

**Living with husbands with a label of dementia. The experience and meaning of  
Punjabi Sikh wives.**

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**A thesis submitted for the degree of Clinical Doctorate in Psychology**

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**Date of submission October 2017**

**For my little bubba. Mummy can't wait to meet you**

**xxx**

## Acknowledgements

First and foremost, I would like to thank Waheguru Ji. You have blessed me with so much my entire life and I'm especially grateful for the warmth and strength you showered me with over the past three years.

Where I am today would not have been possible without the constant love, affection and encouragement of my beautiful parents. Thank you for always believing in me. Your generous souls continue to amaze and inspire me every day.

Bhupinder, you are my absolute rock. Thank you so much for your unwavering support and encouragement. I am so lucky I have had you holding my hand throughout this whole journey, for it would have been a cold and lonely place otherwise!

Thank you to my Bassi family for your continued understanding, love you all immensely.

Thank you to Peter and Penny for your supervision, I have learnt so much from you both, which I will carry with me always.

Lastly, thank you to the women who participated in this research. Your stories have moved me, your wisdom taught me so much and your strength empowered me.

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## **Abstract**

Dementia and caregiving have received increasing research, clinical and political attention over the past forty years. However, such attention has been particularly focused on understanding the biomedical markers and interventions for dementia within majority populations. Little attention has been afforded to understanding alternative conceptualisations of dementia particularly from varying cultural and religious lens'. Existing research which has attempted to explore cultural understandings of dementia has done so in a homogenising manner and masked potential nuances between different cultures and religions.

Research has also tended to shy away from exploring the impact of dementia upon spousal relationships. Given spouses (predominately wives) have been shown to deliver much of dementia caregiving this is an important area to illuminate, both for its clinical and moral implications. Taking in to account these two distinct gaps in knowledge, the present study aimed to explore the experiences and meanings of Punjabi Sikh wives in living with husbands who have a label of dementia.

This study adopts a grounded theory methodology to explore the experiences of Punjabi Sikh wives living with husbands who have been given a diagnosis of dementia. Based on the accounts of eleven wives, a model was generated which revolved around the various processes associated with living with a husband with dementia. The emergent model consisted of three distinct, yet interacting theoretical processes, the wives' responses, systemic responses and resistive responses. The wives' responses centred around how they acknowledged, understood and ultimately lived with changes they experienced in their husbands and themselves. The systemic responses outlined the ways in which participants perceived their wider system to

negate their responses through, ignoring, misunderstanding and denying the changes in their husbands. Finally, participants recounted their resistive responses against such systemic pressures. Based on the accounts of the participants, implications for clinical practice and future research are discussed.

## **1 Introduction**

This thesis explores the experiences of Punjabi Sikh wives who care for husbands with a label of dementia. The term 'label with dementia' will be used throughout this thesis to highlight the social constructionist ethos of this research. To solely adopt the concrete term dementia would, in the author's opinion be propagating an exploration of caregiving experiences through a neurological and biomedical lens. From a social constructionist perspective, this thesis will raise questions and explore the wider systemic influences upon caregiving experiences and understand the connotations of the term 'dementia' within Punjabi Sikh communities. It is particularly interested in developing a theoretical understanding of spousal care giving grounded in unique cultural experiences, with the intention to contribute a much-needed cultural perspective to existing dementia research.

This chapter charts the development of the research aims. It begins with the researcher outlining her personal motivations for undergoing this research study. This is followed by a discussion of the terminology pertinent to the research area, namely; race, culture and ethnicity. It follows with a critically focused examination of dementia in relation to psychological theories, policies and existing research. A brief description of the Sikh religion and Punjabi culture, at both the global and domestic level, is also set out.

This section is followed by two literature reviews. The first provides a thematic overview of the findings from research related to spousal caregiving in dementia. The second literature review outlines the limited research pertaining to dementia as a construct within the South Asian population.

The chapter concludes by bringing together these varying areas of focus to provide a rationale for the research study.

### 1.1 Personal stance

As a British Indian, practicing Sikh and Trainee Clinical Psychologist, I came to this project with my own experiences, values and assumptions. From a personal perspective, I was particularly motivated to undertake research which would help address the deep-rooted feelings of insecurity which had developed during my journey into becoming a Clinical Psychologist.

As a woman from a working class, minority ethnic background, I felt different from my peers. I frequently felt silenced in academic contexts where my cultural experiences of 'wellbeing' went against 'normative standards'. Western derived theories pertaining to mental health, social processes and family systems held little cultural relevance for me. There was little opportunity to explore or even celebrate such differences and instead, they typically were pathologised. My personal feelings of cultural incongruence extended beyond the lecture theatre and I began to observe the ways in which systems (particularly the NHS) lacked curiosity for difference within clients. Instead, I witnessed a strong drive to make *clients* fit interventions despite numerous policies arguing for 'culturally sensitive interventions' (BPS, 2006). During my older adult clinical placement, my professional experience was most at odds with my personal experience. In my local Sikh community, I frequently heard stories about resilience, strength and wisdom within the elderly however, within a clinical context I was confronted with discourses of 'loss and degeneration'.

