EXPLORING THE EXPERIENCES OF
INDIAN GUJARATI PEOPLE IN THE LONDON AREA
SUPPORTING A PERSON WITH DEMENTIA

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ABSTRACT

Dementia care-giving is often constructed as burdensome and stressful. However, there is a growing interest to explore what the positive aspects of care-giving might be. Furthermore, there is little research which has focussed on the experiences of dementia care-giving in minority ethnic groups. Existing research mostly homogenises different ethnic groups, particularly different South Asian communities. It is argued that little is known about the care-giving experiences of specific South Asian subgroups but early research suggests variations in care-giving exists between them. The aim of the present study was to gain an insight into how some British Indian Gujaratis, a specific South Asian cultural linguistic group, felt about supporting a family member with dementia, particularly what care-giving meant to them, what were the positive and negative aspects of care-giving and what helped them to cope.

The present study adopted a qualitative methodology using semi-structured interviews. Ten participants' accounts were analysed using Interpretative Phenomenological Analysis. Four main themes emerged capturing the impact of dementia care-giving for caregivers at an intrapsychic, dyadic, family and community and culture level. Each theme had a number of subordinate themes. Consistent with previous findings were the themes of psychological impact, growth and development, loss of relationship, reciprocity and family support. The study highlighted new themes at a community and culture level around expectations and norms and knowing and talking about dementia. It also highlighted the role religion and spirituality might play in helping some to manage the negative impact of care-giving. The findings have both clinical and research implications which are highlighted.

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CHAPTER ONE: INTRODUCTION

Overview of research

There is a growing interest in the experiences of informal caregivers providing support to family members with dementia. This perhaps in part is due to the increasing incidence rates and cost of care of dementia in the UK (Luengo-Fernadez, Leal & Gray, 2010). Family members are seen as an important source in providing dementia care (National Audit Office, 2007) and subsequently reducing demands on services.

Dementia care-giving is predominately constructed as burdensome and stressful and thus much of the research has focussed on this area. Certain perspectives such as the positive aspects of care-giving, what helps caregivers to cope and the experience of ethnic minority groups is profoundly limited within dementia care-giving research (Milne & Chryssanthopoulou, 2005). Studies which have looked at the care-giving experiences of ethnic minority groups have mostly homogenised different ethnic groups. Despite research suggesting that ethnic variance in care-giving amongst different South Asian subgroups exists (Parveen, Morrison & Robinson, 2011; Burholt & Hobbs, 2010). One particular South Asian subgroup is Indian Gujaratis, but no studies in the UK have specifically examined their views of dementia care-giving.

This chapter aims to highlight gaps in the current literature on dementia care-giving and the importance in examining 'other' experiences. In doing so, the underrepresentation of 'South Asian's' in dementia and mental health services is considered along with the problems of homogenising different ethnic groups in research.

1.1 Review of existing literature

Relevant literature was identified by searching the electronic databases: PsycArticles, PsychInfo and Pubmed. These were considered the most suitable psychological and medical search providers available at the time. The specific terms used for these searches were: 'Gujarati', 'Gujerati', 'Indian', 'South Asian', 'Alzheimer's' and 'dementia care*' was added as a prefix to search for multiple root words such as 'caregiving', 'care-giving', 'caregiver', 'care-giver' and 'carers'. The keywords were required to be present in the title or abstract of articles. See Appendix B for a summary of the search results.

As the focus of the current study is on the dementia care-giving experiences of Indian Gujaratis in the UK, a specific cultural-linguistic group, it was expected the search would generate a limited number of articles. Therefore the inclusion criteria were not too stringent. Only articles published in English were accepted but no start or end date was specified. There were no methodological limitations; studies could be both qualitative and quantitative. However, papers were then sorted by their relevance to the research topic. Reference lists of included articles were also reviewed to identify sources not found in the initial database search. In addition, related books, national statistics and health policy documents were reviewed for key themes.

Due to the limited research on the dementia care-giving experience of minority ethnic groups within the UK, research from other countries has been used for points of reference. However, there are limitations in comparing between different populations and cultural linguistic groups (Daker-White et al., 2002).

1.2 Dementia

1.2.1 The construct of dementia

The word dementia originally comes from the Latin *demens*, meaning 'without a mind' (Walsh, 2006). From the 18th century the term came into common

usage particularly within a clinical and legal context. As a medical term it developed throughout the 19th century and clinically it was used very broadly, particularly referring to those with mental health difficulties (Berrios, 1987). In 1907, Dr Alois Alzheimer published the first clinical case of dementia by identifying a cluster of symptoms which have shaped our current understanding of the condition (Cheston & Bender, 1999). However, it was a German psychiatrist, Emil Kraepelin, in 1910 who classified Alzheimer's dementia as a 'disease'. It has been suggested that Kraepelin's classification was not based on objective findings but rather on political and financial motivations (Cheston & Bender, 1999).

Successive historical convergences have shaped the current notion of dementia (Ames, Burns & O'Brien, 2010). The International Classification of Diseases (ICD-10, World Health Organisation, 1992) defines dementia in the following way:

> *"...a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capability, language, and judgement."*

To meet the diagnostic criteria of ICD-10, the symptoms associated with dementia need to be present for a minimum of six months. In addition, these symptoms have to be impacting on the person's activities of daily living and relationships.

By the 21st century, along with Alzheimer's, a number of different subtypes of dementia had been classified including vascular dementia and less common presentations such as frontal lobe dementia and Lewy Body dementia. The differentiation between these subtypes is based on the profile of cognitive impairment at the mild to moderate stage of the condition and the parts of the brain which is believed to have suffered tissue loss, referred to as atrophy.

Dementia is perceived as a progressive and in most cases an irreversible condition.

From the 1980's onward there were many criticisms towards the biomedical model of dementia and how the condition had been constructed. The main proponent of these criticisms was Kitwood (1987) who believed the model was deficits-focussed, scientifically flawed and therapeutically nihilistic. Others also commented on how the biomedical model ignored the role of psychological factors (Baldwin & Capstick, 2007). Building on the criticisms of Kitwood, Marshall (2004) believed that dementia should be understood within a social model where it is highlighted that a person with a diagnosis of dementia may have difficulties with some cognitive functions but it is how they are treated by others and marginalised in society which results in their 'disability'. Some have suggested that family members or friends supporting a person with dementia have 'accepted' the dominant biomedical explanation (Kitwood, 1987; Gubrium, 1986) and this has impacted on how the care-giving relationship has been constructed for caregivers (King, 1997).

1.3 Dementia in the UK

1.3.1 Prevalence rates

The number of people with dementia in the UK has been reported to range from 684,000 (Knapp et al., 2007) to 822,000 (Luengo-Fernadez, Leal & Gray, 2010). It is believed that around 15,000 are from ethnic minority groups (Department of Health [DoH], 2009). This figure will rise as individuals from these populations get older in the UK, as the incidence of dementia increases with age (Lievesley, 2010). Local prevalence studies from the UK indicate that dementia among older people from ethnic minority groups is similar or higher than that of their UK White counterparts (Bhatnagar & Frank, 1997; Livingston et al., 2001). However, there are a number of methodological difficulties which exist when studying and diagnosing dementia amongst those from ethnic minority groups. This includes small sample sizes, lack of valid diagnostic and screening tools and a tendency for epidemiological studies to amalgamate

different ethnic groups (Shah, Oommen & Wuntakal, 2005). However, when a study by Adelman et al., (2011) used culturally valid cognitive screening tests, it found an increased prevalence of dementia in African-Caribbeans compared to their White UK-born counterparts.

1.3.2 National guidelines and policies

In the last few years dementia has received much focus in terms of government priorities and policy attention. This is largely due to the estimated cost it has for the UK economy, with £23 billion per year reported (Luengo-Fernadez, Leal & Gray, 2010). Another issue highlighted in policies appears to be the concern that people from minority ethnic populations are underrepresented in dementia services (Daker-White et al., 2002), despite, as stated earlier, similar prevalence rates reported with their White counterparts. The National Dementia Strategy (DoH, 2009) and guidelines on dementia by the National Institute for Clinical Excellence and Social Care Institute for Excellence (NICE-SCIE, 2007) emphasise that health care professionals should identify the individual needs of people with dementia and their care network arising from aspects of difference such as age, gender, ethnicity and religion.

1.4 Dementia care-giving

1.4.1 Care network

Early on those believed to have had dementia were cared for in Victorian asylums but after that period little was known about how individuals with dementia were supported (Walsh, 2006). With the introduction and emphasis on community care within the NHS in the 1980's, those with dementia were cared for at home or in a residential or nursing home. A recent picture in the UK suggests approximately two thirds of people with dementia are cared for by their family members within the community (National Audit Office, 2007).

It has been found that in many cases, family members, spouses and friends are providing some level of care and support to the person with dementia before it has been diagnosed (Plassman et al., 2007) and often with no formal training or limited prior knowledge of dementia (Cormac & Tihanyi, 2006). Family members providing care are often referred to as informal 'carers' or 'caregivers'. These concepts have entered common usage by becoming a permanent fixture on the social policy agenda (Godfrey & Townsend, 2001). Feinburg & Pilisuk (1993) define informal caregivers as "one who provides care without pay and whose relationship to the care recipient is due to personal ties: family, friends, or neighbours who may be primary or secondary caregivers, provide full time or part time help, and live with the person being cared for or separately" (p.3).

1.4.2 Impact of dementia care-giving on caregivers

Negative impact

Many have described dementia care-giving as stressful. It is considered to be more physically and emotionally demanding and has been found to result in a greater degree of strain compared with other forms of care-giving (Levin, Moriarty & Gorbach, 1994). NICE–SCIE Guidelines (2007) state that caregivers supporting a family member with dementia, who experience psychological distress and negative psychological impact, should be offered psychological therapy. Care-giving stressors are commonly referred to as 'caregiver burden' in the literature. Cooper et al., (2006) describe this to be a heterogeneous concept comprising of diverse factors relating to the caregiver and care-recipient

The level of stress or burden experienced by those caring for a relative with dementia appears to reflect a number of factors. These include managing tasks of everyday life (Pollitt, Anderson & O'Connor, 1991), the continued and deteriorating nature of the condition (Godfrey & Townsend, 2001), managing challenging behaviour (Reddy & Pitt, 1993) and the loss of the person with dementia as they used to be including loss of relationship and meaningful

interaction (Ingebretsen & Solem, 1997). Care-giving has been found to have a long term impact on caregivers such as significantly affecting quality of life and psychological well-being (Levin, Moriarty & Gorbach, 1994; Aneshenel et al. 1995; Carers UK, 2004). This may be due to the impact of care-giving such as reduced social participation, loneliness and isolation (Rodriguez et al., 2003). The psychological impact experienced by caregivers may also compromise the quality of care provided to the care-recipient (Gainey & Payne, 2006).

The transactional model of stress and coping described by Lazarus and Folkman (1984) is often used as a theoretical framework for understanding caregiver distress. In this model, care-giving situations are not seen as inherently stressful but can be experienced in this way by the individual following an appraisal process. In the first stage, appraisals of the situation are influenced by the person's previous experiences and their background. The second stage of appraisals involves the individual deciding if they feel capable of managing the situation. The secondary appraisal is followed by the selection of a coping strategy. Stress is believed to occur when there is a disparity between the demands of the situation and the coping resources available to the person to manage the event (Lazarus, 2000).

Other models have also been used to understand caregiver distress. For example, in Poulshock and Deimling's model (1984), dementia care-giving is seen as leading to strain. This can present itself in a number of ways that can be made worse by other factors such as challenging behaviour or the caregiver's physical or psychological ill-health. Strain can also be ameliorated by support and coping mechanisms. Another model by Pearlin et al., (1990) describes the different contexts that can trigger stress for caregivers. This includes the background context (availability of support and the impact of other circumstances in the caregiver's life), primary stressors caused by the care-recipient's condition (level of input required by the care-recipient and their psychological and behavioural symptoms), secondary role strains (for the caregiver in their life), and strains at an individual level such as perceived ability to manage and feeling stuck in the role.

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Positive impact and gains of care-giving

Theoretical models of care-giving and the literature focus largely on the negative impact of care-giving, despite recent studies showing that aspects of care-giving can be experienced as positive (Ayres, 2000; Kim, Schulz & Carver, 2007). There are many reasons why the positive aspects of care-giving should be better understood. For example, it has been found to potentially buffer and act as a protective factor against the negative consequences of care-giving (Hilgeman et al., 2007). Kramer (1997) suggests that "a lack of attention to the positive dimensions of care-giving seriously skews perceptions of the care-giving experience and limits our ability to enhance theory of caregiver adaptation" (p.218). Cheston and Bender (1999) have also criticised framing the care-giving relationship as solely in terms of burden and stress, believing that this prevents the examination of other forms of relationships. Much of the research on the positive aspects of care-giving is not specific to dementia care-giving as there is limited research within this area.

There seems to be no consistent or fixed definition of 'caregiver gain' in the literature. However, like 'caregiver burden', it may encompass many different ideas. Kramer (1997) describes caregiver gains as "any positive affective or practical return that is experienced as a direct result of becoming a caregiver such as the satisfactions, rewards, gratifications, or benefits that are perceived (p.240)". Positive gains experienced by caregivers can be short term or can move towards longer term positive outcomes (Siegel & Schrimshaw, 2007). For example, personal growth, a longer term positive outcome, can be the result from finding meaning in challenging circumstances (Davis & Morgan, 2008).

One of the important factors in finding meaning in care-giving appears to be the relationship exchange (reciprocity) between the caregiver and care-recipient (Cartwright et al., 1994; Nolan, Grant & Keady, 1996). A longitudinal study by Hellstrom, Nolan and Lundh (2007) found that important strategies used by spouses for living positively with dementia included maintaining a

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sense of couplehood (partnership) and maintaining involvement through a nurturing relational context.

1.5 Questions on ethnic minority groups accessing dementia services

Older people from minority ethnic groups in the UK have high rates of general practice registration and consultation but their rates of contact with dementia services are apparently low (Shah, Oommen & Wuntakal, 2005). As previously highlighted, the underrepresentation of ethnic minority groups in dementia services is also a policy concern (Daker-White et al., 2002). The findings from several studies have been used to explain this disparity, which will now be discussed. However, it is first important to note that many of these studies, except those stated, have homogenised different ethnic groups. This includes the amalgamation of: Asian and Black groups, different South Asian subgroups (i.e. Indian, Pakistani and Bangladeshi) and White groups. The problems with homogenising ethnic groups will be discussed further on.

1.5.1 Common understandings

Knowledge and understanding of dementia

A lack of knowledge and understanding of dementia, reported by some studies (e.g. Adamson, 2001; La Fontaine et al., 2007; Moreland, 2001; Bowes & Wilkinson, 2003), has been highlighted as one reason why minority ethnic groups are underrepresented within dementia services. Other findings commonly cited is that minority ethnic groups are more likely than their White counterparts to conceptualise the symptoms of dementia as part of "normal ageing" (e.g. Patel et al., 1998; Purandare, Luthra & Swarbrick, 2007; Mukadam, Cooper & Livingston, 2010). However, Rimmer et al., (2005) conducted the 'Facing Dementia Survey' with 1200 members of the general public, 600 primary caregivers for a person with Alzheimer's and 96 persons with Alzheimer's across European countries including the UK. The study found that most respondents were unaware of the early stage symptoms of Alzheimer's and felt that the symptoms were due to old age. This suggests

that a lack of knowledge of dementia is not just limited to ethnic minority groups but also exists with other populations.

Stigma of dementia

A study by Patel et al., (1998) found that dementia, like mental illness, was regarded as shameful in their sample of South Asians. A recent study by La Fontaine et al., (2007) explored the understanding of dementia amongst a non-clinical population of White British and British South Asians (Punjabi and Hindi speaking Indians). They found that with British Indian participants there was a sense of stigma about dementia and seeking help from services. Mackenzie (2006) found that in their sample, South Asians believed that having a family member with dementia may affect the marriage prospects of others in the family and there was a pressure to not disclose dementia to others in the community. However, a study by the Alzheimer's Society (2008) explored the experiences of individuals with dementia and their family members (caregivers) from different parts of the UK. The study had only a small number of participants from minority ethnic backgrounds. One of the themes which emerged was that the stigma of dementia was "pervasive" and the responses of people close to the participants had been negative. This suggests that the stigma of dementia is again not limited to ethnic minority groups or 'South Asians' specifically and that it exists in other populations.

Accessing help elsewhere

There is evidence to suggest that older people from South Asian communities are more likely to seek help from their family network and religious and spiritual healers (Marwaha & Livingston, 2002) and thus less likely to present to services. Mackenzie (2006) believes this is due to the stigma of dementia within South Asian communities and not wanting the condition to become public knowledge. Katbamna et al., (2004) suggest that South Asians seeking and receiving help from family members is largely based on the assumption by others that South Asians in the UK live in extended families and have supportive kinship ties. These ties are often understood as a 'duty' and

'obligation' to provide care to family members, informed by 'cultural' expectations and norms (Burholt & Dobbs, 2010).

Somatisation of psychological symptoms

In the literature and in clinical practice there is a belief that South Asians, and also other groups such as older adults, are more likely to express psychological difficulties in the form of bodily or physical complaints (i.e. somatising). Some believe this is due to the stigma of mental health and favouring non-disclosure of emotional distress in non Western cultures (e.g. Kleinman, 1977). It has been suggested that those from minority ethnic groups may not express the negative impact of care-giving in terms of psychological symptoms but express them in the form of a physical illness (Calderone & Tennstedt, 1998). However, some studies have shown no differences in the level of somatic symptoms reported for psychological difficulties between, for example, White and South Asian groups (Upadhyaya, Creed, & Upadhyaya, 1989, Bhatt, Tomenson, & Benjamin, 1989).

1.5.2 Challenges to common understandings

Although reported much less, other studies have suggested why minority ethnic groups may be underrepresented in dementia services.

