again we Indian we are used to it

AS-How do you feel about it taking that responsibility?

134- Sometimes a bit scary, there are days when, sometimes I think, what if I want something when dad isn't here. Because we take turns now and my kids are young too. I was also told by the nurse, are you sure you want to take this responsibility because it is a lot. But when it a family you can't say no. specially the culture we come from. Ahhh one day it will be up. So, do as much as we can do. If stage comes that we can't do the decisions will be different, the family will sit together and take the decision. But at the moment we are coping alright. Mum is more lively this year than last year, she is more willing to come out from bed , willing to talk to the children and see what they are doing , specially the little one. so

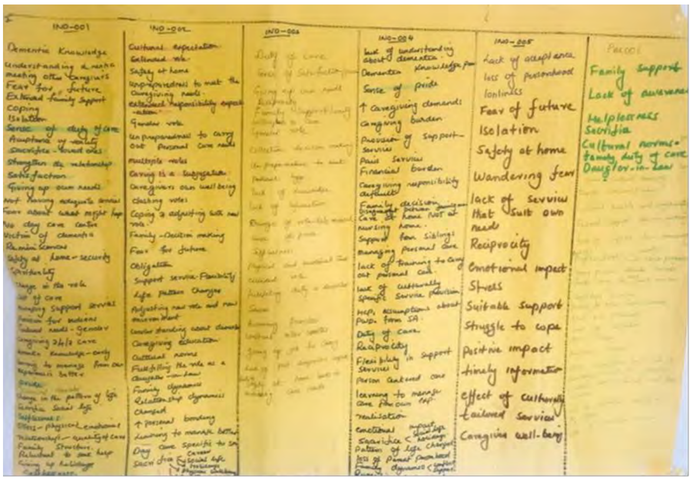
Figure 5.4: Adding Emergent Themes in the Left Hand Side Margin

Step 4: Searching for connections across emergent themes

During this stage, all the themes generated from the entire transcript were drafted in a separate document and compiled in chronological order before looking for patterns and connections between them. At this stage, relatively weak themes which did not fit with the emerging themes were disregarded due to lack of data to support them. The themes were then clustered according to conceptual similarities and a final list of superordinate themes and sub themes were developed. To ensure the thematical interpretations matched what the participant had originally described in the interview, I checked that they had been referred to in the original text frequently.

Step 5: Moving to the next case

The above stages were repeated for all Eight transcripts. Each of the transcripts was analysed independently and where possible the ideas and themes emerging from the first analysis were bracketed to allow for new themes to emerge with each transcript as shown in Figure 5.5.



IND-005
Lack of acceptance
loss of personhood
[illegible]
Fear of future
Isolation
Safety at home
Wandering fear
lack of services that suit own needs
Reciprocity
Emotional impact
Stress
Suitable support
Struggle to cope
Positive impact
timely information
effect of culturally tailored services
Caregiver well-being

Figure 5.5: Emergent Themes from all Transcripts

Stage 6: Looking for patterns across cases

At this stage, a master list of themes was produced to summarise the super-ordinate themes and subordinate themes. The themes were then one by one translated to a narrative account with a strong interpretive focus. Care was taken to distinguish clearly between what the participants said, and interpretation. This study includes both the participants’ accounts of his or her experience in his or her own words, and my interpretative commentary.

5.12 Establishing quality of research

Examining and establishing quality of IPA research is based on how it is conducted, and the richness and trustworthiness of the results generated from the participants’ real world (Yardley, 2000). Smith, Flowers, and Larkin (2013) recommend researchers use Yardley’s (2000, 2011) core principles for evaluating the validity of qualitative research: sensitivity to context, commitment and rigour, coherence and transparency, and impact and importance.

A) Sensitivity to context

As recommended by Yardley (2011), considering “relevant theoretical and empirical literature” was achieved in the first three chapters of my thesis, in which a carefully curated literature review allowed me to establish a strong understanding of the background and to identify the recurring findings and gaps in this area of study. All of these processes, in turn allowed the conception of an appropriate study questions.

b) Commitment and rigor

The second criterion was achieved through in-depth, broad analysis, which allowed the generation of rich, consequential data. Throughout the data collection process, great attention was given to the participant to ensure insightful findings were conceptualised

c) Coherence and transparency

Coherency and transparency, the third principle of IPA methodology entails the clarity and presentation of discussion in a way that can easily be interpreted by an outsider. This was achieved through a thorough explanation of the methodology in a highly transparent manner. Throughout the thesis, the justification and rationale is detailed in the context of the research, methodological fit and theoretical approach thus optimising coherence and transparency

d) Impact and importance

The quality of data stems from its importance, impact, and utility. This was reiterated several times throughout this thesis with a detailed rationale for the necessity of this study highlighted primarily in the introduction chapter. Bracketing is also a fundamental criterion for quality and validity in IPA studies and was discussed in relation to this study previously in sections 5.6 and 5.7.

5.13 Ethical consideration

The aim of ethical research is to protect the participants involved in the research ensuring that their safety, autonomy, and privacy is protected, as well as the confidentiality of the collected data. Any risk in relation to confidentiality, voluntary participation, and informed consent was not assumed but was carefully considered throughout the research process. Details of the ethics application and approval were given in section 5.11.1 earlier in this chapter.

5.13.1 Voluntary participation and informed consent

Informed consent is an integral part of the ethical conduct of research with human participants. A PIS and informed consent form (ICF) were developed, adhering to Health Research Authority (HRA) guidelines and the University ethics committee guidance. The PIS outlined information about the aims and methods of the research project where participants needed to make a decision to participate. A process of voluntary and informed written consent was undertaken to ensure the full rights of the participants. This involved, providing the PIS and consent form to the participants through the gatekeepers at the community centres and leaving at least a 24-hour gap between the time when the participant agreed to participate in the study and the actual time when they signed the consent form before the face-to-face interview. This ensured that the participants had ample time to consider, understand fully, and raise any concerns in relation to the purpose of the study and the processes involved.

Participants who refused to participate would not be asked to explain why they did not participate and would not be approached again. A process of informed consent was adhered to before, during, and after the interview. Participants were reminded regularly that they could refrain from answering any uncomfortable questions. The details of the study were discussed with participants again the day before they signed the consent form. They were also given opportunity to ask any question. The researcher also countersigned the consent form. A copy of the consent form was given to the participant. The signed form was then securely stored separate to any data generated. A copy of the PIS (Appendix 1) and ICF (Appendix 2) can be found in Appendices.

5.13.2 Cultural sensitivity in fieldwork and confidentiality

The recruitment, consent procedures, the interviews, and study assessments were conducted in English. The PIS outlined the measures that were to be adopted to secure the confidentiality of each patient before, during, and after the data collection. The pilot interview was conducted at the University. Two interviews were conducted in community centres, and five participants preferred their homes for semi-structured interviews. Prior to the interview, I explained to all participants my own cultural and ethnic background and the language I speak. I encouraged the participants to discuss how they felt about talking to me about their experiences. I felt being a researcher from a South Asian background enabled better engagement with the participants and that I was able to establish a rapport. I felt that the similarities I shared with them eased the interview process and enabled me to gain access to a potentially underserved group.

At the same time, I knew that I needed to observe some precaution to overcome potential bias associated with this. I had conversations with all the participants if they had any concerns about confidentiality because I am from a South Asian background. Empathising with the participants on shame around dementia, I checked with them how they felt about talking to me and reassured all the participants that maintaining confidentiality was paramount, and that the collected data would be used in an ethical, culturally appropriate, and sensitive manner in order to protect the confidentiality. All personal data collected about the participants was anonymised using pseudonyms and consent was explicitly extended for publication of anonymised verbatim extracts from the interview data.

5.13.3 Data storage and use

The data was collected, stored, and used in a responsible and ethical manner in accordance with EU General Data Protection Regulation (GDPR) and the UK Data Protection Act (2018). To ensure anonymity and protection of the participants' privacy, all identifying information in relation to the participants – particularly the participants' names – was changed upon collection of the data. Each participant's demographic data was collected prior to audio recording to ensure confidentiality. Each participant was assigned with a separate participant ID number starting from either IND001 or PAK001. All data, including the audio-recorded qualitative interviews, were always stored securely in password-protected files on Manchester Metropolitan University's secure computer network space. I transcribed and analysed the interview data myself, hence no data transfer was needed. Original copies of the consent and demographic forms were kept securely in a locked cabinet at the University. It was also ensured that any back-up copies of the electronic data files, where necessary, were only taken on USB drives which were password protected and kept in locked cabinets at the University. In line with the University's policy on storage of personal data for research purposes, the data will be stored securely for five years after the last publication of the study or for 10 years, whichever is the greater. Consent forms will be retained as essential documents, but items such as the contact details of the participants will be deleted as soon as they are no longer needed.

5.13.4 Participant well-being

Participants' well-being was ensured throughout the interview process. They were given detailed information about the study at the start of the interview. Before the interview, each South Asian caregiver was reminded that their participation in study was entirely voluntary, and they could withdraw from the study at any time. It was explained to them that they could share as much information as they were comfortable with. It was also explained to them that if they did not want to share any information or did not want to answer any questions they did not have to. This built up their trust and put them at ease to answer questions freely. It was explained to the participants that the interview was being conducted to hear about their experiences, as I considered them as the experts in caregiving and that there were no right or wrong answers to the questions. Each participant was given ample time to think of an answer to the questions without any rush, demonstrating active listening without any interruptions as recommended by Smith and Nizza (2022).

During the interview, I made sure to allow participants time to finish expressing everything they had to say before moving on to the next questions. Throughout the interview, I made sure that each participant was comfortable by watching their non-verbal cues and responses. During the interview when there were sensitive topics, which led to emotional or distressing moments, the participants were asked if they wished to take a break or complete the interview later. Participants were also reminded that they could withdraw at any point from the interview. The researcher assessed how the participants were feeling at the end of each interview as there was a possibility that the caregivers could remain distressed after the interview. Participants were finally given a private work telephone number where they could reach me, as I have previous experience in supporting research participants through distressing experiences, and in difficult situations, I would be able to refer on to an appropriate support service should they need to access further emotional/psychological support. I also made sure to follow-up the participants after the interview to assess their well-being and sign posted them to relevant services where they had queries or signs of distress.

5.13.5 Reflexivity

Even though, I have knowledge of the experiences of South Asian caregivers due to prior professional experience working with PWD and my South Asian ethnicity, during the interview process, I reminded myself to consciously keep aside my pre-conceptions and listen to the participants, without advice as if I knew nothing about the topic of caring for people with dementia and explicitly asked the participants to share their experiences.

I reflected my interview skills after each interview, which helped me to identify areas where I needed improvement. I listened, relistened, and transcribed the pilot interview data following the IPA analytical process and found that my pilot interview participant misinterpreted one of the questions. My supervisor also reviewed the transcript of the pilot interview and agreed that I would rephrase this particular question. I learned that each interview is a unique encounter between people with its own alchemy.

5.13.6 Researcher well-being

Semi-structured interviews are integral to IPA and interviewing is an important skill that researchers are expected to master. While IPA researchers play an integral role in creating and maintaining an inviting environment in which participants can express their feelings, thoughts, and concerns to generate high-quality data, this can sometimes be overwhelming. Throughout the interview process, it is highly recommended that researchers access their physical, emotional, and psychological well-being without being overlooked. In this study, I made every effort to maintain reflective notes during the data collection period. I was also aware that I had the opportunity to contact my supervisor or university advisors, if any unpalatable or difficult situations arose.

As participants were seen at home, there was an element of risk associated with me working alone. Thus, a risk assessment was done before each interview and I used a 'fieldwork buddy system', keeping the research member informed of the time and place of the interviews, my contact details, and the venue information for the research interview, as well as contacts at the local South Asian community centres. The fieldwork buddy was contacted when each interview/field visit was finished.

5.14 Conclusion

This chapter has laid the foundation on which the research was explored and provided a rationale for choosing IPA as the most fitting methodology for this study in understanding the lived experience of individuals in their social context. This chapter detailed justification of my ontological and epistemological position, explaining how IPA helped in framing the current research to attain the desired and viable findings. The chapter further detailed the research method techniques and processes utilised in this study, from seeking ethical consent to recruitment, and the rationale for the sampling, data collection, and interview process to the data analysis methods in exploring this research. The next chapter presents the findings of the IPA of the data from eight South Asian Caregivers of people with dementia, divided into themes and sub themes.

Chapter 6. Results

Chapter 5 presents the findings of the semi-structured interview data from eight South Asian Caregivers of people with dementia (PWD). This chapter offers an interpretation of the data and an overview of the main themes and sub themes that emerged from the comprehensive IPA. Each theme and its subordinate themes discuss the perceptions of the interviewees regarding each thematic idea, illustrated here through extracts from the interview transcripts. This text is indented and italicised or presented with quotations marks. In order to respect the principles of confidentiality, the participants were given pseudonyms and all personal and identifiable information has been edited/removed.

As a result of the analysis, five master themes were generated which are presented in the Table 6.1 below.

Table 6.1: Themes and Subordinate Themes

Super-ordinate Theme	Subordinate Themes
Now it’s my turn to take care of you	Sense of duty of care, Sacrifice, Purpose of life, Giving up own things, Sense of pride, Recognition
When it’s family, you can’t say no.	Family support, Family unity, Grandchildren in family caregiving, Inconsistence, Conflicts in family dynamics, and Obligation

It is a norm, a good norm, a very good norm to follow	Cultural norms and beliefs
It was a constant roller coaster	Cultural predictors, Caregivers' characteristics, Gender differences, social isolation
Tell us what it is and what the best way is to deal with it	Increasing awareness, Inadequacy in health care system, Tailored support and expectations, Culture and care provision, Gender tailored support.

6.1 Master theme one: Caregivers' motives for caring for the PWD: "Now it's my turn to take care of you"

All participants in this study reported caring for their family member with dementia as a positive experience. They highlighted a number of significant factors that contribute to the multidimensions of positive aspects of caregiving. The reciprocal nature of caregiving was one of the strong themes that emerged from the interpretation of participants' accounts. All participants in this interview expressed a strong feeling of a sense of duty and responsibility to provide care for the older person in their family.

Chawla believed it was his duty of care now to look after his wife living with dementia.

> *Before I did not have any of these responsibility except make a cup of coffee in the morning after I disappear, and she gets on with her stuff. She does everything, she makes breakfast etc. (**Chawla**)*

> *If I can’t support, my loved one what is the idea of my life? If in this life I can’t help my wife that means I don’t sacrifice as I told you... (**Chawla**)*

By stating the above quote Chawla portrayed a sense of purpose in his life. Chawla and his wife have been married for 60 years, and he has strong feelings on their relationship. Chawla believes that his purpose in this life is his wife. He feels that he owes it to his wife to take care of her now she needs help. To Chawla, a family is all about serving for your loved ones as he is taking care of his wife, who has dementia. He supports his wife because, according to him, a loving husband should take care of his wife and other loved ones.

> *If I had made the promise, my wife didn’t ask me to make that promise; I made that promise myself that I want to do it. So, now I’m going to back it up. (**Chawla**)*

In this quote, the repetition of emotive abstract noun “promise” emphasises the intensity of the lifelong love and intimacy Chawla feels towards his wife and a strong sense of commitment to maintain the meaning of their relationship. On a deeper level, this notion of commitment and positive aspects of caregiving is further exemplified by the word promise as it is an allusion to couple’s marital vow ‘in sickness and in health’; therefore, highlighting that Chawla still firmly affirms and wishes to adhere to this marriage vow to promise to take care of one another, which he believes is an integral part of their marital life. Chawla stated the marriage vows they made still stand. He is ready to follow up on the promise he made his wife of always being there for her. He insisted that no one forced him to make the promises to his wife, instead he wholeheartedly believes that he made this self-fulfilling, unfeigned promise from within and that is the main reason for supporting her; he does it whole-heartedly.

> *I never shout on my wife even if she tells me 100 times the same things. She can tell me 1000 times there will be a day I will never get annoyed. I'll tell you because I know you do not remember, because I know what you are, so I cannot force, you to change and I also know your brain is not working properly due to dementia. So, my part is how I can help you; I help you to tell you the same thing again and again. I will remind you, but I will not be angry or annoyed, and I'll not shout at you. It makes me feel happy because I feel happy in the sense that you know the person and you should find some remedy which is suitable for both parties.* ***(Chawla)***

Chawla continued to discuss his profound feelings on how he perceives that caregiving is more than just a 'role.' He emphasised that caregiving has a transcendent nature that is beyond just the physical: it is a social, mental, and spiritual endeavour that can only be achieved when the caregiver has wholehearted, genuine intentions. In this discussion, the use of anaphora with the phrase "I will", which connotes action and determination, highlighted how he is willing to do whatever is needed to support his wife. Additionally, this phrase echoes the previous idea of promises, emphasising that Chawla's feelings of love, commitment, and reciprocity are so heartfelt that they shone through several discussions and evidently display Chawla's deep sense of satisfaction about being able to care for his wife with dementia. Chawla also described that "[he] know[s] [how his wife is], so [he] cannot force, [her] to change and [he] also knows [her] brain is not working properly due to dementia". Again, by utilising anaphora for the pensive verb "I know", Chawla emphasised his firm belief that in order to care he needs a thorough understanding of the condition of dementia and his wife's unique needs. This clear understanding helped Chawla to adapt his own strategies to better manage his wife's condition.

> *It is big responsibility and but, in the end I feel happy. After some time, you are used to it like any their things. So, when I know that the person is suffering with dementia what is the best* ***remedy*** *as a carer I can offer. Anger or* ***love****? But I find it's love but for that I have to sacrifices. Why I'm telling this again and again...I have to say...which I do, and I feel very happy. My wife thinks what's wrong, I do everything, change her clothes and wash her. Whatever it is...so I do. And she feels very happy. In the end what I find myself from my wife...she never talked to me before like that but now she says...****"darling I love you very much"*** *you never told that to me even when we got married. You might be wondering...why I'm telling you all these things. (****Chawla****)*

Chawla continued to share his experience of caring for his wife. It was evident from his soulful eyes, voice, and emotive tone, that caring for his wife provides a profound sense of purpose in his life. It gives him real meaning. In this quote, through the use of a semantic field of nurture Chawla emphasised how his role as a caregiver has brought contentment to him and his wife. Chawla wholeheartedly described that ***love*** is "the best remedy as a carer [that he] can offer". By using such deep, emotional imagery Chawla emphasised that he believes as caregivers it is very important to provide the PWD with a loving, nurturing environment. This idea of positive care is again hinted at when Chawla described that "[he does] everything, change her clothes and wash her. Whatever it is...so [he does]". Through the listing of caring verbs, Chawla highlighted that he is happy to cater to his wife's needs. He stated that his wife is content and grateful for her husband's loving care and he claims that "she never talked to [him] before like [this] but now she says... 'darling I love you very much'. [She] never told that to [him] even when [they] got married". From this profoundly emotional statement it is implied that this change in marital dynamics has brought Chawla a new sense of closeness with his wife and allowed them both to understand the real deepness of unconditional love. Despite the love Chawla feels, he understands that it can be sometimes tiresome to care for PWD and could even test a person's patience. However, he recognises the things he cannot change and tries to adapt to this by being patient, compassionate, and loving to his wife.

> *My only desire is seeing my wife happy in the last stage of her life. That will give inner peace and happiness. That is all last you till the end, not the money or fame. (**Chawla**)*

Chawla gave a very emotional commentary of his experience as a caregiver. He took so much pride about being an amazing carer and husband to his wife. He values the bond between him and his wife much more than materialistic possessions. Throughout the interview, it was apparent how the connections and bond of marriage also equated to the selfless act of caregiving. He cares for his wife deeply. The relationship that he shares with his wife is strong, relating to how much he takes care of her. He intends to support her until death does them part as a justice to her and himself.

Poonam's perspective on caregiving was to some extent similar to Chawla's. She feels incredibly proud of fulfilling her role as a daughter and caregiver, and it helped her to look at life very differently and develop as an adult by increasing her perspective. She also sees the time she has with her mother as a bonding experience, that, according to her, is priceless.

> *I feel very proud of what I have done. It has given me perspective about life, I appreciate life, and I appreciate any day that we have. **(Poonam)***

Poonam's dimensions of reciprocity were different from Chawla's. She has a great desire to "be there" for her mum. Poonam expressed a sense of reciprocity with her mum for the past care that she has received from her throughout her life, and she saw returning this as her "duty of care". She spoke about how her mother protected her when she was a child and fostered her personal growth. Poonam wanted to reciprocate this past care in the form of protection. Returning the care that she received from her in taking care of her mother gives her great fulfilment. She generates a sense of responsibility to her mother in a time of need because her mother was also always there for her.

> *I think, you know, ok, you are growing up, they are* ***always there for you, then it changes****. Yeah, it is a positive time, you know, you are giving back something to your parents, they protected you when you were children, you know. (****Poonam****)*

Poonam feels very proud of what she has done for her mother, and she is happy that she was able to spend some quality time with her mum. She appreciates and values the support that her mother had always given her when growing up and feels it is her time to do the same for her. She values giving back to her parents when they need support which they have not always required. It was also satisfying for her to know that her mum is getting excellent care under Poonam's care.

> *As much as it is challenging, it is rewarding in a way. When I sit down, I don't feel any guilt, think I spend the most quality time with Mum, even though it wasn't pleasant when she needed me most. (****Poonam****)*

Poonam emphasised the deep-rooted relationship, love, and commitment she has for her mum. She feels that since her mum's diagnosis of dementia, the mother-daughter role has been reversed, and she is walking in her mum's shoes; thus, for Poonam, this 'reversal' means that it is she who is now the 'protector'. She stated that although it was a time of balancing everything, she does not feel she has wasted her time. Taking care of her mother has made her spend quality time with her mother, which would not have happened as much if not for the dementia. She has learned to value every minute she spends with her mother as bonding time which gives her a sense of increased meaning and purpose in her life.

> *When I think about my mum, there is something pulling from inside, and I don't know that was the attachment we build between us because of ...maybe our roles reversed? I don't know. I don't know.* ***(Poonam**)*

In this quote "when I think about my Mum, there is something pulling from inside", Poonam portrayed the intrinsic, strong emotional attachment she feels with her mum as an unrelenting force. Poonam stated that what drives her to support her mother is more than just responding to family. She feels that she draws her motives from some more profound attachment that they share. She thinks taking care of her mother came easy because it was like experiencing having their roles reversed. Before it was her mother taking care of her, and then it was her turn to take care of her mother.

For Kamal, an Indian son caregiver, it was the gratitude towards his dad that influenced him to become the main caregiver. Kamal expressed a strong sense of love and commitment for his dad and caring as an opportunity for giving back to his dad who has cared for them.

> *I love my dad...ahhh. I think he worked hard all his life, he brought us all up, what we are now. (**Kamal**)*

By giving care to his dad, Kamal feels he is repaying his parent for his sacrifices while bringing up the children. Kamal explained with sadness, the hardship his dad had to go through when they migrated to the UK. Kamal and his sibling were young, and his dad, as the only earning member in the family, struggled a lot to bring up the family. He feels that he owes his father at least that much for the sacrifices he has made in their life. He takes care of his father because if it was not for him; Kamal would not turn out as he has.

> *I mean It would be sad because he has done everything for, and I felt that. He had done it for us. So, I should be there for him at this moment and time. And that is my reasoning. (**Kamal**)*

Here both Poonam and Kamal, the adult children, became emotional when they thought about their close relationship with their parent with dementia. They both consider taking care of their parents as an honourable duty and believe that they are morally obliged to take care of them in old age. Here honour is linked to what you need, not what you want. They both clearly express a sentiment that questions who else could do it better than those people who know them most. They feel that their parents have the right to be cared for by their children because they had also taken care of them when they were growing up. It is a responsibility to their parents with dementia.

> *But to be honest with you, I think somewhere in his own self he does appreciate. I am not doing it for his approval of appreciation, but I think, and I feel he knows that somebody there he can rely on. And I feel very happy about it. In that respect, it is satisfying. (**Kamal**)*

Kamal is grateful that his father has someone to rely on. He feels even better when the person is him taking care of his father. Kamal is proud and feels a sense of satisfaction knowing that his loved one is getting excellent care, and that his father can depend and rely on him for support. He stated that he does not do this for appreciation or approval but rather because of love. He gets fulfilment in serving his father.

While the adult children in this study sample perceived caring for their parent as more than reciprocity, the grandchildren caregivers shared the influence of reciprocity as an exchange of support between their parents and grandparents. Rahana and Fatima live in an extended family; therefore, they both have experienced the supporting hands and commitment of their grandparents in their life. Rahana recollected that after her dad's death, her grandmother stayed with her family and supported her mum financially and with the childcare.

> *After my dad's death, my grandma stayed with us to look after us the grandchildren because she felt that responsibility to do that because my dad wasn't there. So, yeah... (**Rahana**)*

Rahana remembered seeing her mum taking care of her grandmother despite the difficulties of being a single parent. She described how her mother cultivated compassion and empathy in their family and made many sacrifices. Growing up in such an environment has influenced Rahana's commitment to the values of dedication and selflessness that were nurtured in her family.

> *So, to me, I think it's been positive, I've got probably some of my morals from my mum too, like how she is, and she likes to look after my grandma. I want to do what my mum has done for her mother-in-law. Your parents have done the hard work of bringing the children up... All her life she had*

> *looked after her children. When I get married, I am going to do the same. I want to look after her so that she can relax. (**Rahana**)*

Rahana reflected that she enjoyed the time she spends looking after her grandma and thought it has a considerable impact on developing her positivity. Her family setting has greatly influenced her decision to take care of her grandmother because her mother used to do it too. She understands that her mother has done a lot for them while growing up and needs to rest so that they can reciprocate affection, and she expressed a desire to take care of her mum when needed. When she spoke about her involvement in looking after her granddad with dementia, Fatima’s views echoed Rahana’s perceptions.

> *It feels really responsible. Because I've, I mean I am only a young age, but then I feel like there is a lot of responsibility because not only am I looking after someone, but it is also my grandad as well, and we live in the same house, so you just need to make sure family is ok and that they’re ok as well. (**Fatima**)*

According to Fatima, it is the responsibility of every family member to take care of each other. That is the main reason she takes on the responsibility of assisting her grandfather. She feels that it is a lot of work owing to her young age as usually young adults do not have great, multifaceted responsibilities such as caregiving placed upon them while the expectation is for them to complete their studies. However, she still takes it on so that a member of her family does not feel neglected. At times she feels it is more of a duty to her family rather than a choice since it has to be done.

> *I plan my days around Grandad…I'm only doing a part-time job so that I can look after Grandad as well...sometimes I ring work and go a bit late so that I know everything is set. (**Fatima**)*

Fatima explained that she plans her day based on the needs of her grandfather because for her, family comes first. She expressed a sense of happiness at adjusting her schedule for his well-being. For Rahana and Fatima, their involvement in caregiving for their grandparents with dementia is to help them gain satisfaction and generate reciprocity between their grandparents and parents.

Maya an Indian daughter-in-law, who is currently caring for her mother-in-law with dementia, talked about her experiences as a caregiver.

> *When our own parents are expecting you to do it, so you always think you want to do better and better. (**Maya**)*

Maya feels she has a familial responsibility to make sure her ailing mother-in-law is safe, secure, and getting the attention she needs as she has seen her parents provide care to their elderly parents. Maya expressed a wish that she will be taken care of in the same way that she is taking care of her elders.

> *I wanted to do things for them, and they say "no" but now, when they need help so how could I say no? I looked forward, I wanted to do something for years, that was another thing for me to take the responsibility and get on with it. (**Maya**)*

Maya has seen most children in India take care of their own parents and expects that their children will do the same for them. Living in the UK, Maya still wants to adhere to the traditional value of caring for older parents and she wants to give her best to her in-laws as a daughter-in-law.

Sabina, another daughter-in-law of Pakistani ethnicity finds fulfilment in being a caregiver for her mother-in-law with dementia.

> *And when looking after them gives me inner happiness and I think it is positive for my mentality and I feel positive now I try to and I'm willing to help old people as well, and my kids do the same. Looking after them is a blessing. And if they are happy, the family environment is nice and enjoyable (**Sabina**)*

Sabina feels positive as a caregiver by fulfilling her responsibility as a daughter-in-law. She stresses that it gives her the emotional advantage of feeling she is giving back the love she has received. Sabina finds her role to be a blessing to be able to care for her mother-in-law in need. She discussed the nuanced spirituality of her role. Through the use of the word "blessing", it is shown that she believes her role of being a caregiver is almost like a gift from God.

> *I feel good. As a daughter-in-law, I am looking after my mother-in-law, I feel good from inside and makes me happy, and when I am looking after them, they are happy, and they care for me more, when they are happy my husband is happy and when we all are happy, full stop. (**Sabina)***

By sharing her experiences, Sabina emphasised that her role as a caregiver has provided her with a strong sense of fulfilment. She strongly expressed that caring for her mother-in-law has created a deeper connection between them and they have started enjoying each other's company. Through the repetition of the word, "happy" Sabina also stressed her belief that helping her mother-in-law has the ability to create a nurturing and positive environment in which her family can thrive, thus increasing the strength of family solidarity. This connects to the next theme that discusses the familial factors that influence the motivations of caregivers.

In summary, this theme is a detailed interpretation of how reciprocal notions motivate caregiver among South Asian caregivers when they care for their own. All the participants reflected the multidimensional effects of reciprocity, expressing deep feelings of affection, gratitude, and appreciation which altogether provided the caregivers with a resounding rationale for their caregiving role. This research reflects existing empirical studies on this theme and adds to existing studies by understanding how reciprocal support in families affects the outcomes of caregiving for PWD.

6.2 Master theme two: Caregivers’ motives for caring for PWD: “When it’s family, you can’t say no”

Another dominant theme that was widely reflected by all caregivers in this study was the familial factors that influence the motivation of caregiving. All participants expressed a ‘strong sense of family unity’ which aided them in fulfilling caregiving responsibilities. In the UK, South Asian communities have always been closely knit, and they have maintained a strong view on family care taking of family. All the caregivers agreed that giving care to a family member with dementia had extended the closeness of their family unity in related decision making.

> *In that way, my wife is very lucky to have a caring son and daughter-in-law. They also live here and help me with the care. (**Chawla**)*

Chawla expressed that he feels extremely lucky to have his son and family around him to support him with the care of his wife. He believed in the importance of having an understanding and supportive family, especially his daughter-in-law, which created a positive impact in his caregiving experience. Through a semantic field of commitment, Chawla highlighted that the combined efforts and dependability of his family has created a positive caregiving environment.

> *Their presence means my responsibility is short. Some of my responsibility is taken over by them already. So, when we share the responsibility, which gives me more confidence in everything. I know someone else there to share the care. They are here and take care of her. (**Chawla**)*

The power of familial dependability is further exemplified by Chawla when he says that "[His family's] presence means [his] responsibilities are short". By using the simplistic adjective "short" to describe his responsibility, Chawla metaphorically emphasised that by having his family's aid in the caregiving role, caring has been transformed from a daunting, overbearing task to something more manageable. Echoing this notion by stating "gives me more confidence in everything", Chawla stressed that having familial support has allowed him to feel more self-assured in his role as a caregiver.

Alternatively, by reducing a usually daunting experience to "short", on a deeper level, Chawla implied that this support has also eased the difficult emotions associated with caregiving, particularly his anxiety and worry of being able to handle the burden of care singlehandedly.

> *So, I have someone to depend on right, my son is here if I need any help, they know it, so some of my responsibility is taken over by them already. (**Chawla**)*

Chawla further discussed that this strong cycle of support has certainly made his responsibility as a caregiver more accessible and has reduced the caregiving burden. Emphasising the integral role family unity plays in positive caregiving experiences and through the use of the phrase “share responsibility”, Chawla highlighted the collaborative effort he and his family make to care for his wife. The positive verb “share”, which invokes connotations of stresses that as a family they all have responsibility for the PWD and the burden is not thrust upon one person.

Poonam echoed Chawla’s sentiment of sharing responsibility.

> *As a family you know we very, very lucky that our family is so close each other and we all did the maximum for our mum we all could. (**Poonam**)*

Although Poonam is primarily responsible for the care of her mother with dementia, she acknowledged the positive influence of the family and the collaborative efforts in care. Born and raised in the UK, Poonam strongly supports the strength of family ties and the value of traditional family unity. Poonam expressed that her family all did the “maximum” they “all could.” Through the use of the noun “maximum” and verb “could” Poonam emphasised that her family gave their wholehearted effort to supporting their mum with dementia. Additionally, Poonam continuously uses the collective pronoun “we”, emphasising the closeness and unity that leads to the family’s shared role in caring for PWD.

> *In a way we were lucky, in a way there are always people there to help us. As a family, we understood the situation very well, we had to act very quickly. Sometimes you can advise people things, but when you really live with it, experience it, it is very, very different. (**Poonam**)*

The power of family support was further highlighted when Poonam heavily emphasised the intensifier “very, very” several times when she talked about her family. She expressed a strong sense of loyalty to her family and believes that the traditional concept of “family takes care of family” has been essential during the caregiving experience. For Poonam, her siblings’ support helped ease the caregiver’s physical and emotional exhaustion and was able to give her the strength to give the best care to her mum who had dementia. This overall unity and effort thus highlights the high significance of familial effort and willingness in providing quality care and a positive environment for the caregiver and person with dementia.

Poonam emphasised the love and commitment their family has for her mum, and she wanted to repay her mum for the sacrifices she made while bringing them up. Poonam’s relationship with her mum and siblings appeared to have been very deep and strong. She went on praising her family and their support, which was essential in easing the family burden of caring for her mum with dementia.

Kamal an Indian caregiver, who has the primary caregiver responsibility for his father was no different to Poonam when it came to the importance of a strong familial presence in caregiving. He emphasised that all decision making was a collective process for his family members, instead of an individual choice. This highlights that Kamal echoed Poonam and Chawla’s belief that the process of caregiving should be a familial responsibility, and subtly reflecting, perhaps, the bridging of cultural norms that usually differentiate the role of sons and daughters in a familial structure which is most like attributed to the acculturation of migrant communities in the UK and modernisation.

> *The famIly virtually decided that they didn't want him in a nursing home.*
>
> ***(Kamal)***

Sabina, a daughter-in-law caregiver who positions herself as the primary caregiver responsible for her mother-in-law with dementia, echoed Poonam, Kamal, and Chawla's belief and adds to this an understanding that family members provide the best means of managing the caregiving for an elderly parent with dementia.