Based on these experiences I found myself drawn to choosing a topic area which explored difference and helped amplify voices rarely heard in literature and research, that of the elderly in a minority ethnic community.

## 1.2 Terminology and discourses

To simply present the dominant 'taken for granted' definitions of race, culture and ethnicity within this research would be to assume a position of objectivity, and be incongruent with the researcher's personal stance as a reflexive researcher. To position oneself as a reflexive researcher is to continually reflect upon the process of knowledge construction and be critically aware of how labels are laden with intended and unintended meaning (Sewell, 2008). To exercise critical reflexivity within a research context therefore, requires an exploration of the risks associated with using dominant discourses to convey a shared understanding of a topic area.

This section will therefore seek to examine how race, culture and ethnicity have been constructed within a historical, political and social context. The process of deconstructing such terms will serve to externalise and challenge their dominant internalised discourses and help open new possibilities for this research to address (White & Epston, 1990).

### 1.2.1 Race

The concept of race is often used interchangeably with culture and ethnicity. The Oxford Dictionary (2007) defines race as: "divisions of humankind, having distinct

physical characteristics.’ This echoes the interpretation outlined in the works of Shah, Oommen and Wuntakal (2005, p9): “race is a phenomenological description based on physical characteristics”. Inherent within both definitions is the notion that race is fixed, determined by genetic ancestry and resides within a person.

Whilst the development of the term race can be traced back to Darwinism (Delgado & Stefancic, 2017), psychology too has a history of aligning itself with a biologically fixed construction of race. In its early quest to be recognized as a behavioral science, psychology housed itself within a positivist school of thought. During this period, numerous psychological studies used race as a predictor variable to account for variances in intelligence and personality traits (Eysenck, 1984; Spencer, 1996). Such biological deterministic theories played an integral role in providing scientific legitimacy for the use of race as a classifying scheme (e.g. in the social-political context) (Delgado & Stefancic, 2017).

However, the development of psychological and social thinking resulted in alternative interpretations of race. Indeed, far from a biological interpretation, Fanon (1967) argued that the concept of race had simply been a cultural artefact used to maintain and organise a socio-political hierarchy. Fanon’s (1967) work also explored race in the context of colonialism and viewed the construct of race as being deeply imbued with hierarchical meaning. He further argued that, the social process of racial othering had been used to control and coerce individuals as well as justify discrimination, apartheid, slavery and genocide.

Such views were also evident in the development of more postmodern thinking, including social constructionism. Here, race is seen to artificially divide people into distinct groups based on the social, economic and political needs of a society (Smedley & Smedley, 2005). Within this school of thought, racial categories are hierarchically organized to foster and justify the use of power to marginalize, silence or otherwise subordinate one social group or category (Witzig, 1996).

### 1.2.2 Culture

Similar to race, the concept of culture is equally difficult to define. Culture has been defined by some as ‘the behaviours, beliefs, values, and symbols of a group of people which they accept, generally without thinking, and that are passed along by communication and imitation from one generation to the next’ (Kroeber & Kluckhohn, 1952p.13). Whilst this definition may seem outdated now, it did however set the precedent for how culture was thought about in research, literature and mainstream society. There are many elements within this definition which can be deconstructed further. Firstly, the dominant understanding of culture as ‘fixed’ has been subject to criticism. Sewell (2009) argues that whilst similar threads of tradition may weave through generations and give the illusion of a fixed culture, values and norms are shaped by changing contexts, as well as inter-generational differences.

Secondly, the aforementioned definition implies a sense of passivity on the part of the individual who adopts cultural beliefs ‘without thinking’. However, Cronen and Pearce (1985) challenge the belief that the influence of culture is a one-way process. They highlight the reciprocal nature of culture and position individuals as active beings who can have an implicative effect and use their experiences to shape culture

at multiple levels (e.g. the impact of the 1960s US civil rights movement upon American culture).

Fanon (1967) also supported the alternative conceptualisation of culture as a dynamic and fluid construct through his work on colonialism. He argued that the cultural values of the colonized were prone to change as aspects of the 'host culture' were adopted, due to fear of punishment and rejection. This example brings to light questions which are equally pertinent in contemporary society: What does it mean to adopt the dominant culture of society? What if this culture is at odds with one's native culture? Whose interest does it serve to impose the dominant culture unto others?

Thirdly, the above definition of culture implies that individuals can only subscribe to one culture at any given period. Bronfenbrenner's (1986) ecological-systems theory introduces the idea of numerous cultures all simultaneously shaping individuals in different ways at both a proximal and distal level.

Within western psychological practice, psychologists (research and applied) are challenged to think closely about the potential dangers a lack of cultural reflexivity can cause to practice. This includes a consideration of whether practice has become prone to cultural ethnocentrism, which is the process of one culture imposing their 'superior' belief systems upon other cultures (Afuape, 2012). Cultural reflexivity is necessary to ensure the priorities of psychologists are not misaligned in trying to observe, measure and judge individuals against normative standards widely held in



the dominant culture (and often dictated by predominately euro-centric psychological theories held as a 'gold standard' in professional guidelines; e.g. NICE).