Different expressions of distress

Some believe that GPs and other health professionals have a lack of knowledge of the different ways in which psychological distress may be expressed within different cultures (Nazroo, 1997; Bhui et al., 2001) and this may inhibit referrals to psychology services. For example, within the Western model of medicine the mind and body are seen as separate entities but in, for example, non Western practices such as Yoga and Ayurvedia the body, soul and mind are unified. Furthermore, there are also linguistic differences to take into consideration. In a study by Adamson (2001) there appeared to be differences in the terminology used to describe dementia between some

British South Asian caregivers and White British caregivers. In addition there appears to be no word for 'dementia' in many South Asian languages (Forbat, 2003).

Experiences of discrimination

If it is the case that people from ethnic minority groups rely more on family care than their White counterparts, Cox (2001) suggests that it could be due to experiences of discrimination. Distrust of institutions and services might strengthen what is often seen as 'traditional behaviours' (i.e. turning to the family). Cox (2001) concludes that as a result of experiencing discrimination and oppression, the role of the family may have remained strong and trustworthy for some and therefore discrimination may reinforce reliance on the family as a primary source of support. Interestingly, early research with White working class families in the UK, showed that they relied on a strong kinship network for survival and support due to the lack of welfare provision provided by the state (e.g. Young & Wilmot, 1957; Rosser & Harris, 1965).

Cultural stereotyping and myths

As highlighted there is a general perception, including the views held by some health professionals, that South Asians are well cared for within the family (Willis, 2010) and do not require additional support from services (Okuyiga, 1998). However, some have highlighted that little is known about whether kinship ties and social support networks for South Asian caregivers are considered helpful or have a positive impact on their psychological well-being (Milne & Chryssanthopoulou, 2005; Burholt & Dobbs, 2010).

Katbamna et al., (2004) suggest that even if kinship ties and extended families are considered to be rooted within South Asian families in the UK, this belief must be reconsidered. For example, social change, economic development, acculturation and migration can alter family structure and function thus impacting on the type and availability of informal care (Holmes & Holmes, 1995). These changes can also have a negative impact on the

resources of South Asian families to cope with care-giving and for some within a new environment (Blakemore, 2000). The study by Katbamna et al., (2004) found that South Asian caregivers (Punjabi Sikh, Gujarati Hindu, Bangladeshi and Pakistani) in the UK were no more likely than caregivers from other populations to be assured of support from wider family ties, with variability between families in the quality and quantity of informal support available.

The cultural stereotyping of South Asians having supportive kinship networks is by some considered to have contributed to inadequate service provision to minority ethnic families (Ahmad, 2000). Thus health professionals' own bias, prejudice and stereotyping of those from South Asian communities might inhibit referrals to secondary or specialist services (Shah, Lindesay & Nnatu, 2005). This might explain, in part, the underrepresentation of minority ethnic groups in dementia services. Others have also suggested that cultural myths about caregivers from minority ethnic groups conveniently mitigate the responsibility of service providers (Atkin & Rollings, 1992).

Psychological well-being

Epidemiological studies often ignore the prevalence of mental health difficulties in individuals who do not seek help (Patel & Shaw, 2009) and the factors which help mediate stressful aspects of care-giving (Roth et al., 2001). In the UK there appears to be no research which looks specifically at the coping responses and psychological well-being of different ethnic minority groups within the context of dementia care-giving. However, in the USA research has shown that compared to White caregivers, some African American caregivers appear to have a greater ability to cope with the demands of care-giving, protect themselves from the stressful impact and hold more positive views about care-giving (Haley et al., 2004). Understanding factors which help individuals cope with care-giving and help maintain their psychological well-being is an important and needed addition to the evidence base (Lawton et al., 1992).

1.6 Questions about ethnic minority groups and dementia care-giving

1.6.1 Why study the care-giving experiences of ethnic minority groups?

The previous section suggests there are many reasons why ethnic minority groups may be underrepresented in dementia services. It could be, in part, that this underrepresentation has contributed to knowing little about the dementia care-giving experiences of ethnic minority groups in the UK. The research in this area is also limited but one study found that concepts such as 'stress' and 'burden' were culturally dissonant for some Asian and Black caregivers (Dilworth-Anderson, Williams & Gibson, 2002), suggesting there is a need to capture the diversity of experiences.

Similar to examining the potential positive gains of care-giving, exploring the dementia care-giving experiences of minority ethnic groups can help to widen the conceptual frameworks for understanding care-giving experiences and adjustment (Milne & Chryssanthopoulou, 2005). It also means that the possible impact of one's socio-political and cultural context in shaping such experiences can be considered (Janevic & Connell, 2001) rather than marginalising these aspects and effectively ethnic minority groups from research (Milne & Chryssanthopoulou, 2005).

There are also clinical implications such as health professionals being able to speak more broadly about care-giving. This in turn can also shape carer assessment tools, which can better identify a caregiver's support needs and resources. Furthermore, incorporating perspectives which are familiar or resonant with individuals from specific communities may lead to better clinical outcomes and engagement with services (Seabrook & Milne, 2004).

1.6.2 Dementia care-giving experiences of ethnic minority groups

The previous sections have given some insights into the dementia care-giving experiences of ethnic minority groups. Other findings from studies in the UK suggest that Black and South Asian caregivers experience similar levels of

burden and strain compared to White caregivers in terms of physical and emotional well being, economic difficulties and social isolation (Katbamna et al., 1998; Netto, 1998). However, in the USA some studies have found that African American caregivers report lower levels of symptoms associated with depression, feel less burdened (Roth et al., 2001; Haley et al., 2004) and seem to be able to draw more positive reflections and meaning from care-giving (Haley et al., 2004) than White caregivers. There appears to be no research in the UK which has explored the meaning of dementia care-giving for those from ethnic minority groups.

The literature search found two studies on dementia care-giving with ethnic minority groups which seemed particularly relevant to the current study. The first was a qualitative study by Godfrey and Townsend (2001) which explored how South Asians and White family caregivers of dementia in Leeds felt about their experiences. The study found that care-giving responsibilities for many South Asian participants were rooted in a strong sense of obligation to provide care compared to White participants. This appeared to be reinforced through community networks where conformity with norms of familial obligation was rewarded as being the correct and acceptable thing to do. The study also found that responsibility of care-giving tasks in the South Asian group tended to be shared by different family members. However, a limitation of the study, South Asian participants were homogenised despite being a diverse group in terms of ethnic origin (e.g. Pakistani, Indian and Bangladeshi) and religion (Muslim, Sikh and Hindu). White family caregivers were also considered as one group.

The second study was another qualitative study by Lawrence et al., (2008) which explored the attitudes and support needs of South Asian, Black Caribbean and White British family caregivers of people with dementia. Participants were from London and varied in terms of socio-economic background. The study found that South Asian caregivers were more likely to hold a traditional care-giving ideology (i.e. care-giving viewed as natural, virtuous and expected) whilst other groups held a more 'non-traditional' care-giving ideology (i.e. care-giving viewed as conflicting with expectations, seen

as unnatural and lacking virtue). These ideologies appeared to be underpinned by cultural norms and religious beliefs. However, the study also highlighted that emphasis on strong kinship ties and familial responsibilities were not specifically limited to the South Asian group. Some White caregivers held a traditional care-giving ideology and some South Asian caregivers held a non-traditional care-giving ideology, suggesting variances in care-giving within the same ethnic group as specified by the study.

1.7 Evaluating the evidence base

"If knowledge is to be generated and the research agenda develop, it is essential that researchers address existing limitations" (Milne & Chryssanthopoulou, 2005, p.325).

The following section evaluates the literature on dementia care-giving experiences of ethnic minority groups. This is particularly within the context of the terms race, culture and ethnicity as this is of relevance to the current study.

1.7.1 Race, culture and ethnicity

Shah, Oommen and Wuntakal (2005) describe race, culture and ethnicity in the following way:

"Race is a phenomenological description based on physical characteristics. Culture describes features that individuals share and which bind them together into a community. Ethnic minority individuals have been defined as those with a cultural heritage distinct from the majority population" (p.103-104).

Hinton (2002) argues that the dominant understanding of culture as a shared set of ideas adopted uniformly and in the same way by all those from a particular group (i.e. in terms of their race or ethnicity) is inaccurate. Culture can be altered with generations, country, language and socioeconomic status

(Gelfand & Fandetti, 1980). Thus, both ethnicity and culture should be regarded as concepts which differ greatly between not only countries and communities but also between and within families (Reicher & Hopkins, 2001). Rait & Burns (1997) state that it is imperative to employ accurate and reflexive definitions of ethnicity and culture as then the relative contexts shaping the care-giving experience can be better understood.

It is clear that the concepts of ethnicity, race and culture are complex and immutable. Due to the difficulties in defining them, research examining informal care-giving has tended to use narrow and global definitions of the terms (Janevic & Connell, 2001). In the process the heterogeneity of different ethnic and cultural-linguistic groups is dismissed and instead homogenised. Despite this inaccuracy, claims are frequently made in research about how the behaviour and beliefs of a particular group is informed by their 'culture' and 'ethnicity'. Culture appears to become a determinant of behaviour (Gelfand & Fandetti, 1980).

1.7.2 Problems with the term 'South Asian' in research

Much of the research presented here has amalgamated caregivers from different South Asian subgroups (i.e. Indian, Pakistani and Bangladeshi) into the group of 'South Asian'. However, those individuals in the UK represent different cultures, languages, dialects, religions and traditional and cultural practices (Gunaratnam, 1993) which have then gone through a number of changes through acculturation (Seabrook & Milne, 2004). Despite this, South Asian communities are frequently conceptualised as a homogenous group within research where generalisations are made about them as a whole ethnic group.

Gerrish (2000) states that where research does not account for heterogeneity within South Asian groups it could be accused of being unrepresentative or meaningless. Similarly Nazroo et al., (2002) state the category 'South Asian' has been viewed as inappropriate and is considered too wide and misleading to be useful in research. Thus it could be argued that very little knowledge

exists about the experiences of particular South Asian communities and as different regions of South Asia have diverse cultures, it is likely their experiences of situations will vary (Patel & Shaw, 2009).

A qualitative study by Parveen, Morrison and Robinson (2011) found that ethnic variations in care-giving of different conditions existed between three different South Asian subgroups. Using a thematic content analysis, in their sample there were differences in 'willingness' to provide care and the amount of focus on the negative and positive aspect of care-giving between British Bangladeshis with British Indians (of different cultural linguistic groups) and British Pakistanis. The study concluded the need to examine the cultural and ethnic variations in care-giving within different South Asian subgroups (Parveen, Morrison & Robinson, 2011).

1.8. Chosen focus of the current study

Given the flaws of homogenising 'South Asians' in research, the current study chose to narrow the focus to a particular South Asian cultural linguistic group, Indian Gujaratis. There are several South Asian communities that could have been the chosen focus of this study but I understand a bit about Indian Gujarati communities, particularly Jain communities, due to my own background as a British Indian Gujarati Jain. I also have access to some of these communities in London. I hope that by narrowing my focus on Indian Gujaratis specifically I can employ more accurate and reflexive definitions of ethnicity and culture whereby the relevant contexts informing the care-giving experience can be highlighted (Rait & Burns, 1997).

1.8.1 Indian communities in the UK

The next section focuses on Indian and Indian Gujarati communities in the UK. This is to highlight the vast heterogeneity which exists between these communities but also to 'situate the sample'. The latter I hope will help readers to consider the persons and contexts of which the findings of this study may be applicable (Elliott, Fischer & Rennie, 1999).

The 2011 Census for England and Wales (Office for National Statistics, 2011) showed that South Asian communities form 6.8% of the population in the UK, with Indians the largest of the South Asian subgroups at just over 1.4 million. Collectively Indian groups make up the largest ethnic group in London and the UK after White groups (Office for National Statistics, 2011). Those who refer to themselves as British Indian include individuals who were born in India or other countries and migrated to the UK or those who were born in the UK and consider their ancestral roots to have originated from India. Poros (2011) highlights that Indian groups, perhaps more than other national populations, have significant intragroup differences and are 'worthy' of study for this reason alone.

1.8.2 Heterogeneity of Indian groups

India is comprised of diverse populations which also reflect the composition of Indian communities in Britain. Firstly, there are regional differences: the largest subgroup of British Indians is those of Punjabi origin who originate from the Punjab region of India (Ballard, 1994). British Indian Gujaratis are the second largest British Indian subgroup originating from the Indian state of Gujarat. This is followed by Indian Bengalis (originating from Bengal). There are also many smaller Indian groups such as the Tamils and Parsis. Secondly, there are linguistic differences which include Punjabi, Gujarati, Hindi, Sindhi, Tamil, Bengali, Assamese and Marathi. Each of these languages has more than one dialect. The third main differential is religion; Indian people follow a diverse range of religions such as Hinduism, Jainism, Sikhism and Islam with a smaller percentage practising Christianity, Catholicism, Buddhism and Judaism. Each of these religions has their own denominations and sects. The fourth differential is socio-economic status, which ranges from working class to upper middle class (Clark & Drinkwater, 2007). These are the main intragroup differences but other differences also exist.

<u>1.8.3 Indian Gujaratis in the UK</u>

Indian Gujaratis are a group of people with a common language and cultural heritage (Shah, Lindesay & Jagger, 1998). Most Indian Gujarati people practice the religions of Hinduism or Jainism and some follow Islam. There are a number of Jain and Hindu communities in the UK and London, some share ties with each other. Many Indian Gujaratis migrated to the UK in the 1970's from East Africa (Kenya, Tanzania and Uganda) whereas some families migrated directly from India (Burholt, 2004). As a group in the UK they maintain links with both India and East Africa through kinship ties and cultural practices (Spiro, 2005).

Many Indian Gujarati's migrated to East Africa at the turn of the 20th century for work (Poros, 2011). Under the British rule, many enjoyed a middle-class lifestyle in East Africa where they owned businesses and trade. However, throughout the mid 20th century anti-colonial resistance against the British and Indians grew (Porus, 2011). Following implementations of the Africanization policies in Kenya, Uganda and Tanzania there was an economic shift where control of trade and employment was given to native Africans and very restricted to others. It was a time of political instability in which East African Asians communities, particularly Indian Gujaratis, were threatened and their right to work or trade had been withdrawn. As a result East African Asians were forced out of Kenya and Tanzania and expelled from Uganda in the 1970's. Many migrated to the UK but left their livelihoods behind.

In the UK, Indian Gujaratis faced racial discrimination due to prejudicial attitudes towards immigrants in the 1970's in Britain (Patel & Shaw, 2009). Some believe that the impact of immigration can lead to poorer mental health (Nevo et al., 2006; Cochrane, 1983). However, Indian Gujaratis are underrepresented within mental health statistics and services in the UK (Patel & Shaw, 2009). Others suggest that experiences of migration may help to mediate the psychological distress of care-giving due to previous experiences of coping with oppression and adjustment following migration (Fox, Hinton & Levkoff, 1999). Indian Gujaratis, compared to other ethnic minority groups are

considered to have 'assimilated well' in the UK, particularly in terms of employment, education, status and retaining cultural norms and identities (Ramji, 2006; Poros, 2011; Berry, 1980).

<u>1.8.4 Indian Gujaratis and care-giving</u>

The literature search did not identify any studies which specifically looked at the impact of dementia care-giving on Indian Gujaratis. However, a quantitative study by Burholt and Dobbs (2010) compared the care-giving and care-receiving relationships between different groups of South Asian older parents and their adult children in the UK to the same dyads in South Asia. The participants were stratified in both societies by the following ethnic groups: Indian Gujaratis, Indian Punjabis, and Bangladeshi Sylhetis. The study found that help was more likely to be provided by sons than daughters (except for help to older Punjabis) in the UK than in South Asia. The study also found that older Indian Gujaratis and Bangladeshi Sylheti migrants maintained traditional family values and norms through their care-giving and care-receiving. The authors concluded that research which amalgamates migrant communities by continent of origin needs to be aware of the important differences among specific migrant groups.

1.9 Summary

Most individuals with a diagnosis of dementia live in the community and are supported by informal caregivers such as their family members, spouse or friends (National Audit Office, 2007). Some believe that the dominant biomedical framework for understanding dementia has impacted on constructing the care-giving relationship as burdensome and stressful (King, 1997).

The evidence base for exploring dementia care-giving experiences has particularly neglected the experiences of individuals from ethnic minority groups. In addition, little is known about what caregivers feel are the positive aspects of care-giving and what care-giving means to them. Despite research

showing that these factors can negate the stressful aspects of care-giving and help adjustment.

There seems to be an underrepresentation of ethnic minority groups in dementia services (Daker-White et al., 2002). Some believe this is due to a lack of understanding about dementia, dementia/mental health related stigma and the availability of supportive family networks, particularly for South Asians. These have been challenged by some as cultural stereotyping and services mitigating responsibility (Shah, Lindesay & Nnatu, 2005; Atkin & Rollings, 1992). In addition, little attention is given to what helps individuals to cope with the experience of care-giving and maintain psychological well-being, which may contribute to not accessing services.

An evaluation of the research within the field shows that individuals from different South Asian groups are often homogenised and considered as one group. This includes different Indian groups despite the many intra-group differences which exist between them. Gujaratis are one Indian group who share a language and cultural heritage (Shah, Lindesay & Jagger, 1998). In the UK, Indian Gujaratis are particularly underrepresented within mental health services, even when compared to other South Asian groups (Patel & Shaw, 2009). There are no studies in the UK which have specifically looked at the experiences of Indian Gujarati caregivers supporting a family member or friend with dementia.

1.10 The current study

The current study will explore how Indian Gujarati people in the London area feel about supporting a family member or friend with dementia

Epistemological position

The overall epistemological position of this study is critical realist. This is consistent with an Interpretative Phenomenological Analysis (IPA) methodology (Bhaskar, 1978), which will be employed by the current study. It

does assume that a reality exists for participants but will not focus on whether these accounts are 'true' or 'false'. It also acknowledges this reality cannot be directly accessed and is shaped by the particular time and context in which the reality is shared (Willig, 2008). IPA uses an interpretative framework, accepting that knowledge is constructed through interpretation and thus inherently subjective. Through reflexivity I will implicate myself in the research process and reflect on my own position and how this may have shaped the knowledge produced and constructed. Thus, the current study acknowledges that other interpretations are also possible.