> *Because, she has got problems, and we are the family we need to help her. If she didn't have the support from family.* ***I don't know what was going to happen. It would be terrible.*** *As a family, we look after her and try to make her health better and try to help her to remember everything as before she is good. (**Sabina**)*

Despite not knowing much about the impact of dementia and being aware of the services available, Sabina adamantly stressed that "if [her mother-in-law] didn't have support from family, [she] didn't know what was going to happen". Through this deep sense of hypothetical vulnerability and uncertainty, Sabina emphasised that to her, it was unfathomable to consider how her mother-in-law's well-being would be maintained without the support of familial ties, thus affirming her indubitable willingness and desire to care, which is clearly attributed to her deeply ingrained familism. Sabina believes that family members are in a highly beneficial and better position to help their relatives with dementia. Due to their prior knowledge, relatives know about the patient with dementia's unique needs and can aid in the process of positive reminiscence to recall memories from the past; therefore, allowing the person with dementia to receive a specifically tailored experience, instead of the generic support of institutionalised services.

This ingrained adoption of familism was no different among the third generation, grandchild caregivers of this study. Although Rahana and Fatima were born and brought up in the UK, they also displayed a strong positive attitude towards the concept of familism.

This is mainly due to grandparent involvement in bringing up grandchildren among South Asian migrant families. Rahana and Fatima's grandparents migrated to the UK back in the 1960s and they were involved in helping with childcare while their parents were at work. According to Rahana, her grandma had a major role in teaching and sharing the values of their native culture and discipline, highlighting the innate importance of cultural socialisation in ethnic minority migrant families.

> *My mum says I'm so grateful for her, even in terms of my kids, I didn't have one worry because I knew she was there. Like I would be doing all the work and you would just be left with her, but I know you were in safe hands. So, in terms of that, she says it, like she can't repay my grandma for what she's done. (**Rahana**)*

For Rahana, her grandma was a pillar in supporting her mum after her dad passed away when they were young children. Her grandma stayed with the family; therefore, her mum did not have to worry about childcare while she was at work. This has helped the family financially; they were not in financially sound state to be able to afford childcare costs. Through the use of a semantic field of care in nurturing phrases such as "look after us", the loving relationship between her and her grandmother is emphasised and it is highlighted that the caregiver fondly recollects the love her grandmother displayed during a time of hardship. Additionally, by utilising the words "responsibility" and "stayed" the strong sense of traditional commitment the caregiver witnessed her grandmother uphold is emphasised. This recollection highlighted that due to her grandmother's love and commitment for her as a child, it was only natural for her to reciprocate these actions by being her caregiver during her grandmother's hardships with dementia.

> *It feels really responsible. Because I've, I mean I'm only a young age, but then I feel like there's a lot of responsibility because not only am I looking after someone. You make sure that everything is you know everything is set for everyone and them as well. Yeah, I think it's a big responsibility.*
>
> *(**Fatima**)*

Kamal, Rahana, Fatima, and Sabina all stated that they reached collective decisions with family members regarding the care of their loved ones with dementia, after careful thought and discussion. All family members decided on the right choice to take and then pursued it. They all recognised the importance of family and the critical role it plays in taking care of a person with dementia. Caregivers demonstrated the commitment to upholding the idea of shared responsibility by expressing a sense of closeness and attachment between family members.

6.2.1 Inconsistency and conflicts in family dynamics

While all participants in this study agreed that caregiving for their family member with dementia had strengthened the closeness of their family members' unity, on the other hand some of the caregivers felt a lack of consistent family involvement in essential caregiving and the demands of caregiving led to familial conflict about care decisions.

> *And then I volunteered as the main caregiver, so all the family was saying ohshhhh ...it's not going to be me [laughing]. "As long as it is not me, it's fine!! (**Kamal**)*

In contrast to other participants who affirmed that within their family structure caregiving was equally shared, Kamal frustratingly explained that although his family members desired to be involved in all the key decision making involved with caregiving, when he volunteered as the main caregiver, all his family was happy as they did not want to take the primary responsibility of caregiving. Through his frustrated tone and awkward laugh, it was evident that he found this sentiment painfully ironic. He stated that every family member wants to see their loved one taken care of, yet they are hesitant and reluctant to take the primary caregiver responsibility or contribute. In some cases, he claimed that while members were willing to help, they were unable to take up the huge responsibility as the primary caregiver. They want to help from the side-lines or only when they feel like it but because it is burdensome. Therefore, this caregiving and its associated burden is unfortunately thrust upon one individual instead of being a shared role. Kamal went on and talked about

> *I feel sad because he has done everything for us, and I felt that. He had done it for us. So, we should be there for him at this moment and time. And that is my reasoning, nothing to do with **family members**; they probably would have said to put in him in a care home. You know what I mean.*
>
> *(**Kamal**)*

Kamal expressed his disappointment and despair of the notion that no one wants to take care of the person who has given so much to them by taking care of them while they were growing up. Through a semantic field of commitment, Kamal highlighted the sacrifices his father made for his family. Therefore, he believed that that commitment should be returned. He strongly feels that caring for a family member with dementia should be shared between the family and it is a duty: everyone should participate equally in taking care of their loved ones with dementia.

> *I'm not doing it for others' approval appreciation, but I'm sure my family members appreciate as well about what I do. I don't worry about how they*

> *look into things. We don’t talk about it as a family. I don’t go down on that route. (**Kamal**)*

Kamal knows that every family member is grateful for the role he is playing, although they do not have to say it. He knows that he has relieved them of some pressure; however, he clearly affirmed that his gesture was not for the approval of family members and instead due to the unconditional love he feels for his father. He loves the responsibility he took on and cares little about the scrutiny of others.

In contrast, Maya continually referred to the effects of the watchful eye, repeatedly mentioning the term cultural expectations. It is normal in India to look after older parents irrespective of their willingness. This norm is currently changing in India; however, these traditions are still strong among the migrant communities in the UK, due to the integral role of culture in migration identity and its historical place as a coping mechanism for emigrational trauma. Her culture insists on family taking care of the family; therefore, she cannot neglect anyone in her family.

> *But when it’s family, you can’t say no, especially the culture we come from. (**Maya**)*

> *I wanted to do things for them, and they say “no” but now when they need help, so how could I say no? I looked forward; I wanted to do something for years; that was another thing for me to take the responsibility and get on with it. Yes, it came this way now, when she is poorly. (**Maya**)*

Maya takes on the responsibility of taking care of her mother-in-law with dementia because she has always wanted to help her in-laws out. They have never required her help until her mother-in-law’s dementia got worse and now they need Maya’s help, and is expressed through a semantic field of anticipation in the active phrases “I wanted”, “I looked forward”, and “I wanted to do something for years”. Maya stressed that she was always more than happy to oblige in the role of a caregiver due to her deep desire to successfully fulfil her filial role as a daughter-in-law to her elders. She has always wanted the chance to give back to her family, and she believed this was one of the best opportunities so did this in the past by caring for her parent-in-law with dementia.

> *My time is balanced for everyone. (**Maya**)*

Maya explained that she knows that she is responsible for looking after her older in-laws at their house, and also emphasised her other role: as a young mum, she is responsible for bringing up her children as well. By mentioning her several roles, Maya emphasised her dedication to supporting all her loved ones, highlighting her deep desire to care for the entirety of her family and meet the multiple obligations of women within a family structure. Therefore, she must make and balance time for everyone to fulfil her duties and commitments as a mother, daughter-in-law, and caregiver, an act which is perfectly exemplified by her claim that “[Her] time is balanced for everyone”.

6.3 Master theme three: Cultural motives for caregiving: “It is a norm, a good norm, a very good norm to follow”

All interviews with participants suggested that participant’s general perception about caregiving is a positive one, and this positivity is shaped by the influence of diverse cultural factors and family values.

Rahana is a third generation South Asian from an extended family, feeling proud about sharing the caregiving responsibility of her grandmother who has dementia.

> *I don't see it as a burden... rather we are grateful to our grandma what she has done for us. My mother always says it is important to have an older person at home. As a part of culture, it is a norm, but its good norm...a very good norm to follow. I'm proud that this is part of our culture. (**Rahana**)*

She reflected that her mother is a good example by caring for her mother-in-law in her old age; therefore, Rahana would do the same for her parents and in-laws. She agrees it is a traditional and powerful norm, but she thinks it is a good norm to follow. Through the repetition of the noun "norm" Rahana emphasised that the care of one's elders is one of the fundamental customs within South Asia. Each time this noun is mentioned, Rahana intensifies its positive qualities claiming that "it is a norm, but its good norm.... a very good norm", thus highlighting her admiration and appreciation for this collectivist norm. The act of caring for older relatives is very prominent in South Asian communities and continues to be practised in the UK. These norms are derived from the time prior to migration, and they continue to remain strong in the migrant communities living in the UK. Rahana further mentioned that looking after elders was always something valued by parental figures during her upbringing; it is something that South Asians have been taught since childhood.

> *I think it's massively the way you've been brought up and how, how your mum's brought you up telling you, it's your morals really and like what's right and wrong. To me, it would be wrong for us to leave her to her own, go to a care home, they'll look after you. (**Rahana**)*

While discussing that Rahana found it unfathomable to send her grandmother to a care home, a semantic field of morality is heavily implied. She described "that it is [her] morals" and claimed that the family's decision was bases on their views of what is "right and wrong". To her, it would be "wrong... to leave her to her own". By strongly emphasising her definitive perceptions of right and wrong and claiming “it would be wrong for [her family] to leaves her [grandma]”, it is implied that this cultural belief is concrete and deep-rooted in the South Asian population, to an extent that it become an innate moral instead of just a cultural practice. Alternatively, this sense of morality may also be a discrete allusion to the cultural stigma associated with the abandonment of care. By claiming that the action of not caring for a family elder would be “wrong”, which is a definitive adjective with negative connotations, the South Asian community’s stigma and convictions are subtlety and metaphorically hinted at.

> *I started with those two days a week and then become three days or sometimes four days week depending on how busy. If dad is not at home for any reason, I got to go. So, I was actually enjoying you know…helping out because we come from that culture, you know if we can give a hand, it’s like fulfilling. (**Maya**)*

Initially, Maya did not have full caregiving responsibility, she was supporting her father-in-law with household chores on an ad-hoc basis. However, when the time came, she was happy to take additional responsibility for taking care of her mother-in-law with dementia without any question. For British South Asians, caregiving was described as just a normal thing to do as it was so culturally deep-rooted to care for one’s family. The stereotype of cultural expectations to care for older adults by daughters-in-law is still common among South Asian families. Daughters and daughters-in-law are usually obliged to provide care for older adults.

> *But I was always taught. You know...like seva in another words taking care is do seva [Hindi word] for old family members. All my mum said, and I never knew my mum would say this when I was leaving my house after my*

> *marriage...you know... and when we our own parents doing it, so you always think, you want to do better and better. (**Maya**)*

Similar to other participants, Maya supported this perception as a deep-rooted culturally expected norm that is strongly emphasised and exhibited by parental figures. Maya characterised this norm as the concept of 'Seva', which is the dharmic belief of selfless service that is performed without any expectation of result or award for performing it. This concept was the resounding rationale for caregiving for her mother-in-law. Maya claimed that "[she wanted] to do better and better". Through the repetition of this positive adjective "better", which has connotations of determination and improvement, it is highlighted that she has a sincere desire to give the best quality care to her mother-in-law, a desire that is evidently attributed to the cultural examples she has encountered in her life.

South Asian participants often positioned caring for PWD with family closeness as another factor to help the primary caregiver to manage and share the caregiving responsibilities. In this account, Poonam heavily suggests the semantic fields of effort and unity.

> *That was sort of main bit but as a family you know we very, very lucky that our family is so close to each other, and we all did the maximum for our mum we all could. (**Poonam**)*

Poonam expressed that her family all did the "maximum" they "all could." Through the use of the intense noun "maximum" and modal verb "could" Poonam emphasised that her family gave their wholehearted effort to supporting their mum with dementia. Additionally, Poonam continuously uses the collective pronoun "we", emphasising the closeness and unity that leads to the family's shared role in caring for a person with dementia. This unity and effort thus highlight the underlying notion that she was able to give the best care to her mum who had dementia due to the intersectional willingness of her family; this was attributed to culture and a close-knit family structure.

> *I think as a family we just have to try and do, so I did most of the weekend and my aunt helped, my brother came after work and every weekend. Like my other brother came and helped as well. (**Poonam**)*

Although cultural obligation is an important underlying value in caregiving among South Asians, according to Poonam the willingness to care for PWD is also equally important. Thinking further about willingness to care Sabina, another daughter-in-law added,

> *I feel good. As a daughter-in-law, I am looking after my mother-in-law, I feel good from inside and makes me happy, and when I am looking after them, they are happy, and they care for me more, when they are happy, my husband is happy and then we all are happy full stop. (**Sabina**)*

When asked about where her willingness to care Sabina claimed that “As a daughter-in-law” she “[felt] good” looking after her mother-in-law with dementia. Through the repetition of her definitive introductory phrase “I [felt] good”, it is evident that she has a sincere sense of satisfaction, a willingness which, like Maya, implied a rootedness to the cultural associations of a daughter-in-law’s role of care within the family structure.

Additionally, through the continual repetition of “happy”, accompanied by the collective pronouns of the “family” it is emphasised that by looking after her in-laws this enabled her family to metaphorically experience a butterfly effect, giving them a greater sense of happiness and unity due to Sabina’s positive role, further highlighting the contentment she receives, as it has the ability to make everyone happy. This, emphasises the influential role that caregivers have in creating a positive familial environment. However, alternatively, this phrase has undertones of obligation, conformity, sacrifice, and selflessness which are brought to light by the conditional phrase “when I look after them”. This phrase suggests that due to cultural connotations Sabina may feel an obligation to support her family and thus experience deep-rooted family burden when she cannot meet these culturally imposed expectations. Additionally, despite the continual mention of happiness, not once is there a mention of self-happiness, perhaps metaphorically symbolising how cultural roles can lead to caregivers endeavouring to constantly please others at the expense of their own self. Questioning how they felt about caring for the elderly person with dementia was a ‘normal thing’ for them. They perceived caregiving as an expectation among the community, moreover it is a subjugation of something they have been taught to accept since their childhood. Fatima, a Pakistani granddaughter, spoke about her experiences as a caregiver.

> *I was young. When it started… it was hard, but it has become a habit now... I learned a lot… you know…I have been doing it for couple of years now. I like a busy house… always lively. You are constantly busy…you don’t sit and get bored. (**Fatima**)*

From both participants’ accounts, it is evident that looking after the elderly is not just a designated role for them, but instead an innate extension of themselves that has high significance. Despite both caregivers experiencing setbacks, there was a strong justification here for caregiving as a culturally very normal process to follow, which is highlighted through a semantic field of normalisation. Fatima described that although “[she] was young” and “it was hard” over time the role of care had become a “habit”. When her family caregiving role began, despite the initial difficulties she experienced, she quickly became accustomed and happy with the role, possibly due to the deep-rooted cultural socialisation and pride associated with care for the elderly. By creating an association between caregiving and habitual action, Fatima emphasised that the caregiving for her grandad had become commonplace in her life and highlighted the positive outcomes, some being experience and family unity, that the role has given her. Similarly, in Poonam's transcript, she repeatedly experienced drawbacks when she originally started her role of care.

> *Yeah, because she needed me all the time, she was calling me out all the time from work, the work was flexible so that I could get out at lunch time to see her but then what happen is I was bringing work home and she was calling me home as well. It just got too much stress for me, and I couldn't cope my job and supporting my mum and family. That's what really made to take that decision, something has to give way anyway. Because my mum was so close to me and sort of obsessed with me. Except myself someone else in the house was very difficult.. (**Poonam**)*

Poonam felt that "It's just got too much stress for [her], and [she] couldn't cope [with her] job and supporting [her] mum and family". Therefore, eventually Poonam knew that "something had to give way anyway", and for Poonam that was her job. From this, it is evident that to Poonam the more significant role in her life was the cultural obligation to her mother, which was so significant she was willing to sacrifice an important part of her life and identity, thus once again highlighting the deep-rooted cultural norms that contribute to South Asian's willingness to care. From all carers there was the same sense of pride and satisfaction associated with caring for an older person as expressed in this case.

6.4 Master theme four: Impact of caregiving role on the caregivers

Despite the many positive outcomes associated with the role of caregiver, another master theme that emerged from the participants' accounts was the challenges associated with caring and the detrimental impact of them on the caregivers.

> *It was hard because my mum's a single parent, so she had to do things that, you know, s**omeone probably wouldn't want to do**, but she had the choice because we would get the occupational therapist coming in saying would you like a carer or.... and things like going to these sessions or do you want to take her to a care home but with us being maybe an Asian family it's part of our culture to look after the elders so that was not even an option for us. And it was hard to cope with it. (**Rahana**)*

Rahana recollected that as the primary caregiver, her mother had to "do things that, someone probably wouldn't want to do". Through the use of indirect euphemistic language, Rahana highlighted her hesitation and desire to avoid the difficulties associated with caregiving for her grandmother, subtly hinting at the several challenges of caregiving for dementia which can often cause a caregiver to have to carry out uncomfortable tasks that can be physically and emotionally exhausting.

> Because when she wakes up, everyone wakes up. *(**Rahana**)*

Rahana stressed that in one way her pattern of life had not changed significantly due to the fact that her family was taking care of her grandmother even prior to her being diagnosed with dementia; this serves to highlight the deeply ingrained traditional caregiving ideology in the South Asian Community, that is carried out regardless of the receiver's impairment. She mentioned that from a physical caregiving perspective, life was not very different after the dementia diagnosis, by claiming that "in terms of [physical caregiving], it didn't change because she was caring for her anyway", further exemplifying the traditional caregiving ideology prominent in South Asian beliefs. However, alternatively this lack of change in caregiving methods hinted at a lack of knowledge of the condition which meant they could not provide any tailored care that was needed for this cognitive state. They continued supporting the person with dementia the same way they had supported her for other medical conditions prior to being diagnosed with dementia, instead of delving into the nuances of the condition.

However, despite this supposed lack of change, Rahana also described that her mum and the whole family had to cope with the dramatic mood swings of her grandma, which definitely took a toll at their overall well-being. This notion of a change in lifestyle was clearly exemplified when Rahana claimed that "when [her grandmother] [woke] up, everyone [woke] up". Through the use of an impactful epistrophe in this phrase, Rahana emphasised how significantly her family's pattern of life had been affected by her grandmother who had dementia and how their actions and routines had to revolve around her. Furthermore, on A deeper level, the notion of change could also metaphorically symbolise how much their emotional state is influence by their relative with dementia's well-being; therefore, when the person with dementia is distressed, this causes anguish for the caregivers as well. This emphasised that in some instances, the psychological impacts of caregiving are more challenging than physical health issues, yet despite this, these adversities can be easily overlooked during service provision. Alternatively, lack of knowledge about the condition meant they could not provide any tailored care that was needed for this cognitive state. They continued supporting her grandmother the same way they supported her for other medical conditions prior to being diagnosed with dementia, instead of delving into the nuances of the condition.

Rahana recollected sadly that her grandma progressed to a stage in the disease where caring responsibilities added too much strain on the family. The family was offered the choice of a care home; however, they were reluctant to accept it even as an option. Rahana emphasised that although they were finding it very hard to cope with the demand of caregiving, they were unable to come to terms with alternative caring options. Rahana's family retained a strong sense of cultural obligation. They believed it was their responsibility to look after their elderly mum with dementia rather than placing her in a care home. They also felt not being able to care for a family member with dementia within the family is not fulfilling their filial role.

> *Well, I would stress out a lot, yeah so when I am doing my studying I try and finish all the housework, make sure my grandparents are ok, then I do my Uni work, you know my work. But then if that's not done, if I feel like ok grandparents haven't had this, they have not eaten, they have not had their medicines, then it's constantly on my mind, you know like I need to make sure they are ok before I start my work. Then by the time it is time to start work, it's 9, 10 o'clock at night! Yeah, it gets a bit too much sometimes. (**Fatima**)*

Similarly, Fatima, another grandchild participant, described how she felt less equipped to manage her grandfather's dementia. She stressed that "it is constantly in [her] head". Through the long list of demands she had in her life, Fatima emphasised a sense of emotional bombardment highlighting how difficult it is for her to manage multiple demands in her life. Care-related stress affects the productivity of her studies and work, and Fatima sometimes feels angry and frustrated in these situations.

> *And recently, it's just when we say something, they don't agree, because they don't remember. So, it triggers them, it triggers their anger, like they say no you're not agreeing with me, you need to agree with me, this is right, I'm right, I know what's right, I remember what I've done. (**Fatima**)*

Although Fatima is aware that repetitive questioning is a typical presentation of people with dementia due to their impaired short-term memory, at times she feels irritated and frustrated when it interferes with the balance of her own personal activities such as study and work.

> *I think you know when it's just when you're talking to them and you want to have a nice conversation, but when they can't remember things, it's just they start getting angry. And then it ruins everyone's mood because you're scared, ok if I say this, what about if they get angrier? Or if I say this what about if they start shouting or something? So, you must be careful with what you say and how you say it as well, because you don't want to sound too patronising. Yeah. (**Fatima**)*

Fatima showed a thorough understanding of strategies for managing repeated questions from her grandfather who was diagnosed with dementia. She claimed that she can remain calm and polite most of the time especially when she talks to her grandfather. However, from her description it was obvious that sometimes she was frustrated by her granddad's mood swings, especially when she had had a bad day. She went on and talked about all the effort she had to take to keep the family momentum going.

> *It feels really responsible. (**Fatima**)*

It is evident from the above that Fathima is young and would have liked to have a life with less responsibility; however, she feels obliged to take up the responsibility of caring for her grandfather and making sure the needs of her family members are taken care of. By saying "*It feels really responsible" and "I'm only a young age"* we can make out that Fathima found it extremely challenging due to her lack of experience as a caregiver.

> *I feel my commitment affects my general well-being. Well, sometimes when I'm tired, I just want to go to bed but then I just need to make sure Grandad's ok first. So, then I just, I'm sort of dragging myself everywhere! Yeah. (**Fatima**)*

Fatima's general well-being has been affected due to her commitment to be caregiver for her grandad and she emphasised that there are days when she is exhausted; however, her responsibilities mean she could not go to bed before she had made sure her granddad was settled and ok.

> *Well, I'd say it's a bit of both really. Big family because I'm the oldest child as well so I've got more responsibility. We live with my grandparents as well, a really big responsibility. And is the dementia as well because I always, you always have to check up on them, make sure they're ok, how are they, is the food ready, the clothes, you just, you're running around after everyone. (**Fatima**)*

Fatima continued talking about how caregiving for her grandad has turned out to be a challenge for her and the entire family. The behavioural change of her granddad leaves an emotional and physical impact on Fathima and thus leads to burnout and stress. She stressed that living in a joint family and as the eldest female child to her parents there is an expectation in the house for her to perform other household duties.

> *So, I remember before they were quite calm, talking to everyone, used to get their point across, whatever they used to do they used to go and do it. And recently, it's just when we say something, they don't agree, because they don't remember. So, it triggers them, it triggers their anger, like they say no you're not agreeing with me, you need to agree with me, this is right, I'm right, I know what's right, I remember what I've done. (**Fatima**)*

Fatima reminisced about the past when her granddad was quite calm and could talk to everyone to convey his points without any issues. She noted that her granddad now has more disagreements and arguments with them due to his memory problems. She indicated this was mainly due to the frustration associated with her grandfather still expecting to be consulted for decision making due to the feeling that he is still the head of the family.

> *They're the male and it's the grandad as well. So, I think they want to be in role, you know like I'm head of the family. Need to keep things in line. But because they're starting to forget things as well, it's affecting not only their memory but it's affecting their behaviour and how they are with everyone. (**Fatima**)*

Fatima went on and discussed the power and hierarchical classification among South Asian families. It was sometimes difficult for her to manage the hierarchical status within the family. The eldest male person in the family held the head of the family status and made the key decisions in important family affairs. However, the deterioration in cognitive function has cast doubt on the person's ability to make sound decisions in the minds of family members. Loss of control on family decision making leads the person with dementia to further distress and that invariably affects the caregiver's well-being along with the affected person.

> *I think the thing most I felt was just frustration at her even sometimes because she'd go crazy thinking about something that just wasn't there, and I would reach 'that point' crazy trying to explain that it's not there. I would say it's not there; you're just thinking it's there but it's not. And she'd get angry about it like, no, you're not right and you're not listening to me and then I'd feel bad for not listening and I felt guilty at times and like I wanted to help but I felt a bit helpless because I couldn't help because I didn't really know how to fix it and I wanted her to feel happy but I could tell she was always agitated and like wasn't sleeping properly and things like that and that bothered me. Just to see her not how she normally was the thing that affected me the most. (**Rahana**)*

Similar to Fatima, Rahana shared encounters with her grandmother in which she experienced moments of anger and frustration, due to their unpredictable mood swings associated with her condition. She recalled that on several occasion she reached "that point" of frustration because she didn't know "how to fix it". Rahana repeatedly used the word "and" while reflecting the overwhelming nature of caregiving, highlighting the menacing domino-effect like consequences of negative caregiving experiences. Alternatively, on closer inspection, the repetition of "and" was also an instance in which complex emotions broke down the usual logical integrity of speech, thus creating connotations of somewhat childlike fragility. From her description, it was evident that she did not always have enough knowledge or experience to manage the situations with her grandmother. This perhaps suggests that due to a young caregiver's limited experience, they are sometimes less able to deal with situations of conflict during caregiving; therefore, resulting in feelings of hopelessness. This notion of helplessness is further exemplified through the phrase "don't know how to fix it".

Overall, both grandchild caregivers reported sleep disturbances, lack of time for studies, and financial difficulties due to their caregiving role.

> *I do things, do as much as I can, I have expectations with kids you know, my time is more balanced for everyone. When we are here, I don't just think about Mum, I try to do as much as for Dad as well. Because Dad is very independent, but because of his age I need to look after him as well.*
>
> *(**Maya**)*

As a daughter-in-Law, Maya knows that she is responsible for looking after her older in-laws. This sense of dedication was initially exemplified through the phrase "I have expectations with my kids too, you know". By utilising the word "expectations", which has connotations of commitment, it is emphasised that as a woman there are multiple roles she must fulfil. By saying "My time is balanced for everyone" she emphasises that her time must be balanced for everyone as she wants the best for her kids and her elderly in-laws; therefore, she has to fulfil the roles of mother, wife, daughter-in-law, and carer. Even though her father-in-law is independent, she feels responsible for looking after him as well.

> *We... like timing...if suppose Mum has, she needs our help to help her change and if it's time to pick up kids from school then that can be an issue. That thing can happen any day. You know, when dad ...that's why we take turns, if I'm going, you know... that's why always say Dad if you can be*

> *home by this time, because in case mum really needs us then I know one of us is here. Especially when I do school run and when my husband works out of station. So, hygiene again to try and keep the house as less smelly because of the number of accidents. We ourselves trying to adjust here because that is the responsibility we have taken. So, these things have influenced me, and again we Indians we are used to it. (***Maya***)*

Maya stressfully expressed how she found it challenging to balance her responsibility as a mother and as a caregiver of her mother-in-law. With her husband having to work out of town, she found it stressful to manage the constant conflict between household chores, motherly errands, and meeting the needs of her mother-in-law simultaneously. She found herself adjusting to meet her responsibility to take care of her in-laws but acknowledged this was something that the Indian culture is accustomed to.

> *The pattern of our life has completely changed, completely changed, We can go out only if Dad is at home, so it's changed, completely changed. Ahh...and keep reminding Mum what she has eaten, I tried to do in usual basis, you know... Just make her comfortable, I don't know...may be. Pattern of life has changed, such as moving from own to home to parent's house, limited facilities in the current house compared to own home, less independence, restrictions on social life, giving up job. (***Maya***)*

Just as the other participants expressed concerns about their lifestyle, Maya elucidated that her life pattern had changed completely as they moved into their in-laws home to be caregivers. She has had to move with her family into a smaller home with fewer facilities which has affected her social life and professional career. Maya and her family had to prioritise the needs of her mother-in-law and adjust their lives according to her needs, highlighting the immense self-sacrifice that caregiving involves. By repeatedly stating “the pattern of our life has completely changed, completely changed” Maya conveyed a deep sense of frustration, resentment, and disbelief at the immense magnitude of her lifestyle changes and heavily implied that she was left with no choice but to compromise on her own personal well-being.

> *I would have gone back to work if I was not supporting my mum. And still to go back work if I can cope, at least two days a week at least give myself a little break too, even I’m a very homely person, I also need somebody to kick me out of the house otherwise, I’ll say I’m OK at home. Yes, I think it is important when you are out and about. What is stimulating my mind? Nothing at the moment. I suffer with my feet pain on daily basis, that kind of, I’m just thinking, you know taking more and more role kind of become a bit daunting for me. So, maybe one step at a time. I have my break after 10pm, I enjoy what I want to watch on you tube, do my meditation, listen to some music, you know...I just choose random stuff. We have not had any holidays recently. (**Maya**)*

Maya expressed disappointment at how she could not fulfil her desire to return to work due to her overwhelming responsibility as a caregiver for her mother-in-law with dementia. She believed even a part-time job for a couple of days would be a great means of giving her a break and stimulating her mind, which she could not achieve as a full-time caregiver The responsibilities of being a caregiver can be daunting. As a caregiver, Maya has been unable to go on holidays, and her only coping mechanism was being able to get a break after 10 p.m. and then using the time as a way to enjoy music or do meditation to help with her own157 mental health.

> *Yeah, because she needed me all the time, she was calling me out all the time from work, the work was flexible so that I could get out at lunch time to see her but then what happen is I was bringing work home and she was calling me home as well. It's just got too much stress for me, and I couldn't cope my job and supporting my mum and family. That's what really made to take that decision, something has to give away anyway. Because my mum was so close to me and sort of obsessed with me that her except myself someone else in the house was very difficult. (**Poonam**)*

Despite support from the workplace, Poonam was in a stressful situation with her work and the constant needs of her mother whose cognitive ability worsened. When she was working full time and caring she felt rushed and pulled in all directions. Poonam felt that "It just got too stress[ful] for [her], and [she] couldn't cope [with her] job and supporting [her] mum and family". Therefore, eventually Poonam knew that "something had to give way anyway", and for Poonam that was her job. From this, it is evident that to Poonam the more significant role in her life was the obligation to her mother, which was so significant she was willing to compromise on an important element of her life and identity, despite the value and purpose it gave her. Poonam sadly stated that due to the stress of the role, she eventually had to sacrifice her job to take care of her mother's needs.

> *But obviously we didn't know until we been through to this journey, and you know I was really lucky because my husband was very supportive. Me actually leaving work, it was hard decision, which we just got to make sacrifices and the things is if I carried on working, I would have been worried all the time, I know I could call out anytime and which then would have affected my work, then it would just cause the management is being*

> *reasonable but after some time we can't expect them to be so much reasonable If I don't function my best. I'm glad I did it. It was physically mentally tiring, it was 24 hours, 7 days a week. (**Poonam**)*

Poonam stressed that she was very lucky to have a husband who was very supportive of her decision to quit her job to take care of her mother. Although she had options and support from her employer, she recognised that she would not be able to do her job to the best of her ability and therefore she was more than happy to have sacrificed her job to care for her mother.

> *It was difficult, it was very, very hard, but my husband was very supportive but at time where he has got very sort of frustrated and angry. You know. Sometimes its bit a traditional thing saying ...why you are doing? You are the daughter. Why not your sisters-in-law and brothers not taking the lead role. To me, it was all about what keeps my mum happy, keeps her contend. He used to be frustrated about it. (**Poonam**)*

Poonam's husband was very supportive; however, at times it was difficult to balance her own family and her mum's care. In Asian culture, the son and daughters-in-law mostly look after elderly parents. Here the daughter was the primary carer which led to minor conflicts at times.

> *It is very tiring and draining you know. Just having... you know... during the daytime, it is just me and her, all day long really, and then like my aunty used to come for couple of hours, then I started coming in the night as well ...you know... (**Poonam**)*

Poonam found it tiring to be a full-time caregiver who spent most of the day alone with her mother except when her aunty visited them for a few hours or the rest of the family came home in the night.

> *I think it was just constant roller coaster, being on roller coaster from us emotionally, mentally, and physically and for my mum because she was up and down, we just didn't know what we're going to expect. We were really going with flow, because sometimes she had really bad night, up all night, just sitting ...lying down. Sitting, talking ...she will be singing to herself, she likes singing a lot, just bhajans...sometimes the Bhajans calm her down but at times she is fully agitated, really that's just case of her something ...you know. (**Poonam**)*

As a full-time caregiver, Poonam felt her life was a constant roller coaster which affected her emotionally, mentally, and physically. She described how her daily life depended on her mum's day and how her mother felt that day.

> *If you are agitated by what they are doing and the frustration and angry they would pick up on it. So, you need to actually stay calm and lots of time I just walk away to kitchen and come back after some time, because ...I probably said these 20 times, but you just have to control yourself and come back. (**Poonam**)*

When asked about the coping methods she adopted, Poonam explained that despite her mother's cognitive condition she could understand when Poonam was frustrated and angry, hence she had to walk away to the kitchen as a coping strategy.

> *There are lots of things I had to give up while I was caring for my mum. My work, everything. At times I used to feel sad and angry that I had to give up things. Because I missed going to gym, meeting friends, miss the things at work. I loved going to work, seeing lots of people, communities, families, and I end up stuck in here to look after my mum. Very hard. (**Poonam**)*

In order to take up the caregiving responsibility, Poonam had to give up many things including her job. At times she felt sad and angry about giving up things she liked to do such as going to the gym and meeting people. This could have been one of the reasons she felt the caregiving responsibility affected her emotionally, mentally, and physically.

> *Just tired, illness, stress, I think you just keep going and going...but there were times I felt so tired...I used to come home, all I wanted to do is sleep, I didn't clean up, I didn't wash up, things were left here and there I didn't have any energy to do any of those house chores, you know I was at Mum's house, my husband used to come home after work and pick me up from my mum's. These were the big changes in our life and.... [emotional].*
> *(**Poonam**)*

When discussing the impact of caregiving, Poonam became extremely emotional and explained that she felt tired, ill, and stressed as things as the day stretched on. She was so tired some days that she did not clean up or wash up when she came home after a day of caring for her mother.