This paper looks to extend cultural curiosity within research, to question the evidence base and consider the cultural context in which it is carried out. This will ensure the conclusions and recommendations are better able to be applied meaningfully across such cultures.

### 1.2.3 Ethnicity

As a result of the ideological debates surrounding race and culture some researchers have turned to conceptualising and analysing human variation by ethnicity. Nagel (1994) argues that unlike the 'fixed' and 'involuntary' connotations underlying race and culture, ethnicity is a dynamic, fluid and self-defined concept. He argues that individuals can assert any ethnic identity they choose to. Valle (1998) highlights the relational aspect of ethnicity and proposes that it is the relationship between groups that consider themselves 'ethnically similar' that sets the construct of ethnicity apart from its often-misattributed synonyms, race and culture.

Whilst the construct of ethnicity does potentially tackle some of the ideological dilemmas posed by race and culture, namely the ability for individuals to exercise choice and self-identify, it is still important to place ethnicity in a historical and socio-political context. O'Hagan (1999) argues that ethnicity is no less pejorative than race. Stemming from the Latin word, 'ethnikus' meaning 'people who are not Christians or Jewish' (Kroeber & Kluckohn, 1952) the term 'ethnics' was used heavily in the Second world war to refer to people considered 'inferior' to the

dominant group. The historical context of the term ethnicity further highlights society's preoccupation with dividing society into groups fueled by misguided intent.

The above commentary on terminology further highlights the challenges within cross-cultural research. For the purposes of this study, the author sought clarification as to how participants wished to be described in terms of ethnicity and culture. The overwhelming response of all participants was to be described as 'Punjabi-Sikhs', therefore recognising the dual influence of their religion (Sikhism) and cultural (Punjabi) heritage.

### 1.3 Dementia

The following section explores the construct of dementia from different vantage points. It provides a brief overview of the history of dementia, charting the dominant medical trajectory whilst also exploring alternative psychological and social constructionist understandings of the label.

#### 1.3.1 Historical context

The first description of dementia can be found in Ancient Egyptian hieroglyphic writings, which refer to 'an aging person who every night becomes more and more childish.' (Signoret & Hauw, 1991, p.8). In 560 BC Plato also alluded to age related memory changes, describing, "an illness that gives rise to all manners of forgetfulness as well as stupidity" (Boller & Forbes, 1998, p.6). In the centuries that followed, mysticism and spiritual explanations dominated society's understanding of dementia,

with philosopher Roger Bacon arguing that “senility is a consequence of the original sin” (Albert & Mildworf, 1989, p.10).

The shift towards a more biological understanding of dementia only started in the early 1600s when French medical author Etienne Esquirol first coined the term dementia, deriving its meaning from a Latin term meaning ‘without mind’ (Boller & Forbes, 1998). In his paper *Des Maladies Mentales*, Esquirol (1855) presented his ideas about a cerebral disease characterized by an impairment of sensibility, intelligence and will. Such ideas started gaining momentum in Western society and were argued as giving rise to Cartesian dualism (Boller & Forbes, 1998).

At the start of the 17<sup>th</sup> century, Descartes started drawing firm distinctions between the mind and body (Descartes, 1668). He argued that the causes of ill health and disease were due to altered functioning in the body, thus refuting the contribution of the mind or soul completely.

### 1.3.2 Medical model of dementia

It is against the backdrop of mind and body dualism that German psychiatrist Alois Alzheimer began investigating ‘abnormal’ brain structures and associated behaviours (Albert & Mildworf, 1989). He discovered what he believed to be amyloid plaques and neurofibrillary tangles in the brains of elderly patients. These brain anomalies would become identifiers of what later became known as Alzheimer's disease.

Research in to dementia gained momentum in the 1980s. An increasing number of empirical studies in the medical field published findings attributing impairment of

cortical functions to changes in the brain structures of the elderly (Roca, Klein, Kirby & McArthur, 1984; Erkinjuntti, Wikstrom, Palo & Autio, 1986). Furthermore, researchers began identifying subtypes of dementia to account for the variation in behavioural manifestations in the 'senile'. By the 1990s a total of 40 different subtypes of dementia had been logged with the Royal College of Physicians Register (Boller & Forbes, 1998).

The medical model still retains its dominance in the current study of dementia. The ICD-10 (World Health Organisation, 1989) is an internationally utilized medical classification tool that continues to define dementia as “a syndrome due to the disease of the brain, usually of a chronic nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, language and learning” (World Health Organisation, 1989).

#### *1.3.2.1 Critique of the medical model*

The dominance of the medical model in shaping dementia rhetoric in the United Kingdom (U.K.) should not be mistaken for a flawless framework of understanding. There are several elements of the model which require critical examination.