Research questions

The study hopes to address some of the gaps and limitations in the existing literature. The main research question is:

- How do Indian Gujarati people in the London area supporting a family member or friend with dementia feel about this experience?

In addition to the main research question, the following hope to be addressed:

The secondary research questions are:

- What does dementia care-giving mean to them?

- What are the negative and positive aspects of dementia care-giving?

- What helps them to cope with dementia care-giving?

CHAPTER 2: METHODOLOGY

Overview

The aim of the present study was to explore how Indian Gujarati individuals in the London area felt about their experiences of supporting a family member or friend with dementia. I was particularly interested in what dementia care-giving role means to them, what they feel are the negative and positive aspects of care-giving and what helps them to cope.

The present study employed a qualitative approach through the use of Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2011). This chapter will outline the rationale for adopting this approach including how its epistemological position is suited to the research questions of the study. This chapter will also detail the process of recruiting participants and the procedures for data collection and analysis.

2.1 Qualitative methodology

For the present study I have chosen to follow a qualitative framework to inform my choice of methods. Using this approach also reflects my own theoretical and epistemological ideas regarding the nature of knowledge and what can be known and how (Willig, 2008).

There were a number of reasons why a qualitative methodology was adopted rather than a quantitative approach. For example, the latter would have involved testing specific hypotheses from existing theories, which due to the lack of research in this topic area would not have been suitable. In addition, a quantitative approach would have made it more unlikely to discover novel and unexpected insights (Willig, 2008). Rich and contextualised personal accounts, which I hoped to obtain from participants, were considered to be more appropriate for describing and drawing out these unexpected insights and understandings (Willig, 2001). I was also not looking to quantify

participants' experiences as would have been the case using a quantitative methodology.

There are a number of different qualitative methods which this study could have employed. After consideration and with the research questions in mind these methods were felt not to be the best fit for this study. For example, Grounded Theory (Glaser & Strauss, 1967) aims to develop an explanatory level account of peoples' experience but this was not the purpose of the present study. Discourse Analysis (Potter & Wetherell, 1987) was also considered but the study was not focussing on how participants' language constructed their reality for them. The aim of the study was to attend to the phenomenological aspects of peoples' experience thus Interpretative Phenomenological Analysis (IPA) was chosen as a recognised framework. Through reference to participants' accounts, IPA can situate personal experience in the context of meaning, relationships, and one's lived world. The theoretical and epistemological rationale for choosing this methodology is further discussed below.

2.1.1 Interpretative Phenomenological Analysis

Theoretical assumptions

IPA is an experiential and inductive approach (Smith, 2004), which is intended to explore how people understand their everyday experiences of their worlds and the meanings they give to those experiences (Smith & Osborn, 2003). IPA has three major theoretical underpinnings: phenomenology (study of experience), hermeneutics (process of interpretation) and idiography (study of the individual). These are used to explore the defining features of experience (Smith & Osborn, 2003).

Within IPA, Phenomenology is concerned with how a person views and makes sense of their world by focussing upon their descriptive accounts of experience (Giorgi & Giorgi, 2008). The aim of phenomenological analysis is to broaden one's understandings of the phenomena being explored.

Hermeneutics recognises that sense-making of any human experience is largely influenced by the researcher's subjective interpretations. It means that sense-making is "a co-construction between the participant and the analyst" (Osborn & Smith, 1998, p.67). Given the acknowledgement of the researcher's active role in the research process, IPA requires the researcher to be aware and make explicit their own assumptions, biases and position on the area in question through reflexive techniques (Caleli, 2001). The last defining feature, idiography, focuses on unique experience by acknowledging that individuals can hold multiple perspectives of the same phenomena (Barker, Pistrang & Elliott, 2002). This is due to experience being informed by an individual's underlying "thoughts, beliefs, expectations and judgments" (Willig, 2001, p.66).

Epistemological position

IPA has its epistemological roots in critical realism (Bhaskar, 1978). Critical realism suggests there are enduring and stable features of reality that exist separate of an individual's conceptualisation (Fade, 2004). This reality is experienced in subjective ways depending on the individual's personal beliefs and expectations and therefore critical realist approaches such as IPA use in depth personal accounts (Finlay, 2006).

IPA assumes that a reality exists but does not assume that there is an objective reality (world) that can be defined, measured or directly observed (Smith & Osborn, 2003). This aligns the approach with a critical realist epistemological position as both accept that it not possible to gain direct access to a person's life worlds (Willig, 2008). It also assumes the production of knowledge is constructed through interpretation and thus inherently subjective and context bound. The analysis of this interpretation goes beyond the particular context and is placed within the person's broader historical, social and cultural context (Smith, Flowers & Larkin, 2011). Although IPA tends to posit that experience is always the product of interpretation and thus constructed, it is nevertheless 'real' and significant to the individual (Larkin, Watts, & Clifton, 2006).

Relevance to the study

The overall epistemological position of this study is critical realist. It assumes that a reality exists for participants but will not focus on whether these accounts are 'true' or 'false'. It is understood that a participant's reality cannot be directly accessed and is shaped by the context and particular lens in which it is told (Willig, 2008). The study will focus on obtaining in depth and rich descriptions. This study will be attending to both the similarities with other participants as well as the uniqueness revealed by each individual (Hunt & Smith, 2004). Interpretations will be made whilst acknowledging these will be shaped by my own position and assumptions (Smith, Flowers & Larkin, 2011). This seems to be of particular importance given the similarities between my own ethnic and cultural background to those of the participants in the study. Using an interpretative approach, the current study acknowledges that other interpretations are also possible.

2.2 Reflexivity

In qualitative methodology, reflexivity invites us to look both 'inwards' and 'outwards' (King & Horrocks, 2010). It requires a "critical self-reflection of the ways in which the researcher's social background, assumptions and positioning and behaviour impact on the research process" (Finlay & Gough, 2003, p.9). In reflexivity the researcher is as involved and implicated in the entire process of knowledge production as the participant (Fade, 2004). Within IPA, this 'self-reflection' is essential to understanding how meanings are interpreted and described.

According to IPA, my position will have unavoidably affected the research methodology, including the interview process and the analysis of data. Due to this, IPA, like other phenomenological research, encourages reflexive transparency of the researcher's viewpoint to help 'bracket' one's preconceptions (Moustakas, 1994). In the present study, this was achieved by keeping a reflexive log (exert in Appendix K) and being a part of an IPA reflexive group with my peers who were also using IPA in their research. Both

involved making my pre-conceptions and beliefs visible for both myself and others to review. The group sessions were audio-recorded and transcribed to refer back to.

2.2.1 Researcher position

The reflexive log and IPA group helped me to think about some of my own beliefs, positions and preconceptions which may have influenced the research process at many different levels. In making these visible I hoped to become more conscious and mindful of them and the decisions I was making throughout the study. Several aspects were identified which may have influenced what participants shared with me, how they spoke about their experience, the knowledge produced and the interpretations made. These aspects included my position as a:

- British Indian Gujarati individual
- Trainee clinical psychologist
- A critical realist
- Researcher familiar with dementia care-giving literature

The above positions are considered further in the discussion section.

2.3 Ethical approval

Ethical approval for the research was sought and granted from the University of East London's Ethics Committee (Appendix A). This study did not require NHS ethical approval as participants were not recruited from any NHS services.

2.4 Sample

2.4.1 Sampling method

The intention was to select a purposive homogenous sample as this method is theoretically consistent with IPA's philosophy (Chapman & Smith, 2002). In this study homogeneity referred to the selection of participants on the basis they would be able to 'represent' a perspective (idiographically) on a particular phenomenon and within a particular context as explored by the research (Smith, Larkin & Flowers, 2011). Therefore participants were not seen as representing a population. Opportunity (researcher's personal contacts) and snowballing methods (current participants referring other possible participants) were used to recruit participants. These are the most effective and efficient approaches of recruiting samples in IPA research (Smith, Flowers, & Larkin, 2011).

2.4.2 Inclusion criteria

Participants were selected on the basis that they met the following criteria:

- They spoke a good level of English due to the qualitative methodology, as the meaning of the original data can be lost through translation (Temple & Young, 2004).
- Identifies him/herself as an Indian Gujarati living in London.
- Aged 18 years or over, with no upper age limit.
- The care-recipient has received a formal diagnosis of any subtype of dementia.
- Are a partner, relative or friend of the care-recipient.
- Have been providing informal care to the care-recipient for a minimum of six months. This is to allow for a sufficient amount of time to be able to draw and reflect on their experiences.
- Identifies him/herself as one of the main caregivers although other people may be involved in providing care to the care-recipient at some level.

- Does not have to live in the same residence as the care-recipient.

2.4.3 Recruitment of participants

The recruitment of participants took place over a six month period from August 2012 to February 2013. The recruitment period ended after 10 participants had been interviewed. A sample between five and ten participants is considered to be a suitable number for idiographic research (Smith & Osborn, 2003). There was only one participant contacted who did not respond to the invitation to participate in the study. Participants were recruited from six London boroughs: Enfield, Brent, Harrow, Westminster, Ilford and Barnet. The participants were not previously known to me and only two were a part of the Indian Gujarati Jain community that I and my family belong to.

Participants were recruited in the following ways:

- Three participants were recruited through the snowballing method.
- Two participants were recruited via two family friends who personally knew the participants.
- One participant was recruited via a dementia carer representative who gave a talk on dementia to an Indian Jain Gujarati's women's community group which I attended. This representative personally knew the participant.
- Three participants responded to an email sent on my behalf by one of the organisers of an Indian Jain Gujarati community group for older people which a family member belongs to.
- One participant was recruited through another Indian Jain Gujarati community group, known to one of the participants of the study. The Chairperson of the organisation knew this participant.

Except for the three participants who responded to the email, all other participants were initially informed of the study by the person known to them.

They all gave their consent to have their contact details passed onto me before I made contact with them.

2.4.4 Participants

Of the 10 participants interviewed, six were female and four were male. All identified themselves as Indian Gujarati. Eight participants practised the religion of Jainism and two described themselves as Hindus. Participants ranged in age from 32 to 75 years. The sample reflected different kin relationships (spouses, adult children, sister and daughter-in-laws). Seven participants lived with the person with dementia. Two participants (a husband and his daughter) were supporting the same care-recipient.

The following services were used by participants:
- Two care-recipients were residing in a care home whilst others lived at home with their family members.
- Six care-recipients had paid carers and two had befrienders working with them on a daily basis.
- Five care-recipients were under the care of Memory Clinics within Mental Health Care of Older People services (MHCOP).
- Two care-recipients were under the care of an outpatient neurology clinic.
- Two care-recipients attended groups for people with dementia whilst two others attended Indian Gujarati community groups for older people.

Table 1 provides further details of the participants and the care-recipient. Their names and exact ages have been removed to protect their anonymity.

Table 1. Participant information

	Sex	Age	Migration Route	Years in UK	Relationship to care-recipient	Dementia diagnosis
1	Female	70s	India, UK	35	Wife	2009
2	Female	50s	Tanzania, UK	33	Daughter-in-law	2006
3	Male	40s	Kenya, UK	39	Son	2005
4	Male	70s	Kenya, UK	5	Husband	2008
5	Female	40s	Kenya, UK	26	Daughter	2008
6	Female	50s	Kenya, UK	40	Daughter-in-law	2007
7	Female	30s	Kenya, UK	23	Daughter	2007
8	Male	50s	Uganda, UK	40	Son	2009
9	Male	30s	UK	30+	Son	2006
10	Female	70s	Uganda, UK	31	Sister-in-law	2009

2.5 Procedure

All potential participants who had agreed to be approached were contacted by email or telephone. Further information about the study was given and their details were confirmed to meet the inclusion criteria. They were sent, via post or email, the participant information sheet (Appendix C) to read and consider. A time was arranged to contact them again to discuss whether they would like to take part in the study and if they had any questions about the research.

Arrangements were made with the person as to when would be the most convenient time and place to be interviewed. Most participants chose to be interviewed in their own homes and one chose their workplace. It was explained that whilst the interview was taking place it would be preferable for the person with dementia not to be present as it might impact on how comfortable they felt in discussing their experiences and also taking into consideration the care-recipient's own emotional well being.

On the day of the interview participants were taken through the participant information sheet. Participants were given the opportunity to ask any further

questions. They were taken through the consent form (Appendix D) and asked to sign two copies, including a copy they retained for their own records. Participants were then asked to provide some demographic information such as their age, migration history and use of services (Appendix E). Participants were then interviewed guided by the semi-structured interview schedule (Appendix F).

2.6 Ethical issues

Consent

An information sheet clearly outlining the research study and what it involved was given to all potential participants. Participants were given time to consider the information and were encouraged to discuss the study with other family members or friends before taking part. Participants were given the opportunity to ask questions at all points.

Confidentiality

Before the interviews I explained to all participants my own cultural and ethnic background and the community that I belonged to. Conversations were had around how they felt talking to me about their experiences and if they had any concerns such as breaches to confidentiality.

Interviews were conducted in a private room in the participant's home or workplace with no one else present in the room during recording.

Interviews were transcribed only by the researcher. During this process, the transcripts were anonymised with names and other identifiable information removed.

All data were securely stored with access restricted to only the researcher, supervisor and thesis examiners. The signed consent forms were kept separately to the digital recordings, transcriptions and participants'

demographic information. Audio recordings will be permanently deleted once the research has been examined. The transcripts will be destroyed after five years in accordance with the Data Protection Act (1998).

Participant wellbeing

Before the interview started it was explained to participants that they could share as much as they felt comfortable with. It was also explained that if they did not want to answer any questions they could let me know. I was mindful that for some they may not have been used to sharing their stories.

Due to the sensitive topics explored in the interview there was a possibility that some participants may have found it upsetting or distressing to speak about certain issues. In this situation, participants would be asked if they wished to continue with the interview, take a break or wished to complete the interview at a later date. Participants would also be reminded that they could withdraw at any point from the interview.

Contact information of dementia and carer support organisations was included in the participant information sheet in case participants felt they needed further support and advice.

2.7 Data collection

Apparatus, resources and materials

Materials included the participant information sheet and consent form. The structure and content of these were based on information sheets and consent forms used in previous clinical research. Other materials included the demographics form which captured a range of information to help situate the sample and to consider the range of persons and contexts to which the findings may be applicable (Elliott, Fischer & Rennie, 1999). An interview schedule was also used.

An MP3 recording device was used to record the interviews.

Interviews

A semi-structured interview was used to interview participants. The interview schedule consisted of a set of pre-determined topics to be explored which could also be changed in response to what the participant brought to the interview (Larkin, Watts & Clifton, 2006). All interviews were digitally audio recorded. The interviews varied in duration, from 40 to 80 minutes.

Semi-structured interviews

Most IPA research has used face to face semi-structured interviews to obtain data as it is thought to be the most exemplary method for IPA (Smith, Flowers & Larkin, 2011). This is because they are considered optimal for drawing out in depth stories by enabling the participant to speak free and reflectively about their thoughts and feelings (Kvale & Brinkmann, 2009). Furthermore, using a semi-structured interview positions the participant as the experiential expert on the topic under exploration (Smith & Osborn, 2003).

A draft semi-structured interview schedule was developed in collaboration with my supervisor to provide a 'loose agenda' of the topics to potentially be covered in the interview. These pre-identified topics were based on the findings and issues which emerged from the literature review. Questions were re-drafted in an attempt to make them more open, inviting and to not be leading (Smith, 1996). It was hoped that this would allow participants to speak about issues which were personally meaningful to them. Where needed questions were followed with prompts such as "could you tell me more" and "how did you feel..." to further stimulate discussions (Robson, 2002). Although questions were available to guide the interview it was used flexibly as it felt important to follow up on issues not on the schedule as long it might be relevant to the research questions (Smith, Flowers & Larkin, 2011).

The interview questions were piloted with some colleagues to become familiar with the schedule and to gauge the clarity and organisation of the questions. The finalised interview schedule consisted of the following questions:

1. Can you tell me about your experience of supporting x?
2. Can you tell me how you came to supporting x?
3. What do you feel have been the more difficult or stressful aspects of care-giving?
4. How might things have been different for you if you were not supporting x?
5. Do you feel there have been any positive aspects of care-giving?
6. What do you feel care-giving means you?
7. What helps you to cope?

2.8 Interview transcription

The interviews were all transcribed verbatim, producing word for word transcripts of the participant's account. This is referred to as descriptive validity and is one of the key factors in ensuring validity in qualitative research (Ratcliff, 1995). Transcription also included recording the exact length of pauses and non-verbal utterances (i.e. laughter). However, in IPA the detailed prosodic aspects of the recordings are not required as the focus is on the meaning of the content of the participant responses (Smith, Flowers & Larkin, 2011). The transcription system used is given in Appendix G.

2.9 Process of data analysis

The current literature on IPA has not prescribed one single method for working with the data and IPA researchers are encouraged to be innovative in the way they approach analysis (Smith, Flowers & Larkin, 2011). However, an IPA help sheet (Appendix I) was created to keep in mind the processes and principles generic to all methods. The information taken from Smith, Flowers & Larkin (2011) was referred to alongside their step by step IPA stages of analysis, as outlined:

Step 1: Reading and re-reading

Each of the interviews was transcribed verbatim. The first transcript was then read and re-read several times. This involved 'active engagement' with the data such as noticing shifts from generic explanations to specificities of particular events. Re-reading enables new insights and ideas to be generated (Hunt & Smith, 2004).

Step 2: Initial noting

The semantic content, language and context were examined on an exploratory level. Notes were made in the right hand margin of the transcript of anything which was of interest. The specific ways in which a participant spoke about an issue was noted. This involved a close line by line analysis of the participant's experiential concerns and understandings (Larkin, Watts & Clifton, 2006).