> *We didn't know this was something related to dementia, but we did notice things like she leave cooker on, or she forgets things microwave etc. She*

> *had a routine of putting washing on in the morning and sometimes I notice she is still washing in the evening. (**Poonam**)*

At first Poonam and her family noticed that her mother left the cooker on and forgot things in the microware. Later her mum's routine morning wash was continuing till the evening, and they did not know that this was all related to dementia.

> *It was difficult caring for and understanding dementia, there wasn't much information, when I went to...I tried to find information because when my dad had terminal illness they came and spoke to us all about it. But when my mum was diagnosed with dementia I got hold of Alzheimer's Society. (**Poonam**)*

Poonam felt that she was unprepared to provide care to her mum who has dementia. She did not know much about dementia care, and she did not receive any sort of guidance at the beginning; however, she later got in touch with the Alzheimer's Society.

> *That's the sad part now with dementia he cannot remember anyone.* That is the most stressful part of it. Dad is not that difficult to look after. He is very easy going, he doesn't stress me out at all. If I compare him with my *M*um, *M*um stresses me out more because she only eats certain things, she doesn't like certain things, whereas with *D*ad, there isn't this issue, you know...he is happy with whatever he gets. They only thing that stresses me out is care that he gets from care workers. That is quite stressful. ***(Kamal)***

In Kamal's case his dad is not difficult to look after as he is easy going and the only thing that stresses him out with regards to his dad is the care that he gets from other people. The sad part was that his dad cannot remember anyone.

> *I would have carried on with my own life. I'm actually have put my life on hold because of the situation really, ahh...I would have been able to go on holidays which I quite like to do. I would be able to go away during weekends, whatever that's not happening in the past 6 months since Dad have been here. Ahh... all that has finished now until something happens with Dad. So that's how it has impacted me, see if I didn't have this responsibility I would have gone for holidays, going out general things like that. (**Kamal**)*

Due to his caregiving responsibility, Kamal has had to compromise on his own needs such as holidays and going out on weekends. He misses his social life and believes his life will be without holidays and other outings until something happens to his dad.

> *This has changed the pattern of my life completely; I wouldn't do it for anyone else like this. This is because he is my dad, I know, the way we come through in life together. Yeah, it will be very difficult, and I wouldn't do it for anybody else. I wish, he would remember certain things. You with me? (**Kamal**)*

Kamal's pattern of life has completely changed since he took over his dad's care. He clarified that it is extremely difficult to change lifestyle and that he would not do that for anyone other than his parents as he still remembers how they all came through together in life.

> *My dad is not there anymore, not there in his mind, you with me?*
> *Although, I care for my dad, but my dad isn't there. My dad, that person, I used to know doesn't recognise me anymore. I would say I was looking*

> *after someone close to me, and I wouldn't like to see any harm come to him but as far as that relationship, because he is forgotten which the sad part is now. This has changed the pattern of my life completely; I wouldn't do it for anyone else like this. (**Kamal**)*

Kamal believes his dad is not there anymore because his dad cannot recognise anyone. Although he cares for his dad, he feels it is just someone close but as he does not want to see any harm come to his dad, he continues to care for his dad which he would not do for anyone else.

> *We always make decision it together. We were not those Indian couple where husband does everything alone without consulting wife. We talk it over… I do miss that.. I haven't got anybody to talk it over...[emotional gaze]...I got one son here…but they go to work, and grandchildren go to school…during the day we are bored, really, really, bored…and in fact...I sometimes think have I done the right thing. He got dementia. And we are sitting here being bored. We are an older couple... (**Pooja**)*

By contrasting the previous semantic fields of unity and isolation as Pooja described her relationship with her husband, the immense changes and loneliness that caregiving causes is starkly emphasised. While in the past Pooja had her husband as a confidant and companion, now as a caregiver she feels a deep sense of loss watching her husband lose his sense of self. Not only has dementia caused her to feel isolation due to her husband's interpersonal absence, but caregiving has also led to social isolation due to a lack of time to completely commit to other social activities, highlighting the two-fold immense isolation and emotional burden caregiving causes.

> *You know, you want to talk things over sometimes about personal things… this things... that things and I missed that. Right! I miss that…I miss having the husband… this is it just said before I think I haven't got a husband I remember that I'm not a child. (**Pooja**)*

Further echoing the notion of isolation and loss, Pooja tearfully recounted the way her relationship with her husband has changed. Previously her husband was someone she could confide in and discuss "personal things" with. Through the use of the adjective "personal" which connotes closeness and intimacy, it is evident that previously her husband was her romantic equal and they had a relationship in which they had mutual support for each other. Now in contrast Pooja describes her husband as "a child" more like her son, further exemplifying the immense loss caregivers feel coming to terms with their loved one's independent sense of self and becoming a dependant.

> *We talked about the typical day... which has kind of fallen on me. I didn't have expectations at all. It was quite hair raising thing really, although I knew I could do it, in terms of actually doing total bed care for him, I don't mind as a person. (**Kamal**)*

Kamal talked about a typical day where he did not have expectations at all. However, he emphasised that the caregiving had "kind of fallen on [him]" from this, it is evident that he had a sense of choice. Having to help his dad with his personal care needs was uncomfortable and Kamal felt unprepared to carry out this aspect of caregiving at the beginning.

> *It's like I'm looking after an adult. So little bit more work for me as a career. Otherwise, I would have got time to spend time with my kids, I can spend*

> *more time with my children's studies, with myself ...yes, sometimes I do get depressed with this stuff...I had a depression episode last year, but I'm fine now [laughs] I had depression I got to tell you. (**Sabina**)*

In Sabina's case, she had a depressive episode after she started as a caregiver. The unexpected additional workload as a caregiver and the lack of support contributed to Sabina's depression. She wanted to spend time with her kids, help them with their studies, and study herself; however, with the additional responsibilities as a caregiver to a person with dementia she has had to adapt.

> *I like to start some classes, I would like to study, I would like to join some classes. I'm doing some classes at the moment like childcare classes, English but sometimes I find it difficult going to classes because there is no one to look after mum. (**Sabina**)*

Sabina started her studies in childcare; however, she sometimes finds difficult to attend the classes because she cannot find anyone to look after her mother-in-law,

> *most difficult thing to cope was that she is on pads now so if she has fallen sleep and she doesn't realise when she does things. So, everything has to get changed. That I had to prepare in my mind that I have to do it. (**Sabina**)*

One of the most difficult tasks as a caregiver for Sabina was when she had to change the pads for her mother-in-law when she had fallen asleep. It took some mental preparation for Sabina to take up this tough task.

6.5 Master theme five: “Tell us what it is and what the best way is to deal with it”

As previously noted above in theme four, dementia caregiving is multifaceted and stressful. Due to the complex nature of the caregiving role, it is crucial that caregivers feel prepared to take on this role. This section gives us an insight about the preparedness for the caregiving role and expected service provision of South Asian caregivers. All participants in this study highlighted an evident lack of support services and reported a whole array of negative experiences of service support, including concerns of basic needs not being met.

> *So, it’s only when you know something about it that you know how to deal with it. But I think that was the challenge for us as well because we’ve never seen anything like that before, we didn’t really know how to deal with it, we kind of just went for what we thought was right. (**Rahana**)*

Rahana reported that lack of knowledge about the condition left them unprepared and they found it difficult to deal with. It was a challenge for her family as they had never seen or had to take care of anyone with dementia before, hence they struggled to deal with the complexities of the condition. This notion of lack of knowledge is highlighted through the repetition of negation in phrases such as “never” and “didn’t” emphasising how unknown and difficult the experience of caregiving initially was. This hesitance and tentativeness, indicates that the family were provided no post-diagnostic support, instead being left to cope unaided.

> *It was hard because my mum’s a single parent, so she had to do things that, you know, someone probably wouldn’t want to do, but she had the choice because we would get the occupational therapist coming in saying would you like a carer or... and things like going to these sessions or do you want to take her to a care home but with us being maybe an Asian family*

> *it's part of our culture to look after the elders so that was not even an option for us. And it was hard to cope with it. (**Rahana**)*

> *it was just impulse moments, like certain times where she would... My Grandma wasn't that bad to look after, like the dementia didn't affect her in terms of my mum's looking after her got more. There wasn't more workload in that aspect for my mum. It was the same as what she was doing before but she was just having to put up with the moods. But that wasn't just her, it was all of us. Because when she wakes up, everyone wakes up. But it was just sometimes she'd fall but everyone would get up to help her. So, in terms of that it didn't change because she was caring for her anyway. (**Rahana**)*

Rahana recollected that her mother was taking care of her grandmother even prior to her being diagnosed with dementia, highlighting the traditional caregiving ideology in the South Asian community. She mentioned that from a physical caregiving perspective it was not very different, but despite this, her mum and the whole family had to cope with the dramatic mood swings of her grandma, which definitely took a toll on their overall well-being. This emphasises in some instances that the psychological impacts of caregiving are more challenging than physical health issues, which can be easily overlooked.

Through the static nature of the phrase "*it didn't change because she was caring for her anyway*" it is implied that due to a lack of knowledge about the condition the family did not provide any tailored care that was needed for this cognitive state. The caregiver and relatives continued supporting her grandmother the same way they had supported her for other medical conditions prior to being diagnosed with dementia, instead of delving into the nuances of the condition.

> *For me the most difficult thing to cope was that she is on pads now so if she has fallen sleep and she doesn't realise when she does things. So, everything has to get changed. That I had to prepare in my mind that I have to do it. (**Fatima**)*

Fatima was unprepared to perform personal caregiving needs to her grandma at that time and found it extremely difficult to cope. Over time, the degree of caregiving demands had changed which the family did not anticipate; therefore, there were many feelings of hesitance, and it took Fatima some time to mentally prepare for this change to perform certain tasks of caregiving.

> *We didn't know this was something related to dementia, but we did notice things like she leaves cooker on, or she forgets things microwave etc. She had a routine of putting washing on in the morning and sometimes I notice she is still washing in the evening. (**Poonam**)*

Poonam realised during reflection that her mum displayed early signs of dementia such as forgetfulness and misplacing things. However, her family were not able to recognise the symptoms due to a lack of understanding about the condition, which is common among South Asian families. Hence, by the time she was referred to the memory clinic, it had progressed to stage where she had functional impairment.

> *In the beginning, it was just start we were not taking that much care except reporting to GP, having examined and she has given some medicine, blood pressure, BP, blaa blaa, whatever they call you. But we were not taking that serious that it will be the end, but at the same time my experience with other people I knew it was dementia. My wife didn't know it was sign*

> *of dementia. But I, been involved with elderly people and listening to them then I realise it is dementia…Sometimes you say it's very bad disease. We listen but how can be it bad... in my experience this disease is very bad until unless I'm really involved in my own with my own wife. So, I find lots of problems, lots of changes, good and bad mostly it is not very good.*
>
> *(**Chawla**)*

Like anyone else, Chawla also thought his wife's symptoms were usual age-related troubles. Through the use of the dismissive phrases "170bla bla170" and "not taking that much care" it appears that Chawla is not observant of medical details and nuances; however, on closer inspection, it becomes apparent that he is in fact observant which allowed him to deduce that the symptoms his wife presented with were the early signs of dementia through his previous experiences with people with dementia. Chawla emphasised that even though you see and hear about the difficult side of dementia, when it comes to your own experience it is different and it was difficult to cope when his wife's condition got worse. However, he thinks you learn from your experience and then learn to cope better.

> *It was difficult caring for and understanding dementia, there wasn't much information, when I went to...I tried to find information because when my dad had terminal illness they came and spoke to us all about it. But when my mum was diagnosed with dementia I got hold of the Alzheimer's Society. (**Poonam**)*

Poonam expressed feelings parallel to those of Fatima and Rahana. She stressed that she was unready for her role as a caregiver and while she was eager to assimilate, Poonam had to take the initiative to obtain information instead of being provided with services. She did not know much about dementia care, and she did not receive any sort of guidance or support in the beginning. She compared the difference between obtaining information and support for terminal illness for her father to the amount of information that was available about dementia and its care, which fell short of expectations.

> *We talked about the typical day... which was kind of fallen on me. I didn't have expectations at all. It was quite hair raising thing really, although I knew I could do it, in terms of actually doing total bed care for him, I don't mind as a person. (**Kamal**)*

Kamal's account regarding personal care assistance was no different to others and he claimed that having to help his dad with his personal care needs was uncomfortable. By stating "which was kind of fallen on me," which has connotations of being obliged to take up something unprecedented, Kamal highlighted the difficult obligations that were placed upon him and hinted at his initial feelings of unpreparedness to carry out this caregiving element. When he took on the caregiving responsibility, Kamal immediately agreed believing it would not be demanding or burdensome. However, gradually as the role's nature became more demanding Kamal realised it was quite "hair raising".

> *So, it's only when you know something about it that you know how to deal with it. But I think that was the challenge for us as well because we've never seen anything like that before, we didn't really know how to deal with it, we kind of just went for what we thought was right. (**Kamal**)*

Kamal echoed the recurring notion that there is a severe lack of understanding about dementia. He claimed that a family can only manage symptoms if they have understanding and knowledge about this medical condition. This notion of lack of knowledge is further highlighted through the repetition of negation in phrases such as "never" and "didn't" emphasising how unknown and difficult the experience of caregiving is if caregivers are not offered support. Therefore, it is imperative that those experiencing dementia first-hand share their experience, giving others access to information on the condition.

> *Yeah, they were offering help, but I think back to it and I do think they could have done a lot more. Because my grandma was Pakistani, she couldn't speak English very well so in terms of that I don't think they took that into consideration. They used to say oh your grandma should come to this event and talk to these people that have dementia and things. How's she supposed to do that when she can't communicate with them properly and I know that situation would make her feel uncomfortable. And they say it would be better for her, but we don't think it would be because she would feel uncomfortable not having to be able to communicate with these people it's frustrating when you can't understand what another person is saying. So, I... they offered help, but I don't think they offered it to an extent of like they understood the situation. (**Rahana**)*

Rahana recollected and shared her experience of the dementia service that was offered was not adequately meeting the needs of PWD from a Pakistani background who do not speak English. Information about dementia events were given by an occupational therapist; however, the family never felt it would be comfortable for the grandmother especially since she does not communicate in English. This is emphasised through repetition of the adjective "uncomfortable", highlighting that without careful cultural considerations, events that are supposed to support PWD and their caregivers instead become a difficult burden. This again questions the availability of culturally tailored services for South Asian PWD.

> *Yeah, because we had one specific occupational therapist that would come around and she knew that when she would want to say something to her she'd like talk through me or my mum and ask like oh translate or anything like that. So, they were aware of it. (**Rahana**)*

They had a visit from an occupational therapist; however, the family members had to translate on behalf of their family member. This is challenging for the healthcare providers, PWD, and family caregivers, especially during assessments. Rahana indicated they were unable to understand the explanation about dementia given by the service providers and management within their context. Therefore, this highlights a need for more cultural and linguistic diversity in occupation therapy to make this support mechanism more effective in identifying the PWD's difficulties and supporting them to function in day-to-day activities.

> *Erm, I don't think culture ever got brought into it at all. I don't even think even once they brought it up. The fact that oh, because you're from this community, maybe this would be better for you. It was never, never... (**Rahana**)*

Through the repetition of the adverb "never", Rahana spotlighted her dissatisfaction with the healthcare services they had received which did not take into consideration the family's culture and way of life. She evidently voiced the real need for understanding of culturally tailored needs when considering care.

> *To be honest I don't think we were told very much about it at all. No, I don't think she knew anything about it to be honest because it's such a, it was never something you've ever heard of, like it's not happened in any of our*

> *family members or anything like that, like all the elder people who have like passed away, it's never been through something like this. (**Rahana**)*

Rahana proceeded to continue to use "never" and other negative phrases such as "not" to express how little knowledge her family had on the condition. Unlike most of her family elders, who had passed away from other conditions, when her relative was diagnosed with dementia, she had had no exposure to the condition's nature. This highlights the urgent need to increase awareness surrounding dementia to make caregiving a less daunting task.

> *Even though she still remembered all of our names, and we are in the future, she would think she was back at home in Pakistan, when she was younger or like living in that house. So, she would… when you'd ask her when she was in the hospital she would talk about her family in Pakistan and be like where is he, where is she and we're just like, you're in the UK and, she's like no, no I'm in Pakistan, I'm at home in Pakistan and her just like wouldn't believe it, she was just like, am I? And then she'd be confused, so that, yeah. So, I don't think that's her forgetting, I just think it's her being a bit confused. It was never a thing of like'oh she's forgotten. (**Rahana**)*

Through Rahana's long, cryptic, and complex description of her grandma's memories, Rahana emphasised the confusing nature of the cognitive state of dementia and by extension highlighted the lack of knowledge Rahana's family and many other Asian families have to deal. The condition heavily relies on reminiscences.

> *No because I don't even understand what they came to do really. Like it was to check up on her but it's like, it's like right so you're coming and*

> *you're asking ..oh.. how is she ...but you're not actually asking her. Like we're having to translate anyway, you're not really getting how she's feeling really anyway. And maybe if my grandma could communicate with her she could tell her how she was actually feeling but that as well, so she came but she didn't talk to my grandma, she spoke to us, like how are you dealing with it? So, we were just like ok and then it didn't feel like oh that was a good help. (**Fatima**)*

Through this frustrated description, Fatima highlighted the futility of untailored support services for South Asian PWD. When care providers came to visit, Fatima described that the service did not understand the true effect of dementia on the family as whenever they did visit their family member appeared fine and they did not enquire into how she was during difficult periods of the day such as night-time, instead making assumptions. This highlights that the timing of care-provider visits should be at the time the family needs assistance most instead of at inconvenient periods. This inability to fully grasp the PWD's state of mind was further amplified by language barriers which meant that instead of helping the PWD and asking them about their well-being this was done through family translation; therefore, undermining the effectiveness of this services. This experience thus emphasises that for services to be effective and worthwhile they must be tailored to the patients.

Again, highlighting the cultural need for services and resources specific to the communities who live in specific areas, Kamal said:.

> *Yeah, I mean...the care in North West, where we live isn't many Indian nursing homes, so whereas in Leicester or Birmingham there is lots of*

> *Indian care homes for Indian people, so that means with Dad he will be eating English food, he is total vegetarian. (**Kamal**)*

When asked why a nursing home was not considered as an option, the caregiver highlighted a very important point. There are no Indian nursing homes in the North West area, which means that if he did move his dad to a British nursing home, he would have to live in non-Indian environment; this would be difficult for South Asian elders in such a cognitive state. This is again drawing attention to the need for culturally sensitive services specific to Asian communities.

> *We noticed in the hospital he wasn't getting total vegetarian meal, which we were quite shocked at. They served him chicken curry and when we said he is a vegetarian, they will go and come back with cheese sandwich or something like that which is...you know. They...in their mind. You know. Will do for him. Otherwise, he will on mashed potato or mixed vegetables...It wasn't just working for him. That was the main aspect. (**Kamal**)*

> *I mean his English is perfect, the only thing is his hearing, but they will think it is because of his English, he doesn't speak English, I mean we had this at hospital. Oh, does he not understand English. Of course, he understands English!! He has been here all this time, you know…over 50 years ...you know. There were very many assumptions about it...he has been dealing with public all this time. Ahhh you know, instead of you telling me to tell him do this and that...tell him directly, because he understands you...you know...So there was a lot of this happening. (**Kamal**)*

Kamal’s description of his experience in hospital paralleled Fatima’s experience with care providers, emphasising the drawbacks of healthcare services when they do not take into account the background of PWD to create a tailored experience and instead make assumptions about them. A very important point is highlighted here. Kamal pointed out that the healthcare professionals had assumptions that his dad did not speak English when he had communication difficulties. This was due to his hearing issues not because of his English. Kamal stresses that it is important for healthcare professionals to have a clear understanding about PWD’s comprehension issues when planning care.

> *They do tea and coffee…and they do sessions... they sing English songs... I was joining in because I been brought up here in Newcastle. So I was alright but he wasn’t...he wasn’t sitting there bored or anything but he wasn’t enjoying it. Then we tried another one similar as well. These dementia places not good to us. Then I found out. (**Pooja**)*

> *Because it was not suiting him...you know being an Indian, he loves Indian music and Indian songs...he does enjoy them. He doesn’t like English songs...because he doesn’t know them, the old songs as you said. I think we were the only Indian couple...you know…that I mind at all... I don’t mind being amongst them…and coping with it, so that was alright. But it wasn’t getting him involved in those songs. Because I know music is good for dementia. (**Pooja**)*

By using negation and a semantic field of discomfort through the verbs “bored” and “coping” it was evident that Pooja desired the sessions she and her husband attended to be more culturally tailored to engage him. While she appreciated the efforts of musical reminiscence, the lack of cultural competency meant that for her husband the session was not effective.

> *Erm, obviously in terms of communication, maybe they should do like something where they bring different communities together because I think maybe it's the location you live in as well maybe. Because we live in [name of area], which is quite a white area. So maybe that didn't help either. If we lived in a like more cultural place, it would've been a bit more different. (**Rahana**)*

> *Erm, I think they should really be a bit more empathetic towards families that do it. Because they know how hard it is for caregivers to do it in professional levels. And my mum's not professional, you know, I mean so she, but she's having to have to do all that on top of looking after children, being a single parent, they never really saw that as oh wow like we should do something to help her. (**Rahana**)*

> *I just don't think they were helpful at all, at all. They just left you to it. They would ask you what happens, explain oh she was like this last night, oh ok, change the topic, ask about something else. It was never discussed like maybe you should try... we never got any like dementia specialists or even if there are any, to tell us that if this happens maybe you should try this to make her feel better. Do you know what I mean? It was just you deal with it, that's it, you're doing it so you deal with it. Or it was just the option of a care home. But they didn't understand that that was not an option for us. They just never really got it, so... And that made us a bit angry because it was just like I don't think you understand like... maybe they got frustrated*

> *about it because it's like well that would make sense but to us it was like no you don't understand. (**Rahana**)*

Rahana raised an important point that care services should offer more support to family caregivers as although they have volunteered to become caregivers, family caregivers do not have some of the knowledge that professional caregivers have; therefore, at times the role can be extremely overwhelming without support. Through the use of a confident tone when stating "I just don't think they were helpful at all, at all", and the repetition of the intensifier "at all", Rahana's blatant dissatisfaction with support services was evident, echoing the view of other participants who expressed that those services were not useful, mainly due to the lack of consideration into cultural requirements. Rahana reiterated this notion when she claimed that services had no understanding into her family's choice to not put their relative with dementia into a care home. Rahana also stressed the importance of having specialist nurses.

> *Tell us what it is and what the best way is to deal with it in terms of your individual person that has dementia. Like look at my grandma, see what kind of dementia she has got and then tell us how we can help her and what would be best for her. But they never did that, we had to kind of figure it out for ourselves, and we probably did things wrong along the way and did some things right, but you never know. (**Rahana**)*

Her family highlighted that they expect service providers to advise and support the family appropriately based on their individual needs, because the extent of the impact can vary between individuals and families.

> *But I know that it would help her if we had maybe help from like healthcare professionals. And my family. But we had it but not a lot so... (**Rahana**)*

According to this caregiver, if they had help from other family members and healthcare professionals that would have been very beneficial. She also mentioned that more resources about dementia such as leaflets in different languages would be helpful to encourage ethnic minorities to step forward.

> *Definitely...I think I've got the skills to deal with it a lot more, I'm more, I know more about dementia, I know the different types and I know maybe there are certain things best to be, to do in that situation and I wish I'd have known it then, maybe I could have helped a bit more. And all of us would feel more confident in looking after someone if we had to do it in the future maybe because we've seen our mum do it and we would go how, we would go on how she did it. And I think, you just have to educate yourselves on it in the end to be honest, that's what I did anyway. (**Fatima**)*

Fatima emphasised the need for education about dementia within the Asian community. She believed that after having seen her grandad with this progressive condition, how her mum took care of him, and with her education about this disease she is now better prepared. She believed that if she had had the knowledge earlier, she could have helped with the care of her grandad a bit more.

> *We didn't realise it. We thought it was just old age, you know.. like as you get older. But when things started getting serious, when it started affecting his behaviour, that's when we said to ourselves ok we need to go, you know get a scan done, get your tests done. (**Fatima**)*

Like many Asian families, Fatima and her family observed the gradual progression of memory problems with her grandad and believed it was old age-related due to their lack of awareness of dementia. The family, however, started taking things seriously when the behaviour of her granddad started changing. They finally decided to get medical advice and got tests done when they we made aware of this condition.

> *I just think that there needs to be more you know things, services for dementia in different languages. Because most of them are only in English. And then it's hard for like the Asian people to understand. That's one reason why they don't go to the groups is because they're not in, you know, our language. (**Fatima**)*

Fatima expressed the lack information about the services available in different languages for people with dementia and their caregivers. She identified language and cultural barriers as one of the main reasons for the Asian caregivers avoiding joining support groups that might be available.

> *There were two care workers used to come four times a day when she came back from hospital after the hip surgery. Then they reviewed the situation and decided to provide one care worker. It was lots of money around £1800 per month. We have property and source of income. Yes, that's fine but those care workers for no use, I complained against them to their company, Ie they were for no help. When she wanted to go to toilet if there is no one available... I had to do things. Then what is the point. The care worker asks my wife "do you need anything", she will say" No, I'm alright". They will just go but we pay for each visit they come.*

> *We pay £15 but no work, so I complained I do not want one in the night, sometimes 11 pm in the night instead of 9pm when my wife in sleep and they say they were busy. So, I stopped them. They used to come any time on Saturdays and Sundays. There was no control on things. The company who was providing care workers was just using the city council for grabbing the money. And so, they ask, why are you worrying? You are not paying the money the council is!*
>
> *And then they started sending male care workers to be washing and cleaning my wife. That was it then I stopped them... sorry you are not entering into my house, right! If it is woman, then it is fine. I do not want any male workers coming to my house. Then we stopped their services. Them. Then we reduced in the night, and they will… Then we stopped their services. So, the care worker we have now is very, very nice, she comes every day for 30 minutes, they get on so well. (**Chawla**)*

Chawla raised very strong points about the support they received from the service providers which was without any cultural consideration. He emphasised that the service providers were not available for the times when care was needed the most and were commercially motivated without any real concern for the patient. He was unhappy about male caregivers cleaning and washing his wife, again indicating the importance of tailoring caregiving needs.

> *It was participants and the one who organise it he would sing a song and mostly they sung Bhajans because it was mostly Hindus here ... They all sang Bhajans and he started singing they asked him does he want to sing and he sung, he did poetry first, he's into Kavita's. (**Pooja**)*

> *Then gradually and we found out that yoga on Wednesdays and exercise on Thursday. So I was going to the gym, we were going to the gym on the other days but really he wasn't able to participate he was going through very bad patch, very bad patch and I would put him in the disabled class and they were like wheelchairs so he was the able bodied in that but he, you know, doing exercises and sitting down so it made him busy and I could go for a Aqua. I loved Aqua! (**Pooja**)*

In contrast to most experiences with sessions and services, one Indian participant, Pooja emphasised the immensely positive impact of culturally tailored services on both PWD and caregivers. By finding activities that Pooja's husband can connect with this has enabled him to regain some aspects of independence and sense of self, reciting 'Kavitas' (poems) and enjoying 'Bhajans' (Hindu religious songs). Additionally, by finding culturally tailored services, this has enabled Pooja to have more time for leisure activities. Pooja recounted that after finding these sessions she had more time to invest in activities she enjoyed such as Aqua and the gym, highlighting how appropriate services have a significant positive affect on both the caregiver and PWD's overall well-being, which can alleviate the degree of caregiver burden. All of these support systems significantly reduce caregiver burden.

6.6 Conclusion of chapter

Chapter 5 presented the findings of the IPA from eight South Asian caregivers of PWD. Exploring five master themes and the sub themes within them, this chapter offered comprehensive and in-depth analysis that strove to fully represent the rich anecdotal accounts of the participants. Through the contrast of positive and negative themes, the complexity and conflict involved in dementia care was truly emphasised as participants expressed feelings of reciprocity, familism, and cultural inclination, which were the resounding rationales for caregiving. However, they also experienced a high level of burden due to turmoil, stress, and lack of cultural competency. The next chapter discusses the thematic findings of the study, making links between theoretical frameworks, empirical research, and new findings.

Chapter 7. Discussion of Findings

The results of this research study focused on the experiences of caregivers from the South Asian community in the Greater Manchester area, supporting family members affected by dementia. This discussion chapter summarises how the caregivers of people with dementia feel about caring for a family member with dementia as well as what might be interpreted from their interviews about the motives and challenges in caregiving. It then investigates further the specific meaning of identified concepts and trends and other experiences shared by the participants. The discussion is based on five main themes that emerged from the data: “Now it’s my turn to take care of you”; “When it’s family, you can’t say no”; “It is a norm, a good norm, a very good norm to follow”; “It was a constant roller coaster”; and “Tell us what it is and what the best way is to deal with it”. Theories underpinning findings from this study will be further explored in this discussion chapter in order to enhance transferability and add rigour to the study.

7.1 “Now it is my turn to take care of you”

Although there are a number of studies that explore the detrimental effects of dementia caregiving, the South Asian participants in this study strikingly displayed a strong account of the positive aspects of caregiving associated with the positive dimensions of well-being. All the participants in this study collectively reported that caregiving gives them a sense of pride and satisfaction that manifests as beyond the prescribed role. They expressed a strong sense of love and responsibility in taking care of their family member with dementia and perceived caregiving as fulfilling their duty of care. The evidence in this study finds that family caregivers viewed caregiving as an intrinsic duty and emphasised that they wanted to reciprocate the care they received from the family member who now has dementia. This particular finding mirrors the principles of the theoretical viewpoint of the Transactional

Model of Stress and Coping by Lazarus and Folkman (1984) whereby positive aspects of caregiving are incorporated as an intervention to mitigate the effects of the caregiving burden (Quinn et al., 2018).

The interpretative account of both spousal caregivers in this study revealed that their motivation for caregiving was strongly linked to the notion of reciprocity, intrinsic rewards in upholding their marriage vows (Cash and Hodgkin, 2019). This was consistent with fulfilling a sense of duty for each other through their life course, which has been emphasised in previous literature (Murray et al., 1999; Ray et al., 2006; Ribeiro & Paul, 2008; Lloyd et al., 2016). Reid et al. (2005) suggest the effects of reciprocity in caregiving include intrinsic motivation and enhanced self-esteem. According to Gouldner (1960), the norm of reciprocity is classically defined as “certain actions and obligations which work as repayments for the benefits received” cited by Ugargol and Bailey (2020).

The findings from this IPA study imply that the caregiver’s willingness to volunteer to care for their family member with dementia is significantly dictated by the reciprocal love that a caregiver has towards them. The accounts of spousal caregivers in this study reflected that their marital relationships were strongly connected with a strong sense of love and commitment to provide care, which facilitated their willingness to be supportive even during challenging situations whereby their spouse was affected by dementia. One husband caregiver in this study wholeheartedly expressed that love is “the best remedy as a carer”. From this profoundly emotional statement it is implied that this change in marital dynamics has brought a new sense of closeness in the spouses’ long-term relationship and allowed them both to understand the real deepness of unconditional love.

Cash and Hodgkin (2019) argue in their recent study, that in a challenging situation like dementia care, love does not develop automatically unless there is a positive influence of a particular magnitude, but a strong sense of love and commitment is the only way to foster a relationship's true meaning among couples. The uplifted spousal caregivers in another study by Donovan and Corcoran (2010) stressed that a sense of love helped them to maintain a positive approach to care and brought fulfilment in life. As has been seen, an early finding in this study supports previous findings on how love helped family caregivers put their partner first and be compassionate to them in times of difficulty (Shim et al.,2013).

Although there was a shift in the participants' roles from sharing a mutual relationship with their spouse to being a caregiver of their spouse with dementia, their perceptions of love were solely based on the experiences of the caregiver instead of the mannerisms of the care recipient, highlighting the subjective nature of spousal caregiving (Reid et al., 2007). One of the participants explained that the care role was his "will" and emphasised that "it's his turn" now to take care of his wife with dementia, exemplifying the previous countless times his wife had cared for him during their long marriage. This give and take is a further illustration of the reciprocity.

It was essential to have a sense of duty for this spouse to take care of his wife in times of challenges, and he expressed a sense of pride in being able to care for his wife. This was because of the high-level of intimacy in their long-term relationship and the other means of honouring the marriage vows and remaining true to the promises made at their marriage (Hellström et al., 2017). The continued anaphora of the phrase "I will" by one of the spousal caregivers had connotations of action and determination, echoing the previous idea of "promises" and an allusion to the marital vows of a couple, 'in sickness or in health'. In this case, there is a predominant aspect of mutual dependence and support that is considered as one of the pillars that form the foundations of marriage (Carruth, 1996; Call et al., 1999; Leopold et al., 2014). For instance, even older adults feel that it is their responsibility to take care of their spouse who is likely to be affected by ill health condition at their advanced ages, and this is indicative of the trust they have in each other.

In this study, all participants reflected a sense of love and commitment towards their family member with dementia, and that stood out as the main motivating factor. Shen et al. (2011) further argue that the scope and degree of reciprocity changes in cultural contexts; however, this was not evident across the accounts of spousal caregivers in this study. The interpretation of the spousal caregivers' accounts in this study is contrary to this argument as both spousal caregivers did not indicate whether cultural factors had any influence in their motives for caregiving. Instead, the results supported previous studies suggesting that the long-term reciprocity of marriage counterbalances momentary difficulties and challenges of spousal care provision (Ray, 2006). This level of reciprocity by spousal carers reflects the original Social Exchange Theory (1976), subtlety implying that there is no cultural disparity affecting the reckoning of reciprocal actions. This situation was supported by the accounts of spousal caregivers in a previous study where they demonstrated individual and social obligations of care in their marital kinship (Schulz et al., 2012). In contrast to the effect of culture in spousal caregivers' motivations in the caregiving role, other participants in this study discussed the effect of cultural reciprocity.

A literature review conducted by Quinn et al. (2018), corroborated the effects of a long and reciprocal relationship when looking after a spouse with dementia. The review findings found a range of positive factors, including altruism, love, reciprocity, obligation, guilt, and commitment to the marital relationship to be resounding motivational factors for caregivers in formal care between older spouses (Quinn et al.,2018). In addition to the above, the male spousal caregiver in this study perceived taking care of his wife with dementia as an emotional reward and social appreciation (Ribeiro and Paul, 2008).