Firstly, research has shown that diagnosis based on medical properties alone is not accurate. Curran and Wattis (1989) found that in post mortem examinations only 6 out of 13 diagnosed cases of dementia had the disease. Similarly, Harding and Palfrey (1997) found that 20 per cent of cases with a clinical diagnosis of dementia were found to have other conditions at autopsy. Such inconsistencies with medical diagnosing have huge implications for individuals and families.

Methodological inaccuracies aside, others have questioned the ideology of the medical model. The medicalisation of dementia has attracted criticism as looking to provide a cure or fix for society's preoccupation with ageing and death. It has also been identified as segregating the elderly as medically incompetent, which serves the purpose of a neo-liberal society in which the younger generations compete with one another to dominate society (Harding and Palfrey (1997)).

Tom Kitwood (1990) a strong critic of the bio-medical model of dementia, highlights several flaws within the framework. He argues that, the medical model portrays a reductionist perspective of the individual in which, their unique traits and values are masked by narratives of debilitation, degeneration and passivity. He further contests that the reductionist thinking propagated by medical frameworks of dementia gives rise to malignant social practices (MSP) (Kitwood, 1997). MSP are acts, narratives and behaviours orchestrated by society which further marginalise individuals with labels of dementia and in turn negatively impact their wellbeing.

Furthermore, cultural and medical conceptualisations of dementia are not entirely congruent. Kleinman and Seeman (2000) suggest that culture strongly affects the understanding of illness, health and care. This may therefore account for the findings in Jutlla's (2014) study in which she found a distinct absence of an equivalent term for dementia in the Punjabi and other South Asian languages.

Globalising the biomedical interpretation of dementia as a degenerative disease may represent invalidation of diverse cultural models, assume authority over other cultural models and reflect cultural insensitivity (Mukadam, Cooper & Livingston, 2011).

### 1.3.3 Psychological models of dementia

In contrast to the aforementioned biomedical model of dementia, many theorists and researchers have proposed alternative explanations. The following section critically examines some of the key explanations of dementia rooted in psychological theory.

#### *1.3.3.1 Person centred care*

Kitwood (1993) a staunch critic of the medical model, aimed to shift the focus of dementia care from a disease rhetoric toward a more interpersonal formulation. Kitwood (1997) questioned the extent to which existing practice (mainly medicalised assessment and treatment) contributed toward the preservation of self, or what he referenced to be personhood.

Kitwood (1993) particularly highlighted the relational aspect of self and identified personhood as the “standing or status that is bestowed upon one human being by others, it implies recognition, respect and trust” (p.8). He argued that biomedical disturbances were not a sufficient explanation for the varying behavioural manifestations shown by individuals with a diagnosis of dementia. Instead, the way in which society positioned individuals with dementia and subsequent interactions were the relational factors impacting personhood (Kitwood 1993).

Kitwood (1997) identified this social process as ‘malignant social psychology’, citing instances of intimidation, infantilization and disempowerment. A common thread amongst such malignant social practices included denying the individual’s agency and competencies, that often manifested itself through threatening behaviour and language. This reflects many of the findings in the Francis Inquiry (NHS Confederation, 2013) in which bullying and abusive behaviour by nursing staff toward elderly patients as well as the lack of a person-centered culture in the hospital led to an exceptionally high mortality rates.

Kitwood (1990) emphasised the importance of mutual reciprocity in relationships as being key to the promotion and sustainability of personhood. This included instances where an individual with a diagnosis of dementia was receiving care, which recognized and promoted their preserved capabilities.

Kitwood’s attempted paradigm shift toward a more person-centred interpretation of dementia attracted much critique. Some suggest that Kitwood (1993), through his theory of personhood, had further fuelled a passive perception of an individual with a diagnosis of dementia. Specifically, critics noted that the focus upon relying on others to preserve and enhance personhood diminished the agency of an individual (Downs, 2000; Hulko, 2002).

The validity of personhood as a construct has also been criticised due to the lack of supporting research. (Hulko, 2002; Rudman, 2008). Kitwood (1993 p.4) himself acknowledged that the methods he used may seem “highly subjective and undisciplined”. Psycho-social approaches which have drawn upon the tenets of

personhood theory e.g. life story work have had contradicting outcomes in empirical research. For example, Bates, Boote and Beverley's (2004) systematic review of psychosocial interventions only drew on a total of six studies, all of which took place in group settings and their impact upon the individuals' cognitive functioning was negligible. However, a study by Brodaty, Greem & Koschera, (2003) found that psychosocial approaches compared well to drug treatments and carers and individuals reported experiencing an enhanced quality of life. This contradicting research highlights the predicament in dementia research, outcomes are subjective and a rise in cognitive functioning may not necessarily reflect the needs of carers and individuals.

Whilst person-centred theories have been influential in taking the deficit focused spotlight off the individual and bringing to light the importance of relational factors in dementia, they have neglected the equally important role of the socio-political context. It has been debated whether Kitwood's (1990) theory of personhood is a social constructionist theory of dementia (Hulko, 2002). To constitute a social constructionist theory, his work should encompass a clear exploration of how societal narratives or the political agendas of the time potentially impact experiences of dementia and caregiving, which one could argue that it lacks.