Step 3: Identifying and developing emergent themes

The transcript and initial notes were reduced in terms of volume of detail. The complexity remained by mapping the interrelationships, connections and patterns between notes. In this stage, notes were turned into themes reflecting both the participant's original words and researcher's interpretations. Emerging themes were written on the left hand margin of the transcript.

Step 4: Searching for connections across emergent themes

The emergent themes were reproduced on a separate document and listed in chronological order to start looking for patterns and connections between them. Some of the following ways were used to search for these patterns: abstraction (putting like with like and developing a new name for the cluster which was labelled as a super-ordinate theme), subsumption (an emergent theme became a super-ordinate theme by connecting together a number of

related themes) and contextualisation (relate themes to life events). All themes (interpretations) were referred back to the original text several times to ensure they reflected what the participant had originally described in the interview. At this stage some emergent themes were also disregarded due to a lack of data to support them. A table was produced to summarise the development of super-ordinate themes and subordinate themes.

Step 5: Moving to the next case

The above stages were repeated for the remaining nine transcripts. Each of the transcripts was analysed on its own terms and where possible the ideas and themes emerging from the first analysis were 'bracketed' to allow for new themes to emerge with each transcript. This was achieved through following the above steps systematically.

Stage 6: Looking for patterns across cases

Connections and patterns were examined between and across interviews, which included relabeling some themes. A master table was produced for the final super-ordinate and subordinate themes for the whole sample. At this stage, it was also ensured that the analysis maintained a strong interpretive focus.

2.10 Validity and reliability

Issues of reliability and validity were considered throughout the research process. Golafshani (2003) states that what we traditionally understand by reliability and validity needs redefining so that it can be meaningfully applied to qualitative research. Ratcliff (1995) suggests that reliability within qualitative research can be strengthened by outlining a clear research process, with examples of the original data and how the data analysis was conducted. Furthermore validity can be demonstrated by examining whether another researcher can draw similar conclusions (Coolican, 2004) through the co-checking of data and interpretations (Ratcliff, 1995).

An evaluation of how the study attended to issues of reliability and validity are detailed in the discussion chapter.

CHAPTER 3: ANALYSIS

Overview

The present study explored the views of Indian Gujaratis in the London area who were supporting a family member with dementia, particularly what care-giving meant to them, the negative and positive aspects of care-giving and what factors helped them to cope. The interview data were analysed using an Interpretative Phenomenological Analysis. This chapter presents the four main themes that emerged which reflected the impact of dementia care-giving at different levels for caregivers. Each theme and its subordinate themes (Table 2) will be discussed in turn and illustrated by extracts from the interview transcripts. In the extracts ellipses indicate omitted text.

The themes are not presented in any particular order nor are they entirely separate from each other. It is also important to highlight that the analysis represents one possible interpretation of the data, as intimated in sections concerned with epistemology. This interpretation will have been influenced by my experiences, beliefs and assumptions. My understanding of participant's ethnic and cultural background, which is both similar and different to my own as a British Indian Gujarati Jain, was used in the analysis to help describe participants' possible contexts.

Table 2. Themes and subordinate themes

Theme	Subordinate Themes
Intrapsychic	- Emotional impact - Changing how I think about the situation - Growth and development
Dyadic	- Loss of relationship - Reciprocity
Family	- Family support - Family strains - Support from dementia services
Community and Culture	- Expectations and norms - Knowing and talking about dementia

3.1 Theme 1: Intrapsychic

The intrapsychic level referred to the impact of dementia care-giving on care-givers' internal state. This focussed on the emotional impact of care-giving, changing the way a situation was thought about to help cope with the difficult aspects of care-giving and feeling a sense of personal growth and development.

<u>3.1.1 Emotional impact</u>

Caregivers spoke about the emotional impact of care-giving. Reflecting on her earlier experiences, one caregiver spoke of how difficult it was for her at the beginning to cope with care-giving.

> *P2:...I would sit there and cry...I thought even I am getting depressed in the house, because staying in the house seven days a week, people can go into depression...(lines 438-445)*

Another caregiver believed that care-giving could have made him feel 'depressed' due to the stressful nature of it at times. He spoke of how meditation and yoga helped by giving him the strength to cope.

> *P4:...*without this knowledge [yoga and meditation as helpful] *I could have fallen down, gone down quickly completely, might have gone into depression also I don't know. Because when you are having stress naturally you are going to go down…(lines 128-130)*

Before paid carers started working with his father, one caregiver spoke of the difficulty in coping with the emotional impact of care-giving and working at the same time.

> *P9:...it [caring for his father] was emotionally very very heavy. Trying to keep down a job as well as knowing that you had to come back to*

this [caring for his father], there was never no time for personal life as such (lines 102-104)

One caregiver spoke of how care-giving made her feel mentally tired at times, particularly as she felt there were no outlets where she could express her anger and frustration around managing her mother-in-law's dementia and care-giving.

P6: Yeah and mentally as well [as well as being physically tiring] because you know you get angry, and you can't get your anger out because she doesn't understand...(lines 107-108)

One caregiver described how at times he felt less equipped to manage his father's dementia. In these situations he would sometimes feel angry and frustrated by some of his father's cognitive difficulties. He also spoke of the mental rather than physical exhaustion he experienced.

P8:...he [father] keeps repeating himself over and over again, while you know that it's his illness that makes him to do it [repeat himself] you tend to be okay and forgive him but sometimes you know I've had a bad day, I don't really want all that on top of me and that additional pressure would make me feel very angry and uptight...Mentally I get very very tired...(lines 157-163)

Other caregivers also spoke about how they felt frustrated by their family member's cognitive difficulties but that it felt wrong to feel that way towards their family member who had a "disease". One caregiver gave an example of the frustration he felt at times:

P3:...to accept that all of a sudden something that he could do a year ago he's not been able to do now and you try and tell him to do it, you try and tell him to do it again and you try and tell him again and then you yourself start getting agitated...and no matter what you know you

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start raising your voice which you shouldn't do...so that's been
difficult...(lines 145-149)

Other caregivers spoke of feeling a similar way and this frustration was perhaps a reflection of the complex acceptance process for people supporting a family member with dementia, where one is constantly adjusting to and accepting the progressive decline that dementia causes.

One caregiver expressed the difficulty she had in making sense of how her sister-in-law came to have dementia, despite being an "able person" and having done "many good things in her life".

P10...she was an able person in all sorts of ways, then to get
dementia is the hardest, that is what it is for me, that is very painful
(lines 103-105)

In her account she spoke of Hinduism and in her extract below she seemed to make an indirect reference to karma and reincarnation, key ideas in Hinduism and Jainism. For example, some Hindus and Jains believe that committing a 'bad' deed will bring some form of "suffering" in a person's current or next life, thus karma and reincarnation are interlinked. When asked whether she felt the experience or care-giving had changed her in anyway, she said:

P10: Yeah, perception of life, yeah, it has [laughs]. That the suffering
[the suffering her sister-in-law has gone through with dementia] we
have to go through is...I am thinking about our previous life and the
life after...that if we have go through all this, you have to, you have to
be a better person (lines 294-297)

Questioning how dementia occurred and how her sister-in-law came to have the condition despite being a "good person" was recurrent throughout her account. It perhaps challenged some of her long standing religious beliefs and what did it mean to be 'good'. It seemed she believed that dementia could be

prevented with "money", "care" and "love" but realising it could not left her and her husband feeling worried.

> *P10: That is worrying me actually, at the moment that is the worrying factor because I can see if she with a lot of money, a lot of care and love has gone through this [dementia], what about us [her and her husband]? (lines 184-186)*

> *P10: That is the worry, how am I going to cope with my husband, if he has got problems, health problems and I can see that he's getting worries that he's going to get dementia...(lines 189-191)*

3.1.2 Changing how I think about the situation

Linked with the previous theme, caregivers spoke about how changing how they thought about a situation by letting go of negative feelings (i.e. anger, frustration, worry) helped them to cope with and adjust to the impact of dementia care-giving. This theme recurred throughout some caregiver's accounts, where they appeared to be aware of their cognitions at a meta level and regarded their thoughts as something which they could control and change. These beliefs for some caregivers were linked to spirituality and religion and for another caregiver it was a long term "philosophy", used previously in his work.

When asked what helped one caregiver to cope with strained family relationships, which earlier in the interview he described as the most stressful impact of care-giving, the following dialogue took place:

> *P4: I don't worry.*

> *I: You don't worry.*

> *P4: I take as it comes...If you start worrying or thinking too much about it then you are nowhere, then your thinking is going somewhere*

else so what is going to happen is going to happen so don't worry about it. Past is the past so forget about it. Now I'm talking about this [his experiences of care-giving] because you have come to see me otherwise I would not have talked about it [laughter].

I: You wouldn't?

P4: The past is the past, so why do you need to remember it, there's no power on that, past has no power and it cannot be unturned also, what has happened has happened just forget about it. See for the present and the future (lines 299-310)

There seemed to be an idea of freeing oneself from negative feelings such as worry and leaving it behind with the past. When this conversation was explored further, he spoke of the following:

P4:...if it [worry and frustration] hurts you it's not going to gain you anything, if it hurts then your feelings are hurt also, so just forget about it. Just let go....you have to leave everything, even our bodies is not ours, it's only our soul, isn't it. Our soul is the one having our body, we are saying we are dying, we are not dying we are changing the clothes. You believe in reincarnation isn't it so (lines 371-378)

The idea of holding onto negative feelings was seen as more harmful to the self. This belief seemed to be connected to ideas of reincarnation (i.e. "*you have to leave everything, even our bodies is not ours, it's only our soul"*). A central idea in Jainism and Hinduism is that the soul continues to live until it frees itself from bad karmic particles. Freeing the soul of negative feelings and not taking this through to the next life is seen as a type of purification process.

Earlier in the conversation, the caregiver spoke about how he believed events were predetermined (e.g. "fixed in a drama"). He felt these beliefs had helped him to accept his wife's dementia and his role in caring for her.

> *P4: What is going to happen is going to happen and that is what I believe. We cannot stop, because we didn't know that we [he and his wife] were going to meet each other but that was fixed in a drama...that we will know each other and this is what I believe in...(lines 154-158)*

In the above quote, there seemed to be an indirect reference to determinism (i.e. *what is going to happen is going to happen...that was fixed in a drama*). Some Jains and Hindus believe that events and consequences are out of one's control as is it determined by one's previous karmic lives, thus karma is seen as deterministic.

Another caregiver spoke similarly about letting go of negative feelings such as frustration as he believed it was more harmful to himself. He gave an example of how he dealt with his frustration towards his siblings, who he felt were not taking on enough of the care-giving responsibilities for their father.

> *P8:...ranting and raving and saying things, the only person who gets upset is me you know, they [his siblings] don't care, it's not going to harm them...so as far as I'm concerned why should I put myself in that position so I just blank it out (lines 201-204)*

When further explored as to what helped this caregiver cope with care-giving in general, he described concentrating on things which he could change.

> *P8: I don't tend to worry about anything until it happens. If I can't change it I take it for a fact of life and I look for a solution. What's the next best scenario and that's what I aim for. I've always done that in business and I've always done I've been successful because I've used that model (lines 223-228)*

In his account he spoke of taking a solution focussed approach to coping with dementia care-giving (i.e. focusing on what he could change). It was apparent in his interview that he did not want to focus on the problems such as his

conflicts with his siblings and instead wanted to move forward with the conversation.

One caregiver appeared to find some assurance and help in turning to religious texts for letting go of things which she found stressful about care-giving. This was despite dementia care-giving making her question some of her religious beliefs.

> *P10: Gita [main religious text for Hindus] shows quite a lot of things which, I do go for Gita classes and things like that which helps me to hold onto the good parts and let go of the other things which is difficult (lines 120-122)*

One caregiver believed that her "spiritual understanding" helped her to think differently about care-giving and remain hopeful in challenging situations.

> *P5: I'm quite spiritual as well so I think that helps and that's where the hope comes in and the fact that you don't give up hope as well...in that way if the strength I have is hope...there's a lot of spiritual understanding and I guess in a way experiences...Yes, you feel sometimes that "Oh gosh, why us [mother's dementia] or whatever but I think overall you've got to change the way you think and you have to have that hope otherwise it's a bit difficult to survive and go through the experience...(lines 258-268)*

3.1.3 Growth and development

Some caregivers reflected on the positive change they had noticed about themselves and believed this was as a result of care-giving.

> *P2: I mean myself I wasn't a calm person...I use to get angry quite a lot, I think when you are young you're always like "I want it my way" but after dealing with my mother-in-law I have calmed down a lot (lines 282-285)*

This caregiver further described how asking for help from dementia services gave her the confidence to speak up, from previously being a "very quiet person". She felt this confidence and assertiveness enabled her to get support from services and other family members.

Another caregiver spoke of the positive change he noticed in himself.

> *P9: I also think it [caring for my father] also made me a lot less self centred [laughs] and thinking about myself constantly and just doing things for others you know (lines 359-361)*

> *P9:...it's [caring for my father] bettered me as a person (line 365)*

He also described how dementia care-giving had made him think about the possibility of caring for others and had helped him to consider other options to pursue.

> *P9:...it also me made think of what I do aside from my 9-5 job, do I go out and help more people, do I do voluntary work, do I want to become a part time carer and help other people or not, it opens up opportunities, it opens up thoughts and you think what do I do... (lines 349-353)*

One caregiver felt care-giving had made her more aware of the strengths she had, in a way that she had not noticed before.

> *P5:...it's brought me even closer to them [her parents] and maybe highlighted probably the strengths that I have and built a character and I kind of recognise that probably much more than I did before (lines 216-218)*

3.2 Theme 2: Dyadic

This theme referred to the impact of dementia care-giving on the relationship between the caregiver and care-recipient, both in a negative and positive way. The former included coping with the loss of relationship whilst the positive impact focussed on reciprocity. Both seemed to reflect the close relationship had between the caregiver and care-recipient prior to the dementia.

3.2.1 Loss of relationship

One caregiver, who supported her husband, spoke tearfully about how he had become argumentative and accusatory. Due to her emotion, she struggled to articulate her experience in the first extract.

> *P1:...he is negative sometimes with me...Sometimes it's hard...I know it's because of his illness but sometimes he's talking all the negative things. I know it's...but sometimes it's not...that way (lines 70-74)*

> *P1: Sometimes I say something that's not right [something he doesn't agree with it] and then he gets angry at that time, for 10-40 minutes he's completely upset, and then I go out and then he says "Oh, you go out, you don't want to listen to me", all these things (lines 88-91)*

She spoke of how she was not used to arguing with her husband and seeing him in this way. Despite this, they seemed to still be able to maintain a sense of togetherness.

> *P1:...sometimes he says "I want to go for a madaf [coconut water, popular drink in Kenya] in xx [name removed] road", so I say, "Okay, let's go, I don't mind". We go by bus or whatever because now he can't drive because of the dementia (lines 38-40).*

Caregivers spoke of how they felt they had lost a parent due to the changes in personhood they had noticed in their family member following the dementia.

P5: It's quite tough at times cos you want your mum to be your mum but actually she's not, it's role reversals...(lines 155-156)

P7: For me she's a completely different person, she's got the same appearance but mentally and emotionally she's a completely different person (lines 31-33)

P7:...what I tell people is that my mum who was my mum died, so she's gone and this person has taken over her body but it's not my mum (lines 67-69)

Participant seven went on to emotionally describe the perceived loss she believed she would experience in the future.

P7:...when my niece was born, 50 or 60 people came in one day, you know we had this whole penda thing [an Indian Gujarati custom where Indian sweets are exchanged between family/friends to mark a celebration], you know the penda giving thing, we invited every single person to come in one day. But she [her mother] made all the pendas [Indian sweet], and she made like kachoris [Indian pastry] and she made food for that many people and you know those kinds of things. You know it's the little things, it's like when my sister and my brother got married she made all these karis [embroidery work] with that bhandari thing [embroidery work], you know those are things that have not even happened to me but those are the things I would miss from my mum (lines 404-415)

Despite this, she also described noticing exceptions and seeing "bits of mum", before the dementia, coming through at times.

Another caregiver described her "good" relationship with her sister-in-law, who had been "very supportive" to her before the dementia. However, after being

"accused" by her sister-in-law, due to her memory difficulties, of not giving food to her, this caregiver felt she was no longer able to care for her.

> *P10: Five minutes later she said xx [participant's name] has not given me food and that according to our customs, Bhabhi [Gujarati word for sister-in-law, brother's wife] not giving food is the height of everything...that hurt me. So that was hurt, now I can't, if she's going to accuse me of everything, I'm not going to be able to look after her at all and that was the reason why we had to put her into a care home, when it comes to this type of accusation it was for me unbearable (lines 65-78)*

The above quote reflects the different levels of impact that dementia care-giving seemed to have for this caregiver. At a dyadic level, the relationship between the caregiver and care-recipient had changed, which also affected the caregiver at an intrapsychic level (e.g. "*it was for me unbearable*"). At a community and culture level, it was the worry she would be seen as not fulfilling the expected roles and duties of looking after her husband's family, which for her generation were the cultural norms for most married Indian Gujarati women. This is discussed further in the subordinate theme of expectations and norms.

I explored the above conversation further with this caregiver and she focused again on the relationship between her and her sister-in-law.

> *I: What do you feel was so unbearable about it do you think?*

> *P10: That how can a relationship, when she, she knew she would call me xx [participant's name] Devi [divine/supreme Godess], the word Devi and suddenly from xx Devi, xx [participant's name] is not giving me food. That accusation you can't accept you know...(lines 80-83)*

It seemed the positive and close relationship they had before made dementia care-giving even more difficult to make sense of and accept. Similarly,

another caregiver, in the extract below, believed that if she had been closer to her mother she would not have been able to cope emotionally with caring for her.

> *P7: I know that there are some mums out there who are completely like you know like daughters and mums are best friends, I never had that so I think it would have killed me if we had a relationship like that because at the moment I mean it's hard enough [dementia care-giving] but to have a relationship like that and then go through this, I don't think I would have been able to cope (lines 264-268)*

Another caregiver described how his wife constantly worried about whether he would visit her at the care home. He also reflected on their close relationship and believed at times this was problematic.