This study also shows that the interpretation of religious beliefs expressed by spousal caregivers contributes to the positive aspects of care. One of the spousal caregivers in this study reflected that those strong religious beliefs offered him a feeling of spirituality, fulfilment, and comfort which alleviated the challenges of familial caregiving. The results of a number of studies that are consistent with this topic (Godfrey & Townsend, 2001; Bowes & Wilkinson, 2003; Adamson & Donovan, 2005; Mackenzie, 2006; Lawrence et al., 2008; Lawrence et al., 2010; Qadir et al., 2013). Even though there are a number of recent studies highlighting the significant influence of religious values, some even claiming them to be the resounding rationale for caregiving, it was insightful to note that in this study no other caregivers cited religion as a motivating factor shaping caregiving. This emphasised that for many caregivers in this study, the taking up of the role as a caregiver was an innate decision that surpassed the constructs of religion and instead came from a place of love and reciprocity.

It is crucial to note that the reciprocity dimensions significantly varied among the caregivers. The findings from this study further draw on principles of Pearlin et al.'s (1990) Stress Process Model whereby the dimension of reciprocity varies depending on the relationship between the care receiver and caregiver. Consistent with this idea and building on it, the current research shows that the dimensions of the daughter caregiver's reciprocity were different from the spousal caregivers' among South Asians. This finding mirrors the first and fourth domain of Pearlin et al.'s (1990) Stress Process Model domains, i.e., characteristics of the carer, family, and intrapsychic strains where the carer's self-concept, competence, and psychological state. A daughter caregiver in this study perceived caregiving as fundamental to the mother-daughter relationship and as her “love in return” for her mother for “always being there for her”. When a family member develops dementia, this dyadic relationship appears to shift from equal help exchange to a greater burden on the caregiver where the role has reversed (Fauth et al., 2012). Based on reciprocity, when giving care, it is vital to understand the care receivers’ perceptions of the relationship with caregivers as it affects how they receive care (Walker, Pratt, & Oppy, 1992). It appears to also be a means of giving gratitude that the care receiver created in the caregivers’ life and expressing love to them.

Further exemplifying this notion, adult caregivers in a study conducted by Horowitz (1985) echoed that while caring for their older parents there was a belief that the social, emotional, and familial burden they experienced was attributed to their varying perception of the caregiver role. In this study, daughters were the family members predominantly in the caregiving role, with sons much less likely to inherit the role and instead relying on female relatives such as sisters or spouses. Typically, South Asian men were prescribed less intensive tasks such as financial management and administrative tasks, while more intensive hands-on tasks were reserved for mainly female caregivers; therefore, male caregivers would only need to inherit the difficulties of a caregiving role in the absence of female relatives.

This hierarchal disparity in the prescribed caregiving roles led to women in this study usually experiencing higher levels of stress due to the need to balance their caregiving role, family responsibilities, and other commitments. This caused them to feel that they have very little time for their own well-being, limited time for leisure activities, and their sense of agency is disrupted. Daughters and sons’ attitudes toward caregiving were reciprocal, as they stated they were giving back to their older parents who gave them life and provided care when they were younger; now it was the children's time to provide care for their parents (Lawrence et al., 2008).

In an ideal situation, reciprocity is both motive and behaviour based on individual self-interest (Bruni et al., 2008) and the reciprocally altruistic behaviour of the caregiver is mutually beneficial for the care recipient immediately and the carer in the long run. Primary adult caregivers rely on the 'demonstration effect' established by Cox and Stark (1996), hoping that their children will observe the caregiving process and emulate it later. This particular outcome extends to different circles within the South Asian community and are based on the influence of cultural reciprocity within the family that led to their care motives (Ng & Indran, 2021). The South Asian caregivers in this study described an ingrained notion of reciprocity which entails positively responding to a particular concern with positive actions to reward kindness.

According to Pearlin et al.'s (1990) Caregiving and Stress Process Model, the reciprocal effects encompassed under the fourth domain, intrapsychic strains, are the carer's self-concept and psychological state. Where, in Lazarus and Folkman's theory (1984), positive aspects of caregiving are seen as a method to alleviate the effects of caregiving stress. The transcendent nature of caregiving was perceived as more than just a physical 'role'. Caregivers claimed it is beyond a prescribed job but instead a duty that has social, mental, and spiritual aspects. In such a situation, caregiving is portrayed as a means of appreciation. As a way of giving back, caregiving stands out as a constructive activity. The caregivers have a crucial chance to share quality time with the people affected by dementia, making them feel proud. So, every minute the caregiver spends with their relative living with dementia significantly helps enhance the pre-existing bonds and increase the quality of their relationship. In other instances, the caregivers feel that it is also their responsibility to boost the life experiences of the people they are closely related to with the challenges they face with dementia. The support attained from their elderly family members is reciprocated by the younger caregivers, ensuring they are in as stable a situation as possible when affected by dementia. The reciprocation of previously received affection seems to have developed traits like positivity and a sense of satisfaction in being able to care for elders. These achievements serve as sources of motivation to perform caregiving functions and help caregivers enjoy every activity.

The adult children in this study expressed a perception that caring for their parent was beyond the idea of reciprocity; the grandchildren caregivers also seemed to share the influence of reciprocity as an exchange of support between their parents and grandparents. The benefits of reciprocity have been identified as motivating the exchange of care between the elderly and their younger family members (Ugargol & Baily, 2020). Several studies have examined family exchange and how older parents have received reciprocal support from their younger family members (Neufeld & Harrison, 1995; Hsu & Shyu, 2003; Funk, 2015). In this study, one participant described how her mother cultivated compassion and empathy in their family and made many sacrifices to look after her mother-in-law with dementia. Growing up in such an environment with a strong traditional caregiver ideology has influenced her commitment to the values of dedication and selflessness that were nurtured in her family. Leopold et al. (2014) argue that if it is true that reciprocity directs care provision between generations, then the support provided by adult children to older parents will not erode even amid ethnically diverse modernised and ageing societies.

In summary, this theme is a detailed interpretation of how reciprocal notions motivate caregiver among South Asian caregivers when they care for their own. All the participants reflected the multidimensional effects of reciprocity, expressing deep feelings of affection, gratitude, and appreciation which altogether provided the caregivers with a resounding rationale for their caregiving role. The study integrates the findings of empirical studies on this theme and contributes to understanding on how reciprocal support in families affects the outcomes of caregiving for dementia. Reciprocity often has the ability to increase, the strength of family solidarity, which consequently connects to the next theme that discusses the familial factor that positively affects the motivations of the caregiver.

7.2 Motives of caregiving- “When it’s family, you can’t say no”

While theme one highlights that motivation for caregiving in South Asians is strongly linked to the dimensions of reciprocity, another superordinate theme that was widely reflected by all caregivers in this study is the familial factors that influenced their motivation of caregiving.

7.2.1 Family support

A strong sense of loyalty to familial values is certainly attributable to the traditional concepts that immigrant families continued to uphold while migrating the UK. In the modern world, the family structure has changed significantly, and in most cases, there is substantial advocacy for individualism, whether directly or indirectly. Such a situation jeopardises the possibility of attaining an appropriate result if a person from these families develops dementia. In the UK, South Asian people are more likely to live within closely-knit communities, and they have maintained a strong view on family taking care of family (Katbamna et al., 2004; Jutlla, 2013; Parveen et al., 2013). Findings from this study indicate that a strong attachment to family members and the support system creates a positive impact on their caregiving experience. All caregivers in this study agreed that caring for a family member with dementia, with the simultaneous support of other family members, helped them to share the burden of caring, thus easing the emotional burden of care.

Although the degree of support received from other family members varied for each participant, it appears to have extended the closeness of family unity and was crucial in fulfilling their role as a caregiver.

The findings reflect on the enduring principles of the revised model of Sociocultural Stress and Coping for Caregivers by Knight and Sayegh (2010) where the authors endorsed familism as a positive influence on caregiving which lowers perceptions of caregiving as burdensome. According to Sabogal et al. (1987), familism is a concept where an individual or group of people has a strong attachment to their families, and thus express strong feelings of loyalty, reciprocity, gratitude, and solidarity for members of the same family. Mendedz-Luck et al. (2016) in their study on Mexican origin elderly caregivers highlighted that the original concept of familism has changed in various contexts hence there is always a need for continuous assessment. Knight and Sayegh's (2010) work that explored East Asian caregivers supported that familism as an important concept to help the caregiver to cope with the stress of caregiving. The South Asians in this study, echoed this notion; one participant stated, "it gives me more confidence in everything", stressing that having support from family has allowed him to feel more self-assured in his role as a caregiver. The power of family support was further alluded to when another caregiver heavily emphasised the intensifier "very, very" several times when talking about the family.

Findings from this study correlate with the findings of Pinquart and Sorensen (2005) where lower levels of stress were found to be attributed to the positive impacts of a familial caregiving structure in ethnic minority caregivers. This aspect of familism, further supported by Losada et al. (2020), where familism entails the idea of prioritising the family over individuals when undertaking certain roles (Pinquart & Sorensen 2005; Parveen, Morrison, & Robinson, 2011). Therefore, if certain benefits are linked with a specific action plan, family members will be the first to enjoy the gains before any other group of people the subject will consider later. This term 'family' has been continuously utilised by participants in this study, especially when advocating that people need to be responsible for the care of related people or family members rather than waiting for assistance from the government or other support services.

7.2.2 Family unity

All the caregivers in this study expressed a strong sense of family unity, pointing out that family is embedded in their day-to-day lives and even in the extended family network, consistent with findings from previous studies (Pinquart & Sorensen 2005). Caregivers in this study acknowledged the collaborative efforts of family in the care of PWD, mirroring the multidimensional aspects of familism (Sabogal et al., 1987). As in Knight and Sayegh's (2010) Sociocultural Stress and Coping for Caregivers Model, the concept of familism in an ideal situation is multidimensional. The values of familism enhance the relationships in a family and have been associated with positive outcomes even in non-caregiving situations (Kiloren et al., 2016). It is characterised by family importance attitudes and other forms of behavioural traits that showcase certain family ties (Hernandez & Bamaca-Colber, 2016). The attitudinal form of familism presents the family as a crucial support system. A participant noted that it should be a family's duty for caring for another family member with difficulties or problems, regardless of which role people will play in the situation.

Throughout the caregiver's accounts, it was evident that the aspect of familial kinship is inevitable when it comes to the entire experience of caring for people with dementia. Consistent with the work of Katbamna et al. (2004) and Sayegh and Knight (2011) the kinship that lies within South Asian generations has direct effects on physical and mental health outcomes on the degree of caregiver burden. In this case, the family members' care needs, specifically those with dementia, are portrayed as paramount and supersede individual interests. However, the primary caregiver alone was not enough to advance the ideal form of care for the PWD. Therefore, unity in the family setup stands out as a crucial facilitating factor that creates an enabling environment that can care for PWD. These familism values enhance the relationships in a family (Kiloren, Alfaro, & Kline 2016).

It is generally revealed in this study that caregivers significantly rely on family as a support mechanism in fulfilling their core functions and activities. This situation aligns with the available knowledge that the minority caregivers observe a strong sense of family unity and attach substantial value to the family unit when it comes to their care responsibilities. This rhetoric was strikingly evident in this study's participants' accounts, all of them emphasising family connections as one of the main motives for their role as a caregiver. This close-knit system was demonstrated in several ways such as shared roles and communal decisions. When one participant described their caregiving experience, they continually utilised the collective pronoun 'we', emphasising the closeness and unity that led to the family's shared role in caring for the person with dementia.

Familism also stands out as a coping mechanism during the caring process (Song, Yan, & Sorensen 2017). To avoid interference in such a situation, the caregivers significantly advocated for establishing a traditional family structure. In most situations, the traditional family set up includes the extended family members. Such establishment makes it easy to undertake different duties and activities collectively and, in turn, guarantee unity suitable for the effective care for people with dementia. The traditional set up generally takes care of all the needs of a family. As a multidimensional concept, familism is categorically portrayed as a crucial referent when formulating key decisions. When delivering care for a person with dementia in a united family, it is easy to explore situations collectively and make informed decisions jointly. This was evidently manifested in the study, with each of the participants stressing the collective nature of decision making in care. When describing this process, one participant continuously utilised the collective pronoun ‘we’, highlighting the united nature of caregiving that can be achieved in an ideal familial structure.

Additionally, since the family members have been interacting with the patient with dementia closely for years, it is easy to guide them in revisiting some critical memories. Therefore, in this case, the family serves as an ideal provider of care for PWD. Given that families offer support to each other through different situations, caring for PWD is easier since it is a usual undertaking, which is common and does not need new complex procedures. However, the experiences of families when dealing with a dementia patient vary significantly (La Fontaine et al., 2016).

At the base of the familial concept, there is a form of cultural frame of reference regarding the family centrality, which is integrated into the population’s behaviour and attitudes that endorse this integral unit of society. Therefore, these particular familism proxies are usually used in other domains as the basis of parenting or caregiving. For instance, in the Asian family culture, there is the attribute of ‘filial piety,’ which includes a child’s responsibility to care for the parents (Ihara, Tompkins, & Sonethavilay, 2012). For example, Maya stated that she knows it is her responsibility to care for the older in-laws in the family. Caregivers cite that their care work is highly influential and exhibits a positive influence on the family structure. However, caring for PWD is a difficult endeavour, and such tasks are mostly assigned to women, which negatively impacts female caregivers’ burden perceptions and reinforces the traditional familial structure in which the shared responsibilities required from idealised familism are not achieved (Flores et al., 2009

7.2.3 Grandchildren in family caregiving

Although there is sound evidence on the experiences of family carers of PWD within the context of spouses and adult children, which form the two most predominant types of family caregivers for PWD, there is a lack of conclusive empirical studies which delve into the experiences of grandchildren, particularly from South Asians communities, who have a grandparent with a diagnosis of dementia. The relationship between grandchildren and grandparents is often portrayed as unique and impactful. For grandchildren, grandparents play a multifaceted role as supporters, caregivers, and educators from childhood to adulthood (Hodgson, 1992; Roberto & Stroes, 1992; Weston & Qu, 2009). These impactful roles mean that strong grandchild-grandparent connections have also been found to have a significant influence in the social and psychological welfare of grandchildren and grandparents alike (Ruiz & Silverstein, 2007).

In my study, grandchild caregivers expressed positive relationships with their grandparents correlating with previous empirical studies that stated strong relationships provided cause to act as a caregiver. This role that grandparents play in the development of their grandchildren leads to the grandchildren highly regarding them later in life. Thus, ascribing South Asians to the dimension of filial piety and values concerning family supportiveness may have more positive health effects for caregivers within the sociocultural model of Knight and Sayegh (2010), displaying principles similar to those of East Asian caregivers. This is a significant new finding in this study. One participant described how her grandmother stayed with them to “look after” the grandchildren because she felt that responsibility to do that because her dad was not there. Using nurturing phrases such as “look after us”, the loving relationship between her and her grandmother is emphasised and it is highlighted that the caregiver fondly recollects the love her grandmother displayed during hardship. Additionally, by utilising the words “responsibility” and “stayed” the strong sense of commitment the caregiver witnessed her grandmother uphold is emphasised. This recollection highlighted that due to her grandmother’s love and commitment for her as a child, it was only natural for her to reciprocate these actions by be her caregiver.

In an idealised position, when caring for PWD together, it is possible to involve all family members for caring tasks. This mainly results in bringing them close to each other when performing crucial functions like decision making for the person with dementia. When faced with challenging situations, this unity makes it easier to respond together and achieve reliable outcomes. However, it was noted that some family members remain unwilling to perform the core primary care activities in other situations. Therefore, it is crucial to have well laid out plans on which specific function or activity a person will perform. Taking the core responsibility for caring for people with dementia is a suitable means of supporting family and giving back. Through the provision of high support, familism enhances psychological health (Campos et al., 2014)

7.2.4 Inconsistency, conflicts in family dynamics, and obligation

However, in some cases this reciprocity comes from a lack of choice to care. The caregiver feels obligated to care, thus the attention the caregiver gives to the person with dementia feels strained and the role is a burden. While the influence of familism was found to have a positive effect on the caregiving process, the interpretation of participants’ accounts showed that other variables such as familial obligation are found to have a negative influence on caregivers’ physical and mental health. Some of the caregivers felt a lack of consistent family involvement in essential caregiving and the demands of caregiving led to familial conflict about care decisions.

All participants in this study reflected a family-centred ideology. It appeared that most of the interviewed South Asian carers showcased views correlating to a traditional ideology that perceives caregiving as an innate natural, expected, and virtuous endeavour and expressed an integral feeling of obligation to provide care. This strong adherence to traditional family values perhaps traces back to the notion that for many immigrants, before the processes of integration and acculturation, family unity provided survival and kinship in a new land (Foner,2012). However, despite the positive implications of familism, when this concept of cultural norms is adopted in immigrant families, it simultaneously has the ability to increase caregiver burden on individuals due to increasing cultural assimilation to majority-ethnic individualism ideologies. This changing support system also negates the benefits of caregiving as tasks in British immigrant families cannot be shared as equally as they would be traditionally due to a smaller extended family structure.

One way the aforementioned familial burden was manifested in this study was how the participants noted that there is a lack of involvement and commitment from other family members in some instances. This can thus negate the positive support framework to mitigate burden and in some cases further adds to the caregiver’s stress. In this situation, an Indian participant explained that while the other family member wished to see their relatives being taken care of, they were unwilling to participate in the primary caregiving activities. Some caregivers cited that the concept of familism complicates caregiving duties due to a lack of sociocultural facilitation prompting negative feelings like frustration (Gelman, 2014). There is substantial research evidence that there is a caregiving gap for people with dementia in most settings. This study introduces a new prompt for future research to confirm family unity’s identified influence in caring for people with dementia.

Such information will be influential in mitigating situations whereby dementia patients do not get suitable assistance.

Based on the theme of familism, the results of this study suggest that caregivers can express both positive and negative reactions to caring for their family member with dementia. The available literature links family cohesion with self-efficacy development and as an efficient tool for recurrent social crisis management and advanced qualities of parenting like monitoring. From its multidimensional nature, it is evident that familism sits more comfortably within the concept of the communalism, like the prioritisation of strong networking with other family members. Therefore, any interest that favours family is highly prioritised. Additionally, being a form of cultural value, familism helps understand the complex needs of the caregivers. Therefore, tailored support provided to the family can significantly help them in advancing positive experiences and to create better unity for the families where there is a person with dementia (Losada et al., 2020).

7.3 Cultural motives for caregiving: "It is a norm, a good norm, a very good norm to follow"

This particular theme was seen as another core theme, which linked in with the other superordinate themes of reciprocity and familism. The current study produced findings which corroborate the previous literature evidence as cultural foundations are a critical component of caregiving. The present study findings show that there is a degree of relationship between culture and caregiving among South Asians. The South Asian caregivers in this study described about how their cultural values and norms significantly influenced their positive perception of caregiving as to what they consider important when providing care. The discussion of this theme will be critically based on the interpretation of the findings of this study while taking into consideration the expertise of attested evidence and relevant theoretical frameworks.

Brislin's (1990) well used definition, referred to culture as "widely shared ideas, values, formation, and uses of categories, assumptions about life, and goal-directed activities that become unconsciously or subconsciously accepted as right and correct by people who identify themselves as members of a society" (Wong et al., 2006). The present study findings are also in strong agreement with previous studies where culture is considered as a powerful human tool and plays as a key role in caregiving among South Asian immigrant communities in the UK (Dilworth-Anderson et al., 2002; Pinquart & Sorensen, 2003; Botsford, Clarke, & Gibb, 2011; Guo, Kim, & Dong, 2019). Like many communities, the South Asian diaspora living in the UK also have a long history of appreciating, perpetuating, adapting, influencing, and assimilating their own cultural values and norms while adapting to Western culture (Needham et al., 2017). Regardless of the influence of the host culture, British South Asians exhibit strong attributes of their ancestral cultural values, and these values are still deeply entrenched among the South Asian diaspora in the UK. It is important to highlight that these cultural norms are derived from the time prior to migration, that is during 1950s and 1960s (Botsford & Dening, 2015). What is interesting to note is that such norms have changed in their own countries of origin such as India and Pakistan, but interestingly, from the findings from this study, it is evident that cultural norms continue to remain strong in the South Asian migrant communities living in the UK.

The finding in this study explains how the cultural norms in South Asian communities are embedded and have a high capability to influence the coping style to reduce burden. General perceptions of South Asian caregivers in this study about caregiving are positive and they proudly reflected that such positivity is shaped by the influence of diverse cultural factors and family values. For example, taking care of an elderly parent is a traditional and powerful norm among South Asians and the admiration and appreciation for this collectivist norm is very prominent among the South Asian communities living in the UK (Hanssen & Tran, 2019). Jolley et al. (2009) highlighted that this is largely due to their own need to maintain their self-identity in a foreign land. The participants of my study echoed these cultural perceptions, consistent with the findings from earlier studies that explored the correlation between culture and caregiving motivations (Needham et al., 2017).

Over the years, many researchers have widely explored the importance of cultural variables that motivate caregiver decisions (Dilworth-Anderson, 2002; Jutlla, 2013; Hossain, 2020). Although the findings from this study aligned with the familism spectrum of the revised sociocultural model of Knight and Sayegh (2010), there are subtle contrasts to the variables of the model where the role of cultural values appears to have less influence in caregiving. All grandchildren and adult child caregivers in the study expressed that their strongly rooted cultural values had a positive impact on their role as a caregiver. Interestingly, this contrasts with the findings of spousal caregivers in this study where they did not mention whether cultural factors had any influence in their motives for caregiving.

In the UK particularly, carers of South Asian ethnic descent tend to feel more culturally obligated to care for their ageing family than their white British carer counterparts. Lawrence et al. (2008) and Parveen and Oyebode (2018) were of the view that South Asian carers of the ageing population with dementia, tend to hold a more traditional caregiver ideology rooted deep in their culture as compared to white British carers. The former view caring for their elderly as natural and expected. The belief of caring for elderly parents is also visible in other communities around the world, such as the African American minority in the USA. Knight et al. (2010) in their findings state that African Americans and South

Asians tend to feel more culturally obligated to care for their family member with dementia compared to their white American colleagues.

Sluder (2020) further explored this and pointed out the frequent misconceptions regarding BAME communities, that the family members are under cultural obligation to take care of their elders and that they can do so with the support of their large extended families. To support this stereotypical misconception, evidence has shown that assumption has led to carers not being offered the services they need (Carey et al., 2017). This is most likely due to clashing ideologies of collectivism and individualism. In a traditional minority society, a collective approach may be undertaken during caregiving, with care tasks being distributed within a community (Hanssen & Tran., 2018). In contrast, Western society usually adopts an individualistic approach for caregiving, with care mainly given by main caregivers. Thus, when ethnic minorities migrate to the UK and adopt Western ideologies, collectivism within caregiving evolves, and the previous networks of support disappear. This causes care tasks to fall on only immediate family members, while services assume minority caregivers have the support of the wider community (Mackenzie, 2016). This clash of ideologies then results in increased burden for minority caregivers, due to the perceived lack of need of service support (Parveen et al., 2017).

Although there is a significant shift towards the individualism spectrum due to Westernisation and assimilation, the comparative conservative nature of the South Asian culture is directly captured in the caregivers' accounts in this study (Knight & Sayegh, 2010; Parveen et al., 2013). Despite the fact that third-generation caregivers in this study are of a young age, they strongly demonstrated the culture based natural motivation that mimics the expressions of previous generations towards caregiving. One of the participants highlighted that caregiving responsibilities at a "young age" was "hard" but becomes a “habit” as they became accustomed and happy with the role, possibly due to the deep-rooted cultural socialisation and pride associated with care for elderly family members with dementia. Parveen's work (2013, 2013, 2017 and 2018) primarily corresponds to the familism spectrum of Knight and Sayegh's (2010) revised sociocultural model, which focuses on the perspectives of second-generation South Asian caregivers. In my study, I not only support these findings but also delve deeper into the experiences of third-generation caregivers and male caregivers.

Among South Asians, culture is absorbed, not always spoken about, and most of the cultural attributes supporting caregiving advanced from one generation to the next. Cultural values and beliefs are usually taught to the children at young ages and caring for elders is culturally a very normal process to follow (Helman, 2005). Given such trends are evident within the family culture, even the caregiving activities among South Asians, including for the family members with dementia, could become a continuous inclination and it appears to be considered as a normal or routine expectation. Family attachment usually captures the essence of care provision obligation as one of the crucial values and in turn develops positive feelings about offering support to relative (Sayegh & Knight, 2011). One of the caregivers explained how her mother insists on the importance of having an older person in the family as a norm. It is considered as a good norm as an integral part of the community’s culture. Therefore, with such knowledge from a young age, caring for the elderly will be positively approached and considered to be a noble activity.

The role of culture on gender roles has always been intricate and is a complex, tightly weaved, and dominating factor embedded into the South Asian community. In the UK particularly, South Asian daughters are more likely to help aging parents than sons: a notion that is soundly supported by an abundance of studies (Hirst, 2001; Bhattacharyya &

Shibusawa 2008; Jutlla, 2015; Hossain, 2020). This is mainly due to the notion that traditionally intergenerational ties are closer for women, with daughters bonding with their mothers more strongly than sons. As well as this, the traditional perception, as observed by Parveen (2013), that women caregivers are influenced by traditional feminine roles and are much more emotionally involved in caregiving, is a contributing factor (Hirst, 2001). In most South Asian families, there is still a highly prevalent gender presumptions that the female spouse, daughters, or daughters-in-law take responsibility for familial caregiving (Jutlla, 2011; Sharma et al., 2016; Ugargol & Bailey, 2020). As observed by Parveen (2013), this is due to women caregivers being influenced by traditional feminine roles of being much more emotionally involved in caregiving.

Ethnic minority carers are at particular risk of developing depression and stress-related health complications. In the past, women carers, especially daughter-in-law carers, have expressed their concerns about the lack of appreciation and lack of support from their husband, brothers, and other family members. Godfrey and Townsend (2001) further explored the concerns of daughter-in-law carers and pointed out their ‘invisible’ status in the family. When Jutlla re-investigated this concern (2015), the author hoped to see a change in the ideology of traditional gender roles, but the results were consistent with previous studies. The findings from this study support the empirical findings and contribute additional evidence. The stereotypical cultural expectations of care for older adults by daughters-in-law are still common among South Asian families. Daughters and daughters-in-law are usually obliged to provide care for older adults.

Most care aspects are the responsibility of daughters-in-law and daughters who deliver care services for long hours without support or recognition (Parveen, 2012). Like other cultural aspects before, one of the respondents was married, she was reminded by her own mother about this obligation of caring for her in-laws. Given that elderly people are more prone to dementia, providing care for them stood out as a suitable means of honouring them culturally among South Asians. Taking on this role by the daughter-in-law was connected to providing happiness for the entire family. Subsequently, the respondents also confirmed that by performing their duties of caregiving for their elderly relative, in turn, as daughters-in-law they created happiness for the entire family including their husbands. Past studies on South Asian caregiving for the elderly established that there were low reports of care delivery perceived burden (Gupta & Pillai, 2002). The cultural values and norms made the caregiving process a means of pursuing happiness among the South Asian caregivers, unlike other settings where the process is usually dominated by challenges. The cultural provisions, in this case, placed high importance on in-laws by always being considerate and willing to take care of them in case of ill health. This approach included undertaking all the main caregiving activities. A respondent reported that when her mother-in-law developed dementia, she did all the activities without question since it was a cultural norm.

Women caregivers in this study expressed a sincere desire to give the best quality of care to their elders. This desire is evidently attributed to the multifaceted nature of their socialisation. Throughout their life, particularly during developmental stages, a caregiver experiences several forms of socialisation which contribute to their distinct caregiver identity. For example, South Asian women may encounter several examples of cultural socialisation and gender socialisation emphasising the importance of caring for the elderly, thus leading to women possessing an innate caregiver identity. This distinctive identity shapes their perceptions of caregiving, consequently providing South Asian women a rationale for positive caregiving contributions. In this study, participants also mentioned that their role has had the power to create a positive environment and impact wider familial well-being. One participant claimed that caring for her family made her "happy", her husband "happy", and her in-laws "happy". This is a subtle allusion to the presence of the metaphorical butterfly effect: the idea that even the slightest change in the starting point can lead to greatly different results or outcomes. In this context the caregiver's positive actions contributed to not only the caregiver and the recipient of care, but also the entire family's overall well-being; therefore, emphasising the influential role that caregivers have in creating a positive environment within a collectivist familial structure.

Overall, in the south Asian context, culture has been shown to often have a direct influence on most of the caregiving functions for patients with dementia. There are strong norms and values which are usually shared from one generation to the next, advocating for the critical need to take care of family members unconditionally. The family was positioned at the heart of these cultural aspects, and it was an honour to care for relatives with adverse health conditions like dementia. The overall influence of the cultural norms and values was facilitating positivity among the caregivers and increasing their motivation to undertake the caregiving activities.

7.4 Impact of caregiving role on the caregivers: "It reached that point"

So far, the focus of the discussion has been about the positive aspects of caregiving. While caregivers in this study found that caring for a family member with dementia gave them a perceived sense of satisfaction and a greater meaning and purpose in the experience, interpretation of the data shows contrasting results that emphasise the adverse effects of caregiving. In this theme, I will discuss the different experiences of South Asian caregivers and the challenges that contribute to this negative impact. This finding mirrors the theoretical viewpoint of Lazarus and Folkman (1984). Their caregiver burden multidimensional phenomenon demonstrated a correlation between the attributes of a caregiver and the behavioural, functional, and cognitive impairment of the patient. According to Given et al. (2001) caregiver burden is a negative reaction to the impact of providing care on caregivers' social, occupational, and personal roles. The majority of caregivers in this study strongly believed and admitted that the caregiving experience gave them a sense of satisfaction and pride. At the same time the challenges associated with this could also be a burden because of the high levels of burnout and stress they experienced during their time of care.

There is strong evidence in the present study that family caregivers caring for their loved ones with dementia have experienced physical, emotional, and mental exhaustion that has had a negative impact on their quality of life. The results of this study have also shown a link between greater demand for care, and poor general well-being. Although these negative impacts do not appear to be associated with just South Asians specifically, other sub themes beneath this master theme do seem to lean towards findings within the general literature, indicating culturally and characteristically specific ideologies around South Asian caregiver burden.

It is evident in this thesis that the extent of psychological health issues was deemed to be more challenging than physical health issues. Consistent with previous studies (Pinquart & Sörensen, 2003; Lindeza, et al., 2020), it is suggested that caregiving for PWD is stressful and more demanding than caring for a person with a physical disability. Thus, most participants in this study voiced a high degree of frustration, fatigue, physical health issues, and psychological effects from their caregiving. This is mainly due to dealing with the conflicting emotions of watching PWD's gradual decline in cognitive and functional abilities. Dementia involves the disruption of the normal functioning of the brain. As there is no cure for this condition, the support PWD receive from their family members makes a significant difference to their quality of life (Zahed et al., 2019). This is because the family caregivers provide quick, personalised caregiving for the person with dementia in contrast to institutionalised care which requires more time and effort to secure resources and does not provide a service that caters for the needs of PWD as efficiently (Sagbakken et al., 2017). Additionally, family caregivers reduce the strain on the national economy's demand for caregiving due to the increasingly aging South Asian population. However, caregiving is a complex task and caregivers experience diverse challenges due to the additional responsibilities that are required to fulfil the caregiving tasks.

Jennings et al. (2019) emphasised that family caregivers of people with dementia are often called the invisible second patient due to the burden associated with caregiving such as depression, physically illness, poor social networks, and poor quality of life (Tatangelo et al., 2018). In such cases, measuring the extent of caregiver burden may be a poorly defined assumption and mostly tends to be inaccurate. This is true for participants in this study who expressed the presence of contrasting emotions as a caregiver of a family member with dementia. Although participants displayed a sense of care, satisfaction, and pride in their role as caregivers, they were overwhelmed by the increased amount of time involved in caring for the PWD. This resulted in detrimental emotional tiredness, mental stress and depression. For example, through the active use of a dissonant phrase "constantly in my head" by one of the caregivers, the emotional distress of the role is highlighted. This notion was further exemplified by another caregiver who claimed she had reached "that point" of frustration because she did not know "how to fix it" and another caregiver felt her life was a constant "roller coaster". To add to that turmoil, the spousal caregiver also felt depressed because she missed her husband. For every caregiver, this is one of the most painful struggles of dementia: slowly watching a loved one lose their sense of self.

These interpretations show the frustration of caregivers, due to their management of dementia care without sufficient knowledge or experience. However, on a deeper level, the caregiver’s statement, “how to fix it”, also suggests an undertone of helplessness: a sense of despair that they could not fulfil the filial role adequately. Again, in this instance caregivers felt unsupported and less equipped to manage the care while they were required to meet the multiple demands of life. Almost all caregivers in this study indicated that they did not know much about dementia care, and they did not receive any sort of guidance when their family member received a diagnosis of dementia.

7.4.1 Caregiving burden and cultural predictors

In the previous theme, the researcher discussed how cultural norms and values positively influenced caregiving experiences and why cultural values and norms are the underlying cause for the decision to provide caregiving. This cultural belief is beneficial for creating a lineage of care for the family member with dementia. However, such cultural justifications have shortcomings and come at the cost of caregiver distress and poorer quality of life. The findings in this study also shows that the intensity of caregiver burnout among South Asian caregivers is much higher because the nature of traditional caregiving ideologies is deeply rooted among the community compared to their white counterparts, as discussed in master theme three.

This is consistent with similar findings that were reported by earlier research studies conducted in the UK which highlight the cultural obligation among South Asians living in the UK (Adamson & Donovan, 2005; Godfrey & Townsend, 2008; Jutlla, 2011; Carers UK, 2011; Carers UK). They consider caregiving as natural and South Asian carers feel more culturally obliged to provide care for their own than white British carers. (Parveen & Oyebode, 2018; Hossain et al., 2020). In the South Asian community, it is traditionally considered as a strong cultural and religious duty to care for an ageing parent, particularly when affected by dementia, at home rather than seeking alternate care options such as external help for care or institutional care. Another common stereotype is that South Asians believe sending family members with dementia to a care home or day care center is 'unfilial' and brings guilt and shame upon the family (Livingston et al., 2017; Hossain et al., 2020). This level of moral obligation to care for 'their own' is strictly observed but judged negatively by the wider South Asian community, as highlighted by Parveen and Oyebode (2018) and Hossain et al. (2020) in their recent studies.