#### *1.3.3.2 Psychoanalytic theory*

From a psychoanalytic perspective, it has been argued with increasing age, the ego (the part of an individual which is grounded in reality) becomes weakened due to diminished mastery and increased dependency upon others due to physical frailties (Solomon & Szwabo, 1992). Whilst in younger age, individuals are adept at defending against unresolved conflicts through resorting to their repertoire of defence



mechanisms, the weakened ego in old age diminishes the adequacy of such defences and triggers a lifetime of unresolved trauma's (Solomon & Szwabo, 1992). In earlier stages of dementia, the weakened ego still tries to protect itself from such traumatic conflicts, often through less skilful defence mechanisms such as denial, splitting, or withdrawal. These defences manifest behaviourally as some of the symptoms most synonymous with dementia such as increased anger toward others, withdrawing from social environments and memory loss as a severe form of denial. Eventually, the defence mechanisms completely fail and the individual becomes more distressed, showing isolation, aggression, hostility and even psychosis, this stage is most consistent with later stages of dementia.

Unterbach, (1995) argues that as defences become weaker with growing age, individuals become increasingly reliant upon others to provide them with a grounding in reality. This may account for the way individuals with dementia exhibit heightened dependence upon spouses and family. Unterbach (1995) highlights the importance for individuals with weakened ego functioning to be surrounded by individuals who can reliably fulfil this function through helpfully merging their past experiences with their present to better tolerate unresolved conflicts. This contrasts with individuals who may further damage the ego through denying the individual with dementia to reminisce about past experiences and further damage their defences (e.g. mocking of memory loss or punishment for hostile behaviour).

### *1.3.4 A Social constructionist model of dementia*

A social constructionist exploration of dementia does not aim to negate the work of bio-medical or psychological models, but rather, it strives to provide a corrective balance, whereby societal and systemic factors are given equal consideration.

Liberation psychology has strong roots within social constructionism and essentially, is concerned with understanding wellbeing within a social, political and historical context. Unlike dominant theories of distress which place a strong emphasis on assessing and treating the individual, liberation psychology aims to liberate individuals from such pathologising individualistic spotlights and places problems within a social context. Very little has been written about liberation psychology and dementia and caregiving practices, however, much of the theories key tenets can be readily applied to a social constructionist understanding of dementia.

Martin-Baro (1994) is most associated with liberation approaches and advocates that individuals (especially those aligned with modern 'psy' disciplines) engage in critical consciousness, a process of understanding what discourses influence our practice. Regarding dementia conceptualisations, from a liberation psychological perspective, Martin-Baro (1994) would potentially argue that psychologists should not blindly adopt such labels without critically examining the socio-political context which gives rise to the bio medicalisation of ageing.

Firstly, one must focus a critical lens upon language and how it gives rise to, and silences certain discourses about the elderly and dementia. Foucault (1979) has written extensively about the use of diagnostic labels in explaining mental distress.

He purports that society has long been paralysed by a fear of “the ill, the old and the infirm” (p.12). When society is faced by individuals seen to lack self-control (as with mental distress and dementia) society feels threatened and seeks to exert control over their unpredictability. One such form of control is the use of diagnostic labels and historically, the confining of sufferers within institutions. Whilst scientific labels such as dementia are propagated in research, practice and even popular culture, one cannot assume they offer an insight into an objective reality or an ultimate truth. Sociologists argue that medical constructs such as dementia are in large, influenced by the social and cultural needs of the society (Harding & Palfrey, 1997). By this notion, dementia can be thought of a social construct devised by the powerful hierarchies within society to exert power and control over the “unknown and senile” (Foucault, 1979).

One can chart the rise of dementia related research in the 1980’s against the rise of neoliberal ideology within the UK and globally. Briefly, neoliberalism refers to a branch of political thought most synonymous with free markets, individualisation and high competition (Harvey, 2007). However, the impact of neoliberalism ideology is not solely reserved for the field of business and economics, it has far reaching implications for how society is organised and behaves. The dominance of Thatcherism politics in the 1980’s propelled neoliberal ideology in to all domains of society (Harvey, 2007). People were urged to engage in competitive self-interest and extreme individualism if they wished to succeed and prosper. The social inequality gap increased in the 1980’s and became even more divided in to “those who can and those who don’t” (Peck & Tickell, 2007). It is against this backdrop that society began to rely heavily on labels such as depression, personality disorder and dementia.

These labels enabled society to further cut out the competition and serve its own purpose of individuation. Furthermore, the use of labels such as dementia allowed the powerful field of medicine to align itself with a neoliberal agenda and expand its business interests through the medicalisation of ageing, opening of nursing homes and ultimately conduct heavily funded research into the cause of cognitive degeneration (Wimo, Jonsson, Bond, Prince, Winbald & International, 2013). Indeed, this example demonstrates Foucault's (1979) central hypothesis of how language, particularly diagnostic labels help serve the needs of society.