> *P4: You know when that attachment is there this is what happens and that is creating more problems (lines 261-262)*

3.2.2 Reciprocity

This subordinate theme referred to giving back to the care-recipient and being there for them in a time of need.

In this sample, the spouses' spoke of how it could have been them in a position requiring support and if they were their spouses would have cared for them. These beliefs seemed to be a source of motivation for care-giving and helpful to accepting the situation.

> *P1: It's okay, I don't mind [caring for her husband] because I want him to be happy first...If it happened to me, he would look after me...We never know what our position might be after. We say all this...but we don't know (lines 375-379)*

> *P4:...how can you leave alone someone, when someone is sick, suppose something happens to you what happens, people don't think that way...but within a minute what is going to happen you don't know (lines 393-397)*

Also at a dyadic level, some caregivers, who were adult children, believed that care-giving was a chance to reciprocate the support and care they had received from their parents throughout their lives.

> *P9:...having someone as a support in your life since day dot you don't walk away from that and you support him just as he supported you as a child and it is neither here or there it [supporting his father] just came a second nature to be honest (lines 371-374)*

> *P7:...my mum loved Boondi [Indian sweet] and you know when I made it for her she was so happy...so now it's role reversal, so now I look after my mum cos she's done it all my life. So that's why I find I should do this [caring for her] for her (lines 574-578)*

Participant nine spoke of how his father had instilled values of caring for others and participant seven spoke of how her mother had taught her how to cook Indian food. These values and qualities instilled in them by their parents, it seemed were being reciprocated back.

Some caregivers saw reciprocity as an "opportunity" to be altruistic and compassionate and an opportunity which others may not get.

> *P9:...I am doing something that maybe they [his friends] may have the opportunity to do later on in their life or they may not...I think I am a lot more advantaged than other people because I've done something in my life that other people haven't done (lines 346-350)*

> *P3:...you sort of got to be in a sense blessed that you've been given this role to do – to help somebody else and that's I think the way we*

> *look at it... what higher duty can you actually do... You've been given
> this opportunity to do a duty that I guess very few people get the
> opportunity to do so you know...(lines 288-298)*

The use of the words "blessed" and "higher duty" in the last extract seemed to refer to spiritual and religious references.

One caregiver saw care-giving as an opportunity to also be more aware of the wider issues in society.

> *P5: I don't look at it [supporting her mother in a care home] as a
> burden or anything, but I think it's an opportunity really to be aware of
> what's going on within society, what people are going through and
> how you can just to be more compassionate with everything (lines
> 224-226)*

3.3 Theme 3: Family

Caregivers spoke of how care-giving impacted on their relationships with other family members. Immediate and extended family members were seen potentially as both a source of support and conflict. Caregivers also spoke of the role of dementia services in providing support to themselves and other family members.

3.3.1 Family Support

Family support seemed to mean different things for caregivers. One caregiver spoke of having her sister, who had experiences of supporting family members with dementia, to talk to as support. She reflected on her early experiences of care-giving and not feeling able to cope but felt her sister helped to instil confidence in her.

> *P2: I've got my sister, her in-laws they had dementia both of them, so
> she has helped me a lot with this...I would talk to her over the phone*

and then I would sit there for an hour and I would think what she said to me and I could do it you know, I could deal with it (lines 435-448)

Another caregiver spoke of having family members to call on and share the care-giving responsibilities with as a source of support.

P3:...we're very very lucky because we've got quite a big family so you know you're not just on your own, if I can't do things my brother's there...his wife is there, my wife is there, my sisters are just you know less than half an hour away from here (lines 334-337)

One caregiver also felt supported by his family, particularly his daughter and son-in-law.

P4:…my daughter has helped me quite a lot, she has always supported me, even her, my son-in-law. Even now they are supporting. And they are always there, they visit regularly [his wife in a care home]...(lines 355-357)

Earlier in his account he spoke of:

P4:…people [family] are not visiting her [his wife in the care home]. They try to keep away. Well if you try to help, if you come and visit them they'll be feeling happy (lines 76-77)

The meaning of support for this caregiver also seemed to refer to his family spending time with his wife and helping to improve her psychological well-being. He felt some family members were not supportive in this way, this is further discussed in the 'family strains' theme.

Two other caregivers also felt that it was their family members or partners who were their main support systems:

P6:…he's [husband] always given me full support...(line 475)

> *P9:…my support mechanisms are my siblings, my brothers and my sisters (lines 574-575)*

Some caregivers felt that through supporting each other in care-giving, it had brought them closer with their family or with the care-recipient. Caregivers also reflected on other positive aspects they had noticed in their relationships with their family members.

> *P5: It's probably even made us [with her parents] stronger (line 168)*

> *P5: I mean I was close to mum and dad anyway but it's brought me even closer to them (lines 214-215)*

> *P7:...it's brought us closer [with her father and siblings] definitely, we work as a team (line 277)*

> *P7:...I think we're a lot more open and honest about things you know (lines 310-311)*

Participant seven spoke of how it had taken time for her and her family members to become "more open and honest" with each other. She felt in the early stages of care-giving her "calls for help" were not being listened to by her siblings and she felt alone in caring for her mother. However, she realised that she needed to give her siblings time to "speed up" and come to terms with her mother's dementia.

3.3.2 Family strains

Caregivers felt that not all family members were as supportive as they could be and at times this was a source of conflict and stress.

One caregiver felt that her husband's family were reluctant in taking on care-giving responsibilities and expected too much of her as the daughter-in-law.

P6: I would like a little bit of help [in terms of the care-giving] from the family, I've got many sister-in-laws and brother-in-laws but I don't get any help from any of them and that's quite frustrating as well. They just say you're the sister-in-law, say it's your duty to look after her. You know in Indian culture, Bhabhis [Gujarati word for sister-in-law] or Vows [Gujarati word for daughter-in-law) looks after...but not anymore' (lines 134-138)

As previously highlighted with another caregiver, the perceived generational expectations and norms for a married Indian Gujarati woman will be further discussed under the theme of community and culture.

Participant six continued to speak of the strained relationships she had with some family members. She spoke of feeling unappreciated and believed her husband's family felt she was not doing a good enough job in looking after their mother, this had an impact on her at an intrapsychic level.

P6:...even if you don't want to look after your mum, enjoy her company while you're here, say nice things. Why do you want to say bitter things to me you know which is...cause a bad atmosphere you know so...I just...and then that hurts me, that really hurts me as I'm trying to do good things for your mum and all you do is see the negative side of it. We're all human, I'm not saying I'm perfect (lines 629-634)

As discussed previously, the following caregiver felt his siblings were not helping out enough with care duties for their father and he felt he was not able to call on them if he required additional support with looking after him.

P8: Sometimes it's frustrating, sometimes it's...you know I kind of say "Why is it down to me you know, why aren't the others [his siblings] going to help". Unfortunately not all of my siblings are helpful...I live with it (lines 198-200)

Despite feeling frustrated at times with his siblings, this caregiver did not feel it was a source of stress or conflict as he believed that "ranting and raving" would only be harmful to himself.

One caregiver felt that dementia care-giving had at times caused strains in his relationship with some of his family members. He felt there was a lack of understanding on their part in considering his wife's dementia. Although it was not easy to see his wife living in a care home, he felt it was the best place for her psychological well-being.

> *I: How did it feel for you when your wife went into a home?*
>
> *P4:...Well, it was bad but what can you do. It's better to have something somewhere for her peace of mind instead of having trouble here in the house (lines 462-465)*

He did not want to talk at length about family tensions but indicated in the interview that this had been the most difficult aspects of care-giving. The above extract also comes under the following theme.

3.3.3 Support from dementia services

One of the factors which seemed to mediate family strains and increase family support was input from dementia services.

One caregiver felt paid carers had helped his mother (also a primary caregiver for his father) in relieving the pressure of daily care-giving duties, which in turn had helped the family.

> *P3:…for the last two years we've had carers coming in as well, and that's been a great relief cos that's gives my mum a break, so they take care of dad for a couple of hours everyday...So that's been just a*

real great thing for us because without that it would be just so much
more difficult (lines 240-246)

Some caregivers found it helpful to talk to paid carers and draw on their expertise. This information was then communicated to other family members in the house to help interact with the care-recipient at home.

There were still issues caregivers had to consider by having paid carers. Some caregivers felt it was important to have Asian carers to make it easier in conversing with the care-recipient and other family members, whilst also providing the care-recipient with some aspect of familiarity.

> *P9: We have an Asian caring company, we moved away from that*
> *other company. They were a lot more better...some of them can't*
> *speak Gujarati [laughs], so they talk in Hindi which Dad understands.*
> *One time, Dad had a Mahastran carer and Dad is from Bombay, so*
> *he spoke sometimes to Dad in Maharati and you could see Dad smile*
> *(lines 453-456)*

One caregiver spoke of how it was not important for dementia care services to be specific to Indian Gujarati individuals. When asked about the topic in relation to his father attending an Indian Gujarati community group for older people, he said:

> *P8: As far as Dad's life is concerned, as long as he's out doing*
> *something that is not what he would do in the house and he's happy*
> *and he's comfortable regardless of what it is, it doesn't have to be an*
> *Indian community, it can be a community local...(lines 510-514)*

It seemed for this caregiver he did not mind the integration of services for all ethnic and cultural groups.

3.4 Theme 4: Community and Culture

This theme centred around two subordinate themes of expectations and norms and knowing and talking about dementia to others in the Indian Gujarati community.

3.4.1 Expectations and Norms

This subordinate theme referred to cultural expectations and norms but it was also underpinned by multiple levels of context including generational, gender and family norms.

As discussed under the theme of family strain, one caregiver spoke of the expectations she believed were placed on her as a daughter-in-law having to care for her mother-in-law.

> *P6:...the sister-in-laws say it's your duty to look after her [mother-in-law]. You know in Indian culture, Bhabhis [Gujarati word for sister-in-law] or Vows [Gujarati word for daughter-in-law) looks after...but not anymore you know (lines 136 -138)*

She went on to describe why she felt she did not speak out about these expectations and norms.

> *P6:...my generation or the generation before that you know, people in their 70's or 60's sort of...we accept loads of things, you just take it you know. But these days, you tell youngsters, [laughter] they would say "How dare you talk to me like that?" but with us you say "Okay", you don't want to be rude because they're your sister-in-law or brother-in-law or...you just want to respect and sort of take it (lines 649-656)*

However, in her account, the caregiver described generational stories of women working hard and providing for the family, thus cultural expectations and norms seemed to also be a part of generational and family norms.

> *P6:…she [mother-in-law] has had a hard life and she had to be with so many children...certain things my husband's says like, in xx [year removed] they went to India, and her brother-in-law's son said go to village with all your kids and do the farming there and she goes "Why, I'm not here to...I'm not gonna make my children work on a farm, I'm gonna educate them" and she had to fight you know to make them educated....So where they are and what they are, it's all to do with her and same thing with my mum, what she did for us. I mean they all worked hard for...to see the future for their children rather than what they were going through. And we do the same for our children, don't we (lines 822-832)*

In her account she also made reference to herself as a "hard working daughter-in-law" and seemed to connect her care-giving role with the generational stories of her mother and mother-in-law as hard working women, their strong work ethic and providing for the family.

Another caregiver spoke of experiencing similar expectations to fulfil her role in caring for her husband's family. In the extract below, she spoke of this experience before her sister-in-law went into a nursing home.

> *P10: I thought as a Hindu woman you are supposed to look after the husband's family, that's what I did, I had no say...but that did not mean that I have to be all the time underdog, that I have to keep on doing things all the time [for them]...(lines 133-138)*

However, she spoke of how she now fought for Asian women's rights on a public and political platform.

P10...as a Hindu woman I didn't speak out so that part perhaps is a bit role modelling perhaps or changing the way the society is run...I am a feminist [laughs] and that's what I've fighting for with UK Asian women...and that's why I have been going to United Nations twice and fighting for all the women's rights (lines 139-147)

Other references to expectations and norms, were associated with perceived community norms, which seemed to help some caregivers to understand how they came to be in the position of supporting their family member with dementia. This understanding also seemed to help them accept and adjust to care-giving.

P1: It's our, you know in our Indian community, if a child or a disabled person we have to look after and it's our family, whatever way we can, that's in our religion, in our...we don't want to do anything wrong, whatever we can, we can help (lines 388-391)

P8: It's a part of my responsibility...and that's because of the way our community works, our upbringing works. You don't really think that it's a chore or anything like that, it is a done deal, so I don't really dwell on it and I don't mind you know (lines 579-582)

When explored further, participant eight described that during his upbringing he had seen his father looking after his grandfather. Like another caregiver, he seemed to be able to connect to of generational stories of care-giving. It seemed he saw himself continuing with this generational pattern.

P8:...the way we we've been brought up, we've been brought up in an extended family so to speak. My father looked after my grandfather...so we've just followed on from that...(lines 592-596)

3.4.2 Knowing and talking about dementia

Some caregivers reported that their knowledge of dementia was limited before their family member was diagnosed with the condition. Caregivers spoke of how they developed a better understanding of dementia so that they could provide better care for their family member.

One caregiver spoke of how she attended a course on dementia:

> *P2: I went onto the dementia course and that was very helpful, from that I can actually understand what dementia means to me and how to look after them, how to care of them (lines 12-14)*

Other caregivers spoke of researching the topic on the internet and looking for interventions which helped to maintain their family member's personhood.

> *P5: I mean once we knew it was dementia we did quite a lot of research on the internet, also from kind a family perspective to say…what could we do to help her, to just keep her busy, to keep her occupied because she's a very independent woman...(lines 47-51)*

> *P9: We did a lot, a lot of reading on the internet. Not on cures for Alzheimer's and stuff, we knew it wasn't curable but how to support...trying to look at activities to stimulate them...a lot of it was saying focus on things that they like so we do that. Dad is a heavy heavy follower of Sai Baba [Indian spiritual figure] so we put that on, I play bhajans [religious songs] or artis [religious prayers] to him (lines 406-413)*

Some caregivers believed there was a lack of knowledge about dementia within the "Asian community". One caregiver believed this was in part due to linguistic differences, but he felt it was largely due to South Asian people's reluctance in wanting to talk about dementia due to stigma.

I: You spoke about the belief you have that there is a "void in Asian people's knowledge about dementia".

P9: Yeah.

I: Where do you think that belief comes from?

P9: Because it's...I'd say it isn't something that is spoken about a lot. Yes people face it in within their families but it's not something that is openly spoken about. You know if someone's gone downhill in your family or if someone's messed up in your family you don't openly talk about it in your community because...sometimes it' shameful, sometimes you just don't want your public laundry aired kind of thing and that's what I felt it was like with Alzheimer's (lines 475-485)

Another caregiver believed there was reluctance to 'hide' older people and not acknowledge older adult issues rather than not wanting to talk about dementia.

P5:...in Asian communities a lot of families just don't even want to acknowledge that there are issues [older adult issues] with family members especially the elderly and almost want to box them [older people] up and sort of shy them away...so I think it's a lot of education that needs to happen (lines 199-204)

However, despite the perceived silencing of dementia and reluctance in acknowledging older people, some caregivers wanted to be open with the community about their family member's dementia. For example:

P3:...we try and take him [his father] out as much as possible cos there's no point in hiding because we're in such a big community and we have to attend functions, we'd rather he comes than he stays at home with somebody else and so far as long as we can manage it, manage the process and he's ok and his dignity is...fine... uhm then

we'll carry on doing that and then I think by now most people have
realised...you know his condition [dementia] (lines 100-106)

It seemed that in being open with others about his father's dementia they as a family could remain integrated within their community and "attend functions". He spoke earlier in the interview about how his father had been a leader within the community.

Another caregiver spoke about wanting to talk about his wife's dementia to others but some family members did not want to disclose it. This caregiver believed that in being open about dementia the availability of further help and support could be highlighted to him by others.

P4:...when you see the people, some disease [e.g. dementia] is there
or some mental health difficulties is there, people don't won't to talk
about it but I'm open always and talk about it [wife's dementia]. These
people [some family members] are trying to hide but I'm not trying to
hide, I don't hide any of it. Whatever is there is there, whether you
hide or not, what is going to happen. If you converse with people then
you know exactly what and you can get some help also sometimes
(lines 64-69)

When asked, participant four spoke of how he had told other members of the community about his wife's dementia and he continued to take her, where possible, to community functions.

I: And would you tell members of the community that your wife has a
diagnosis of dementia?

P4: Yeah, I do talk. And they saw her [wife] this time you know my
brother-in-law, her brother passed away...and she came to the Sadhri
[marking after someone dies; family and community members come
together] and she knew a lot of people...(lines 196-200)

One caregiver spoke also of how he had told others in the community about his father's dementia and did not feel it was "any bad thing". He felt most responses to this in his community had been "alright".

> *I: Have you had experiences of telling other people in the family or in the community that your dad has dementia?*
>
> *P8: Yeah, I do. The Indian Jain community centre [for older people] where he goes, they all know that my dad has an issue, they recognise it and they're very helpful...I don't think telling people that he's got dementia is any bad thing not since the government's been advertising the fact that you know that people have got dementia just be patient with them and things will be okay, and most people are alright (lines 562-576)*

Another caregiver also spoke about how it felt important to be transparent about her mother-in-law's dementia but not just to the Asian community.

> *P2:...don't be ashamed of what she [mother-in-law] has got right. Be open with people and don't try and hide things, be open. Because the public can see, people can see it so why are you going to hide it, don't hide it, be open with them so at least they know you're telling the truth and they will handle them better, yeah.*
>
> *I: Did you ever at any stage feel you had to hide that your mother-in-law has dementia?*
>
> *P2: No, I didn't. First I thought I should but then I said no, why should I? People need to know what her needs are...(lines 428-435)*

It seemed that being open about her mother-in-law's dementia, this caregiver hoped others would be more sensitive and understanding to those with dementia and their needs.