There is a plenty of research to support that those cultural norms are particularly prominent in South Asian communities, and they continue to remain strong in the migrant South Asian communities living in the UK (Godfrey & Townsend, 2001; Adamson & Donovan, 2005; Lawrence et al., 2008; Jutlla, 2010; Botsford et al., 2011; Sagbakken et al., 2017). This affiliation to cultural beliefs creates an added burden to the relatives for having to offer such care without sufficient knowledge and understanding of how to manage people with dementia. This inclination of culture in South Asians indicates how it can be challenging at times to perform duties that may be beyond one's ability and knowledge (Jennifer et al., 2014).

As pointed out by Katbamna et al. (2004) and later by Parveen and Oyebode (2018), a caregiver may be restricted by the obligations of family and culture to offer care and support and may not be doing it willingly. Most caregivers are of working age and are parents who are responsible for their young families. Having to take care of their elderly relatives and those with dementia is an added responsibility. Lack of preparedness was another factor that was expressed by all participants in this study. Therefore, the additional responsibility of taking care of a family member with dementia adds increased risks of caregiver burden and depression. There is also a high likelihood of not being effective in offering care to PWD where the relatives lack understanding of the required skills and knowledge (Parveen & Morrison, 2009). There is a psychological relationship when a family member who is taking care of a relative with dementia can feel love and importance which contributes to their well-being (Say, Sayegh, & Knight, 2011). This means that caregivers must be competent and prepared to provide all aspects of caregiving to improve the well-being and health of people with dementia.

The finding in this study is also consistent with the perceived stigma associated with placing responsibility for care on the oldest son and daughter-in-law (Jutlla, 2010; Adamson & Donovan, 2005; Godfrey & Townsend, 2001). Some participants in this study felt under pressure and claimed the caregiving responsibility had “kind of fallen on [them]” as the oldest son or daughter-in-law because of the cultural norms. Through the use of the active verb “fallen” by caregiver, a slightly forceful tone is created, highlighting the lack of choice and somewhat stifling obligation that is imposed upon on relatives by the South Asian community.

This interpretation contrasts with the previous themes in this thesis; instead of caregiving being perceived as a positive experience of love and reciprocity, it is manifested as an overwhelming pressure without freedom or choice. In a situation where a daughter had taken primary responsibility as a caregiver, this had sometimes led to conflict with their spouse due to the cultural stereotype expectation that care responsibility should be taken by the son and daughter-in-law. This may have led to additional pressures on participants, leading to emotional and mental stress on them and their family dynamics. Thus, this reinforces previous findings that it is a cultural obligation for sons to look after their parents. However, there are contrasting findings where we see a positive shift in these cultural norms of gender caregiving and change in responsibility, this will be discussed in sub theme 7.4.3.

7.4.2 Caregiving burden and caregiver characteristics

Disruption of brain function is not the sole reason for caregiving difficulties. The caregiver burden experienced by the participants in this study so far correlates with the multidimensional concept of the theoretical framework of caregiver burden (Given et al., 2001). The correlation between the intensity of caregiver burden and characteristics of the caregivers is extensively evidenced in empirical literature. Consistent with this concept and further building on it, the results of the study indicate that variables such as age, gender, and dyadic relationship can predispose caregivers to burden. This concept will now be expanded in more detail. The theme now goes on to discuss the notion of the relationship between caregiver burden and the degree of variation in the characteristics of caregivers included studies.

There has been ample exploration of the common family carer demographics, with sound evidence documenting the experiences of spousal and child caregivers; however, there is a lack of empirical studies into the experiences of South Asian grandchildren who have a grandparent with a diagnosis of dementia. A recent systematic review has been conducted in the UK by Ventors, and Jones (2021) to address this gap in the literature, by focusing on the experiences of grandchildren and great-grandchildren who provide care for their grandparent or great-grandparent with a diagnosis of dementia. The review included studies from France, Spain, and the USA. It summarised how dementia impacts on multiple members of the systems especially grandchildren ((Venters & Jones, 2021). The relationship between grandchildren and grandparents is often portrayed as unique and impactful because of the supportive roles that grandparents play during childhood (Weston & Qu, 2009; Venters & Jones, 2021). The result of this research study compliments the evidence from the review completed by Venters and Jones which identified and recommended the need for more research adopting qualitative designs to obtain comprehensive data regarding the experiences of grandchildren caring for a grandparent with dementia, as well as expanding further research to include participants from diverse ethnic and cultural backgrounds.

The grandchildren in the current study portrayed a strong sense of reciprocity, consistent with findings from Godfrey and Townsend (2001) who found reciprocity, love, and respect as the motivational factors for providing care to their family members with dementia. In addition to these positive factors, both granddaughters in this study portrayed a sense responsibility and duty of care towards their grandparents with dementia in support of previous themes of familism and reciprocity. On the other hand, both grandchild carers clearly signaled how caregiving limits their family and leisure activities. They also experienced a higher level of frustration, anger, and guilt due to their lack of experience in managing the care requirements of PWD.

Grandchildren may not be old enough to offer care to people with dementia. If culture obliges them to do so it could be complicating their lives and subjecting them to responsibilities beyond their abilities. One participant described that while caring for her grandmother she experienced moments of anger and frustration due to her relative’s unpredictable mood swings associated with her condition. Another grandchild caregiver repeatedly used the word “and” while reflecting on the overwhelming nature of caregiving. On closer inspection, the repetition of “and” also creates connotations of somewhat childlike fragility. Perhaps suggesting that the young caregivers' limited experience may result in feelings of hopelessness. This notion of helplessness is further exemplified through the phrase "don't know how to fix it". Both grandchild caregivers reported sleep disturbances, lack of time for studies, and financial difficulties due to their caregiving role.

Another new finding which triggers grandchild caregivers' burden is their difficulty managing their hierarchy status within the family. There is wider concern over the changes in the power dynamics within the family. In the typical familial setting in South Asia, older people are afforded an elevated level of respect and importance (Braun & Browne, 1998). As such, the grandchildren in this study had wider concerns over the changes in the power dynamics within the family. They were quite concerned about how dementia dramatically changes the grandparents' position in the family's hierarchy of power and how it contributed to their grandparents' behavioural changes and mood swings.

Mostly, the male person living with dementia still holds the status of head of the family and still may be the key decision maker in family affairs. A deterioration in cognitive function placed doubt in the minds of family members as to their ability to make sound decisions. Through the juxtaposition of being someone who is the head of the family, a phrase which usually has connotations of power and hierarchy status, but who forgets things creates a sense of weakness. It is emphasised that dementia can reduce the autonomy of PWD. As a grandchild, the caregiver is of a lower hierarchical status, and they respect their elders (Adamson & Donovan, 2005). However, due to PWD's cognitive impairment, there is a role transition in decisions making which can create cultural conflicts, causing added stress and increasing caregiving burden.

7.4.3 Caregiving burden and gender differences

The findings from this study indicate that the gender of a caregiver also has a major role in the caregiver's burden, further supporting the Sociocultural Stress and Coping Model of Lazarus and Folkman (1984). Two third of participants in this study were women caregivers. As discussed in theme two, dementia care in South Asia is predominantly informal and managed by family members, who are mostly women, within the home. This situation is mirrored in the UK within the South Asian community (Katbamna et al.,2004; Parveen et al., 2011; Jutlla, 2013). The burden of care falls predominantly on women, who are invariably daughters or daughters-in-law of the person with dementia. Drawing from the response of the six women caregivers interviewed, the findings were supportive of this evidence. The two daughters-in-laws interviewed in this study expressed a sense of obligation to take up caregiving responsibility for their in-law with dementia, due to traditional gender norms.

A recent systematic review conducted by Hossain et al. (2020) also revealed that women, particularly daughters and daughters-in-law, in South Asian households have multifaceted roles which are vital to ensuring familial well-being. The distinctive expectations to care for their husband as a wife, their young children as a mother, and, additionally, their parents-in-law as a daughter-in-law, places significant physical and emotional burden on them, particularly due to the feeling of guilt that caregivers experience when they cannot fulfill their other filial, social, and professional roles (Godfrey & Townsend, 2001; Jutlla, 2011; Lawrence et al., 2008; Qadir et al., 2013).

The present findings correlated with this review as both daughter-in-law participants echoed the notion that they wanted to fulfil their familial roles. One caregiver stated that their "time is balanced for everyone", highlighting her desire to care for all of her family to meet the obligation of women within a family. The use of the emotive phrase “taking care of family, it feels good from inside” it is emphasised that through helping others the caregiver felt a sense of happiness and fulfillment. This notion of happiness is further demonstrated through the caregiver explaining that “When I am looking after them, [my in-laws] are happy…when they are happy, my husband is happy and then we all are happy, full stop.” Through the continual repetition of “happy” it is emphasised that by looking after her in-laws this allows family happiness and unity. However, on a deeper level this phrase has undertones of obligation, conformity, sacrifice, and selflessness. Despite the continual mention of happiness, not once is there a mention of self-happiness, perhaps suggesting that this caregiver makes an endeavour to constantly please others at the expense of their own self. This self-sacrifice can lead to stress and depression, increasing the caregiver burden. This sense of dedication was further exemplified through the phrase “I have expectations with my kids too, you know”. By utilising the word “expectations” it is emphasised that as a woman there are multiple roles she must fulfil.

Both daughters-in-law interviewed in this study came to the UK after marriage, and expressed tensions between not being able to work, life pattern changes, and juggling their responsibilities; however, they did not signal any sign of feeling entrapped or isolated. They both, instead, talked about cultural expectations and the fact that caring for in-laws is a subjugation that they had been taught since childhood. This finding is contrast to the conclusions from Jutlla’s (2011) study theme of ‘being trapped and powerless’ due to being a caregiver. One daughter-in-law referred ‘taking care’ of her elderly mother-in-law as a ‘seva’. In Hinduism and Sikhism ‘seva’ is a selfless service champion towards the vulnerable and it is valued as a service to God, as cited by Trivedi and Lorenz (2021) in their recent study. The concept of seva is deeply rooted in South Asian culture as a religious responsibility, and the taking care of family members as a normative cultural expectation, the link between seva, family kinship, religion and caregiving was evident in this study. The daughter-in-law in this study positioned dementia care for the family member as a seva. This finding builds on the current understanding of traditional kinship ideologies among the South Asian in caregiving. In South Asian families, it is common for daughters-in-law to take on caregiving responsibilities to demonstrate cultural sensitivity, deep respect to elders at home and a sense of commitment. In the present study, caring for those in need is to be seen as a privilege and seva was described as an altruistic approach to caring. While this ideology provides a positive cause for caregiving, it also can challenge journey for daughter-in-law when it led to caregivers feeling guilt and shame for not carrying out their cultural duty.

At times, caregiving can seem like a cultural subjugation (Parveen, 2018). This understanding is consistent with one participant account in the present study. Another participant was a single mother and when she was expected to take care of a family member with dementia, this extended role become overwhelming and tiring. However, the caregiver is still willing to abide by the confinement of cultural beliefs and practices. The quality of life of such caregivers is likely to be affected negatively by having no time to invest in self-fulfilling activities that promote their well-being. Traditionally, the anxiety and depressive symptoms credited to the tribulations of life are undermined in the South Asian community, with these intense mental struggles being seen as a predictable and natural response. Therefore, at times when these symptoms are expressed by an individual, their condition is sometimes not viewed seriously. This understanding is consistent with the accounts of the participants in this study, with one of the daughter-in-law caregivers laughing when she talked about the episode of depression, she had recently experienced.

From her lighthearted and avoidant tone, it is emphasised that South Asian caregivers often overlook their own mental health and are reluctant to seek help from services, which may lead to conditions such as depression worsening, severely amplifying caregiver burden.

The results identified a degree of variation in traditional gender stereotypes in dementia caregiving. Contrasting to previous empirical studies that highlighted some South Asian men's belief that caregiving is a woman's familial role, it is worth noting that in the current study, both male caregivers expressed their willingness to carry out their duty of care and did not view caregiving as a task exclusively for women. During the interview, both male participants never explicitly mentioned a cultural obligation for their female relatives to carry out the role of care. Instead, the caregivers highlighted their gratitude for the support they received from their female relatives. This demonstrates a shift away from the usual aforementioned stereotypes of gender roles within the South Asian communities that participated in this study.

7.4.4 Caregiving burden and social isolation

In addition to the above challenges, South Asian caregivers chose to continue performing full caregiving duties due to the cultural obligation and more importantly the feeling of responsibility or concern for what could happen to person with dementia's care during their absence (Bowes & Wilkinson, 2003). These concerns may contribute to further challenges such as social isolation. The prevalence of social isolation and associated loneliness is another negative impact of caregiving indicated by caregivers in this study. This challenge is often faced by family caregivers of PWD and linked to increased stress, depression, and mental health problems (Courtin & Knapp, 2017). However, there are only a few studies that have examined social isolation and loneliness in caregivers of people with dementia, yet these studies do not particularly explore these symptoms in South Asian communities, thus highlighting the dire need for exploration into the impacts this demographic faces.

It is estimated in a survey conducted by Carers UK (2015) that at least eight out of 10 caregivers have felt lonely or socially isolated due to their caregiving situation. This need for additional studies into ethnic minority demographics was further emphasised by a study conducted by Victor et al. (2021) which stressed that there are noticeable ethnic differences that impact the quality of family caregivers' psychological health, support systems, and service provisions (Pinquart & Sörensen, 2005). This has been highlighted in the UK government loneliness strategy which identifies the demographic of caregivers who are susceptible to loneliness, especially ethnic minority carers (DCMS, 2018).

The findings from this study support this theme; almost all caregivers felt they were limited from socially engaging due to the nature of caregiving demands (Sanders et al., 2008; Wawrziczny et al., 2011). Caregivers have to balance their time to meet multiple life requirements in addition to their role of care; therefore, they may compromise previous habits and lifestyles. There is limited evidence from other research suggesting that due to the nature of the family care system among South Asian carers they need to spend more time on caregiving aspects; therefore, they have less time to spend on their own well-being. This can trigger burn out and they are much more likely to experience increased levels of depression, anxiety, and burden than their white British counterparts (Parveen & Oyebode, 2018). One caregiver in this study stated "my time is balanced for everyone" and the "pattern of our life has completely changed". By using the phrase "balance for everyone", the time and dedication required for caregiving is highlighted. By stressing "the pattern of our life has completely changed", the change from previous habits and lifestyles is evidenced. Additionally, this phrase emphasises that many caregivers have other responsibilities such as parenting and employment, which also require the caregiver's time and attention, further adding to the caregivers' burden. On a deeper level, this participant conveyed a profound sense of disappointment as she was left with no time for herself highlighting that due to the demands of caregiving and other responsibilities, it can be exceedingly difficult for caregivers to dedicate time for leisure and social networking. This lack of time for oneself thus contributes to decreased well-being.

Another caregiver in this study felt her life was a constant "roller coaster". Through the use of this metaphor with its connotations of adrenaline and unpredictability, it is emphasised that caregiving is a constant and taxing role which affects the caregiver emotionally, mentally, and physically. When asked about a typical day, caregivers described that their daily life depended on the person with dementia's day, due to the mood swings associated with the condition. However, regardless of these challenges, many caregivers continue to perform their full caregiving duties instead of seeking support due to the guilt of not fulfilling their filial responsibility for the person with dementia. This feeling of burden could further contribute to the stress associated with social isolation. Nearly two thirds of caregivers in this study indicated that they had had an episode of depression after they started as a caregiver. The unexpected additional workload as a caregiver, social isolation, and the lack of support contributed to their depression. Although the Care Act (2014) recognize the role of carers and emphasis the importance of assessing and supporting their needs, the above findings give us an indication that the Care Act 2014 has not had a significant impact on South Asian dementia caregivers in the UK.

7.5 “Tell us what it is and what the best way is to deal with it”

7.5.1 Increasing awareness

Lack of preparedness for a caregiving role was identified as one of the strongest causes of caregiver burden in this study. Participants reported that mainly the lack of knowledge about dementia left them unprepared and finding it difficult to deal with the condition. All caregivers in this study reflected that the PWD presented with some symptoms of dementia in the early stages; however, family members failed to notice or recognise these symptoms due to poor awareness about the condition. By the time most PWD were referred to a GP or memory assessment clinic, the condition had progressed to moderate to severe dementia, which significantly affected their activities of daily living. On reflection, caregivers emphasised that if they had initially had the awareness they have gained through caregiving, they would have been able to identify symptoms of the condition in the early stages instead of allowing the condition to progress.

Caregivers in a number of studies consistently expressed the delay in seeking a diagnosis was because they lacked information about dementia and believed these symptoms were signs of normal ageing (Becqué et al., 2019; Shim et al., 2021). Furthermore, caregivers in this study echoed the recurring notion that there is a lack of understanding about dementia. This challenge has been raised by several studies in the past decade including the first Manchester study conducted by Purandare et al. (2007). The present study hoped to see a change in this trend and a positive shift in South Asian awareness about dementia. Instead, what was found in this study, as with previous findings, was that there is still a great need to promote awareness of dementia in the South Asian community. Participants described it as a challenge for the family as they had never seen or had to take care of anyone with dementia before, hence they struggled to cope with the complexities of the condition.

Lack of knowledge of the condition meant they could not provide any tailored care that was needed for this cognitive state. This hesitance and tentativeness indicated that the family were not provided with post-diagnostic support, instead being left to cope unaided. Another participant recollected that they continued to support the family member in the same way they had previously supported them prior to the dementia diagnosis, instead of delving into the nuances of the condition. They claimed that a family can only manage symptoms if they have an understanding and knowledge about this medical condition. The present thesis elucidates the potential importance of raising awareness about dementia as it can lead to early recognition of dementia symptoms, so PWD and caregivers can receive timely services such as symptomatic treatment of dementia and post-diagnostic support for the family (Blackmore et al., 2018). Another account echoed that early recognition would also help the caregiver to understand the condition and have better strategies for coping with care (Becqué et al., 2019). This is further compounded by an inability to successfully navigate the system with language barriers being cited as a major obstacle to accessing relevant information (Giebel et al., 2016).

7.5.2 Inadequacy in the healthcare system

As well as a lack of knowledge about dementia, the present study also highlights the potential importance of recognising shifts in caregivers' willingness to seek support. Despite the traditional means of support coming from the extended family in the South Asian community, most caregivers in this study expressed their willingness to manage the needs of elders. However, there are limitations to this; this is significantly managed within the psychosocial care of PWD (Herat-Gunaratne et al., 2020). The service providers need to appreciate the responsibility that families are taking on to manage PWD. In addition, as posited by Herat-Gunaratne et al. (2020) the service providers also need to acquaint themselves with the psychosocial needs of PWD who need care. With this knowledge, they will be better positioned to support PWD appropriately.

The findings of this study align with the results reported by Parveen and Oyebode (2018a), indicating that the majority of second-generation South Asian caregivers in this study expressed a willingness and need for external assistance and support. This shift in mindset can be attributed to their acculturation to Western values. The participants in this study specifically mentioned their intention to seek help from professional caregivers, signifying a significant change in the thought processes of South Asian carers.

Furthermore, the study revealed that despite the reduced stigma associated with caregiving to elderly family members due to modernisation, many participants faced numerous challenges. These challenges were primarily attributed to the lack of culturally sensitive services that could adequately address their cultural and religious requirements. Several participants expressed dissatisfaction with the healthcare system, highlighting its inadequacy in meeting their specific needs.

Since the implementation of the National Dementia Strategy (2009) specialist services have been tailored to meet the needs of people with dementia. However, these services are generic and cannot meet the needs of the UK’s diverse population; therefore, services should be created to meet the specific requirements of the South Asian community. All participants in this study highlighted an evident lack of contact with psychosocial support services and reported a whole array of negative experiences of service support, including concerns of basic needs not being met. One caregiver explained that after her family member was given a diagnosis of dementia, she did not receive post-diagnostic support such as a caregiver assessment, caregiver training, assistance in completing carers' allowance forms, or information in their South Asian language. Furthermore, when they attempted to find resources detailing dementia, they were not readily available. Reflecting on this experience, the caregiver compared the difference between obtaining information and support for a terminal illness to the amount of information that was readily available about dementia and its care, which fell short of expectations.

All the caregivers interviewed in the sample care for their relative with dementia at home. Participants highlighted that they expected service providers to advise and support the family appropriately based on their individual needs, because the extent of impact can be varied between individuals and families from different communities. These statements emphasised the growing need to create more tailored services to meet the needs of the UK's culturally and ethnically diverse population ((Vertovec, 2007), as cited by Hussain et al., 2020). Services often lacked cultural awareness, an interest in delivering culturally aware services, and diversity to interact with different cultural communities (Vydelingum, 2006; Alexis and Vydelingum, 2005). Those services that did cater to the needs of minority patients were often geographically widely dispersed with long waiting lists, resulting in poor accessibility for carers and patient.

On being questioned about their dementia services experience, one participant reported that in their case culture was “never” ever brought into their care needs. Through the repetition of the adverb “never”, the caregiver spotlighted the lack of satisfaction with the healthcare services they received, making it important for service providers not to assume healthcare services are not required. The real need of culturally tailored services when considering care is an issue that must be considered here, but also in future research and practice in this area. Several participants shared their experience of when their relative with dementia was hospitalised, which highlighted the crucial shortcomings of healthcare services. One caregiver pointed out that the healthcare professionals had assumptions that his family member with dementia did not speak English when he had difficulties in communicating; the communication difficulty was in fact due to his hearing issues not because of his English. Another participant was shocked when their exclusively vegetarian relative was served with a non-vegetarian meal. These instances of individual assessment were examples of a lack of ability to understand the cultural preferences of the diverse South Asian population and inadequate flexibility to meet their needs at an expected level of quality. This could be due to a lack of understanding from the healthcare professionals with regards to cultural differences or unconscious bias, which was not only an inconvenience and indignity to the patients but also detrimental for the actual cultural requirements of South Asian PWD.

Instead of making assumptions about patients, it is essential that healthcare professionals have a clear understanding about PWD’s personal needs and their comorbidity issues when planning care. Consequently, this indicates the serious need for more training of health professionals to develop better understanding of South Asian cultural or religious practices (Kenning et al., 2017). Additionally, there should be greater attempts to achieve ethnic diversity in the workforce by employing more culturally and linguistically competent staff from South Asian ethnic backgrounds (Hussain et al., 2020). Care services are not tailored to meeting the caregivers’ specific needs. It is important to reiterate that according to Donnellan et al. (2017) in the Asian community elderly people in the UK are highly dependent on their older children for caregiving. However, this is common practice regardless of whether the relative has any health needs or not.

7.5.3 *Culturally tailored support and expectations*

With regards to cultural differences in gendered needs, one of the spousal caregivers expressed disdain at seeing a male support worker assigned to care for his wife which contradicts some South Asians' cultural expectation of being cared for by the same gender. This raises a serious question about the provision of care agencies in the development and provision of services to contribute to the satisfaction of a user (Donthu & Yoo, 1998). Another participant's account expressed their frustration about not only the cost but also the practicality of paid home care provision. The carers came at a fixed time that was not when the person with dementia needed the service. Moreover, carers only visit for a short period of time to ensure medication adherence or to get a person in and out of bed for example, with little time for interaction. Moreover, it is rarely the same paid carer who visits the home, so it can be difficult for the care recipient to build a rapport with the carers or for them to support or reassure a person with dementia who has memory issues. The carer sounded frustrated when talking about the gender consideration, cost, and practicality of the care worker service provision.

The findings in this study clearly show that the impact of The Equality Act on South Asian PWD in the UK has been limited. When asked about the reason for not considering a care home as an option, one of the caregivers highlighted a very significant reason for his decision. There are no nursing homes that offer culturally specific services for South Asians in Greater Manchester. That means if the family move their relative to a British nursing home, they will have to live in a culturally insensitive environment. This would be a difficult experience for PWD as they rely on familiarity, reminiscence, and routine as a reassuring and constant factor. This again draws attention to the need for culturally sensitive services specific to South Asian communities and the significant barriers they face when accessing support despite the introduction of The Equality Act (2010).

While there are some services that cater for South Asian elders, these services do not have the facilities to address the specific needs of PWD. One participant raised concerns that while an Indian well-being centre group in Manchester created a positive impact for some South Asian elders, it does not have the resources or expertise to adequately support PWD due to lack of funding from social support services. The caregiver expressed that there were risks for the safety of PWD due to the lack of risk assessment and careful consideration into the physical and psychological aspects of dementia. This is probably due to the lack of training and funding from local service providers to understand the condition, in other findings it was found that there was no gender tailored support for the elderly in the Asian community living in the UK (Raleigh V, Holmes J., 2021).

In most instances, the study found that women have always been the predominant providers in most informal sectors throughout the world for families with elderly adults and those with mental illness (Cheston & Bender, 2019). As a result of societal views and how some societal structures have been laid out, women are expected to take care of the elderly. It should be structured and even tailored so that male and female older people feel its benefit and be comfortable with it (Xue and McMunn, 2021). A study conducted by Sharma et al. (2016) found that women experience greater psychological stress and also strains when providing care. Therefore, they should be given much attention and guidance when it comes to caregiving routines (Bieber et al., 2018, pp, 532). This will enable them to adequately carry out their caregiving work without succumbing to the strains that they experience.

Knowing these symptoms and how to eradicate them at the outset goes a long way. Family caregiving is always vital since family members are always seen as the silent and second invisible doctors. Botsford and Dening (2015) posited that family caregiving has its positive impacts, which have always been outweighed by negative impacts such as a higher rate of burden and even psychological morbidity to the elders they are taking care of. They often get exposed to illness too, regardless of whether they are the caregivers. It is crucial for family caregivers to be given prior knowledge identify and understand some of the common diseases that occur to the elders they are taking care of (Botsford and Dening, 2015). This will greatly help them to take better care of their elders. Moreover, as raised by Botsford and Dening (2015), conducting psychological interventions for family caregivers is another key critical intervention that should be investigated. Families should be well acquainted with anything that could happen during caregiving.

In some respects, as the caregiver tries to take care of the person with dementia, they may develop comorbidities which the caregivers have less knowledge of. In any instance that the caregiving had been well-tailored to fit well in what it is intended, there could not have been any occurrence of any other disease. Caregiving should always be connected to its central role of ensuring that the receiver gets the necessary comfort they need. As posited by Becqué et al. (2019) in an instance where support is not well-tailored to the receiver, there will be difficulties for the caregiver and even the elders who are receiving the caregiving services. This may also result in damage such as that seen or experienced by the elders in Asia (Becqué et al., 2019).

In contrast to most experiences with health and social services and sessions, one Indian participant, Pooja, emphasised the immensely positive impact a culturally tailored services had on both her and her husband. By finding activities that Pooja's husband could connect with enabled him to regain some aspects of independence and sense of self, reciting ‘Kavitas’ (poems) and enjoying ‘Bhajans’ (Hindu religious songs). Additionally, by finding culturally tailored services, Pooja has had more time for leisure activities. She recounted that after finding these sessions she had more time to invest in activities she enjoyed such as Aqua and the gym, highlighting how appropriate services have a significant positive affect on both the caregiver and PWD’s overall well-being. These support systems can significantly alleviate caregiver burden.

7.5.4 Conclusion

The results of this research study focused on the experience of caregivers from the South Asian community in the Greater Manchester area, offering support to the family members affected by dementia. Through the exploration of five master themes, the discussion chapter aimed to highlight the inner workings of how the caregivers of PWD feel about caring for a family member, as well as what might be interpreted about their motives and challenge in caregiving. This chapter investigated further the specific meaning of the identified concepts and other experiences shared by the participants, making links between theoretical frameworks, empirical studies, and this study’s findings. Next, the concluding chapter summarises the overall findings of the study and provides vital recommendations and implication for practice.

Chapter 8. Conclusion to the Thesis

The final chapter concludes the key findings of this thesis and sets out the potential implications for future practice. This chapter outlines how this study can contribute to existing knowledge and provides suggestions on how to effectively support South Asian caregivers to reduce their care burden and thus improve their quality of life. Furthermore, this chapter discusses the strengths and limitations of this qualitative study, making recommendations for future practice and potential research.

8.1 Summary of the key findings and dissemination

This research has sought a deeper understanding of how South Asian caregivers experience supporting a family member with dementia. In this study, an IPA methodological approach was used, and findings concluded that South Asian caregivers experienced both positive and negative dimensions of caregiving. The study findings emphasised the multidimensional effects of reciprocity, expressing deep feelings of affection, gratitude, and appreciation which altogether provided the caregivers with a resounding rationale for their caregiving role. The study integrates the findings of empirical studies and contributes to the understanding on how reciprocal support in families affects the outcomes of caregiving for dementia.

This study provides a comprehensive exploration of the various factors influencing caregiver burden within the South Asian community. The results provide valuable insights into how South Asian culture has both positive and negative impacts on dementia care experiences; however, it is evident that these experiences are not associated with South Asians alone. The factors underlying this topic do lean towards findings within the general literature, indicating culturally and characteristically specific ideologies around South Asian caregiver burden. Due to the projected population growth of the visible, but underserved South Asian group in the UK, it is expected that there will be a greater demand for family caregivers for relatives with dementia compared to their white counterparts. The high degree of familism and cultural influence on caregiving embedded in the South Asian community precludes the caregivers from questioning their role and seeking support. The level of support, extent of isolation, and degree of stress can be critical in sustaining the health and well-being of caregivers. Participants in this study shared their negative experience of service support, with a whole array of challenges and barriers. This served to highlight an evident lack of support services tailored to meet the specific needs of South Asians in the UK. This study gives an insight about preparedness for the caregiving role and expected service provision by South Asian caregivers.

Through the understanding of experience, this study has bridged the gap in knowledge, presenting new findings with the support of theoretical frameworks to interpret the data, and deepening understanding about how caregivers from distinct cultural backgrounds in the Greater Manchester area are differentially affected by dementia caregiving. There is strong evidence in the present study that family caregivers caring for their loved ones with dementia have experienced physical, emotional, and mental exhaustion that has had a negative impact on their quality of life. While this research study strongly supports the existing knowledge of understanding and current demands of dementia caregiving highlighted by South Asians, it facilitates a powerful systemic understanding of how caregivers from distinct cultural backgrounds are differentially affected by caregiving challenges and how the positive aspects of caregiving can be beneficial for reducing the burden of dementia caregivers thus improve their well-being. This study compliments the review completed by Venters and Jones (2021) which identified and recommended the need for more research, adopting qualitative designs to help and obtain comprehensive data regarding the caregiving experiences of grandchildren and expanding research to include participants from different ethnic and cultural backgrounds.

8.2 Implication for practice and recommendations

Findings from my study indicate that a lack of awareness about dementia is still an ongoing problem among South Asians in Greater Manchester. Lack of awareness affect South Asian PWDs and their caregivers' ability to assert their rights and benefit from the provision of The Equality Act 2010. Diagnosis was significantly delayed in all cases in this study; by the time families received a diagnosis, the PWD appear to have progressed from moderate to severe dementia. This affects the prognosis of dementia, thus significantly aggravating the caregiver burden – both issues could have been alleviated if a timely diagnosis had been given. All caregivers in this study, except one participant, highlighted a lack of preparedness and confidence to carry out caregiving responsibilities and emphasised that they did not know much about dementia care at the time of diagnosis; however, they did not receive any of the widely available services to aid in dementia care. Therefore, there is an urgent need for great improvements in the quality and accessibility of dementia awareness and service provisions to meet the unique needs of the South Asian demographic in the Greater Manchester region. This thesis highlights the potential importance of raising awareness about dementia among South Asians that could lead to early recognition of dementia symptoms so PWD and caregivers can receive timely symptomatic and person-centred treatment and post-diagnostic support for the family, especially the caregiver.

The first step is to increase the general awareness of dementia within the South Asian community through community engagement in the form of displaying awareness raising material and empirical data in local community-led organisations. These provisions will enable families to notice early symptoms of dementia and seek a timely diagnosis, as well as providing a foundation for dementia care.

It was evident from the study that the current provision for post-diagnostic support does not successfully access South Asian caregivers. This may be a two-way problem: one being the previously mentioned lack of awareness but also, a combination of unconscious bias from health care professionals who may assume that all South Asian have strong family networks for care and support. While this service is widely available, it is striking to note that in this study, only one participant received post-diagnostic support, despite the fact that they all reiterated that they did not have prior experience of dementia care, and they did n0t know “how to fix it”. It is therefore essential to improve community accessibility and awareness of service provisions to improve the experience of caregivers.

Another challenge that caregiver faced was the cost of care of dementia caregiving as discussed in Chapter 7. However, most caregivers in this study were unaware of the government benefits available to them as a caregiver or did not receive these services in a timely manner. Some caregivers were instead self-financing the cost of care for their relative; however, of these caregivers, the majority found paid service provision to be incredibly generic and not tailored to meet the specific cultural needs of South Asians, greatly increasing the possibility of frustration and strain. Two examples of this were the cultural expectation of a same-gender caregiver for personal care, and consideration of religious practices such as prayer times.

Participants emphasised an acute need for cultural consideration when offering services. This struggle seemed to be the resounding rhetoric of all participants, stretching across multiple situations. In order to improve the quality of dementia care for South Asians, from the point of diagnosis itself, there is a need for provision to overcome linguistic barriers by providing translation services during assessments and improving the availability of caregiving resources in the patient and caregivers first language, ideally providing these services in easily accessed places by the South Asian community, such as places of worship and community centres. There must be significant work to dispel the stigma of dementia to challenge this inequality. Alzheimer's Society calls for increased awareness, better focus on preventative services, local community action and improved access to services for people from BAME communities (Alzheimer's society Dementia UK, 2014).

Another recommendation that interviewees in this study heavily stressed was the need for person centred care services during the later stages of dementia. This aligns with The Care Act (2014) emphasis on promoting the well-being and individual needs of those receiving care. In the South Asian community there is stigma attached to care homes due to the deeply ingrained cultural notion of duty of care. Therefore, there is very little interaction between the Asian community and these services. However, despite the increasing adaption of individualism in the family structure, for South Asian carers of people in the later stages of dementia, in which more suitable care is usually provided in care homes, there is a strong sense of resistance against the use of them due to the cultural disparities that limit the quality of care. All participants reiterated a sense of dissatisfaction with care facilities as they did not take into account the cultural needs of the person with dementia. Despite Manchester's aging South Asian population increasing there is no respite care or care home in Manchester that caters to the unique needs of South Asians. Therefore, a beneficial implication would be to harness and adapt the construction of these services to create a culturally sensitive care structure for people with dementia locally, regionally, and nationally. An efficient, economic way to do this could be harnessing the existing workforce of healthcare professionals from the South Asian diaspora, as these professions have both medical and cultural understanding of the needs of South Asian people with dementia, therefore significantly improving quality.