The language used to conceptualise dementia in UK policy also warrants critical examination as ultimately, such policies are the driving force for research and clinical practice. The National Dementia Strategy (NDS) (Department of Health, 2009) defines dementia as “an illness caused when parts of someone’s brain stop working properly” (p.7, NDS). Similarly, the Prime Ministers Dementia Challenge (2012) adopts a purely medicalised explanation of dementia and defines it as; “symptoms which occur when the brain is damaged by certain diseases” (p.11). These definitions evoke images of “broken machinery” which by extension, is ultimately the fault of the machine controller, the individual himself (Hewa & Hetherington, 1995). There is little exploration or curiosity of how adverse social conditions contribute to such “damages”.

More recent governmental efforts such as the ‘One You’ initiative (Public Health England, 2016) reflect the growing dementia rhetoric within society that, the responsibility for protecting against dementia and other ‘diseases’ lies solely with the individual whilst, societal or governmental responsibility remains largely absent.

Research has shown that under the last Conservative government, a high proportion of care homes were shut down, community elderly resources stripped of government funding and arguably, the worst social care crisis in UK history. Such cuts have led to increased social isolation, poor living accommodation and fewer leisure opportunities for the elderly (Lowndes & Gardner, 2016). The impact of this upon the mental wellbeing of the elderly is detrimental but, to inoculate the government against any responsibility or blame, labels such as dementia and depression give the powerful (government and medical organisations) a sense of control and power to silence the already marginalised in society (Harding & Palfrey, 1997).

Finally, to better understand the social construction of dementia one must also consider how the elderly within society are positioned. Role theory (Phillips, 1957) purports that a loss of significant roles is the dominant factor in the psychological distress of the elderly. Phillips, (1957) argues that with growing age, individuals must contend with, a relinquishment of roles which give social standing in society such as employment and the assuming of the negative roles which society ascribes to the elderly such as “burdensome, incompetent”.

Role theorists argue that within western society, roles for the elderly are not as well defined as they are in other cultures. Instead, ageing in western society is punctuated by uncertainty, discourses about burden and no specific privileged roles. From the perspective of role theory, successful ageing requires an individual to seamlessly adapt to new roles. Herein lies a problem, if society does not clearly define what positive roles are available for the elderly and takes away resources which can be used to adapt to new roles, one is left isolated and at risk of social exclusion. Without

a clear purpose for the elderly, labels such as dementia are propagated to further highlight their lack of usefulness to society. In the context of this study, it would be useful to explore the ecological validity of role theory and ascertain if the Punjabi Sikh culture provides meaningful roles for the elderly and what impact this has upon understandings of dementia.

### 1.3.5 Psychological models of dementia caregiving

Very few psychological theories exist which specifically provide psychological formulations of dementia caregiving. It is important therefore to apply existing theoretical frameworks to better illuminate the processes which underlie dementia caregiving practices.

#### *1.3.5.1 Attribution theory and dementia caregiving*

Briefly, attribution theory is centred upon the process of how individual's ascribe meaning to their surroundings. Heider (1958) argues that the process of constructing meanings about those around us is a fundamental task of being a social and relational being. Through assigning meaning to our experiences and others around us, we are better equipped at managing uncertainty and difficulties.

Heider (1958) differentiated between two types of attributions, internal and external. The former ascribes meaning to others using internalised factors such as personality traits and emotions. Whereas external attributions assume that human behaviour is not deliberate but rather, due to factors outside of the individuals control.

Polk (2005) linked attribution theory with dementia caregiving and sought to examine how internal and external attributions regarding the causes of dementia impact communication patterns with caregiving dyads. He found that caregivers who adopted external medical attributions alleviated their relatives of blame and instead attributed their challenging behaviour to physical impairments in the brain, outside of the relatives control. Such external attributions resulted in more compassionate and understanding communication patterns. However, caregivers who believed their relatives to be malingering and attention seeking (internal attributions) reacted with increased hostility and aggression toward their relatives.

This theory provides a different perspective to that outlined by Kitwood (1990) who, suggested that biomedical understandings of dementia have the potential to obscure individual uniqueness and tarnish interactions. Support for this theory comes from Robinson, Clare and Evans (2005) who found that spouses who relied on medical knowledge and expertise to understand their husbands reported feeling more connection and love toward them. Conversely however, Hyden and Nilsson (2015) reported that medical attributions of dementia further distanced spouses from one another. The disparity in findings warrants further research in this important area.

Attribution theory of dementia caregiving highlights the significance of dementia conceptualisations upon interactions. Given that research has shown that the majority of dementia caregiving occurs within spousal contexts, this theory provides increased rationale for exploring how wives attribute meaning toward their husbands with

dementia. Furthermore, there is a paucity of research exploring how religious and cultural attributions of dementia mediate spousal relationships.

#### 1.4 Sikhism

Guru Nanak Dev Ji developed an ideology and religion based on the principles of equality, compassion and social justice in the 15th century (McLeod, 2000). Sikhism was extremely critical of the medieval spirit which dominated Indian culture at the time, and instead tried to align itself with more post-modern thought (Bhogal, 2014). The following section outlines key Sikh values and principles. The section concludes with a short commentary of the Sikh population in the UK.