Summary

Four main themes were identified completing an IPA on ten accounts of Indian Gujarati people in the London area who were supporting a family member with dementia. These themes represented the impact of dementia care-giving felt at different levels by caregivers. The impact was felt at an intrapsychic level, dyadic level, family level and community and culture level. Each of these themes were interconnected and had a number of subordinate themes. These will be considered in further detail in the following chapter.

CHAPTER 4: DISCUSSION

This chapter provides a summary of the findings that emerged from the analysis and discusses these within the context of the study's research questions and the wider literature. The discussion then moves towards the research and clinical implications of the study. The chapter concludes with a critical review and evaluation.

4.1 Summary of findings

This study's central aim was to explore how Indian Gujarati people in the London area who were supporting a family member with dementia felt about their experience.

In speaking about their experiences at an intrapsychic level, caregivers spoke of the emotional impact of dementia care-giving. This included at times feeling 'depressed', mentally exhausted, worried and guilty for feeling frustrated with the care-recipient. At an intrapsychic level, caregivers also spoke of changing how they thought about a situation, which was used as a coping strategy to manage the stressful aspects or consequences of dementia care-giving (i.e. family strains). This included letting go of negative feelings which was seen as harmful to the self. This belief seemed to be connected to religious and spiritual beliefs around karma and reincarnation. Finally, at an intrapsychic level, caregivers' spoke of the growth and development they had experienced from dementia care-giving.

In speaking about their experiences at a dyadic level, caregivers spoke of the impact of dementia care-giving on their relationship with the care-recipient, centring on loss of relationship and reciprocity. The former referred to changes in the care-recipient's personhood. Reciprocity referred to being there for their family member, giving back the support they had received from them and opportunities for altruism. Both subordinate themes seemed to

highlight the close relationship had between the caregiver and care-recipient before the dementia.

In speaking about their experiences at a family level, caregivers spoke of the importance of family support in dementia care-giving, referring both to emotional and practical support. Whilst caregivers spoke of feeling closer to some of their family members, they also spoke of the stressful impact of family strains. This related to feeling frustrated by the lack of support shown with care-giving duties and a lack understanding of the care-recipient's dementia. Finally, at a family level, caregivers spoke of the support provided by dementia services. This seemed to mediate family strains and increase support to the family.

In talking about their experiences at a community and culture level, caregivers spoke about expectations and norms and knowing and talking about dementia. The former, for two caregivers, referred to negotiating expectations with their husband's family of was expected of them as married Indian Gujarati women. For other caregivers this theme was associated with community norms of supporting family members. This theme also highlighted generational stories and multiple levels of context of care-giving. Knowing and talking about dementia referred to how caregivers developed their understanding of dementia. It also related to how open caregivers were with community members about their family member's dementia and the gains experienced (i.e. positive responses, remaining integrated within their community and made aware of other help and support available).

4.2 What did dementia care-giving mean and what were the positive aspects of care-giving?

The analysis suggested that these two research aims were connected for caregivers. Thus the meaning of dementia care-giving was part of what caregivers felt the positive aspects of care-giving to be. This supports the findings from studies which have shown that care-giving can be experienced

as positive, rewarding and meaningful (Ayres, 2000; Kim, Schulz & Carver, 2007).

The theme of reciprocity captured what the role meant to some caregivers. Two spouses spoke of how it was an opportunity to be there in a time of need for their partners and maintain a sense of closeness to them. They felt that one day it may be them who needed looking after and as older adults this issue may have felt closer to them. Both spouses believed their partners in the same position would do the same and care for them. The literature review identified no research which specifically highlighted these ideas of reciprocity. However, a study by Narayan et al., (2001) found that spouses experienced dementia care-giving as positive, such as finding it to be self-fulfilling and affirming.

In a different dyadic context of care-giving, two adult children spoke of reciprocity as an opportunity to give back to their parents the care and support received from them. Reciprocity was not framed or labelled as 'familial duty', as is often found in the literature on care-giving within South Asian families. This contrasts with the findings of Lawrence et al., (2008) and Godfrey and Townsend (2001). Both reported that for South Asian caregivers supporting a relative with dementia, care-giving was rooted in a strong sense of obligation and was expected, as underpinned by cultural norms. ''Familial duty' suggests a passivity and an obligation to care but this did not seem to be the case for caregivers in this study. Care-giving was a more active process and motivations for care-giving seemed to be based upon reciprocity.

The reciprocal relationship between the care-recipient and caregiver has been identified as a salient factor for caregivers finding positive meaning in the role (Cartwright et al., 1994; Nolan, Grant & Keady, 1996) and this mediating the stressful aspects of care-giving. Although this study cannot conclude such findings, it seemed that close relationships had with their family members prior to the dementia helped caregivers to derive positive meaning from the care-giving role (i.e. reciprocity). Furthermore, some caregivers reported

feeling closer to the care-recipient or other family members through dementia care-giving.

Some caregivers felt care-giving was an opportunity to do something good. It was a chance to be altruistic and have the "opportunity" to do something which others may not get the chance to do in life. One caregiver described care-giving as a "higher duty" and feeling "blessed" to be in a position to support another person, which suggested religious and spiritual connotations.

Some accounts highlighted generational stories of care-giving which caregivers seemed to connect to and understand their current role in care-giving role by. For example, one caregiver spoke of generational stories of women working hard to care and provide for their family, which resonated for her. Another caregiver spoke of how he had seen his father care for his grandfather and that he was continuing with this generational pattern by looking after his father with dementia. It seemed that for some caregivers, their current care-giving role meant that they could be a part of these generational stories and continue with tradition. The finding suggests that care-giving must be understood within multiple levels of context (Cronen & Pearce, 1985). It also supports the finding from Fox, Hinton and Levkoff (1999), who showed that by highlighting caregiver stories, meaningful connections between historical experiences and cultural representations of the care role can be understood. The authors suggest this can have theoretical implications in helping to develop conceptual frameworks for understanding how caregivers adjust to their role.

Some caregivers spoke of experiencing a sense of personal growth and development as a result of care-giving. One caregiver, caring for her mother-in-law, spoke of the confidence she developed particularly with becoming more vocal in asking for help. Another caregiver spoke of how he felt care-giving had "bettered" him as a person by making him less selfish and more mature. He felt the care-giving role had made him think differently about what he could achieve in life and widened his thinking around job possibilities. Davis & Morgan (2008) suggest that long-term positive gains such as growth

and development can help caregivers find meaning in challenging situations. This study cannot draw such conclusions but does highlight that some caregivers did appear to experience personal growth and development through care-giving.

4.3 What were the negative aspects of dementia care-giving?

Caregivers spoke of the emotional impact of care-giving, such as feeling "mentally tired" and "depressed", particularly in the earlier stages of supporting their family member. These findings are consistent with studies which have shown the adverse impact of dementia care-giving on caregivers' emotional well-being (e.g. Aneshenal et al., 1995, Levin et al., 1994).

Some caregivers described feeling frustrated at times with their family member's dementia. In their accounts, this frustration seemed to be connected to the complex process of accepting dementia, where one has to constantly adjust to a family member's progressive decline. For other caregivers, feelings of frustration towards their family member seemed to occur when they were less equipped to manage their difficulties (i.e. after a stressful day at work). Some caregivers believed that feeling frustrated in this way was 'wrong' as it was their family member and it was their "illness" or "disease" that caused them to behave in that way.

The loss of relationship with their family member was considered by some caregivers as a negative aspect of dementia care-giving. This is similar to findings by Ingebretsen and Salem (1997) who found that levels of distress experienced by those caring for relatives with dementia was influenced by their family member's loss of personhood and relationship changes. As discussed previously, a close relationship between the care-recipient and caregiver has been identified as a salient factor for helping caregivers to adjust to care-giving. However, it seemed that having a close relationship made care-giving more difficult in that the loss felt was more painful for some caregivers. Hunt and Smith (2004) believe this is something which is not highlighted strongly in the literature. Indeed, a quantitative study by Fauth et

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al., (2012) found that caregivers' relationship closeness with their family member with dementia predicted both positive and negative outcomes for their physical health and psychological well-being.

It was strained relationships with family members that was a potential source of stress for some caregivers. This was usually caused by caregivers feeling unsupported in their role and undertaking more of the care-giving duties than their relatives. This finding challenges the commonly held assumption of South Asians having extensive family networks in which to draw emotional and physical support from. The finding also supports a study by Katbamna et al., (2004), who found that the quality and quantity of informal support available to South Asian caregivers in the UK varied greatly and families' willingness to support caregivers. However, it is important to note that not all who reported strained family relationships felt it to be a cause of stress. Indeed, caregivers spoke of how they coped with these challenging situations by letting go of feelings frustration and anger felt towards their family member. This is discussed in further detail later on in the chapter.

One caregiver spoke of how dementia care-giving made her question some of her long standing religious beliefs. She found it difficult to make sense of how her sister-in-law came to have dementia despite being a "good person" and having care, love and money. It seemed this belief was underpinned by ideas of karma that carrying out 'good' deeds means one will have a life without 'bad' things happening to them. This caregiver worried about her future, whether she had done 'enough' good deeds or if she would be the "right candidate" for dementia. However, her account showed that she dealt with this internal conflict by turning to her religion and attending Gita [religious text for Hindus] classes where these issues could be debated. Furthermore, whilst questioning some of her religious beliefs she was also able to use her faith to help her cope with the negative aspects of care-giving by letting go of the "difficult parts" or difficult feelings.

In this sample, two women spoke of their difficulties in fulfilling the role of caring for their husband's family as married Indian Gujarati women. Under the

theme of expectations and norms, this study uncovered how two Indian Gujarati women had to negotiate these expectations within a dementia care-giving context. This finding does not seem to be highlighted in previous studies. Brah and Minhas (1985) suggest that racialised and colonist discourses about 'Asian culture' constructs women as passive and victims of supposed oppressive patriarchal cultures. It could be easy to make this or a similar interpretation based on the accounts of these two women. However, what seemed to be highlighted was how these women were questioning and challenging these perceived cultural norms which they felt they had to conform to. Indeed, one caregiver spoke about her work for a UK Asian women's group and fighting for women's right on a more public platform.

A study by Raval (2009) explored the narratives of married Indian Gujarati women in India and Canada on the issue of family relationship. The study found that the women, both mother-in-laws and sister-in-laws, actively engaged in negotiating conflict between what they wanted and what their in-laws expected of them. However, their mode of agency was more relational rather than individualistic, where negotiations occurred within the boundaries of their familial roles rather than rebelling against traditional family structures. At the centre of their decision-making and actions was the welfare of their children. Raval (2009) concluded that if we are to understand the lives of women from different cultures, then we need to broaden existing western conceptualisations of agency and feminism.

Some caregivers believed that there was a lack of knowledge and dementia related stigma in their community. Certainly some of the literature discussed in the introduction (e.g. Adamson, 2001, Bowes & Wilkinson, 2003, La Fontaine et al., 2007) on dementia in South Asian communities suggests this to also be the case. As highlighted before, there are flaws with homogenising 'South Asians' in research. The other flaw seems to be that these findings are rarely compared with other populations and therefore dementia related stigma and lack knowledge of the condition becomes a problem only specific to 'South Asians'. However, studies have found that these issues exist within other populations (e.g. Rimmer et al., 2005; Alzheimer's Society, 2008).

Indeed, some caregivers in this study spoke of their openness and transparency about their family member's dementia within their community. Importantly, this transparency meant that they and their family member with dementia could remain integrated within the community and not 'hide' away. Caregivers also spoke of community reactions as positive and accepting of dementia. This finding does not appear to be documented in the literature, despite the literature often emphasising how important 'the community' is to 'South Asians'.

4.4 What helped some Indian Gujarati caregivers cope with care-giving?

There were a number of factors which caregivers felt helped them to cope with dementia care-giving.

Some caregivers' spoke of changing how they thought about the situation helped them to manage what were considered the negative aspects of dementia care-giving. This process involved letting go of feelings of anger and frustration as it was believed that holding onto these feelings were harmful to oneself. Some caregivers linked these beliefs to ideas of reincarnation and karma, which are central tenets in Hinduism and Jainism. As mentioned, one caregiver spoke of how "Gita (main religious text in Hinduism) classes" had helped her to let go of the "difficult parts", referring to the difficult feelings which arose from care-giving. Indeed, Farran, Paun and Elliott (2003) found that religious and spiritual beliefs provided an explanatory framework resulting in greater acceptance of the challenges of care-giving, an enhancement of caregiver's ability to cope with stress and find meaning from care-giving. The role of religion and spirituality in care-giving is discussed further in the section on clinical implications.

Family were viewed as potentially a source of conflict but also of great support in care-giving. Caregivers spoke of family members as offering emotional and practical support. These findings are consistent with that of Marwaha & Livingston (2002), who found that South Asian dementia caregivers used

other family members as a resource in helping with care-giving. The role of family is also discussed further in the section on clinical implications.

Despite the important role of family, all caregivers had additional support from paid carers and input from dementia services. The accounts revealed how support from dementia services mediated family strains and enhanced support. These findings challenge the literature that suggests 'South Asian' dementia caregivers do not access outside help due to worry about how their community will respond and therefore are more likely to access help from family and spiritual healers (e.g. Mackenzie, 2006, Marwaha & Livingston, 2002). There were issues to consider with accessing outside help, some caregivers felt it was important to have paid carers who were Asian or Indian Gujarati so that they could converse with the care-recipient and other family members in the household who were also providing care.

4.5 What does this study add to existing literature?

<u>Consistent with previous findings</u>

The study highlighted that in this sample many aspects of the dementia care-giving experience for Indian Gujarati caregivers was similar to that of the general population. This was in relation to themes of psychological impact, loss of relationship and finding meaning in dementia care-giving.

Also similar to previous findings was that the availability of family support varied for caregivers (e.g. Katbamna et al., 2004), which seemed to consequently lead to family strains. This challenged the cultural stereotype of South Asians having access to supportive kinship relationships and extended family networks.

<u>New findings</u>

Religious and spiritual ideas of karma and reincarnation (central tenets in Jainism and Hinduism) helped caregivers to think about the negative aspects

of care-giving differently. Holding onto negative feelings were seen as harmful to oneself in the present and next life. This belief seemed to be important in helping caregivers to let go of negative feelings and thus was used as a positive coping strategy.

The theme of expectations and norms at the community and culture level, in this sample, was apparent in the accounts of two Indian Gujarati caregivers who were women. The study highlighted how they had to negotiate expectations of caring for their husband's family within the dementia care-giving context.

The findings of the study also revealed how some caregivers were open about their family member's dementia to others in their community and took their family member to community functions. They felt there had been little negative reactions towards them. Being transparent about the dementia seemed to mean they and their family member could remain integrated within the community.

4.6 Implications for clinical practice

This study showed there was variability in support available to caregivers from other family members. This led to strained relationships between caregivers and some members of their family and it was a significant source of stress. This finding challenges assumptions in the literature of the availability of family support for 'South Asians' and that all family support is a positive resource for them. These ideas have been put forward as reasons why 'South Asians' are less likely to access help from services (Mackenzie, 2006). Furthermore, input from dementia services were seen to enhance support and consequently mediate family strains. This finding highlights the need for health and social care professionals to not make assumptions about the role of kinship ties for Indian Gujarati people. Such assumptions and cultural stereotypes means the support needs of those who do not have such networks or where family relationships are a significant source of stress could be ignored.

The findings from this study supports the idea that approaches such as mindfulness or Acceptance and Commitment Therapy (ACT) may have a good fit for some Indian Gujaratis, particularly those who follow religions of Jainism or Hinduism. Some caregivers spoke of how changing the way they thought about a situation and letting go of negative feelings was used as a way of coping with the challenging aspects of dementia care-giving. Holding onto negative feelings were seen as harmful to the self in one's current and next life and this belief seemed to be informed by ideas of reincarnation and karma, central to Hinduism and Jainism. Mindfulness and ACT use techniques that involve letting go of negative thoughts and thinking about the values which are important to the person (Robb, 2007). In contrast, cognitive behavioural approaches which focus on one's negative thoughts and feelings may not resonate for some Indian Gujaratis and thus may lead to poorer clinical outcomes.

Some caregivers spoke of generational stories of care-giving and connected their current care-giving role with these historical stories. It seemed to help caregivers find meaning in care-giving and to accept the role. Indeed, Fox, Hinton and Levkoff (1999) highlight the importance of caregiver stories in helping to understand meaningful connections between historical experiences of migration and settlement and cultural representations of the care-giving role. Thus it may be helpful to have conversations which illuminate caregiver stories which may help caregivers find meaning in the role and subsequently help adapting to the role. Narrative and systemic approaches may be better suited in uncovering such stories and attending to multiple levels of context in care-giving.

4.7 Recommendations for future research

Kleinman (1977) points out that those from South and East Asian cultures often somatise psychological distress or suppress negative feelings, as non-disclosure is seen as favourable in these 'cultures'. In the western world, the 'ability' to express one's psychological state is privileged and favoured over

those who do not. However, in this study, the reason why some Indian caregivers chose not to focus on the negative feelings resulting from aspects of care-giving seemed to be connected to their religious and spiritual beliefs of karma and reincarnation. Holding on to such feelings were seen as harmful to the self and letting go of them were used a positive coping strategy for coping with what were considered the negative aspects of care-giving. This study highlights the role of religion and spirituality and how it might influence one's way of thinking and coping with care-giving situations. More research is needed into how these factors might help some to alleviate psychological distress and adapt to dementia care-giving. Furthermore, research is needed into how psychological interventions can integrate and utilise people's faith systems.

The role of expectations and norms were evident in this sample in the accounts of two caregivers who were women around negotiating the expectations of caring for their husband's family. Both were primary caregivers for their husband's family member. It was evident from their accounts that these caregivers were challenging these cultural norms and expectations rather being 'victims' of their culture, which could be interpreted. As Raval (2011) states, agency might be shown in different ways in women from different cultures and the construction of feminism itself may be too Eurocentric. Furthermore, Brah (1996) suggests that "women of Asian origin in Britain are actively setting their own agendas...and marking new cultural and political trajectories" (p. 69). Further research in the UK could explore the different ways in which agency is shown by Indian Gujarati women or women from other cultures and how expectations of others are negotiated within a dementia care-giving context.