Cultural sensitivity can be achieved through the exploration of multiple means such as music, dance, art, food, language, and religious practices. In this study, participants emphasised their desire for healthcare providers and policy makers to have a deeper understanding of South Asian cultural practices, particularly spiritual ones, before engaging with PWD and their families. One example is the adaptation of the memory café in places of worship and community centres, to include Bhajans, prayers, and Bollywood songs as a form of musical reminiscence. A memory I is a wonderfully welcoming place for individuals with Alzheimer's Disease or any other form of dementia, or other brain disorders.

I discussed migration struggles in Chapter 1, many South Asian elders affected by dementia migrated to the UK after partition so their memories are mostly connected to their roots, and they cannot relate to the general reminiscences in memory cafés. Therefore, another important practical implication is to adapt currently accessed places to include reminiscence that can stimulate PWD's memory.

The best way to address all of the above challenges and successfully integrate these recommendations, in line with The Care Act,2014 is to adapt the current one-size-fits-all model, by modifying toolkits for South Asians as in other geographical areas in the UK, tailoring them to Greater Manchester's unique requirements. The Care Act, 2014 promotes multi-agency collaboration and joint working between different agencies to ensure holistic support for individual.

As expressed by a participant, even if you see and hear about the challenging side of dementia, when it comes to your own experience it is different and difficult. In this sense, it is imperative that family caregivers of PWD who experience dementia care share their experience first-hand and give others access to information about the condition.

Additionally, family caregivers provide quick personalised caregiving for PWD in contrast to institutionalised care which requires more time and effort regarding resources and in addition, it does not provide a service that caters for the needs of PWD as efficiently. Training programmes that teach caregivers efficient coping strategies are needed in order to increase their use of effective and healthy coping strategies. Furthermore, psychosocial support should be provided by governmental and non-governmental organisations to reduce the care burden on caregivers of PWD.

8.3 Contribution to knowledge and implication for future research

Although we have a few decades of evidence about caregiver burden, there is little research about the specific experience of caregivers of PWD in the South Asian community and this is clearly in its infancy stage. This study contributes to the original research in psychology, medicine, and nursing with important and useful knowledge. While this research study strongly supports the existing knowledge of understanding and current demands of dementia caregiving highlighted by South Asians, considerably more research will need to be done to expand our understanding about the magnitude of this phenomenon.

The drive for this research mainly comes from my anecdotal experience as a dementia researcher from a South Asian background which was underpinned by current policy recommendations in the UK. This study supports the recommendations of Jutlla (2013) and the All-Party Parliamentary Group (2013) that further research should be carried out on the experiences of carers of PWD from BME communities to provide a better understanding of their support needs. This study has provided an in-depth insight into South Asians in the Greater Manchester region; it would be beneficial to carry out further qualitative research to examine the experience of caring in a range of geographical locations across the UK to assess if there are any similarities or differences in carer experiences, attitudes, and needs.

This research has thrown up many questions in need of further investigation regarding underrepresented caregiver demographics such as South Asian male caregivers and grandchildren who have a significant caregiving role. Future research in this area should address a gap in the literature in terms of capturing the experiences, attitudes, and needs of these group.

The findings of my research examined the impact of demographic variables, such as age, generation, geographic location, and socioeconomic status, on caregivers' experiences. While my research closely aligns with the work of Dr Sahdia Parveen and colleagues (2013, 2013, 2017 and 2018) it offers a more comprehensive insight into the similarities and differences in the experiences, attitudes, and needs of South Asians residing in the Greater Manchester region. These differences highlight the necessity for continued research and the significance of considering contextual factors in future studies.

Parveen et al. work (2013, 2013, 2017 and 2018) primarily corresponds to the familism spectrum of Knight and Sayegh's (2010) revised sociocultural model, which focuses on the perspectives of second-generation South Asian caregivers. In my study, I not only support these findings but also delve deeper into the experiences of third-generation caregivers and male caregivers.

While Parveen et al. (2013, 2013, 2017 and 2018) research emphasises the significant influence of religious values as a driving force behind caregiving, my study reveals that religion was not frequently cited as a motivating factor among the caregivers interviewed. Instead, it was noteworthy to observe that many caregivers in this study chose to take on the caregiving role out of inherent love and reciprocity, transcending religious constructs.

According to Dhar (2011a), “Culture plays a crucial role in immigrant and ethnic societies. Culture defines the identity of the transnational caregiver”. It is important to achieve a more meaningful understanding of how culture informs the experience of dementia care in this world where globalisation is leading to fast paced migration across borders.

Knight and Sayegh’s (2010) study explored the correlation between culture and caregiver burden. They argued that there is an urgent need to deepen our understanding of culturally diverse caregiving and, therefore, strongly recommended the testing of their current conceptual framework and the conception of new framework for specific ethnic minority communities. Although this study could not endeavour to test this framework, the findings of this study aligned with the principles of Knight and Sayegh’s (2010), Sociocultural Stress and Coping for Caregivers Model. However, there are a few intricacies to South Asian culture which would be beneficial to take note of when considering cultural burden. Therefore, it is highly recommended that a new cultural framework be developed, using this study’s findings, to specifically delve into the role of South Asian culture on caregiver burden.

It is evident in this study that caregivers burden is multidimensional; however, in order to understand the magnitude and impact of being a caregiver, there has been a move towards developing carer assessment scales (Mareca et al. 1993; Gort et al., 2007). Unfortunately, no scales to date have been developed to exclusively address the unique socio-demographic aspects of caregivers from the South Asian community in the UK. This has the potential risk of inadequately estimating the impact of being a dementia caregiver, leading to a dearth of appropriate service provision and support. Thus, to address this urgent need, a caregiver burden assessment tool that is suitable for use in the context of South Asian culture is needed; therefore, future studies should aim to quantify the experience of dementia caregivers by creating a comprehensive scale to measure caregiver burden.

8.4 Strengths and limitations of the study

Although this study offers a unique insight into the South Asian caregivers' experience of caring for a family member with dementia, there are strengths and limitations for this thesis. When the idea of this research first developed, little was known about how South Asian caregivers in the Greater Manchester geographical area perceived caring for a family member with dementia. This is the first study to specifically explore the experiences of South Asian caregivers of dementia in Greater Manchester and it provides a comprehensive understanding about the impact on caregivers within this community. The key strength of this study is embracing the various aspects of IPA where an in-depth, nuanced, idiographic analysis was carried out to get a deeper level of understanding on the real-life experiences of South Asian caregivers of PWD.

Another strength is the diversity of recruitment strategies adopted in this study, which enabled me to recruit a diverse sample from a hard-to-reach group in the UK through collaboration with local South Asian community groups. My previous experience in conducting semi-structured interviews on PWD and their caregivers, my linguistic competency, knowledge, and awareness of culture was key to collecting such rich data.

This study adopted a small, purposive, homogeneous sample and the participants came from a wide age range that gave the study the advantage of capturing the experiences of family caregivers from different generations. It should be noted as a potential limitation that this study relies on a small sample. Although the number of participants in this study is small, the diversity of caregivers in this sample extends knowledge beyond the experience of dementia and other specific care types. The demographics of the interview participants was diverse as they were migrants from India and Pakistan or second-generation South Asians with different religious backgrounds (Hindu, Sikh, and Muslim) and genders (male/female/they). Demographics and diversity in the recruitment of participants are strengths of this study that have allowed me to capture distinct aspects of their experiences. However, the heterogeneity of the sample also made it difficult to fully examine how characteristics such as gender, socioeconomic status, and age might influence the individual's experience. It does not include all the demographics of the South Asian community in the UK due to the variation in mass migration. Although heterogeneity is difficult, given the lack of research with people with dementia in the South Asian community, this study is an essential first step in building the knowledge base in this area.

Having employed recommendations from previous studies to assess the experience of South Asian caregivers in a specific location, this study helps to assess the similarities and differences in carer experiences and their needs depending on their geographic location, and this is a strength of the study. The available results are only from one geographical region; therefore, generalisation is not effective for understanding the situation for the entire population of South Asians regarding caring for a family member with dementia. However, the study findings provide a distinctive overview of the subject issue and may be able to provide some underlying knowledge applicable to other minority communities in the UK. The caregivers exhibit positive attitudes towards the concept of caring for people with dementia. In this case, caregivers' perceptions of dementia are crucial and significantly dictate the undertaking's outcomes. Most caregivers recognise caregiving as a positive experience in which they find satisfaction and enjoyment when undertaking the role. They feel that they should take care of people with dementia to reciprocate good deeds done to them. Additionally, there is an overall conclusion that the family is an integral unit when offering care and significantly dictates the entire process's outcomes. Caregiving is portrayed as a sensitive undertaking and that caregivers should assume the main responsibilities as it facilitates their lives and positively impacts people's lives.

The in-depth interviewing technique adopted in this study and my previous experience in interviewing patients with dementia and their family members added strength, idiographic depth, and a deeper and more nuanced exploration of caregivers' experiences. In addition to my experience in dementia research and interviewing patients with dementia and their family, my ethnic background (South Asian Indian) has been helpful to progress the interviews with the participants. Many participants expressed their gratitude towards me for the opportunity to speak openly about their experiences, and they believed that the research about caregivers of patients with dementia focusing on their communities might help develop support systems for them in the future.

It is evident in this study that caregiver burden is multidimensional; however, in order to understand the magnitude and impact of being a caregiver, there has been a move towards developing carer assessment scales (Gort et al., 2007). Unfortunately, no scales to date have been developed to exclusively address the unique socio-demographic aspects of caregivers from the South Asian community in the UK. This has the potential risk of inadequately estimating the impact of being a dementia caregiver, leading to a dearth of appropriate service provision and support. Thus, to address this urgent need, a caregiver assessment tool that is suitable for use in the context of South Asian culture is needed; therefore, future studies should aim to quantify the experience of dementia caregivers by creating a comprehensive scale to measure caregiver burden.

8.5 Concluding remarks

This study explored South Asian caregivers' experience of caring for a family member with dementia in the Greater Manchester area. From the multidimensional effects of reciprocity, expressing deep feelings of affection, gratitude, and appreciation that highlighted the positive impacts of caregiving in conjunction with the evident turmoil of cultural incompetency, familial interpersonal loss, and the immense degree of physical, social, and emotional burden, the intricate, complex, and ambivalent innerworkings of dementia caregiving in South Asian communities is truly epitomised. This, showcases the urgent need to overturn the one-size-fits-all model to instead carefully take into consideration the multifaceted identities of people with dementia and their caregivers, enabling the provision of effective, high quality, and suitable care for all.

References

Adamson, J., & Donovan, J. (2005). Normal disruption: South Asian and African/Caribbean relatives caring for an older family member in the UK. *Social Science & Medicine,* 60, 37–48.

Alderwick H, Dixon J. *The NHS long term plan BMJ 2019; 364 :l84 doi:10.1136/bmj.l84*

Alexis, O & Vydelingum, V. (2005). Overseas black and minority ethnic nurses: *a systematic review. Nurse researcher. 12. 42-56. 10.7748/nr2005.04.12.4.42.c5958.*

All Party Parliamentary Group on Dementia (2013) Dementia Does Not Discriminate. The Experience of Black Asian and Minority Ethnic Communities. Alzheimer's Society, London.

All Party Parliamentary Group on Dementia (2021) Dementia Report. The Experience of Black Asian and Minority Ethnic Communities. *Alzheimer's Society, London*.

Alzheimer's Association. Alzheimer's disease facts and figures. Special report — *alzheimer's detection in the primary care setting: Connecting patients and physicians 2019.*

Alzheimer's disease facts and figures (2020). *Alzheimer's Dementia.*, 16: 391-460. https://doi.org/10.1002/alz.12068

Alzheimer's Disease International. The prevalence of dementia worldwide. http://www.alz.co.uk/adi/pdf/prevalence.pdf. Accessed November 25, 2010.

Alzheimer's Society (2014) Dementia 2014: opportunity for change. Available at: *http://www.alzheimers.org.uk/site/ scripts/download_info.php?fileID=2317 (accessed on January 2015).*

Alzheimer Society (2016) Number of people with dementia in minority ethnic groups could rise seven-fold by 2051 and yet awareness and support is lacking. *Accessed on 2ndMay2016 http://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=1659*

Alzheimer's Society (2020). Alzheimer's Society view on demography. *Available at: https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/demography#:~:text=Research%20conducted%20shows%20that%2C%20in,the%20current%20 rate%20of%20prevalence [Last accessed on 26-Jan-2022]*

Alzheimer Scotland. Facing dementia together—post-diagnostic support pilot. http://www.dementia.stir.ac.uk/pdffolder/LDP-CollaborationWithAlzScot.pdf. Accessed November 26, 2010.

American Academy of Neurology. Diagnosis of Dementia, Guideline Detail, *American Academy of Neurology*. (2001). Available online at: https://www.aan.com/Guidelines/home/GuidelineDetail/42 (accessed July 12, 2018).

Andrés Losada, María Márquez-González, Carlos Vara-García, Samara Barrera-Caballero, Isabel Cabrera, Laura Gallego-Alberto, Ricardo Olmos & Rosa Romero-Moreno (2020) Measuring familism in dementia family caregivers: the revised familism scale, *Aging & Mental Health, 24:5, 784-788, DOI: 10.1080/13607863.2018.1562537: https://doi.org/10.1080/13607863.2018.1562537*

Andruske, C. L., & O'Connor, D. (2020). Family care across diverse cultures: Re-envisioning using a transnational lens. *Journal of Aging Studies*, 55, 100892. https://doi.org/10.1016/j.jaging.2020.100892

Baethge, C., Goldbeck-Wood, S., & Mertens, S. (2019). SANRA-a scale for the quality assessment of narrative review articles. Research integrity and peer review, 4, 5. https://doi.org/10.1186/s41073-019-0064-8

Bantham, A., Ross, S. E. T., Sebastião, E., & Hall, G. (2021). Overcoming barriers to physical activity in underserved populations. Progress in cardiovascular diseases, 64, 64-71.

Bayly, J, Bradshaw, A, Fettes, L, Omarjee, M, Talbot-Rice, H, Walshe, C, Sleeman, KE, Bajwah, S, Dunleavy, L, Hocaoglu, M, Oluyase, A, Garner, I, Cripps, RL, Preston, N, Fraser, LK, Murtagh, FEM, Higginson, IJ & Maddocks, M 2021, 'Understanding the impact of the Covid-19 pandemic on delivery of rehabilitation in specialist palliative care services: An analysis of the CovPall-Rehab survey data', *Palliative medicine*, vol. 36, no. 2. https://doi.org/10.1177/02692163211063397

Becqué, Y. N., Rietjens, J., van Driel, A. G., van der Heide, A., & Witkamp, E. (2019). Nursing interventions to support family caregivers in end-of-life care at home: A systematic narrative review. *International Journal of Nursing Studies, 97, 28–39. https://doi.org/10.1016/j.ijnurstu.2019.04.011*

Beeson, R. (2003). Loneliness and depression in spousal caregivers of those with Alzheimer's disease versus non-caregiving spouses. *Archives of Psychiatric Nursing*, 17(3), 135–143. Doi:10.1016/S0883-9417(03)00057-8

Benton, D. C. & Cormack, D. F. S. (2000). Reviewing and evaluating the literature. In D. F. S. Cormack (Ed.) *The research process in nursing (4th Ed.). Oxford: Blackwell Sciences Ltd.*

Bettany-Saltikov J. (2010). Learning how to undertake a systematic review: part 1. Nursing standard (Royal College of Nursing (Great Britain): 1987), 24(50), 47–56. https://doi.org/10.7748/ns2010.08.24.50.47.c7939

Biggerstaff, D. and Thompson, A.R. (2008). Interpretative phenomenological analysis (IPA): *A qualitative methodology of choice in healthcare research. Qualitative research in psychology, 5(3), pp.214-224.*

Bhattacharyya, S & Benbow, S & Kar, N. (2012). Unmet service needs of ethnic elders with dementia in United Kingdom. *Indian Journal of Gerontology. 26. 242-258.*

Botsford J, Clarke CL, Gibb CE. (2011). Research and dementia, caring and ethnicity: A review of the literature. *Journal of Research Nurse*. 16(5): 437–49.

Bowes A, Wilkinson H. (2003). 'We didn't know it would get that bad': south Asian experiences of dementia and the service response. *Health Soc Care Community*;11(5):387–96.

Braun V, Clarke V. (2013) *Successful qualitative research: a practical guide for beginners. Sage Publications, USA.*

Brocki J.M., Wearden, A.J. (2006) A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychol Health 21: 87-108.*

Brodaty, H.; Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues Clin. Neurosci, 11, 217–228.*

Bruni, L., Gilli, M., Pelligra, V. (2008), Reciprocity: Theories and Facts (Introduction to the Special Issue), *International Review of Economics (Springer) n.55(1-2), April, p.1-12*

Carers, U.K. (2011). Half a million voices: improving support for BAME carers. London: Carers UK.

Carers UK. (2019a). State of caring. A snapshot of unpaid care in the UK. Carers UK.

Carers UK. (2019b). Facts about carers 2019. Policy Brief. 000: 1–11. https://www.carersuk.org/images/Facts_about_ Carers_2019.pdf.

Cash B, Hodgkin S, Warburton J. (2019) A transformative approach to systems theory in caregiving research. Qualitative Social Work. 2019;18(4):710-726. doi:10.1177/1473325017749988

Chadda, R. K., & Deb, K. S. (2013). Indian family systems, collectivistic society and psychotherapy. Indian journal of psychiatry, 55(Suppl 2), S299–S309. https://doi.org/10.4103/0019-5545.105555

Chan, Z. C. Y., Fung, Y. L., & Chien, W. T. (2013). Bracketing in phenomenology: only undertaken in the data collection and analysis process? The Qualitative Report, 18(59), 1-9. Retrieved from http://www.nova.edu/ssss/QR/QR18/chan59.pdf

Charmaz, K. (2008). Grounded theory as an emergent method. In S. N. Hesse-Biber & P. Leavy (Eds.), *Handbook of emergent methods (pp. 155–170). The Guilford Press.*

Centre for Research in Race and Education (CRRE) (2021) David Gillborn et al,*Evidence for the Commission on Race and Ethnic Disparities*. Birmingham: University of Birmingham CRRE. DOI: 10.25500/epapers.bham.00003389

Crotty, M. (2003): The Foundations of Social Research: Meaning and Perspectives in the Research Process, London: Sage Publications, 3rd edition, 10.

Cuthbertson, L.M., Robb, Y.A. and Blair, S. (2020). Theory and application of research principles and philosophical underpinning for a study utilising interpretative phenomenological analysis. Radiography, 26(2), pp.e94-e102.

Davidsen, A.S. (2013). Phenomenological approaches in psychology and health sciences. Qual Res Psychol 10: 318-339.

De Jong, L., Stahmeyer, J. T., Eberhard, S., Zeidler, J., & Damm, K. (2021). Willingness and preparedness to provide care: interviews with individuals of different ages and with different caregiving experiences. BMC geriatrics, 21(1), 207. https://doi.org/10.1186/s12877-021-02149-2

Department of Health and Social Care (2009). Living well with dementia: a national dementia strategy London: Department of Health. Accessed on 2nd April 2014. https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy

Department of Health and Social Care (2012). 'Prime Minister's challenge on dementia: delivering major improvements in dementia care and research by 2015', London: DH

Department of Health (2014) 'Care and support statutory guidance: Issued under the Care Act 2014', *London: Department of Health*.

Diabetes UK. Diabetes in the UK 2012. London: Diabetes UK, 2012. Available at http://www.diabetes.org.uk/Documents/Reports/Diabetes-in-the-UK-2012.pdf Last accessed 20 May 2014.

Dilworth-Anderson, P., & Gibson, B. E. (2002). The cultural influence of values, norms, meanings,and perceptions in understanding dementia in ethnic minorities. Alzheimer Disease and Associated Disorders, 16(2), S56–S63

Eatough V, Smith, J. (2006).'I was like a wild wild person': understanding feelings of anger using interpretative phenomenological analysis. Br J Psychol 97: 483-498.

Eatough, V. and Smith, J.A.(2008). Interpretative phenomenological analysis. The Sage handbook of qualitative research in psychology, 179, p.194.

Fauth, E., Hess, K., Piercy, K., Norton, M., Corcoran, C., Rabins, P., Lyketsos, C., & Tschanz, J. (2012). Caregivers' relationship closeness with the person with dementia predicts both positive and negative outcomes for caregivers' physical health and psychological well-being. Aging & mental health, 16(6), 699–711. https://doi.org/10.1080/13607863.2012.678482

Fernandez P. C, Xi K, Simha A, Shah NS, Huang RJ, Palaniappan L, et al. (2022) Leading causes of death in Asian Indians in the United States (2005–2017). *PLoS ONE 17(8): e0271375. https://doi.org/10.1371/journal.pone.0271375*

Finlay, L. (2011). Phenomenology for psychotherapists: researching the lived world. Wiley-Blackwell, USA.

Giebel, C. M., Zubair, M., Jolley, D., Bhui, K. S., Purandare, N., Worden, A. and Challis, D. (2015). South Asian older adults with memory impairment: Improving assessment and access to dementia care. International Journal of Geriatric Psychiatry 30, pp. 345–356. Available at: DOI: 10.1002/gps.4242 [Accessed 28 January 2017].

Giebel, C., Challis, D., Worden, A., Jolley, D., Bhui, K. S., Lambat, A., & Purandare, N. (2016). Perceptions of self-defined memory problems vary in south Asian minority older people who consult a GP and those who do not: a mixed-method pilot study. International journal of geriatric psychiatry, 31(4), 375–383. https://doi.org/10.1002/gps.4337

Gill, M.J., 2014. The possibilities of phenomenology for organizational research. Organizational research methods, 17(2), pp.118-137.

Giorgi,A. (2010) Phenomenology and the practice of science. J Soci Existent Anal 21.

Given B., Kozachic S., Collins C., Devoss C. & Given C.W. (2001) Caregiver role strain. In Nursing Care of Older Adults diagnosis: Outcomes and Interventions

Given, B., Wyatt, G., Given, C., Sherwood, P., Gift, A., DeVoss, D., & Rahbar, M. (2004). Burden and depression among caregivers of patients with cancer at the end of life. Oncology nursing forum, 31(6), 1105–1117. https://doi.org/10.1188/04.ONF.1105-1117

Godfrey M., Townsend J. (2001). Caring for an elder with dementia: The experience of Asian caregivers and barriers to the take up of support services. Nuffield Institute for Health, University of Leeds, UK.

Godfrey M, Townsend J. Older People in Transition from Illness to Health: Trajectories of Recovery. Qualitative Health Research. 2008;18(7):939-951. https://journals.sagepub.com/doi/pdf/10.1177/1049732308318038

Gort AM, Mingot M, Gomez X, et al. 2007. Use of the Zarit Scale for assessing caregiver burden and collapse in caregiving at home in dementias. Int J Geriatr Psych 22: 957– 962.

Green, B. N., Johnson, C. D., & Adams, A. (2006). Writing narrative literature reviews for peer-reviewed journals: secrets of the trade. Journal of chiropractic medicine, 5(3), 101–117. https://doi.org/10.1016/S0899-3467(07)60142-6

Greenwood, N., Pound, C., Brearley, S. and Smith, R., 2019. A qualitative study of older informal carers' experiences and perceptions of their caring role. Maturitas, 124, pp.1-7.

Gyollai, D. (2020). Getting into it in the wrong way: Interpretative phenomenological analysis and the hermeneutic circle. Nursing Philosophy, 21(2), e12294.

Guo, M., Kim, S. and Dong, X. (2019). Sense of Filial Obligation and Caregiving Burdens Among Chinese Immigrants in the United States. J Am Geriatr Soc, 67: S564-S570. https://doi.org/10.1111/jgs.15735

Hanssen, I. and Tran, P. T. M. (2019) 'The influence of individualistic and collectivistic morality on dementia care choices', Nursing Ethics, 26(7–8), pp. 2047–2057. doi: 10.1177/0969733018791342.

Harrison Dening, K., Sampson, E. L., & De Vries, K. (2019). Advance care planning in dementia: recommendations for healthcare professionals. Palliative care, 12, 1178224219826579. https://doi.org/10.1177/1178224219826579

Hefferon, K., Gil-Rodriguez, E. (2011). Methods: interpretative phenomenological analysis. The Br Psychol Soci 24: 756

Helman, C. G. (2005). Cultural aspects of time and ageing. Time is not the same in every culture and every circumstance; our views of aging also differ. EMBO reports, 6 Spec No(Suppl 1), S54–S58. https://doi.org/10.1038/sj.embor.7400402

Hennink, M., Hutter, I., Bailey, A. (2011). Qualitative research methods. Sage Publications, USA.

Henriksson, C., Friesen, N., Saevi, T. (2012) Hermeneutic phenomenology in education: method and practice. Sense Publishers, Netherlands.

Hodgson, L. G. (1992). Adult grandchildren and their grandparents: The enduring bond. The International Journal of Aging and Human Development, 34(3), 209-225. DOI: 10.2190/PU9M-96XD-CFYQ-A8UK.

Hossain, M. Z., Stores, R., Hakak, Y., & Dewey, A. (2020). Traditional gender roles and effects of dementia caregiving within a South Asian ethnic group in England. Dementia and Geriatric Cognitive Disorders. https://doi.org/10.1159/000506363

Hossain, M.Z., Stores. R., Hakak. Y., Dewey. A.(2019). Traditional Gender Roles and Effects of Dementia Caregiving within a South Asian Ethnic Group in England. Dement Geriatr Cogn Disord. ;48(5-6):330-336. doi: 10.1159/000506363. Epub 2020 Mar 24. PMID: 32208389.

Hussain, B., Sheikh, A., Timmons, S., Stickley, T., & Repper, J. (2020). Workforce diversity, diversity training and ethnic minorities: The case of the UK National Health Service. International Journal of Cross Cultural Management, 20(2), 201–221. https://doi.org/10.1177/1470595820938412

Jennings, L. A., Laffan, A. M., Schlissel, A. C., Colligan, E., Tan, Z., Wenger, N. S., & Reuben, D. B. (2019). Health Care Utilization and Cost Outcomes of a Comprehensive Dementia Care Program for Medicare Beneficiaries. JAMA internal medicine, 179(2), 161–166. https://doi.org/10.1001/jamainternmed.2018.557

Johl, N., Patterson, T. and Pearson, L. (2016) What do we know about the attitudes, experiences and needs of Black and minority ethnic carers of people with dementia in the United Kingdom? A systematic review of empirical research findings. Dementia, volume

Jolley, D., Moreland, N., Read, K., Kaur, H., Jutlla, K., & Clark, M. (2009). 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. Ethnicity and Inequalities in Health and Social Care, 2, 5–9.

Justin, B. N., Turek, M., & Hakim, A. M. (2013). Heart disease as a risk factor for dementia. Clinical epidemiology, 5, 135–145. https://doi.org/10.2147/CLEP.S30621

Jutlla, K. (2013). Ethnicity and cultural diversity in dementia care: Review of the research. Journal of Dementia Care, 21, 33–39.

Jutlla, K., & Moreland, N. (2009). The personalisation of dementia services and existential realities: Understanding Sikh carers caring for an older person with dementia in Wolverhampton. Journal of Ethnicity and Inequalities in Health and Social Care, 2, 10–21.

Jutlla, K. & Moreland, N. (March 2007). Twice a Child III: The Experiences of Asian Carers of Older People with Dementia in Wolverhampton. Dementia UK: West Midlands.

Katbamna, S., Ahmad, W., Bhakta, P., Baker, R., & Parker, G. (2004). Do they look after their own? Informal support for South Asian carers. Health & social care in the community, 12(5), 398–406. https://doi.org/10.1111/j.1365-2524.2004.00509

Kenning, C., Daker-White, G., Blakemore, A., Panagioti, M., & Waheed, W. (2017). Barriers and facilitators in accessing dementia care by ethnic minority groups: a meta-synthesis of qualitative studies. BMC psychiatry, 17(1), 316. https://doi.org/10.1186/s12888-017-1474-0

Knapp, M., Comas-Herrera, A., Somani, A., & Banerjee, S. (2007). *Dementia: international comparisons.*

Knowles, S., Combs, R., Kirk, S., Griffiths, M., Patel, N., & Sanders, C. (2016). Hidden caring, hidden carers? Exploring the experience of carers for people with long-term conditions. Health & Social Care in the Community, 24(2), 203-213.

Lam, T., Tobert, N., Jutlla, K., Tan, G., Kaur, H., Rahman, D. S., Tilki, M., Garrett, P. (2019). Supporting People Living with Dementia in Black, Asian and Minority Ethnic Communities: Key Issues and Strategies for Change. United Kingdom: Jessica Kingsley Publishers.

Lamb, S. (2013). In/dependence, intergenerational uncertainty, and the ambivalent state: Perceptions of old age security in India. South Asia: Journal of South Asian Studies, 36(1), 65-78.

Lane, M. J., Davis, D. R., Cornman, C. B., Macera, C. A., & Sanderson, M. (1998). Location of death as an indicator of end-of-life costs for the person with dementia. American Journal of Alzheimer’s Disease, 13(4), 208–210. https://doi.org/10.1177/153331759801300408

Lankers, D., Kissler, S., Hötte, S. D., Freyberger, H. J., & Schröder, S. G. (2010). Leben Demenzkranke zu Hause länger als im Heim? [Do dementia patients living at home live longer than in a nursing home?]. Zeitschrift fur Gerontologie und Geriatrie, 43(4), 254–258. https://doi.org/10.1007/s00391-010-0096-7

Larkin, Michael & Watts, Simon & Clifton, Elizabeth. (2006). Giving voice and making sense in Interpretative Phenomenological Analysis. *Qualitative Research in Psychology. 3. 102-120. 10.1191/1478088706qp062oa.*

Lazarus R. S., Folkman S. (1984). Stress, Appraisal and Coping*. New York: Springer [Google Scholar]*

Lazarus, R. S. , & Folkman, S. (1987). Transactional theory and research on emotions and coping. *European Journal of Personality, 1(3), 141–169. 10.1002/per.2410010304 [CrossRef] [Google Scholar]*

Lawrence, V., Murray, J., Samsi, K., & Banerjee, S. (2008). Attitudes and support needs of Black Caribbean, South Asian and White British carers of people with dementia in the UK. *British Journal of Psychiatry, 192, 240–246.*

Leopold, Thomas & Raab, Marcel & Engelhardt, Henriette. (2014). The Transition to Parent Care: Costs, Commitments, and Caregiver Selection Among Children. *Journal of Marriage and Family. 76. 10.1111/jomf.12099.*

Lievesley, N. (2010). The future ageing of the ethnic minority population of England and Wales. London: *Runnymede and the Centre for Policy on Ageing*.

Lindeza, P., Rodrigues, M., Costa, J., Guerreiro, M., & Rosa, M. M. (2020). Impact of dementia on informal care: a systematic review of family caregivers' perceptions. *BMJ* *supportive & palliative care, bmjspcare-2020-002242. Advance online publication. https://doi.org/10.1136/bmjspcare-2020-002242*

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D.,Ballard, C., Banerjee, S., Burns, A., Cohen-Mansfield, J., Cooper, C., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Larson, E. B., Ritchie, K., Rockwood, K., Sampson, E. L., Samus, Q., … Mukadam, N. (2017). *Dementia prevention, intervention, and care. Lancet (London, England), 390(10113), 2673–2734. https://doi.org/10.1016/S0140-6736(17)31363-6*

Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S. G., Dias, A., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Kivimäki, M., Larson, E. B., Ogunniyi, A., Orgeta, V., … Mukadam, N. (2020). *Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet (London, England), 396(10248), 413–446. https://doi.org/10.1016/S0140-6736(20)30367-6*

Losada-Baltar, A., Jiménez-Gonzalo, L., Gallego-Alberto, L., Pedroso-Chaparro, M. D. S., Fernandes-Pires, J., & Márquez-González, M. (2021). "We Are Staying at Home." *Association of Self-perceptions of Aging, Personal and Family Resources, and Loneliness With Psychological Distress During the Lock-Down Period of COVID-19. The journals of gerontology. Series B, Psychological sciences and social sciences, 76(2), e10–e16. https://doi.org/10.1093/geronb/gbaa048*

Love, B., Vetere, A., & Davis, P. (2020). Should Interpretative Phenomenological Analysis (IPA) be Used With Focus Groups? Navigating the Bumpy Road of “Iterative Loops,” Idiographic Journeys, and “Phenomenological Bridges.” International Journal of Qualitative Methods. https://doi.org/10.1177/1609406920921600

Luciani, Michela & Jack, Susan & Campbell, Karen & Orr, Elizabeth & Durepos, Pamela & Li, Lin & Strachan, Patricia & Mauro, Stefania. (2019). An Introduction to Qualitative Health Research. Professional infermieristiche. 72. 60-68.

Mackenzie, J. (2006). Stigma and dementia: East European and South Asian family carers negotiating stigma in the UK. Dementia, 5, pp. 233–247. Available at: <http://journals.sagepub.com/doi/pdf/10.1177/1471301206062252 [Accessed 29 January 2017].

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: realist, contextualist and radical constructionist epistemologies. British journal of psychology (London, England: 1953), 91 (Pt 1), 1–20. https://doi.org/10.1348/000712600161646

Mayeda, E. R., Glymour, M. M., Quesenberry, C. P., & Whitmer, R. A. (2016). Inequalities in dementia incidence between six racial and ethnic groups over 14 years. Alzheimer's & dementia: the journal of the Alzheimer's Association, 12(3), 216–224. https://doi.org/10.1016/j.jalz.2015.12.007

Mendez-Luck, C.A., Applewhite, S.R., Lara, V.E. and Toyokawa, N. (2016), The Concept of Familism in the Lived Experiences of Mexican-Origin Caregivers. Fam Relat, 78: 813-829. https://doi.org/10.1111/jomf.12300

Milne, A., & Chryssanthopoulou, C. (2005). Dementia caregiving in black and Asian populations: Reviewing and refining the research agenda. Journal of Community and Applied Social Psychology, 15, 319–337.

Meline, T.J. (2006). Selecting Studies for Systemic Review: Inclusion and Exclusion Criteria.