The concepts of tolerance, social justice and egalitarianism are deeply embedded in Sikh thought and practice. For example, the Sikh scripture, Sri Guru Granth Sahib (SGGS), is not entirely wedded to ideas of Sikh Guru's, it defies religious sectarianism and contains hymns also composed by Muslim sufi saints and Hindu vaishnava bhaktas (McLeod, 2000). This spirit of tolerance, respect and curiosity toward the views of others was paramount to the Sikh way of living. Such unique compassion and tolerance toward other religions was also exemplified by Guru Tegh Bahadur, who sacrificed himself to protect the rights of Hindu's and lower castes in society.

Guru Nanak Dev Ji was particularly interested in liberating society from its preoccupation with dividing humans along the lines of race and caste. Through hymns and sermons he spread the message that; "God approves not the distinction of high caste and low caste. None has He made higher than others." (S.G.G.S., p. 53).



All ten Sikh Guru's instilled the spirit of collectivism in to the cultural fabric of India at the time and as a result community action and social communal justice became core Sikh principles. These principles continue to be widely practiced today all over the world through religious acts such as, Guru ka langar (communal dining for all faiths), sangat (collective spiritual reflection), and the Khalsa (initiated baptised Sikhs concerned with social justice).

The concept of collectivism embedded within Sikhism is in stark contrast to the pre-occupation with the individual within western thought. Instead, Sikhs have been urged to practice Sewa (selfless service) as an alternative to the ego-centric way of living dominating society. This is set out in S.G.G.S: "*Those that live caught in egoism are verily dead; Those whose egoism is dead are truly alive.*" (S.G.G.S., p. 374).

Sikh history has been punctuated with vast suffering and difficulties. The Sikh Guru's demonstrated bravery through sacrificing themselves in the face of the social injustices of the time. For example, the fifth Guru, Guru Arjan Dev Ji was martyred for refusing to convert to Islam, the Sixth Guru suffered a long period of incarceration due to defending the rights of the common people and the tenth Guru, Guru Gobind Singh lost two sons in battle and his other two infant sons were bricked alive by Muslims emperors for supporting the religious freedom of non-Muslims.

During the partition of India in 1947, Sikhs were disproportionately impacted, their homeland of Punjab was split in to half, leading to the biggest mass migration known

in history (Pandey, 2001). Death, destruction and dislocation caused by the partition impacted an estimated one million Sikhs in Punjab.

In June 1984, tens of thousands of Sikhs praying at their holiest shrine in Amritsar were killed following Prime Minister Indira Gandhi's orders. This was followed by another genocide of Sikhs in November, 1984 when a further 40,000 were estimated to have been killed by Hindu mobs in Delhi following the assassination of Indira Gandhi (Tatla, 2006)

#### 1.4.1 Sikhs in UK

The 2011 census estimated that a total of 430,000 currently live in the UK (ONS, 2011). Approximately half of the Sikh population in the UK is comprised of migrants who came from the northern Indian state of Punjab, India and/or East Africa. The other half, is made up of Sikhs who are born in the UK, second and third generation Sikhs.

The first recorded wave of Sikh migration was between the 1860's and 1890's. Sikh men who held positions within the Indian Army moved to England to act as security auxiliaries for British firms (Singh & Tatla, 2006). The second mass wave of migration was precipitated by the partition of India in 1947, whereby, the Indian economy stagnated and went into recession, and many Sikhs moved abroad to make a better living for their families (Singh & Tatla, 2006). Changes in British immigration legislation in the 1970's prompted settled Sikh migrants to apply for settlement visas for spouses and relatives and so began the emergence of the second generation of Sikhs (Singh & Tatla, 2006).

Reflective accounts of Sikhs in the 1970's have documented experiences of severe racism, to the extent to which many hundreds of men were forced to remove outward religious symbols (turban, hair and beard) as a means of preventing further abuse (British Sikh Report, 2013). Racism is still a prominent part of the Sikh experience in the UK, the British Sikh Report (2013) found that 53% of Sikhs had experienced repeated severe racial abuse over the past 18 months.

#### 1.4.2 Sikhs and dementia

There is a distinct paucity of research relating to Sikh understandings of dementia. The limited research which has been conducted with this cultural cohort has been done so in-conjunction with other South Asian communities, thus potentially masking the nuances of this religious cultural group. Few studies which have explored Sikh experiences of dementia (Jutlla, 2014; Thompson, 2010) have identified a strong need for increased research exploring the cohort's unique cultural history and its impact upon how they conceptualise dementia. For example, Jutlla (2014) highlighted the strong mediating influence of migration histories on how Sikhs not only cope with dementia but also how it inhibits their use of services. Furthermore, Thompson (2010) found that over 80% of Older Sikh adults interviewed in his study hoped for NHS services to better understanding their religious and cultural beliefs.