There was no reference in the accounts to the migration histories of the caregivers or care-recipient. The current study perhaps due to methodological and epistemological limitations could not access these stories. As highlighted previously, Fox, Hinton and Levkoff (1999) suggest experiences of migration may help to mediate the psychological distress of care-giving due to previous experiences of coping with oppression and adjustment following migration.

Many Indian Gujaratis who migrated to the UK in the 1970's are said to have had 'successful' migration histories first in East Africa and then the UK (Berry, 1980, Ramji, 2006). However, there is little reference to these experiences of migration in the literature. It would be worth exploring how as a community Indian Gujaratis have been able to re-establish their networks in East Africa and in the UK and how this might promote psychological well-being. Fox, Hinton and Levkoff (1999) suggest stories of adaptation and settlement can illuminate stories of adapting and coping to dementia care-giving. A different methodology such as discourse or narrative analysis, which attends to language, historical and cultural contexts, might be able to access these stories more easily.

The wider research implications of this study could be to also examine dementia care-giving experiences of other ethnic or cultural linguistic groups in the UK to offer potential points of contrast with this study. As highlighted previously, research by Parveen, Morrison and Robinson (2011) and Burholt and Dobbs (2010) suggest that ethnic variations in care-giving exist. However these two studies are not specific or only specific to dementia care-giving and thus comparisons cannot be made with the findings of the current study. Thus, the dementia care-giving experiences of Indian Punjabis or White working class families who are family centric in the UK for example could be examined. Early and recent studies have shown the significance and reliance on strong kinship networks for some White working class families (e.g. Young & Wilmot, 1957; Rosser & Harris, 1965; Gorman, 2000).

The findings from this study suggest that further research is required on the issue of dementia related stigma in South Asian communities and other populations. In the current study, some caregivers spoke of telling others (i.e. their community, other family members) about their family member's dementia and that they had experienced little negative reactions from their community. Furthermore, it meant that they and their family member could continue to attend community functions and remain integrated within their community as did not feel they needed to hide. As highlighted above, it would be interesting

to see how dementia related stigma compares across different South Asian communities and populations.

4.8 Critical review

<u>4.8.1 Reflexivity: challenges and limitations of the study</u>

The current study has provided new findings by focussing on a specific cultural linguistic group not previously researched in the UK within the context of dementia care-giving. It has also produced findings which have both challenged and supported the existing literature. However, it must be acknowledged that the study had some limitations. Furthermore, qualitative research can particularly create challenges, as highlighted previously in the methodology chapter. Through reflexivity, a key factor of qualitative research, these challenges and limitations will now be considered.

Sample

The study obtained a small sample from a specific geographical area. Therefore the findings may not be representative of other Indian Gujarati individuals living in the UK. The findings cannot be considered generalisable, however it is important to note that this was not the aim of the study. One of the aims of using a qualitative methodology was to capture the uniqueness and diversity of peoples' experiences.

Homogeneity of the sample referred to the perspective participants represented (i.e. the views of Indian Gujaratis in London on dementia care-giving). However, as highlighted in the introduction, culture and ethnicity are fluid concepts. Heterogeneity will inevitably exist within specific groups, even those who identify themselves as belonging to the same ethnic and cultural group. The current study used a highly defined sample in terms of ethnicity, languages spoken (Gujarati and English) and cultural heritage. However, some differences also existed such as religion (Jainism and Hinduism), migration history, gender, age, socio-economic background and kinship

relationship with the care-recipient. All of these factors may have shaped how a caregiver made sense of dementia care-giving. Furthermore, conclusions cannot be drawn for those who were not approached to take part in the study. These accounts may have uncovered very different perspectives on dementia care-giving.

Heterogeneity also existed in the length of time caregivers had been supporting their family member with dementia and the stage of the condition. The time of diagnosis can give an indication of the likely advancement and severity of dementia but this is not always an accurate indicator. Some individuals present to services much later and their family member may have been providing some level of care before this point (Plassman et al., 2007). Therefore this study provided the caregiver's perspective across the dementia care-giving trajectory. Caregivers made references to their earlier experiences which partly captured some of the changes over time. However, this may have been influenced by how they felt at the present time and their current circumstances.

Similarities and differences

In the methodology section I briefly highlighted the different positions I held which may have influenced the research process. Focussing particularly on my position as a British Indian Gujarati and thinking above about the sample, I shared some similarities with them, most significantly in terms of ethnicity. Some have highlighted the benefit of researchers studying groups of which they are similar to (Egharevba, 2001; Grewal & Ritchie, 2006). Indeed, in some ways I felt my similarities helped the research process. This included having access to a potentially hard to reach group, a sense that participants felt more at ease with someone perceived to be similar to them and a shared desire to highlight a group underrepresented in the literature.

There were other ways I felt the perceived similarities between myself and the participants may have limited some of the discussions. For example, there may have been the assumption that some issues did not require further

explaining as I had previous knowledge about them or could identify with them as an Indian Gujarati. On a few occasions, some participants made some assumptions about my beliefs (i.e. "you believe in reincarnation don't you?") and future circumstances (i.e. that I would be looking after my parents as they got older). It reminded me of the many differences that existed between myself and the participants and it felt difficult on many levels to express difference. I also thought about what implications this might have for rapport and engagement. I was also mindful of how much of my "non research self" I could bring into the interview without 'contaminating' or 'distorting' the interview (Glensne & Peshkin, 1992).

Challenging cultural stereotypes

There were a number of assumptions or cultural stereotypes about 'South Asians' and why they were underrepresented in mental health and dementia services. Although, I critiqued these assumptions in the introduction section, it was a challenging process where I had to acknowledge that I too held some of these beliefs, such as ideas of supportive family networks and stigma of dementia for South Asians. I reflected on how I had ignored the differences and diversity of experiences that existed amongst South Asians. It took some time to 'bracket' these assumptions and to think about the mainstream literature with a more critical perspective. The more I was exposed to literature which challenged these cultural stereotypes, the process became easier. However, I wondered if this may have created a 'distance' between my interpretations of the findings and what some participants hoped to highlight in their accounts. I was aware that if I and many others held such cultural stereotypes about South Asians then some participants may have also held those views. It again made me think about my position and how my familiarity with dementia care-giving literature may have influenced my interpretations.

How to represent British Indian Gujarati individuals

One of the reasons for undertaking the current research was to acknowledge the heterogeneity of South Asians and Indian groups, thus challenging cultural

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assumptions. However, in this process I did not want to label Indian Gujaratis as being so different from the general population and other South Asian groups as I realised that this itself could be problematic. I had to think about the potential impact this research could have on the caregivers who took part in the study and the group they considered themselves to be representing. Throughout the research process I thought about how I might be positioning them, Indian Gujaratis as a group and the interpretations others may make of them.

Thus, reflecting on the above, the process of making interpretations was at times difficult, particularly as it made me aware of the power and responsibility I had in what gets reported. How I was choosing to make sense of the findings I realised may not have resonated with some caregivers. For example, I felt that some participants wanted to take part to highlight some of the struggles faced in dementia care-giving and the support needed for Indian Gujaratis caring for a person with dementia. However, by highlighting the positive aspects of dementia care-giving, one of my research questions, it may be construed that support was not required. Other examples included how I chose to interpret the perceived stigma of dementia reported by some caregivers in their community and fulfilling the perceived expectations in caring for their husband's family, for some female caregivers, of an Indian Gujarati wife. I was aware that including these extracts may further reinforce cultural stereotypes so it felt important, based on my understanding of the literature, to consider alternative interpretations. However, I realised how difficult it was to represent one version of reality. The process of interpretation also made me question my epistemological position and how findings may have been different had another methodology been employed. These reflections have informed my recommendations as discussed previously.

The 'care-recipient'

This study did not focus on the perspective of the person with dementia. However, Braun et al., (2009), following a literature review, found there was a need to integrate the perspective of the person with dementia, which was

neglected by many studies. The author's state that to improve the understanding of the impact of dementia care-giving and to gain a better relational perspective, the viewpoint of the person with dementia must be taken into consideration. Cheston and Bender (1999) suggest that the increased focus on caregivers is due to persons with dementia being seeing as "non-people or as beyond help" (p. 93). Thus, although this study focuses of the relationship between the care-recipient and caregiver, how dementia care-giving impacts on both parts of the dyad remains unknown.

4.8.2 Evaluation of research

Given the challenges, the robustness of qualitative research can be called into question. Elliott, Fischer and Rennie (1999) propose a set of guidelines with which to evaluate the reliability and validity of qualitative research. The next section outlines the steps I took to follow some of these guidelines.

Owning one's perspectives

This involves the researcher first acknowledging their own preconceptions and expectations, which can then be critically reviewed by others. In the introduction and methodology chapters I outlined my epistemological position and the different positions I held that may have shaped the research and the interpretations made. I kept a reflexive journal to make my thoughts and assumptions more visible and transparent to both myself and others. Reflexive journals are a common practice in qualitative research in maintaining rigour (Etherington, 2004). The journal helped me to think about the way I asked certain questions in the interviews and to think about how to help widen the conversations. Finally, being part of an IPA reflexive group further enabled the research process to be transparent, where I attempted to make my assumptions and beliefs more conscious so that they could be discussed in relation to how they were shaping the research and the interpretations made.

Situating the sample

This involves describing the participants in sufficient detail in the context of the study. This can help the reader to consider the range of persons and contexts to which the findings may be applicable (Elliott et al., 1999). In addition to including basic demographic details, I have included other information about the participants' backgrounds such as their ethnicity, language, religion and migration history.

Grounding in examples

This guideline refers to providing examples of the questions asked to and the responses given by participants. I have included extracts from the participants' accounts in the analysis section and some of the questions asked. I hope by including these examples, I have invited the reader to consider the interpretations made and other possible interpretations. As posited by my epistemological position, other interpretations were also possible.

Credibility checks

The main themes and subordinate themes were reviewed by my academic supervisor and also shown to one of my colleagues. Based on these discussions some changes were made to the themes in terms of groupings and labelling.

Resonating with readers

I have attempted to present the material in a way that is engaging and draws interest from others in an area which I consider to be important. I hope that I have expanded others' appreciation and understanding of the topic area.

4.9 Conclusion

This study aimed to explore how some Indian Gujarati individuals in the
London area who were supporting a family member with dementia felt about
this experience. Most of the literature on care-giving homogenises South
Asian communities despite research suggesting that variation in care-giving
exists within different South Asian groups. In addition, the study also aimed to
examine the meaning of dementia care-giving, the perceived positive and
negative aspects of care-giving and the coping strategies used. These areas
with a specific cultural linguistic group, such as Indian Gujaratis, has not been
examined and within the context of dementia care-giving.

Using an IPA analysis, four main themes were evident in ten caregivers'
accounts. These were four interconnecting levels of impact that dementia
care-giving had at an intrapsychic, dyadic, family and community and culture
level. Consistent with previous findings were the themes of psychological
impact, growth and development, loss of relationship, reciprocity and
importance of family support. The study highlighted new themes at a
community and cultural level around expectations and norms and knowing
and talking about dementia. The study also highlighted the role religion and
spirituality may play in helping to manage the perceived negative aspects of
care-giving.

The findings of the study have both clinical and research implications. Clinical
implications include utilising therapies and techniques such as mindfulness
and Acceptance and Commitment Therapy. Research implications included
comparing the findings from this study with other specific groups and
populations in relation, for example, to telling others about a family member's
dementia.

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UEL Ethics Approval Letter

ETHICAL PRACTICE CHECKLIST (Professional Doctorates)

SUPERVISOR: Matthew Jones Chesters   **ASSESSOR:** Donald Ridley

STUDENT: Shilpa Bavishi   **DATE (sent to assessor):** 24/02/2012

Proposed research topic: Exploring the Experiences of Indian Gujarati People in the London Area Supporting a Person with Dementia.

Course: Professional Doctorate in Clinical Psychology

1. Will free and informed consent of participants be obtained?   YES / NO

2. If there is any deception is it justified?   YES / NO / N/A

3. Will information obtained remain confidential?   YES / NO

4. Will participants be made aware of their right to withdraw at any time?   YES / NO

5. Will participants be adequately debriefed?   YES / NO

6. If this study involves observation does it respect participants' privacy?   YES / NO / NA

7. If the proposal involves participants whose free and informed consent may be in question (e.g. for reasons of age, mental or emotional incapacity), are they treated ethically?   YES / NO / NA

8. Is procedure that might cause distress to participants ethical?   YES / NO / NA

9. If there are inducements to take part in the project is this ethical?   YES / NO / NA

10. If there are any other ethical issues involved, are they a problem?   YES / NO / NA

APPROVED

YES		NO

MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: dr   Date: 11 May

RESEARCHER RISK ASSESSMENT CHECKLIST (BSc/MSc/MA)

SUPERVISOR: Matthew Jones Chesters   **ASSESSOR:** Donald Ridley

STUDENT: Shilpa Bavishi   **DATE (sent to assessor):** 24/02/2012

Proposed research topic: Exploring the Experiences of Indian Gujarati People in the London Area Supporting a Person with Dementia.

Course: Professional Doctorate in Clinical Psychology

Would the proposed project expose the <u>researcher</u> to any of the following kinds of hazard?

1   Emotional   / NO

2.   Physical   NO

   NO
            (e.g. health & safety issues)

If you've answered YES to any of the above please estimate the chance of the researcher being harmed as: HIGH / MED / LOW

APPROVED

YES		NO

MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: **dr**   Date: 11 May

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.

UEL
University of
East London
www.uel.ac.uk

School of Psychology

Professional Doctorate Programmes

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

Literature Search Results

Table 3. Summary of Literature Search Results

Search Term	Results Total	Relevant Articles
Gujarati	61	1
Gujerati	12	0
Indian	90	1
South Asian	87	2
Alzheimer's	30	1
Dementia Care*	80	8

Participant Information Sheet

Participant Information Sheet

Exploring the Experiences of Indian Gujarati People in the London Area Supporting a Person with Dementia

Invitation to the study

I would like to invite you to take part in a research project which is being conducted to develop a better understanding of the experiences of Indian Gujarati people in the London area supporting a person with dementia. This study is being conducted as part of my doctorate training in Clinical Psychology at the University of East London. 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 relatives or friends if you wish and then decide if you wish to take part. Please contact me if there is anything that is not clear or if you would like further information.

What is the purpose of the study?

In the UK, the prevalence of people with dementia from different cultural and ethnic backgrounds is increasing. Unpaid 'carers' (i.e. family members, spouses, friends) are the most important source of providing dementia care to the person with dementia. There is no research in the UK which has solely looked at the experiences of people of Indian Gujarati origin supporting someone they know with dementia. Exploring such experiences can help to give health professionals a better understanding of what some Indian Gujarati people go through in this role and to help identify what support needs they might have.

Why have I been invited?

I understand that you are of an Indian Gujarati origin and have experience in supporting/caring for a person you know with dementia for six months or over.

Do I have to take part?

It is your decision as to whether you take part in the study or not. If you wish to take part please contact me or ask another family member/friend to do so

on your behalf via e-mail or telephone. If you decide to take part you are free to withdraw from the interview at any time and you will not be asked to give any reason. You are also free to withdraw your data up until March 2013 after this date the data will be analysed and written up for examination purposes and possible publication.

What will happen if I take part?

You will be asked to read and sign a consent form. You will be asked to provide some basic demographic information about yourself and your family member/friend with dementia. You will then take part in a one to one interview with myself. The interview will only be conducted in English. The conversation will cover how you find supporting/caring for the person with dementia, how you think and feel about this 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). The transcription will only be completed by myself and all identifying information (e.g. names and places) will be omitted for confidentiality purposes.

The study will not involve the person with dementia, nor be able to offer you any specific additional care.

What are the possible disadvantages of taking part?

It is possible that some of the experiences you share may be upsetting to talk about. If this is the case and you feel you need further support or advice you can speak to the Alzheimer's Society helpline (0845 300 0336) which is open from 8.30am to 6.30pm Monday to Friday. Other organisations you can contact are the Black and Minority Ethnic Carers Project on 020 8868 5224, www.harrowcarers.org or Harrow Crossroads on 020 8868 0903, www.harrowcrossroads.co.uk. You can also contact your GP for further advice and support or the care team which may be involved in your family members or friends care.

What are the possible advantages of taking part?

I cannot promise the study will help you. It is an opportunity for you to talk about your experiences of supporting the person you know with dementia. It is hoped that your perspectives and that of others interviewed can help to give a better understanding of what some people from an Indian Gujarati background people go through.

Will my taking part in the study be kept confidential?

Your participation will be kept confidential. All material will be stored in a locked cabinet. Any information identifying you (i.e. consent form) will be

stored separately from the typed copy of your interview. The recording of your interview and the transcript will be kept in a locked cupboard. The recording will be destroyed at the end of the research. Transcripts will be destroyed after 5 years. Only I, the supervisor of the project and examiners will have access to the recordings and transcripts.

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's supervisor Dr Matthew Jones Chesters at the School of Psychology, University of East London, Water Lane, London E15 4LZ or on 020 8223 4174. You can also contact the Chair of the School of Psychology Research Ethics Sub-committee Dr. Mark Finn at the School of Psychology, University of East London, Water Lane, London E15 4LZ or on 020 8223 4493.

What will happen to the results of the research study?

The results of the study will be written up and submitted as a research project as part of a Doctorate in Clinical Psychology. The results may also be published in a research paper. If this is the case, you will not be identified in any report/publication.

Has the research obtained ethical approval?

The research has obtained ethical approval from the University of East London's Ethics Committee.

Contact for further information

If you would like to take part in the study or have any questions please contact me, Shilpa Bavishi on:

E-mail: **xx [Deleted for confidentiality purposes]**
Telephone: **xx [Deleted for confidentiality purposes]**

Thank you for taking the time to read this information sheet.