Moran, D. (1999). Introduction to Phenomenology (1st ed.). Routledge. https://doi.org/10.4324/9780203196632

Morse JM. Determining sample size. Qual Health Res. 2000;10(1):3–5.

Mukadam, N., Cooper, C. and Livingston, G. (2011). A systematic review of ethnicity and pathways to care in dementia. International Journal of Geriatric Psychiatry, 26, pp. 12–20.

Mukadam, N., Waugh, A., Cooper, C., & Livingston, G. (2015). What would encourage help-seeking for memory problems among UK-based South Asians? A qualitative study. BMJ open, 5(9), e007990. https://doi.org/10.1136/bmjopen-2015-007990

Needham, B. L., Mukherjee, B., Bagchi, P., Kim, C., Mukherjea, A., Kandula, N. R., & Kanaya, A. M. (2017). Acculturation Strategies Among South Asian Immigrants: The Mediators of Atherosclerosis in South Asians Living in America (MASALA) Study. Journal of immigrant and minority health, 19(2), 373–380. https://doi.org/10.1007/s10903-016-0372-8

Ng, R., & Indran, N. (2021). Societal perceptions of caregivers linked to culture across 20 countries: Evidence from a 10-billion-word database. PloS one, 16(7), e0251161. https://doi.org/10.1371/journal.pone.0251161

Nolan, L. (2006), Caring connections with older persons with dementia in an acute hospital setting – a hermeneutic interpretation of the staff nurse's experience. International Journal of Older People Nursing, 1: 208–215. doi:10.1111/j.1748-3743.2006.00033.

Office for National Statistics. (2016). Overview of the UK population, February 2016. Available at: <https://www.ons.gov.uk/people population and community/ population and migration/population estimates/articles/overview of the UK population/ february2016> [Accessed 28 January 2017].

Pagani, F. (2013). Empathy, Salvation, and Religious Identity: Hindu Religious Movements and Humanitarian Action in India. In Ethnographies of Social Support (pp. 177-194). New York: Palgrave Macmillan US.

Parveen, S., & Morrison, V. (2009). Predictors of familism in the caregiver role: a pilot study. *Journal of health psychology, 14(8), 1135–1143.*

Parveen S., Morrison V., Robinson C. A. (2011). Ethnic variations in the caregiver role: A qualitative study. *Journal of Health Psychology, 16(6), 862–872.*

Parveen, S., Morrison, V. and Robinson, C. A. (2013). Ethnicity, familism and willingness to care: Important influences on caregiver mood? *Aging & Mental Health, 17 (1), pp. 115–124.*

Parveen, S., Peltier, C., & Oyebode, J. R. (2017). Perceptions of dementia and use of services in minority ethnic communities: a scoping exercise. *Health & social care in the community, 25(2), 734–742.*

Parveen, S. and Oyebode, J.R. (2018) Dementia and minority ethnic carers. Better Health Briefing: 46. Race Equality Foundation: London.

Parveen, S and Oyebode, J. (2018). Dementia and Minority Ethnic Carers A Race Equality Foundation Briefing Paper.

Perugini, M., Gallucci, M., Presaghi, F., & Ercolani, A. P. (2003). The personal norm of reciprocity. European Journal of Personality, 17(4), 251-283.

Petersen R. C. (2011). Clinical practice. Mild cognitive impairment. The New England journal of medicine, 364(23), 2227–2234. https://doi.org/10.1056/NEJMcp0910237

Pham, T. M., Petersen, I., Walters, K., Raine, R., Manthorpe, J., Mukadam, N., & Cooper, C. (2018). Trends in dementia diagnosis rates in UK ethnic groups: analysis of UK primary care data. Clinical epidemiology, 10, 949–960. https://doi.org/10.2147/CLEP.S152647

Pietkiewicz, I. J., and Smith, J. A. (2014). A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. Psychol. J. 20, 7–14. doi: 10.14691/CPPJ.20.1.7

Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. Psychology and aging, 18(2), 250–267. https://doi.org/10.1037/0882-7974.18.2.250

Polgar, S., & Thomas, S. (2013). Introduction to Research in the Health Sciences. (6th ed.) Elsevier.

Prajapati, R., & Liebling, H. (2022). Accessing Mental Health Services: a Systematic Review and Meta-ethnography of the Experiences of South Asian Service Users in the UK. Journal of racial and ethnic health disparities, 9(2), 598–619. https://doi.org/10.1007/s40615-021-00993-x

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, M., wittenberg, A., Adelaja, R., Hu, B., King, B., Rehill, D., & Salimkumar, D. (2014). *Dementia UK: Update. Alzheimer's Society. http://www.alzheimers.org.uk/dementiauk*

Prince, M., Ali, G. C., Guerchet, M., Prina, A. M., Albanese, E., & Wu, Y. T. (2016). Recent global trends in the prevalence and incidence of dementia, and survival with dementia. Alzheimer's research & therapy, 8(1), 23. https://doi.org/10.1186/s13195-016-0188-8

The PRISMA Group Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med. 2009;6(7):e1000097. [PMC free article] [PubMed] [Google Scholar]*

Purandare, N., Luthra, V., Swarbrick, C. and Burns, A. (2007). Knowledge of dementia among South Asian (Indian) older people in Manchester, UK. International Journal of Geriatric Psychiatry, 22 (8), pp. 777-81.

Qualitative Health Research, 11, 273-281. Carpenter, D. R. (2007). Phenomenology as method. In H. J. Streubert & D. R. Carpenter (Eds.), Qualitative research in nursing: Advancing the humanistic imperative (pp. 7599). Philadelphia, PA: Lippincott

Quinn, C., Toms, G., (2019). Influence of Positive Aspects of Dementia Caregiving on Caregivers' Well-Being: A Systematic Review, The Gerontologist, Volume 59, Issue 5, October 2019, Pages e584–e596, https://doi.org/10.1093/geront/gny168

Raleigh V, Holmes J (2021). The health of people from ethnic minority groups in England [online]. The King's Fund website. Available at: www.kingsfund.org.uk/publications/healthpeople-ethnic-minority-groups-england (accessed on 20 April 2021).

Ray, Mo. (2006) Informal care in the context of long-term marriage: the challenge to practice. Practice, 18 (2). pp. 129-142. ISSN 0950-3153

Richardson WS, Wilson MC, Nishikawa J, Hayward RS: The well-built clinical question: a key to evidence-based decisions. ACP J Club 1995,123(3):A12–A13

Roberto, K. A., & Stroes, J. (1992). Grandchildren and grandparents: Roles, influences, and relationships. The International Journal of Aging and Human Development, 34(3), 227-239

Roche, M., Higgs, P., Aworinde, J. and Cooper, C., 2021. A review of qualitative research of perception and experiences of dementia among adults from Black, African, and Caribbean background: What and whom are we researching? The Gerontologist, 61(5), pp.e195-e208.

Sabogal, F., Marín, G., Otero-Sabogal, R., Marín, B. V., & Perez-Stable, E. J. (1987). Hispanic Familism and Acculturation: What Changes and What Doesn't? Hispanic Journal of Behavioral Sciences, 9(4), 397–412. https://doi.org/10.1177/07399863870094003

Sackett, D. L., Straus, S. E., Richardson, W. S., Rosenberg, W. M. C., & Haynes, R. B. (2000). Evidence-based medicine: How to practice and teach EBM (2nd ed.). New York, NY: Churchill Livingstone. [Google Scholar]

Sagbakken, M., Spilker, R. S., & Ingebretsen, R. (2018). Dementia and Migration: Family Care Patterns Merging With Public Care Services. *Qualitative health research*, *28*(1), 16–29. https://doi.org/10.1177/1049732317730818Sandelowski M. (1995). Sample size in qualitative research. Research in nursing & health, 18(2), 179–183. https://doi.org/10.1002/nur.4770180211

Schweitzer, P., & Bruce, E. (2008). Remembering yesterday, caring today: Reminiscence in dementia care: A guide to good practice. Jessica Kingsley Publishers

Shah, A. (2008), "Estimating the Absolute Number of Cases of Dementia and Depression in the Black and Minority Ethnic Elderly Population in the United Kingdom", International Journal of Migration, Health and Social Care, Vol. 4 No. 2, pp. 4-15. https://doi.org/10.1108/17479894200800008

Shawl et al, 2014; Dementia in South Asian in the United Kingdom: An overview the physician, Vol 3 Issue1. Nov 2014

Shen, H., Wan, F., & Wyer, R. S., Jr. (2011). Cross-cultural differences in the refusal to accept a small gift: The differential influence of reciprocity norms on Asians and North Americans. Journal of Personality and Social Psychology, 100(2), 271–281. https://doi.org/10.1037/a0021201

Shinebourne, P., Smith, J.A. (2010). The communicative power of metaphors: an analysis and interpretation of metaphors in accounts of the experience of addiction. Psychol Psychother 83: 59-73.

Shinebourne,P., Smith, J.A. (2009). Alcohol and the self: an interpretative phenomenological analysis of the experience of addiction and its impact on the sense of self and identity. Addic Res Theor 17: 152-167.

Singh, V., Dhamoon, M. S., & Alladi, S. (2018). Stroke Risk and Vascular Dementia in South Asians. Current atherosclerosis reports, 20(9), 43. https://doi.org/10.1007/s11883-018-0745-7

Smith, J.A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. Psychol Health 11: 261-271.

Smith, J.A., Dunworth, F. (2003). Qualitative methods in the study of development. Sage Publications, USA.

Smith, J.A., Osborn, M. (2003). Qualitative psychology: a practical guide to research methods (2nd edn.). Sage Publications, USA.

Smith, J. A. (2004): Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. Qualitative Research in Psychology 1, 39 – 54

Smith, J.A. and Osborn, M. (2007). Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. Psychology and health, 22(5), pp.517-534.

Smith, J.A. and Osborn, M. (2008). Interpretative phenomenological analysis. In JA Smith (Ed) Qualitative Psychology: A Practical Guide to Methods (second ed) London: Sage

Smith, J.A., Flowers, P. and Larkin, M. (2009). Interpretative Phenomenological Analysis: Theory, Method and Research, London: Sage

Smith, J. A., & Nizza, I. E. (2022). Essentials of interpretative phenomenological analysis. American Psychological Association. https://doi.org/10.1037/0000259-000

Snell-Rood, C. (2015). Marital Distress and the Failure to Eat: The Expressive Dimensions of Feeding, Eating, and Self-care in Urban South Asia. Medical anthropology quarterly, 29(3), 316-333.

Sokolowski, R., (2000). Introduction to phenomenology. Cambridge university press.

Sörensen, S., & Conwell, Y. (2011). Issues in dementia caregiving: effects on mental and physical health, intervention strategies, and research needs. The American journal of geriatric psychiatry: official journal of the American Association for Geriatric Psychiatry, 19(6), 491–496. https://doi.org/10.1097/JGP.0b013e31821c0e6e

Spinelli, E. (2005). The interpreted world: an introduction to phenomenological psychology (2nd edn.). Sage Publications, USA.

Stake, R.E. (1995). The art of case study research. Sage Publications, USA.

Stucki, B.R., & Mulvey, J. (2000). Can aging baby boomers avoid the nursing home: Long-term care insurance for aging in place. Executive Summary. Washington, DC: American Council of Life Insurers.

Tangalos, E. G., & Petersen, R. C. (2018). Mild Cognitive Impairment in Geriatrics. *Clinics in geriatric medicine*, *34*(4), 563–589. https://doi.org/10.1016/j.cger.2018.06.005

Tatangelo, G., McCabe, M., Macleod, A., & You, E. (2018). “I just don’t focus on my needs”. The unmet health needs of partner and offspring caregivers of people with dementia: A qualitative study. International Journal of Nursing Studies, 77, 8–14. https://doi.org/10.1016/j.ijnurstu.2017.09.011

Torgerson, Carole. (2003). Systematic Reviews.

Trivedi R, Lorenz KA. (2021). Supporting Indian and Other South Asians Facing COVID-19 and Other Serious Illnesses. J Pain Symptom Manage.Oct;62(4):e1-e3. doi: 10.1016/j.jpainsymman. Epub 2021 Jul 14. PMID: 34271145; PMCID: PMC8479549.

Tuffour, Isaac (2017) A critical overview of interpretative phenomenological analysis: a contemporary qualitative research approach. Journal of Healthcare Communications, 2 (4). p. 52. ISSN 2472-1654

Venters, S., & Jones, C. J. (2021). The experiences of grandchildren who provide care for a grandparent with dementia: A systematic review. Dementia, 20(6), 2205–2230. https://doi.org/10.1177/1471301220980243

Vertovec, S.S. (2007). Super-diversity and its implications. Ethnic and Racial Studies 30(6): 1024–54

Victor, C. R., Rippon, I., Quinn, C., Nelis, S. M., Martyr, A., Hart, N., Lamont, R., & Clare, L. (2021). The prevalence and predictors of loneliness in caregivers of people with dementia: findings from the IDEAL programme. Aging & mental health, 25(7), 1232–1238. https://doi.org/10.1080/13607863.2020.1753014

Vydelingum, V. (2006), Nurses' experiences of caring for South Asian minority ethnic patients in a general hospital in England. Nursing Inquiry, 13: 23-32. https://doi.org/10.1111/j.1440-1800.2006.00304.x

Weston, R., & Qu, L. (2009). Relationships between grandparents and grandchildren. Family Matters, 81, 58-60.

Willig, C. (2008). Introducing qualitative research in psychology (2nd edn.). Open University Press, UK.

Wittenberg, R., Knapp, M., Hu, B., Comas-Herrera, A., King, D., Rehill, A., Shi, C., Banerjee, S., Patel, A., Jagger, C., & Kingston, A. (2019). The costs of dementia in England. International journal of geriatric psychiatry, 34(7), 1095–1103. https://doi.org/10.1002/gps.5113

Wittenberg, R., Hu, B., Jagger, C., Kingston, A., Knapp, M., Comas-Herrera, A., King, D., Rehill, A., & Banerjee, S. (2020). Projections of care for older people with dementia in England: 2015 to 2040. *Age and ageing*, *49*(2), 264–269. https://doi.org/10.1093/ageing/afz154

Wohland, P., Rees, P., Norman, P., Boden, P. & Jasinska, M. (2010) Ethnic Population Projections for the UK and Local Areas, 2001-2051, Leeds: University of Leeds, School of Geography.

http://www.geog.leeds.ac.uk/fileadmin/downloads/school/research/projects/migrants/WP_ETH_POP_PROJECTIONS.pdf

Wright, T., & O'Connor, S. (2018). Reviewing challenges and gaps in European and global dementia policy. Journal of public mental health, 17(4), 157–167. https://doi.org/10.1108/JPMH-02-2018-0012

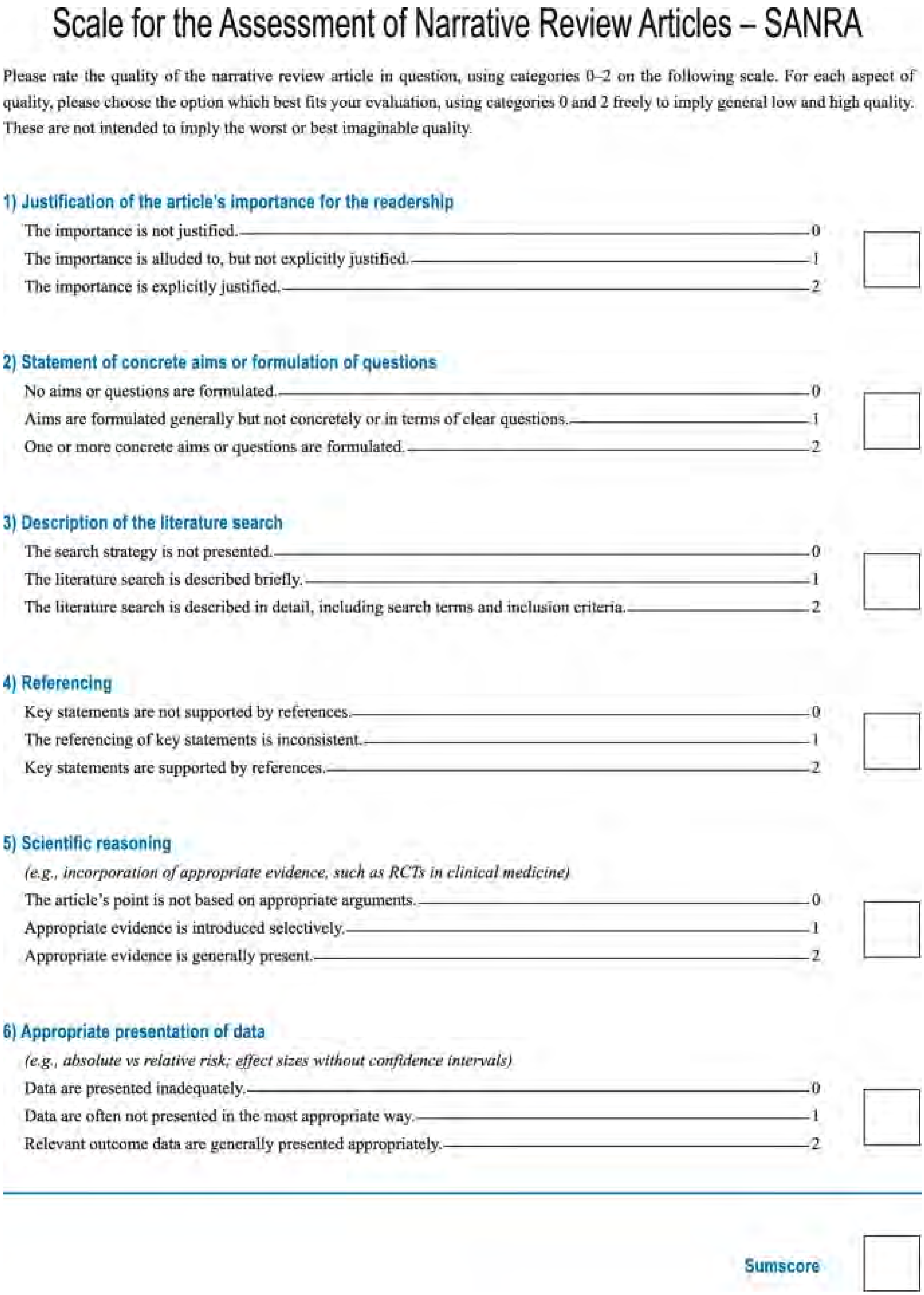
Yardley, L. (2000). Dilemmas in qualitative health research. Psychology and Health, 15, 215-228.

Yardley, L. (2011). Demonstrating validity in qualitative research. In J. A. Smith (Ed.), Qualitative psychology: A practical guide to research methods (pp. 234-251). London: SAGE.

Zahed, S., Emami, M., Bazargan-Hejazi, S. et al.(2019). What motivates informal caregivers of people with dementia (PWD): a qualitative study. BMC Palliat Care 18, 105. https://doi.org/10.1186/s12904-019-0491-9

Appendices

Appendix 1: SANRA- Scale for Narrative Review Articles



Scale for the Assessment of Narrative Review Articles – SANRA

Please rate the quality of the narrative review article in question, using categories 0–2 on the following scale. For each aspect of quality, please choose the option which best fits your evaluation, using categories 0 and 2 freely to imply general low and high quality. These are not intended to imply the worst or best imaginable quality.

1) Justification of the article's importance for the readership

The importance is not justified. 0
The importance is alluded to, but not explicitly justified. 1
The importance is explicitly justified. 2
☐

2) Statement of concrete aims or formulation of questions

No aims or questions are formulated. 0
Aims are formulated generally but not concretely or in terms of clear questions. 1
One or more concrete aims or questions are formulated. 2
☐

3) Description of the literature search

The search strategy is not presented. 0
The literature search is described briefly. 1
The literature search is described in detail, including search terms and inclusion criteria. 2
☐

4) Referencing

Key statements are not supported by references. 0
The referencing of key statements is inconsistent. 1
Key statements are supported by references. 2
☐

5) Scientific reasoning

(e.g., incorporation of appropriate evidence, such as RCTs in clinical medicine)

The article's point is not based on appropriate arguments. 0
Appropriate evidence is introduced selectively. 1
Appropriate evidence is generally present. 2
☐

6) Appropriate presentation of data

(e.g., absolute vs relative risk; effect sizes without confidence intervals)

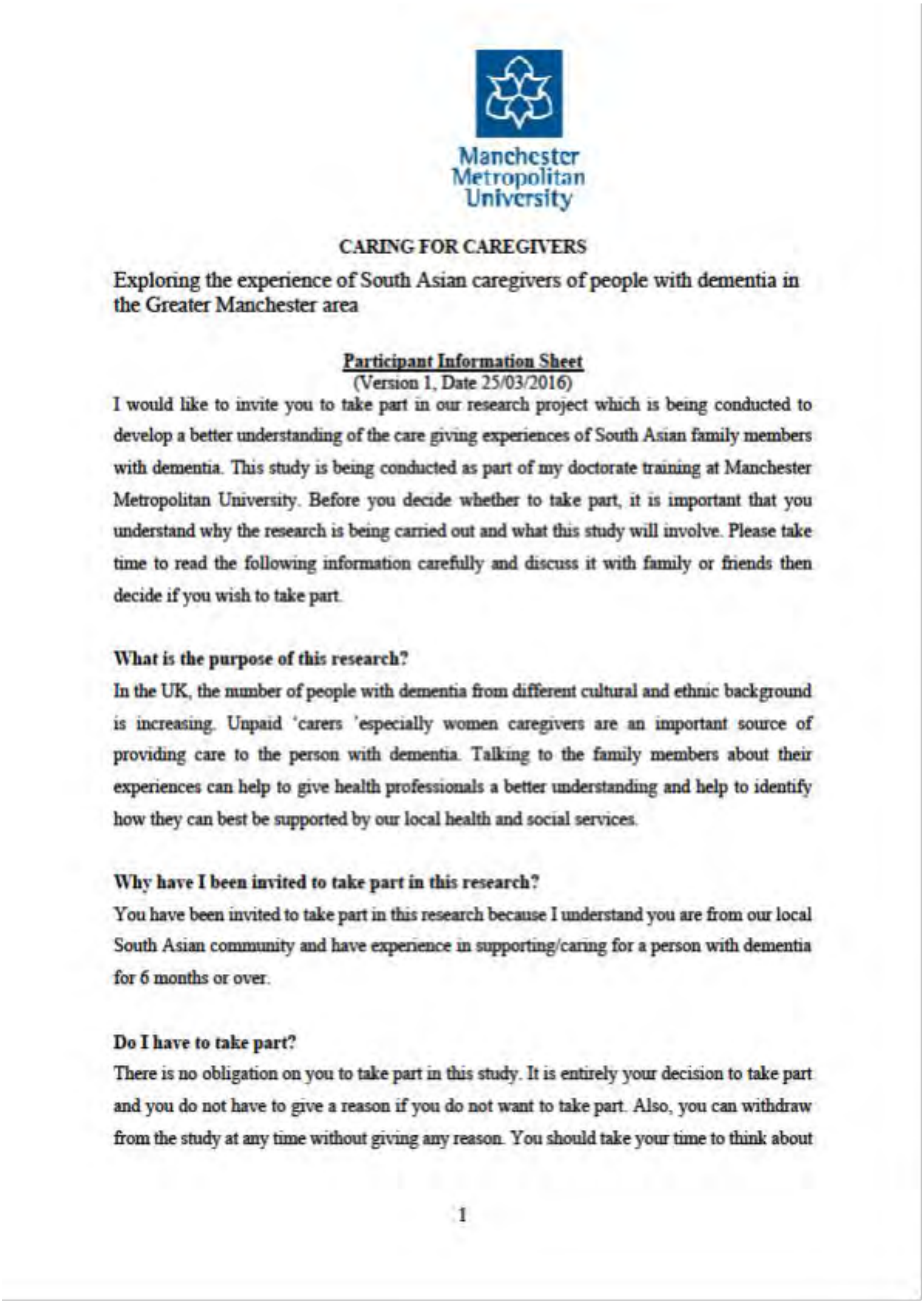
Data are presented inadequately. 0
Data are often not presented in the most appropriate way. 1
Relevant outcome data are generally presented appropriately. 2
☐

Sumscore ☐

Appendix 2: Narrative Review Theme Matrix

Godfrey & Townsend, 2001	Bowes & Wilkinson, 2003	Adamson & Donovan, 2005	Lawrence et al.,2008
-Traditional ideologies -Lack of knowledge about dementia leads to isolation from services, community, and family life. -Daughter-in-law carers	- Caregiving is a natural obligation - Intense psychological and physical challenges -Need for culturally sensitive response from support services -Lack of awareness about the dementia -Negative experience about the service provision -Additional responsibilities -Isolation from wider contacts -Caring role is obligatory	- Cultural norms associated with caregiving - Caregiving is a normal role - Traditional caregiver ideologies	-Cultural attitudes and beliefs surrounding caregiving role -Traditional caregiver ideologies as part of cultural identity -Prioritising care receipt needs over own needs. - Attitudes towards formal healthcare services.
Mackenzie, 2006	Purandare et al., 2007	Jolly et al.,2009	Jutlla et al., 2015
-Lack of knowledge about dementia -Diagnosis of dementia will bring shame upon the family -Caring identified as religious obligation to the family and faith -Dementia as a mental illness. -Religious and spiritual influence. -Hiding the dementia diagnosis and person -Isolation to avoid rejection -Mechanism to protect family reputation	-Lack of knowledge about dementia -Poor attendance in the local dementia clinics	-Lack of knowledge about dementia -Poor attendance in the local dementia clinics Stigma, Mistaking symptoms with old age Carers remaining isolated Service provision Lack knowledge of dementia among GPs Lack of cultural awareness, including language barriers - Caregiver ideologies	-Lack of awareness of dementia -Caregiving burden to led to social isolation and increased burden -Daughter-in-law carers invisible status - Caregiving is just an extended role
Mukadam et al.,2015	Giebel et al.2016	Parveen et al., 2013	
-Barriers reported when trying to access dementia services -Lack of awareness about dementia -Stigma- Not conceptualising dementia as an illness is a normal consequence of ageing -Stigma- Dementia symptoms of the condition to madness.	-lack of knowledge of dementia and mental illness -lack of awareness of local services on offer - stigma -culturally preferred coping strategies, and cultural or religious appropriateness of the services	Familism Dementia is normal part of ageing Not seeking help due to barriers such as language barriers, migration, and ethnicity, societal perception about dementia, ageing, and socio-cultural and religious factors Stigma	

Appendix 3: Patient Information Sheet (PIS)



Manchester
Metropolitan
University

CARING FOR CAREGIVERS

Exploring the experience of South Asian caregivers of people with dementia in the Greater Manchester area

Participant Information Sheet
(Version 1, Date 25/03/2016)

I would like to invite you to take part in our research project which is being conducted to develop a better understanding of the care giving experiences of South Asian family members with dementia. This study is being conducted as part of my doctorate training at Manchester Metropolitan University. Before you decide whether to take part, it is important that you understand why the research is being carried out and what this study will involve. Please take time to read the following information carefully and discuss it with family or friends then decide if you wish to take part.

What is the purpose of this research?

In the UK, the number of people with dementia from different cultural and ethnic background is increasing. Unpaid 'carers 'especially women caregivers are an important source of providing care to the person with dementia. Talking to the family members about their experiences can help to give health professionals a better understanding and help to identify how they can best be supported by our local health and social services.

Why have I been invited to take part in this research?

You have been invited to take part in this research because I understand you are from our local South Asian community and have experience in supporting/caring for a person with dementia for 6 months or over.

Do I have to take part?

There is no obligation on you to take part in this study. It is entirely your decision to take part and you do not have to give a reason if you do not want to take part. Also, you can withdraw from the study at any time without giving any reason. You should take your time to think about

1

taking part in this study. You can ask questions if you need more information, or if there are things you do not understand about the study.

What does taking part involve?

You will be asked to read and sign a consent form. You will be asked to provide some basic information about yourself and your family member with dementia. You will then be asked to take part in a one-to-one interview with the researcher. The conversation will cover how you find supporting/caring for the person with dementia, how you think and feel about the role, what have been the more difficult/positive aspects and what helps you cope. There are no right or wrong answers as the study is interested in hearing about your personal experience. The interview will last approximately 40 minutes to one hour. It will take place at a date, location and time which is convenient to you. The interview will be digitally audio recorded and transcribed (typed into text). However, you will also have the choice to participate in the interview without having it audio-recorded. The transcription will only be completed by myself and all identifying information will be omitted for confidentiality purposes.

What are the possible disadvantages and risks of taking part?

There are no major risks involved in taking part in this study. The study does not involve any physical examination or blood test. Your comfort and welfare as a participant in the study will be considered during the interviews.

What are the possible benefits of taking part?

There are no immediate benefits to you. If you would like to know more about memory problems, I will let you know of an appropriate person you can contact who will be able to help you with more information.

What if there is a problem?

If you have any questions or concerns about any aspect of this study, you can contact the researcher who will do their best to answer your questions. You can also contact the study supervisor, Prof Josie Tetley at the Faculty of Health Ageing & Social Care, The Manchester Metropolitan University, Brooks Building, 53 Bonsall Street, Manchester, M15 6GX, or on 0161 247 2529.

You can also contact the Research & Innovation Manager of the faculty on 0161-276 2000.

Will information about me remain confidential?

All your personal details will be kept strictly confidential and will not be shared with anyone beyond the supervisory team. Any information that you give me as part of this research will not be discussed with any third parties including your doctors, except in rare circumstances when I believe that not sharing such information will put your health and wellbeing at an immediate risk. I will inform you beforehand if such circumstances do arise during your participation in this study.

What will happen to the results of the research study?

The result of the study will be written up and submitted as a research project as a part of doctoral research project. The results may also publish as a research paper. We will publicise the findings from the research study to academics, health and social care professionals and our South Asian community groups so that all these groups (including our local South Asian communities) can benefit from what we learn. We will publish the findings in scientific journals and also make oral presentations to academics, health professionals, and our local South Asian communities and community groups. When publicising the findings from the research, we will not use individuals' real names and ensure that confidentiality and privacy of all those taking part in the research is maintained throughout.

Contact details of the researcher

Researcher: **Ambily Sathish; a.sathish@stu.mmu.ac.uk**

Address: Faculty of Health, Psychology & Social Care
Manchester Metropolitan University
Brooks Building, 53 Bonsall Street
Manchester
M15 6GX
Phone number-0161-247-2529, Mob- 07739120575

Appendix 4: Informed Consent Form

Consent Form

Title of Project: Caring for caregivers: Exploring the experience of South Asian caregivers of people with dementia in the Greater Manchester area.

Ethics Ref No:

Name of Researcher: xxxx

Please initial all boxes

1 I have read and understand the information sheet dated 25/03/2016(version 1) for this study and I have had the opportunity to ask questions about the study. ☐

2 I have read and understand the information sheet dated 25/03/2016(version 1) for this study and I have had the opportunity to ask questions about the study. ☐

3 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that if I withdraw this will not affect my health care or my legal rights in any way. ☐

4 I understand that if I withdraw from the study the researchers will use the information I have provided up to that point, unless I indicate that I do not want them to. ☐

5 I understand that if I withdraw from the study the researchers will use the information I have provided up to that point, unless I indicate that I do not want them to. ☐

6 I agree to the interview being audio recorded ☐

7 I understand that the information I give to the researchers will only be used for the purposes of research and direct quotes by me may be used anonymously in the publications. ☐

8 I understand that if the researchers hear or observe anything that causes serious concern about my health, safety or well-being, they have a duty to inform my GP or another appropriate professional. ☐

9 I agree to take part in the study. ☐

___________________________ _________________ _________________

Name of Participant Date Signature

___________________________ _________________ ________________

Researcher taking consent Date Signature

Appendix 5: Ethics Approval Letter

Manchester Metropolitan
University

Faculty of Health,
Psychology & Social Care

Brooks Building
Birley Fields Campus
53 Bonsall Street
Manchester
M15 6GX

+44 (0)161 247 2569

HPSCresearchdegrees@mmu.ac.uk

M E M O R A N D U M

FACULTY ACADEMIC ETHICS COMMITTEE

To: Ambily Sathish

From: Prof Carol Haigh

Date: 28/06/2017

Subject: Ethics Application 1493

Title: Caring for caregivers: Exploring the experience of South Asian caregivers of people with dementia in the Greater Manchester area

---

Thank you for your application for ethical approval.

The Faculty Academic Ethics Committee review process has recommended approval of your ethics application. This approval is granted for 42 months for full-time students or staff and 60 months for part-time students. Extensions to the approval period can be requested.

If your research changes you might need to seek ethical approval for the amendments. Please request an amendment form.

We wish you every success with your project.

Prof Carol Haigh
Chair
Faculty Academic Ethics Committee

INVESTORS IN PEOPLE | Champion

www.mmu.co.uk

Appendix 6: Interview Schedule

Interview Schedule

Caring for the Caregivers: Exploring the Experience of South Asian Carers of People with Dementia in the Greater Manchester Area: An IPA study

Before starting the interview:

Brief introduction of the study and obtain informed consent. Collect demographic features of the participant and the person with dementia.

This project is looking into the experience of caregivers who is caring for a family member with dementia.

This is an informal interview, there are no right or wrong answers.

Participation in this study is entirely voluntary. I will ask you some questions, but it is your space to speak about your experiences therefore I will not speak at times but will be listening to you. Where needed, I might ask some follow-up questions to get more detail or if the conversation feels as if it is going off topic I will re -direct you back.

Please feel free to share as little or as much you feel comfortable with. If there is any question which you do not want to answer than do let me know or give me a cue to agree with the participant] and we can move on.

You can take a break during the interview if it feels too upsetting to talk about a particular experience. I will check with you afterwards if you wish to continue with the interview.

Prompts to use in the interview:

Would you mind telling me more about that…?
How did/does that make you feel…?
Can you tell me what you mean by that…?
What do you feel that means to you that…?

Main questions

1. **Can you tell me how you came to be in this role of supporting x?**

Prompts/follow-up questions:

- Was it a voluntary decision? Why? Why not others?

2. **What was your expectations of the role, and has it lived up to those?**

Prompts/follow-up questions:

- Were your expectations influenced by any factors?
- Any differences in the role, have you changed the way you support x from the start to now?

3. **Did you have any preparation to take the care role?**

Prompts/follow-up questions:

- Any expert guidance/advise, research or reading

4. **Can you tell me how it is like looking after x?**

Prompts/follow-up questions:

- Can you describe a typical day?
- What difficulties does x have now that x did not have before the dementia?

- What do you have to help x with now which you did not have before?

5. **Could you tell me something about the positive aspects of caregiving?**

Prompts/follow-up questions:

- How did this make you feel?
- What is it means to you?
- What do you feel that has been influenced by?
- Have you made any positive changes to your life?
- Do you feel you have learnt anything from it?

6. **What do you feel have been the more difficult or stressful aspects of caregiving?**

Prompts/follow-up questions:

- What are the differences between a difficult day and a good day? How do you feel after a difficult day?
- What has helped you to manage the difficult aspects?
- What has worked and not worked?
- Impact on others – family, extended family, friends, community

7. **How might things have been different for you if you were not supporting x?**

Prompts/follow-up questions:

  - Would you be working etc?
  - Have you had to stop or 'give up anything? How does that make you feel?

8. **What did help you to cope caregiving?**

Prompts/follow-up questions:

- What helps and does not help?
- Role of family, extended family members, friends, professional services, community groups and networks and religion and spirituality

9. **What support do you think will be useful as a caregiver in Greater Manchester?**

Prompts/follow-up questions:

  - Any support from community/ Council/ government?

<u>Close of Interview</u>

Thank you for taking part. Is there anything else that you wanted to share about your experience which I have not asked you about or you do not feel you have had the chance to speak.

Appendix 7: Caregiver Demographic Collection

Caregiver Demographic Information Collection Tool

1. Age: ____________________ Years

30-39 ☐ 40-49☐ 50-59☐ 60-69 ☐ 70-79 y☐ yes 80 yes and over

2. Gender: Female ☐ Male ☐
3. Ethnicity: Indian or British Indian☐ Pakistani or British Pakistani ☐ Other ☐
4. Religion: Hindu ☐ Muslim☐ Sikh☐ Buddhist ☐ Jain ☐ Christian ☐ Other ☐
5. Marital status: Single ☐ Married☐ Separated ☐ Divorced ☐ Widowed ☐ Other ☐
6. Living with: Living with PWD☐ Living with spouse ☐ Living with family☐ Other ☐
7. 7. Relationship with carer (if applicable) – Carer is: Parent/s Sibling/s Spouse Own child/children Grandchild/children Another relative/s Friend/s
8. Education: No formal schooling ☐ Primary level ☐ Secondary level ☐ Higher education or formal professional qualification/s ☐ Highest qualification obtained: ☐
9. First language: Guajarati ☐ Punjabi ☐ Hindi ☐ Urdu☐ English ☐ Other
10. Years speaking English:
11. English Fluency: Never spoken ☐ Get by ☐ Fluent ☐
12. Place of birth: ___________________________ (Town and Country)

Asia ☐ India South Asia ☐ – Pakistan South Asia☐ Other ☐

Other _____________________

13. Age at migration time: _______Years (Child (Up to 11 years) Teenager (12 – 19 years)

14. Number of years lived in the UK: ____ Years Less than a year □ 1 – 5 years □ Longer (i.e. over 5 years)

15. Number of years caring for PWD: _______________________

16. Medical Information

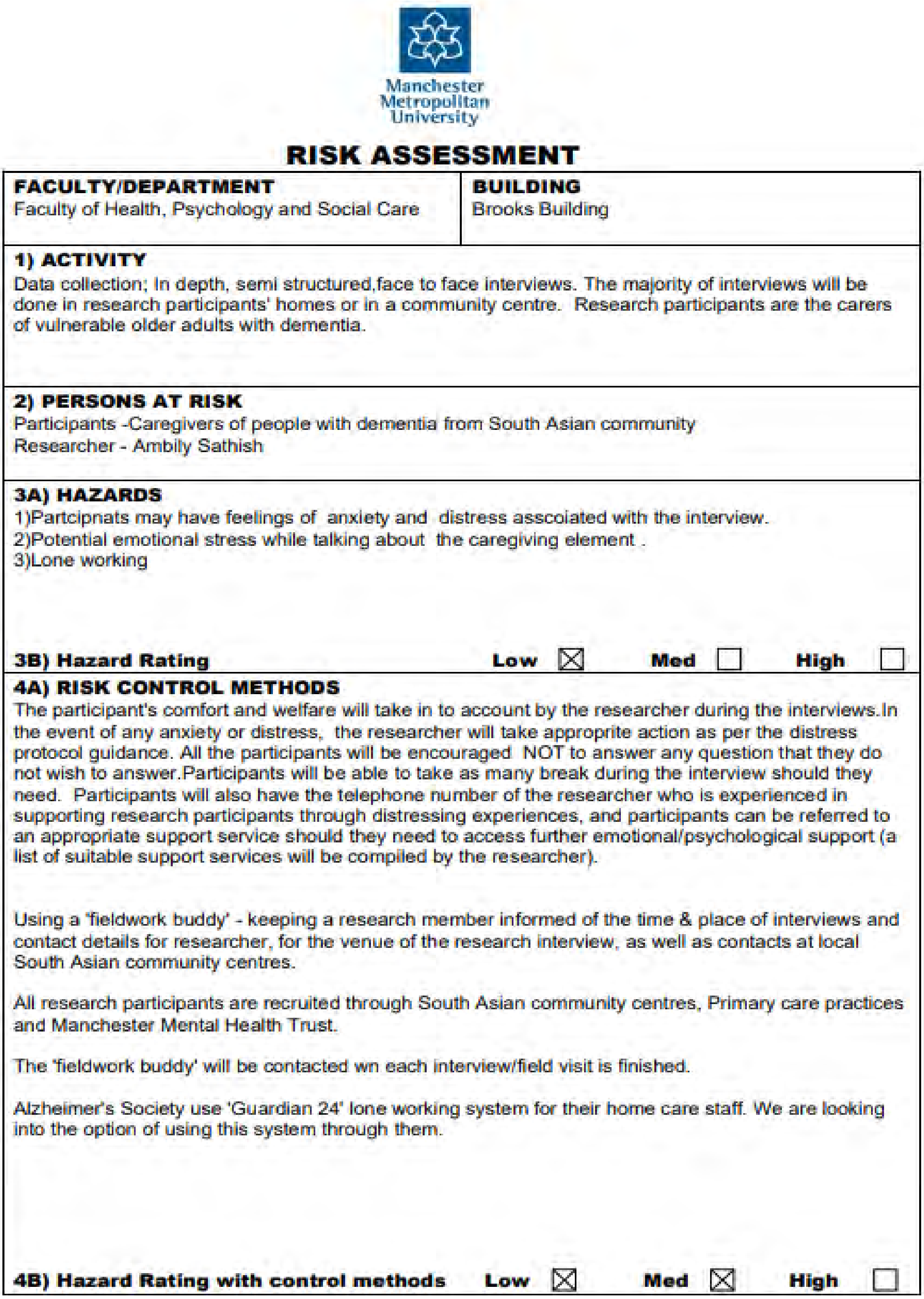
Diabetes: Yes / No ; Heart disease: Yes / No ; Difficulties with vision: Yes / No Difficulties with mobility (i.e. walking and moving about): Yes / No Notes/Details below: ------------------------

----

----

17. Depression (i.e. diagnosed): Yes / No

Appendix 8: Risk Assessment Form



Manchester Metropolitan University

RISK ASSESSMENT

FACULTY/DEPARTMENT Faculty of Health, Psychology and Social Care	**BUILDING** Brooks Building

1) ACTIVITY

Data collection; In depth, semi structured,face to face interviews. The majority of interviews will be done in research participants' homes or in a community centre. Research participants are the carers of vulnerable older adults with dementia.

2) PERSONS AT RISK

Participants -Caregivers of people with dementia from South Asian community
Researcher - Ambily Sathish

3A) HAZARDS

1)Partcipnats may have feelings of anxiety and distress asscoiated with the interview.
2)Potential emotional stress while talking about the caregiving element .
3)Lone working

3B) Hazard Rating **Low** ☒ **Med** ☐ **High** ☐

4A) RISK CONTROL METHODS

The participant's comfort and welfare will take in to account by the researcher during the interviews.In the event of any anxiety or distress, the researcher will take approprite action as per the distress protocol guidance. All the participants will be encouraged NOT to answer any question that they do not wish to answer.Participants will be able to take as many break during the interview should they need. Participants will also have the telephone number of the researcher who is experienced in supporting research participants through distressing experiences, and participants can be referred to an appropriate support service should they need to access further emotional/psychological support (a list of suitable support services will be compiled by the researcher).

Using a 'fieldwork buddy' - keeping a research member informed of the time & place of interviews and contact details for researcher, for the venue of the research interview, as well as contacts at local South Asian community centres.

All research participants are recruited through South Asian community centres, Primary care practices and Manchester Mental Health Trust.

The 'fieldwork buddy' will be contacted wn each interview/field visit is finished.

Alzheimer's Society use 'Guardian 24' lone working system for their home care staff. We are looking into the option of using this system through them.

4B) Hazard Rating with control methods **Low** ☒ **Med** ☒ **High** ☐

5) FURTHER ACTION REQUIRED Set in place risk control procedures (as described above) with PI and fieldwork buddy. Lone worker guidelines		
NAME AND TITLE OF ASSESSOR	**SIGNATURE**	**DATE**
		REVIEW DATE
SIGNATURE OF DEAN/HEAD OF DEPT.		**DATE**
		REVIEW DATE

Appendix 9: Study Advertisement Inviting Participation

Caring for South Asian Caregivers of people with Dementia

I am a doctoral student from Manchester Metropolitan University. I am interested to study the experience of South Asian people supporting a family member with dementia. We feel it is important to hear your views and experiences. This research could possibly highlight issues that needs to be addressed for the caregivers in South Asian community.

I would like you to consider taking part in this research. Manchester Metropolitan University PhD programme funds my research.

If you are Indian, Bangladeshi or Pakistani, aged over 18 years and caring for a person with dementia I will be interested in talking to you.

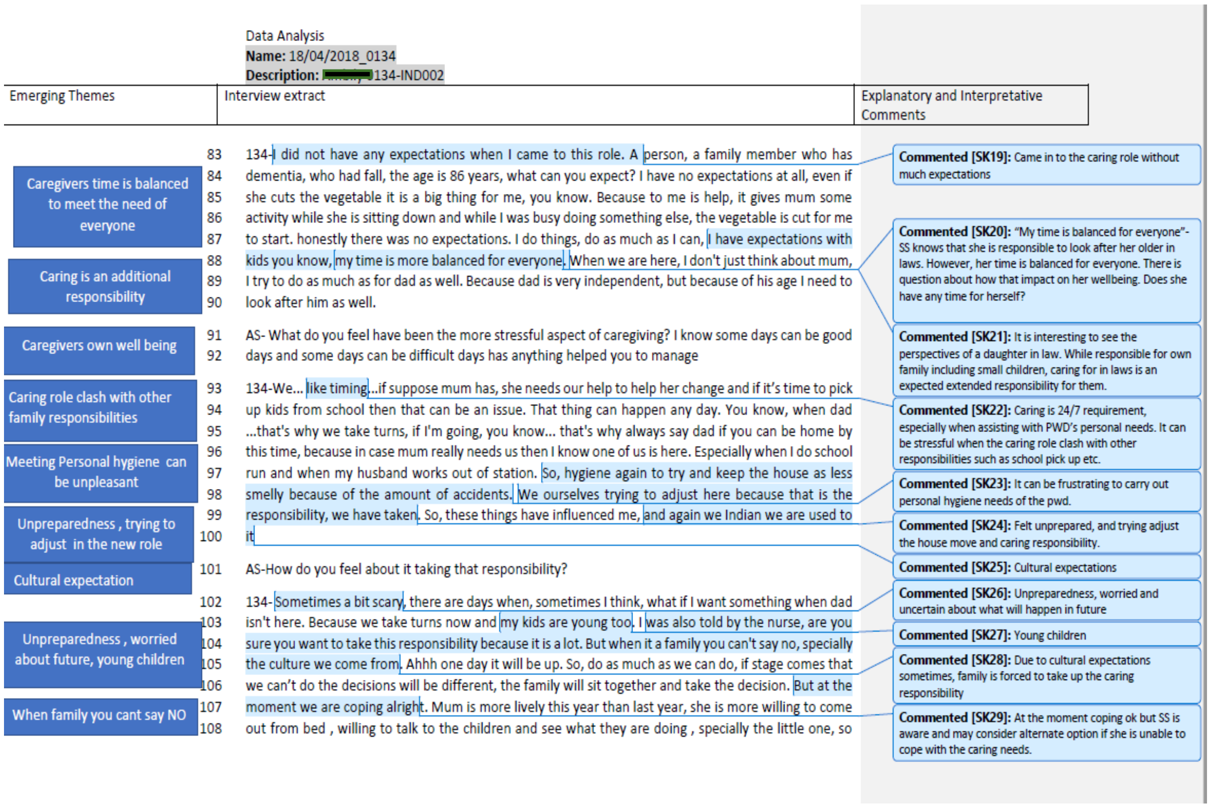
Please contact the researcher If you are interested in learning more about this research project.

Ambily Sathish

Phone-[redacted]

A.sathish@stu.mmu.ac.uk

Appendix 10: Case-by-Case Analysis Example



Data Analysis
Name: 18/04/2018_0134
Description: [redacted]134-IND002

Emerging Themes

- Caregivers time is balanced to meet the need of everyone
- Caring is an additional responsibility
- Caregivers own well being
- Caring role clash with other family responsibilities
- Meeting Personal hygiene can be unpleasant
- Unpreparedness , trying to adjust in the new role
- Cultural expectation
- Unpreparedness , worried about future, young children
- When family you cant say NO

Interview extract

134-I did not have any expectations when I came to this role. A person, a family member who has dementia, who had fall, the age is 86 years, what can you expect? I have no expectations at all, even if she cuts the vegetable it is a big thing for me, you know. Because to me is help, it gives mum some activity while she is sitting down and while I was busy doing something else, the vegetable is cut for me to start. honestly there was no expectations. I do things, do as much as I can, I have expectations with kids you know, my time is more balanced for everyone. When we are here, I don't just think about mum, I try to do as much as for dad as well. Because dad is very independent, but because of his age I need to look after him as well.

AS- What do you feel have been the more stressful aspect of caregiving? I know some days can be good days and some days can be difficult days has anything helped you to manage

134-We... like timing...if suppose mum has, she needs our help to help her change and if it's time to pick up kids from school then that can be an issue. That thing can happen any day. You know, when dad ...that's why we take turns, if I'm going, you know... that's why always say dad if you can be home by this time, because in case mum really needs us then I know one of us is here. Especially when I do school run and when my husband works out of station. So, hygiene again to try and keep the house as less smelly because of the amount of accidents. We ourselves trying to adjust here because that is the responsibility, we have taken. So, these things have influenced me, and again we Indian we are used to it

AS-How do you feel about it taking that responsibility?

134- Sometimes a bit scary, there are days when, sometimes I think, what if I want something when dad isn't here. Because we take turns now and my kids are young too. I was also told by the nurse, are you sure you want to take this responsibility because it is a lot. But when it a family you can't say no, specially the culture we come from. Ahhh one day it will be up. So, do as much as we can do, if stage comes that we can't do the decisions will be different, the family will sit together and take the decision. But at the moment we are coping alright. Mum is more lively this year than last year, she is more willing to come out from bed , willing to talk to the children and see what they are doing , specially the little one, so

Explanatory and Interpretative Comments

Commented [SK19]: Came in to the caring role without much expectations

Commented [SK20]: "My time is balanced for everyone"- SS knows that she is responsible to look after her older in laws. However, her time is balanced for everyone. There is question about how that impact on her wellbeing. Does she have any time for herself?

Commented [SK21]: It is interesting to see the perspectives of a daughter in law. While responsible for own family including small children, caring for in laws is an expected extended responsibility for them.

Commented [SK22]: Caring is 24/7 requirement, especially when assisting with PWD's personal needs. It can be stressful when the caring role clash with other responsibilities such as school pick up etc.

Commented [SK23]: It can be frustrating to carry out personal hygiene needs of the pwd.

Commented [SK24]: Felt unprepared, and trying adjust the house move and caring responsibility.

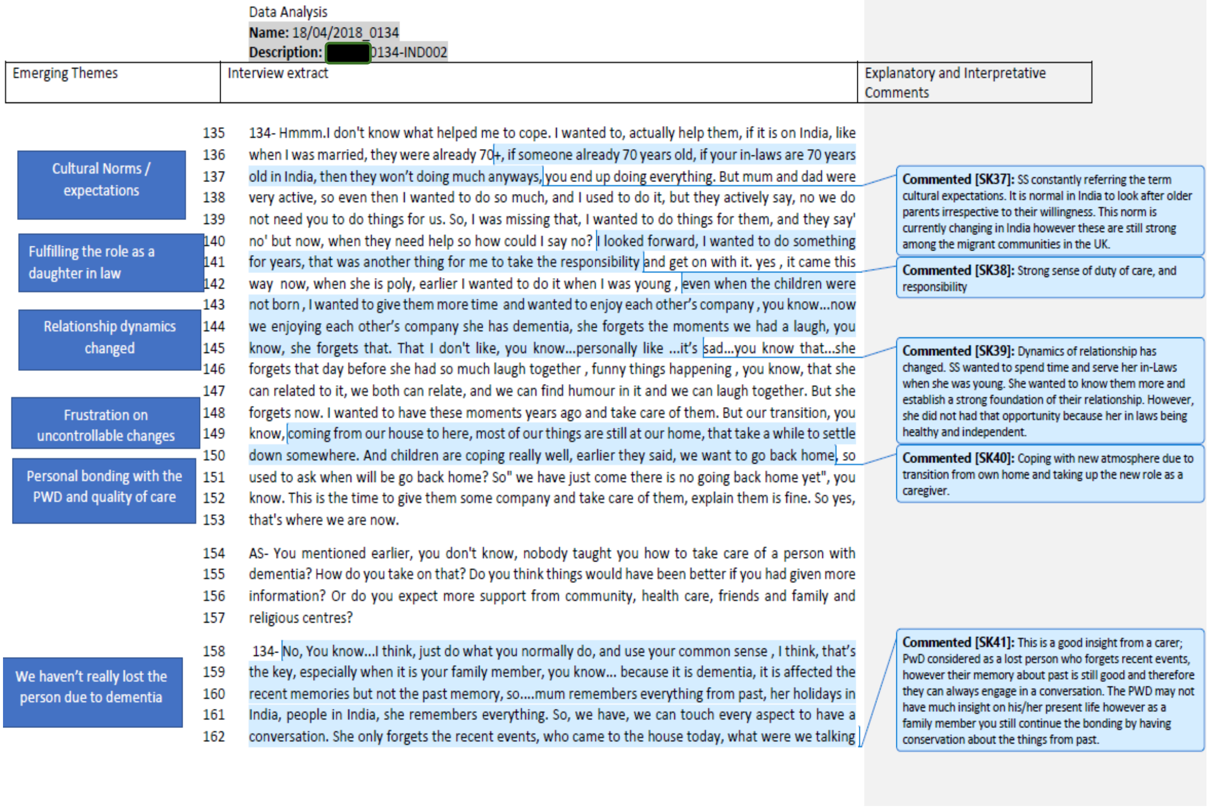
Commented [SK25]: Cultural expectations

Commented [SK26]: Unpreparedness, worried and uncertain about what will happen in future

Commented [SK27]: Young children

Commented [SK28]: Due to cultural expectations sometimes, family is forced to take up the caring responsibility

Commented [SK29]: At the moment coping ok but SS is aware and may consider alternate option if she is unable to cope with the caring needs.



Data Analysis
Name: 18/04/2018_0134
Description: [redacted]0134-IND002

Emerging Themes

- Cultural Norms / expectations
- Fulfilling the role as a daughter in law
- Relationship dynamics changed
- Frustration on uncontrollable changes
- Personal bonding with the PWD and quality of care
- We haven't really lost the person due to dementia

Interview extract

134- Hmmm.I don't know what helped me to cope. I wanted to, actually help them, if it is on India, like when I was married, they were already 70+, if someone already 70 years old, if your in-laws are 70 years old in India, then they won't doing much anyways, you end up doing everything. But mum and dad were very active, so even then I wanted to do so much, and I used to do it, but they actively say, no we do not need you to do things for us. So, I was missing that, I wanted to do things for them, and they say' no' but now, when they need help so how could I say no? I looked forward, I wanted to do something for years, that was another thing for me to take the responsibility and get on with it. yes , it came this way now, when she is poly, earlier I wanted to do it when I was young , even when the children were not born , I wanted to give them more time and wanted to enjoy each other's company , you know...now we enjoying each other's company she has dementia, she forgets the moments we had a laugh, you know, she forgets that. That I don't like, you know...personally like ...it's sad...you know that...she forgets that day before she had so much laugh together , funny things happening , you know, that she can related to it, we both can relate, and we can find humour in it and we can laugh together. But she forgets now. I wanted to have these moments years ago and take care of them. But our transition, you know, coming from our house to here, most of our things are still at our home, that take a while to settle down somewhere. And children are coping really well, earlier they said, we want to go back home, so used to ask when will be go back home? So" we have just come there is no going back home yet", you know. This is the time to give them some company and take care of them, explain them is fine. So yes, that's where we are now.

AS- You mentioned earlier, you don't know, nobody taught you how to take care of a person with dementia? How do you take on that? Do you think things would have been better if you had given more information? Or do you expect more support from community, health care, friends and family and religious centres?

134- No, You know...I think, just do what you normally do, and use your common sense , I think, that's the key, especially when it is your family member, you know... because it is dementia, it is affected the recent memories but not the past memory, so....mum remembers everything from past, her holidays in India, people in India, she remembers everything. So, we have, we can touch every aspect to have a conversation. She only forgets the recent events, who came to the house today, what were we talking

Explanatory and Interpretative Comments

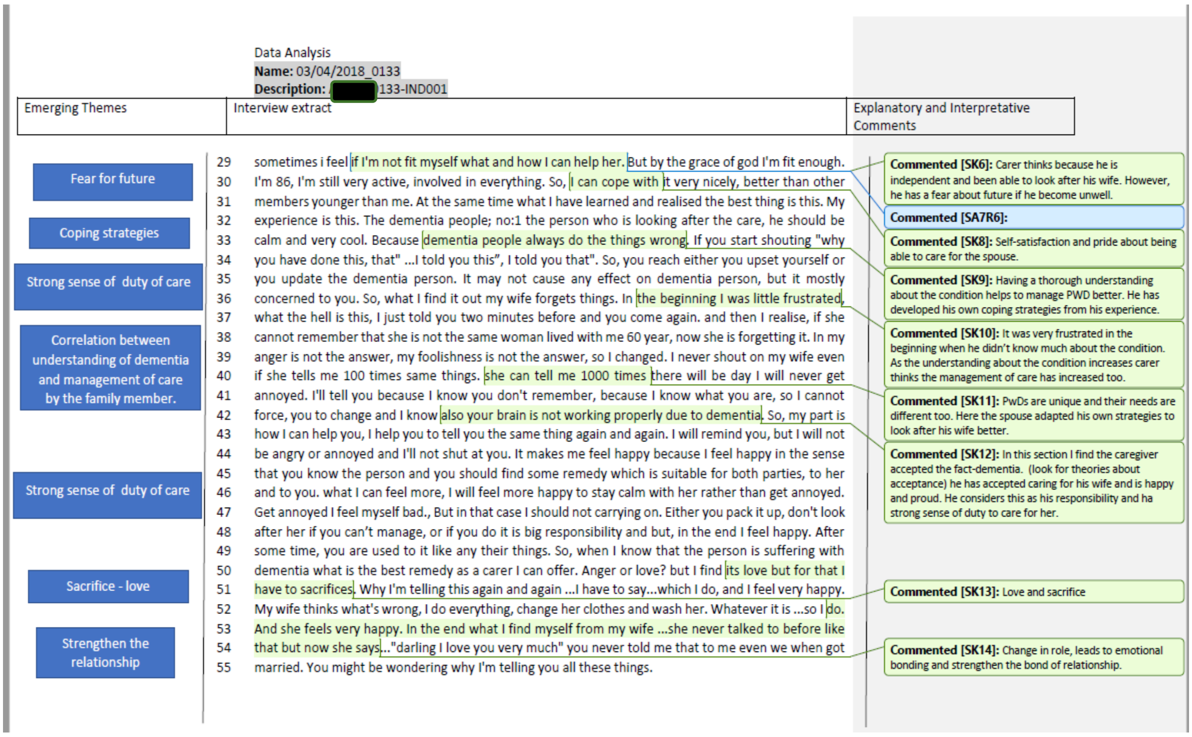
Commented [SK37]: SS constantly referring the term cultural expectations. It is normal in India to look after older parents irrespective to their willingness. This norm is currently changing in India however these are still strong among the migrant communities in the UK.

Commented [SK38]: Strong sense of duty of care, and responsibility

Commented [SK39]: Dynamics of relationship has changed. SS wanted to spend time and serve her in-Laws when she was young. She wanted to know them more and establish a strong foundation of their relationship. However, she did not had that opportunity because her in laws being healthy and independent.

Commented [SK40]: Coping with new atmosphere due to transition from own home and taking up the new role as a caregiver.

Commented [SK41]: This is a good insight from a carer; PwD considered as a lost person who forgets recent events, however their memory about past is still good and therefore they can always engage in a conversation. The PWD may not have much insight on his/her present life however as a family member you still continue the bonding by having conservation about the things from past.



Data Analysis
Name: 03/04/2018_0133
Description: [redacted]133-IND001

Emerging Themes	Interview extract	Explanatory and Interpretative Comments

Emerging Themes:

- Fear for future
- Coping strategies
- Strong sense of duty of care
- Correlation between understanding of dementia and management of care by the family member.
- Strong sense of duty of care
- Sacrifice - love
- Strengthen the relationship

sometimes i feel if I'm not fit myself what and how I can help her. But by the grace of god I'm fit enough. I'm 86, I'm still very active, involved in everything. So, I can cope with it very nicely, better than other members younger than me. At the same time what I have learned and realised the best thing is this. My experience is this. The dementia people; no:1 the person who is looking after the care, he should be calm and very cool. Because dementia people always do the things wrong. If you start shouting "why you have done this, that" ...I told you this", I told you that". So, you reach either you upset yourself or you update the dementia person. It may not cause any effect on dementia person, but it mostly concerned to you. So, what I find it out my wife forgets things. In the beginning I was little frustrated, what the hell is this, I just told you two minutes before and you come again. and then I realise, if she cannot remember that she is not the same woman lived with me 60 year, now she is forgetting it. In my anger is not the answer, my foolishness is not the answer, so I changed. I never shout on my wife even if she tells me 100 times same things. she can tell me 1000 times there will be day I will never get annoyed. I'll tell you because I know you don't remember, because I know what you are, so I cannot force, you to change and I know also your brain is not working properly due to dementia. So, my part is how I can help you, I help you to tell you the same thing again and again. I will remind you, but I will not be angry or annoyed and I'll not shut at you. It makes me feel happy because I feel happy in the sense that you know the person and you should find some remedy which is suitable for both parties, to her and to you. what I can feel more, I will feel more happy to stay calm with her rather than get annoyed. Get annoyed I feel myself bad., But in that case I should not carrying on. Either you pack it up, don't look after her if you can't manage, or if you do it is big responsibility and but, in the end I feel happy. After some time, you are used to it like any their things. So, when I know that the person is suffering with dementia what is the best remedy as a carer I can offer. Anger or love? but I find its love but for that I have to sacrifices. Why I'm telling this again and again ...I have to say...which I do, and I feel very happy. My wife thinks what's wrong, I do everything, change her clothes and wash her. Whatever it is ...so I do. And she feels very happy. In the end what I find myself from my wife ...she never talked to before like that but now she says..."darling I love you very much" you never told me that to me even we when got married. You might be wondering why I'm telling you all these things.

Commented [SK6]: Carer thinks because he is independent and been able to look after his wife. However, he has a fear about future if he become unwell.

Commented [SA7R6]:

Commented [SK8]: Self-satisfaction and pride about being able to care for the spouse.

Commented [SK9]: Having a thorough understanding about the condition helps to manage PWD better. He has developed his own coping strategies from his experience.

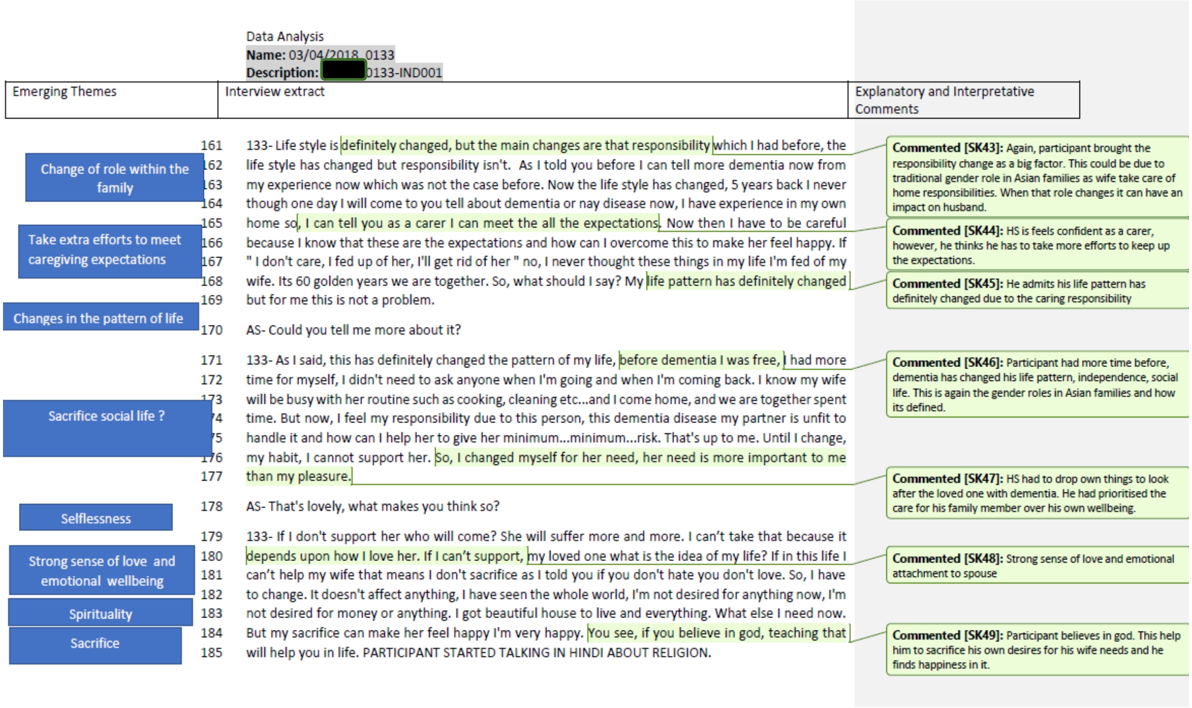
Commented [SK10]: It was very frustrated in the beginning when he didn't know much about the condition. As the understanding about the condition increases carer thinks the management of care has increased too.

Commented [SK11]: PwDs are unique and their needs are different too. Here the spouse adapted his own strategies to look after his wife better.

Commented [SK12]: In this section I find the caregiver accepted the fact-dementia. (look for theories about acceptance) he has accepted caring for his wife and is happy and proud. He considers this as his responsibility and ha strong sense of duty to care for her.

Commented [SK13]: Love and sacrifice

Commented [SK14]: Change in role, leads to emotional bonding and strengthen the bond of relationship.



Data Analysis
Name: 03/04/2018_0133
Description: [redacted]0133-IND001

Emerging Themes	Interview extract	Explanatory and Interpretative Comments

Emerging Themes:

- Change of role within the family
- Take extra efforts to meet caregiving expectations
- Changes in the pattern of life
- Sacrifice social life ?
- Selflessness
- Strong sense of love and emotional wellbeing
- Spirituality
- Sacrifice

133- Life style is definitely changed, but the main changes are that responsibility which I had before, the life style has changed but responsibility isn't. As I told you before I can tell more dementia now from my experience now which was not the case before. Now the life style has changed, 5 years back I never though one day I will come to you tell about dementia or nay disease now, I have experience in my own home so, I can tell you as a carer I can meet the all the expectations. Now then I have to be careful because I know that these are the expectations and how can I overcome this to make her feel happy. If " I don't care, I fed up of her, I'll get rid of her " no, I never thought these things in my life I'm fed of my wife. Its 60 golden years we are together. So, what should I say? My life pattern has definitely changed but for me this is not a problem.

AS- Could you tell me more about it?

133- As I said, this has definitely changed the pattern of my life, before dementia I was free, I had more time for myself, I didn't need to ask anyone when I'm going and when I'm coming back. I know my wife will be busy with her routine such as cooking, cleaning etc...and I come home, and we are together spent time. But now, I feel my responsibility due to this person, this dementia disease my partner is unfit to handle it and how can I help her to give her minimum...minimum...risk. That's up to me. Until I change, my habit, I cannot support her. So, I changed myself for her need, her need is more important to me than my pleasure.

AS- That's lovely, what makes you think so?

133- If I don't support her who will come? She will suffer more and more. I can't take that because it depends upon how I love her. If I can't support, my loved one what is the idea of my life? If in this life I can't help my wife that means I don't sacrifice as I told you if you don't hate you don't love. So, I have to change. It doesn't affect anything, I have seen the whole world, I'm not desired for anything now, I'm not desired for money or anything. I got beautiful house to live and everything. What else I need now. But my sacrifice can make her feel happy I'm very happy. You see, if you believe in god, teaching that will help you in life. PARTICIPANT STARTED TALKING IN HINDI ABOUT RELIGION.

Commented [SK43]: Again, participant brought the responsibility change as a big factor. This could be due to traditional gender role in Asian families as wife take care of home responsibilities. When that role changes it can have an impact on husband.

Commented [SK44]: HS is feels confident as a carer, however, he thinks he has to take more efforts to keep up the expectations.

Commented [SK45]: He admits his life pattern has definitely changed due to the caring responsibility

Commented [SK46]: Participant had more time before, dementia has changed his life pattern, independence, social life. This is again the gender roles in Asian families and how its defined.

Commented [SK47]: HS had to drop own things to look after the loved one with dementia. He had prioritised the care for his family member over his own wellbeing.

Commented [SK48]: Strong sense of love and emotional attachment to spouse

Commented [SK49]: Participant believes in god. This help him to sacrifice his own desires for his wife needs and he finds happiness in it.