Shilpa Bavishi
Trainee Clinical Psychologist

University of East London
School of Psychology
Stratford Campus
Water Lane
London E15 4LZ

Participant Consent Form

Participant Consent Form

Exploring the Experiences of Indian Gujarati People in the London Area Supporting a Person with Dementia

Please tick box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I understand that any information that I give will be confidential and will only be used anonymously in any written work or publications.

4. I agree to the interview being audio recorded for the purpose of transcription by the researcher. I understand that the recording will be deleted once its purpose has been completed.

5. I agree to take part in the above study.

.........…………………........   ....
Name of Participant   Date   Signature

.........…………………........   ....
Name of Researcher   Date   Signature

Demographic Information Sheet

Caregiver Details

Age:

Gender:
Religion:

Relationship to person with dementia:

Country of birth:

Country of upbringing (if different from above):

Year which you came to the UK:

Care-recipient Details

Age:

Gender:

Religion:

Country of birth:

Country of upbringing (if different from above):

Year which you came to the UK:

Any religion followed:

Year of diagnosis of dementia:

Type of dementia (if known):

Support received through NHS and Non-NHS Services:
- memory clinic
- mental health care of older people (CMHT)
- specialist services
- council (carers etc, day centres)
- The Alzheimer's Society,
- care homes
- community groups/network
- spiritual leaders
- other

Interview Schedule

Before starting the interview:

- There are no right or wrong answers

- 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

Can you tell me about your experience of supporting 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 to before?

Can you tell me how you came to be in this role of supporting x?

Prompts/follow-up questions:

Expectations of the role and has it lived up to those?

Were your expectations influenced by any factors?

Differences in the role, have you changed the way you support x from the start to now?

What do you feel have been the more difficult or stressful aspects of care-giving?

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

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?

Do you feel there have been any positive aspects of care-giving?

Prompts/follow-up questions:

Do you feel the role has changed you or your pattern of your life?

Have you made any positive changes to your life?

Do you feel you have learnt anything from it?

What do you feel the care-giving role means you?

Prompts/follow-up questions:

What do you feel that has been influenced by?

What helps you to cope?

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

Close of Interview

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 about to me?

Transcription System

I	Interviewer
P7	Participant number to ensure anonymity
(.3)	A timed pause in seconds
/	Overlapping conversation or interruption
( )	Inaudible or muffled sound/utterance
xx	Identifiable information removed to ensure anonymity
Punctuation	Used to aid reading
[crying]	Indicates a non-verbal activity

Appendix H

Example of Worked Transcript

Emerging Themes		Transcript	Explanatory and Interpretative Comments
	1	Interviewer (I): Thank you for taking part in the project.	
	2	Participant 7 (P7): That's ok.	
	3	I: I'm interested in hearing a bit more about your experiences in supporting	
	4	your mother, isn't it?	
	5	P7: Yes.	
	6	I: Who has got a diagnosis of dementia?	
	7	P7: Yes.	
	8	I: Can you tell me a bit more?	
	9	P7: Sure, initially we when we found out that she had dementia and	
	10	Alzheimer's I think we were all, actually I have two siblings who don't live	immediately brings in family system
impact on family /	11	here, my dad and I live here with my mum so I think we were all in a state	
	12	of denial because we didn't really know what Alzheimer's was. I mean we	denial
	13	knew what it was but didn't really know the ins and outs of it. For me (.) I	little info about dementia
	14	was actually working from home that time and you know I'd been seeing	
acceptance	15	distinct change in her all throughout. Initially she was, my mum has been a	noticed decline in mother's
	16	fantastic cook and a really good home-keeper and you know over the time	previous self
	17	she's completely lost that interest you know. She was extremely	
	18	meticulous and cleaning and really good housekeeping and she lost	CR – losing interest
	19	interest in all of that, lost interest in her own personal hygiene which is	
Negative impact on self	20	very difficult to for me to see because now I have to help her have a	difficult

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Emerging Themes

loss of 'mum'

Change in personhood

Difficult to relate with mum?

psychological impact

Emotional impact on self

Explanatory and Interpretative Comments

'supervise'?

help her with personal hygiene

— 'changes'

→ can't 'recognise mum anymore'

— dementia as a disease biomedical framework

— humour

self talk

→ unrecognisable

repetition of 'difficult'

— feels + frustrated with mum

reminds her of a child

help to take a step back

feels Dad has had a different experience — she experiences it more emotionally

---

21 shower. When we were on holiday and my sister and I took her to Kenya
22 and when we were away we had to constantly be in the bathroom with her
23 to give her a shower. The change, a lot of changes have happened in the
24 last year or so. For me it's extremely difficult to (.3) separate the person
25 she was to person she is so there's very small remnants of my mum
26 before and (.2) it's very hard in my head to sort of sometimes take a step
27 back and say "well hang on a minute, she's actually this is the disease this
28 is not my mum" because she can get violent, she can get aggressive, she
29 mutters, she's developed [laughs] a sort of Tourette's so under her breath
30 she swears like a you know, she swears so much and I didn't even know
31 my mum knew all of these words you know so that kind of you know so.
32 For me she's a completely different person, she's got the same
33 appearance but mentally and emotionally she's a completely different
34 person.

35 I: And what helps you take that step back you said you found it difficult?

36 P7: It's, sometimes it's very difficult to take that step back, sometimes I
37 kind of like get annoyed and but (.1) she you know sometimes she's been
38 violent with me so she comes and lashes out at you so I've had to hold her
39 hands to stop her from hitting me and then she breaks down and she acts
40 like a two year old or saying "you're hurting me" and starts crying and
41 whaling and she is very childlike so I think the fact that she is I have to
42 behave with her like she was a child so that's what helps me take the step
43 back. For me (.3) it's been, I guess for my Dad it's been very functional but
44 for me it's been very emotional because you know seeing I guess seeing
45 you mum in that way and sort of having to give her a bath and the first
46 time I had to give her a bath I found it very upsetting but now I find it like I

difficult to see mum how she is

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Emerging Themes

Explanatory and Interpretative Comments

coping strategy

emotional impact

Adapting

coping strategy
to cope with
emotional impact

mourning loss
grieving loss of mum

way of coping to switch off?

Carer comes to help / eases emotional strain?

Mum has 'no awareness' of changes
- difficult to see her mum get to this stage
- we adapt to her

had to adapt to huge change

constant reminder of her mother's decline
pragmatism helps
mum has 'died' - mourning
BUT - notices exceptions - mum's old self
past tense 'who I knew'
reassuring / comforting?

47 just have to do it you know I don't even think about it, it's very very
48 functional. I don't even think about what I'm doing I know I just have to
49 help her wash her hair and stuff like that and I only do that once a week,
50 now we've got a carer who comes in and as of this week comes in twice a
51 week to give her a proper bath. When she developed incontinence and
52 she wouldn't change her pads and she didn't realise the concept of
53 changing her pads and she's use to smell and I use to find that very
54 upsetting because I just thought "what's happened to you?" She just
55 doesn't realise, she just doesn't realise what's happening to her, and the
56 more we try to explain to her the more she doesn't realise so we've just
57 tried to learn how to work around her but (1) yeah I guess the changes
58 have been in the last (2) In 2009 I took her to Kenya myself and she
59 hardly needed looking after and between 2009 you know till now there's
60 been a huge change. You know we have to look after what she eats cos
61 she still has no idea of tastes, she's lost her taste so she mixes things like
62 you know in Kenya we had mango juice and then she would mix that with
63 orange but you know you shouldn't really mix the two because then you
64 get stomach upset especially when you're eating it with like and then she's
65 putting other things in it and you're thinking "don't do that you know, don't
66 do that, it's not good for you" it gets a bit upsetting very easily which is you
67 know so I've taken a sort of pragmatic approach that actually the way I
68 cope with it is that I (.2) the way, what I tell people is that my mum who
69 was my mum died so she's gone and this person has taken over her body
70 but it's not my mum and then you know then she surprises me in little bits
71 comes through [laughs] and I'm thinking "yeah you know, there's still a
72 little bit of my mum left there" but my mum essentially who I knew you
73 know was my mum is gone completely so (.3)

74 I: And how does that make you feel?

IPA Help Sheet

Information taken from Interpretative Phenomenological Analysis: Theory, Method and Research
(Smith, Flowers & Larkin, 2011)

Aims of IPA

- Interested in learning something about the respondent's psychological, mental and social world and their point of view within this context
- Meaning is central
- Context and personal meanings are critical to one's experience
- Understand the content and complexity of those meanings rather than measure their frequency

What to look for in the text

- A person's beliefs and constructs
- A person's story can itself be said to represent a piece of the their identity
- The use of language by participants
- The sense of the person themselves coming across
- Comment on similarities and differences, echoes, amplifications and contradictions, paradoxes in what a person is saying
- Talking about overall life history to talking about specific thoughts and feelings concerning recent events

Descriptive Comments – stay close to the explicit

- Describe which things matter to the participant – key objects of concern such as relationships, processes, places, events, values and principles)
- Key words, phrases, or explanations
- Meaning of the above – what they are like

Linguistic Comments – Exploratory

- How and why they have these concerns – looking at the language they use
- Pauses, laughter, functional aspects of language, repetition, tone and degree of fluency (articulate – hesitant)
- Metaphors

Conceptual Comments – moving away from the explicit claims

- Abstraction
- How and why they have these concerns - thinking about the context of their concerns (their lived world)
- Overarching understanding of the issues they are discussing
- Draw on your own experiential and/or professional knowledge
- Dialogue between your own pre-understandings and your newly emerging understandings of the participant's world
- Not about finding answers but opening up provisional meanings

Process of Analysis for One Participant

Participant 7

The transcript was read several times with initial exploratory and interpretative comments noted of the right hand column of the transcript. Working with these notes enabled for the development of several emerging themes. Emerging themes developed by looking for connections and inter-relationships between initial exploratory noting. Key words and phrases were retained so that themes were grounded in what the participant said. The emerging themes were then clustered to develop broader conceptual themes, as shown below.
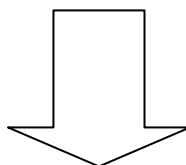
Subordinate Themes	Emerging Themes (plus key word/phrases)	Lines
Previous knowledge/experience of dementia	Heard of it but not the real impact and what it meant in reality Dementia as a disease and illness cruel disease for the family – aware of decline Mum fits FTLD diagnosis	12-13 27, 168 234 76-177
Difficulties - emotionally	Difficult to see even now esp in relation to hygiene extremely difficult to 'see mum' not much left hard to keep mind and distance it's the dementia – no mum left completely different person – emotionally/mentally gets annoyed –lashes out at her and starts crying, loses patience emotional and upsetting before giving her bath continence/smell –upsetting –to see mum in that state it gets upsetting easily – reminder on a day to day basis mum has died – mourning the loss of previous self sad had to leave once as was not sure what she would do would have been harder if emotionally closer "killed me"/not coped get protective and defensive over her but get really annoyed constantly needing me – no break	20 25 26-27, 35 32-33, 71-72 36-39, 215 43-45 50-53 65 68 74 231-233 266- 268 447 450-452, 508 455-56
Coping	Not to think about it – emotional	46-47

	disconnect	
	support system and familiarity of Kenya	102-104
	sister and neighbour	111-114
	family working together – weight off shoulders and shared	350-351 -355
	don't feel alone in it as I did before	315
	changing expectations	382-386, 389-392
	talking to friends	492
	finding a quiet space	494
	spiritual outlook –taught you lessons for life, wherever she'll be with me	550-554, 565-568
	great support – day centres, carers	605
	remind myself it's her illness	637
Previous relationship and self	always been with my mum but not had close relationship	82, 87-88
	taught me how to cook, self-reliance, part of her still with me	89-90, 519-523, 621
	extremely creative	90
	sociable and hosting	159
	never been overly maternal but looked after us and provided	262-265
	Noticing exceptions	69-72, 100-102
Worries and fear	Moving out - cause decline and emotional miss	147-149
	feeling guilty about leaving her father	294-295
	But supported by family to move	293
Impact on rest of family	hard on my father too	153
	emotionally not close so now to look after her is difficult –lived independently (separate interests) – tough/new experience	155-161
	impacts on everyone	223,
	Brought us closer together and team work	277-278, 288, 300
	Worked altogether to find solutions	306, 308
	work in progress and a way to go	309
	more open and honest with other after a wakeup call – a process.	311-314, 335, 341-347
	needed to give family more time to catch up with the dementia	319-320
Dementia transparency	normalises it as condition like diabetes	173-174 210-211
	found courage to tell others off and values of respecting elders	446, 473-478,505-506, 508-509
Living life as before	been on holidays	356
	can live my own life knowing that both mum and dad are being cared for	357-358, 361

|	would have been freer but not necessarily in a good way don't feel burdened	594 596, 600, 606
Future perceived losses	thinking about the future (marriage and kids) loss of mother-in-law and grandmother in an Indian family (upholding traditional and cultural practices) she's been the care-giver, always there upsetting complex grieving – started but hard because she's there	395-398 401, 404 417 425-429
Positive aspects and meanings	appreciate her more, rather have in this state than none at all role reversal – she's looked after me her whole life	437, 441-445, 530-532, 571 574-578
Impacting on future plans	relationships would have to tell future partner about her caregiver role and responsibilities	583-586, 590

The development of several emerging and subordinate themes allowed new themes to emerge and treat the case as an individual. This meant bracketing, as much as possible, the analysis from the previous six transcripts. However, when completing the analysis the research aims were kept in mind and by this stage I was thinking about the different levels the subordinate themes could be grouped into based on the previous analyses.

Themes were then clustered even further into broader conceptual themes through abstraction (identifying patterns between emergent themes). At this stage those themes which were not as significant or prominent for the participant were removed. Some themes were relabelled to more accurately describe the how the participant felt about particular aspects.

Subordinate Themes	Emerging Themes
Difficult Aspects	Future perceived losses Complex grieving – mourning/loss CR lack of awareness Worries and fears Different feelings Impacting on future plans
Psychological Impact	Difficulties in dealing with her change in personhood Negative feelings
Personal difficulties/challenges	Knowing how you might react Get protective and defensive over her but get really annoyed Challenging Behaviour
Positive Aspects/Gains/meaning	Appreciate her more Brought us closer together and team work Worked altogether to find solutions More open and honest as a family Familial Duty and Values/Meaning
Feelings about dementia	Openness with others about dementia
Help and Support	Family as support Changing frame of mind Flexibility Spiritual outlook
Relationship with CR	Previous Relationship and self Noticing Change/Decline Caregiver roles Noticing exceptions
Impact on other members of the family	Impact on father Impact on siblings

Through further abstraction themes were clustered again this time to develop super-ordinate and subordinate themes. The subordinate themes were grouped into levels to form the super-ordinate themes.
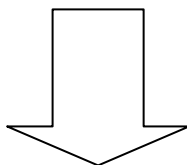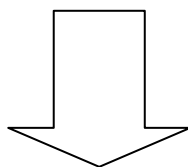

Super-ordinate themes	Subordinate Themes
Individual	Future perceived losses – link to culture Complex grieving – mourning/loss Worries and fears Impacting on future plans Changing frame of mind Spiritual outlook
Relationship with care-recipient	Loss of how she was – no longer recognise her Appreciate her more

	Made me realise I still have her Noticing exceptions
Family	Worked altogether to find solutions More open and honest as a family Brought us closer together and team work Initial difficulties with family
Culture	A chance to care for mum (Values/Meaning) 'Telling other off' – other family members – Talking about dementia to others
Dementia services	Paid carers as helpful

A table of super-ordinate and subordinate themes were produced for each participant following the process described above. The next step involved further looking for patterns across the cases where themes were collapsed and relabelled to produce the final table of themes. For example, participant seven made no direct reference to the Indian Gujarati community but many other participants did. Therefore community was added to the 'culture' theme as the two appeared to be interconnected in participants' accounts. Furthermore, the theme of 'dementia services' was changed into "support from dementia services' and was made into a subordinate theme within the family super-ordinate theme as this represented participant's accounts more accurately.

Theme	Subordinate Themes
Intrapsychic	• Emotional impact • Changing how I think about the situation • Growth and development
Dyadic	• Loss of relationship • Reciprocity
Family	• Family support • Family strains • Support from dementia services
Community and Culture	• Expectations and norms • Knowing and talking about dementia

Exert from Reflexive Journal

The following exert has been taken from the reflexive journal that I kept throughout the research process.

<u>Thoughts after second interview</u>

Following my second interview, I noticed early on how much more 'comfortable' I felt interviewing this caregiver compared to the first one. There was such a contrast in the tone and feel of the interview. It struck me how much more at ease she felt with the care-giving process. She spontaneously spoke of the confidence she had developed and the positive change she noticed within herself as a result of care-giving. The first participant's account mostly focussed on her loss of her relationship with her husband, although she did not use these words herself to describe her experience but that was my interpretation. However, I thought about what it was that made me feel more comfortable with this caregiver. She focussed on the positive aspects of care-giving without me even having to initiate these conversations myself. I think I felt almost relieved and reassured by this, that somehow I was 'right' to question some of the mainstream literature which seemed to highlight a particular view – that care-giving was only difficult and stressful.

Feeling reassured, I wondered what impact this might have had on how I conducted the interview. Did I spend enough time focussing on the more difficult aspects of dementia care-giving, which this participant had once experienced. However, it feels conflicting now to think about this thought, as although I had my research aim in mind, I wanted also to respect and listen to where the participant was currently at with her story of care-giving. By focusing on the struggles she had once experienced, and to a lesser extent now, would have felt like I was silencing her current story of positive change. In her interview she seemed to want to use the space to give advice to other care-givers. There seemed to be this reaching out to others and wanting to

instil confidence in those who were perhaps struggling with the experience, something which she could once relate to.

It made me think about the role of the interviewer and how much we shape the content of what is said according to our own agendas and what personally resonates for us. I was not perhaps expecting such contrasting interviews but it has made me think about how I manage where care-givers are at and how they feel at a particular time. Something for me to think about before my next interview.