#### 1.5 Literature Reviews

The following section presents a thematic analysis of research related to the construct of dementia within South Asian cultures and dementia caregiving in spousal

relationships. Whilst the aim of the current study was to create a deeper understanding of the experiences of Punjabi Sikh wives living with husbands with dementia, it was deemed important to conduct two separate literature reviews looking at different elements of the research question. This decision was in part due to the, extremely limited research specifically exploring spousal dementia caregiving in this cultural cohort but also to explore dementia spousal caregiving more generally so that the findings from the present study could be compared cross culturally and similarities and differences across cultures ascertained.

Outlined below are the two main frameworks utilised across both reviews to synthesis findings across papers but also to appraise the methodological rigour of the research.

#### *Thematic Analysis*

The studies across both reviews utilised qualitative methods, therefore, a thematic analysis (Clarke & Braun, 2014) was undertaken to find common themes across all the studies. This began with entering in the results of each study verbatim in to a database. Each line of text was then coded according to its meaning and content. The author was especially mindful during this stage to not impose any priori frameworks or questions but to allow for descriptive codes to emerge freely. The synthesis process continued through developing new codes with each study whilst also translating concepts between studies. Similarities and differences between the initial codes were analysed and then grouped together accordingly. New overarching codes were then developed which captured the meaning of the initial codes.

### *Methodological Appraisal*

Whilst an exploration of latent themes in research is important, equally important is a methodological appraisal of the studies as not only does it allow one to assess the quality of the study but also learn important lessons for developing one's own study. The critical methodological commentary in both reviews was supported through referring to the Critical Appraisal Skills Programme (CASP, 2013). The CASP Tool (2013) for qualitative research critically appraises research on ten key principles, such as clear articulation of research aims, appropriate recruitment strategy, consideration of researcher and participant relationship and a clear discussion of the clinical implications of the research.

#### 1.5.1 Literature review One: Spousal experiences of dementia caregiving

The majority of research pertaining to spousal experiences of dementia caregiving specifically explores the more negative aspects of caregiving such as, burden (Etters, Goodall & Harrison, 2008), decreased carer wellbeing (Schulz, McGinnis, Zhang, Martire, Hebert, Beach & Belle, 2008) and compassion fatigue (Day & Anderson, 2001). However, it is equally important to consider how individuals with labels of dementia are positioned and constructed within their social context. Therefore, the aim of this literature review was to critically examine research which specifically explored patterns of caregiving and constructions of dementia within spousal relationships. As most elderly people are cared for at home by spouses this was deemed an important question to address (Ostwald, Hepburn, Caron, Burns & Mantell, 1999; Perry & Conor, 2002).

### *1.5.1.1 Search strategy*

When compiling the search strategy, the research question was divided into three component parts; “spousal”, “experiences” and “dementia”. Synonyms for each term were then attached to the search string. For the term ‘spous\*’ synonyms such as ‘wife\*’ and ‘husband’ were also searched. Colloquial terms such as ‘other half’ or ‘loved one’ were not included as, the author did not believe they necessarily denoted a marital element of a relationship. Whilst the term ‘carer’ could have been included, the author was mindful that this may also yield results pertaining to non-spousal or professional carers and therefore was not included in the search strategy.

Synonyms of the term ‘experience’ were derived from a thesaurus and included within the search string.

Whilst the current thesis explores dementia from a social-constructionist viewpoint and remains conscious of the limits concrete diagnostic labels can impose upon the exploration of experience, the majority of existing research does however comply with diagnostic terminology. Therefore, various dementia diagnostic labels such as ‘Alzheimer\*’ and ‘\*vascular dementia\*’ were included in the search strategy. An initial search using solely dementia related terminology yielded several articles which also explored co-morbid conditions such as cancer and depression. It was felt that comorbid conditions added further complexity to the caring process and may detract from the conceptualisation of dementia. Therefore, limiters were added to the search string eliminating articles which explored dementia in conjunction with another disorder.

Each string was searched for independently, and then merged together, to form a complete search string (Appendix A for search string and results generated). The databases searched were, CINAHL Complete, MEDLINE with Full Text, and PsyArticles as these were thought to contain the most relevant health, social care, psychological and medical journals. According to Harding and Palfrey (1997) dementia related research prior to 1980 focused primarily on the biological and neurological exploration of dementia. To explore dementia from a more social and psychological perspective a date limiter was added and only articles published after 1980 were searched for.

Of the results generated, the author imposed the following inclusion criteria:

- a) The study recruited spouses directly involved in the care of the person with dementia. For the purposes of the review, husbands were also included to provide context to the findings and ascertain potential gender differences within caregiving
- b) Only empirical studies were included
- c) The individual being cared for must not have any other comorbid conditions.
- d) Participants were adults over the age of 18.
- e) Articles were published in English

#### *1.5.1.2 Results*

Eleven articles were deemed suitable for inclusion in this research review. All eleven papers utilized qualitative methodologies to explore spousal experiences and conceptualizations of dementia. The study characteristics and key findings are presented in Appendix B. the following themes emerged from the thematic analysis

conducted.

### *A sense of continuity*

Continuity was an important feature in the spousal accounts within all eleven studies. However, the focus and emphasis placed upon maintaining continuity differed considerably amongst all the studies. For example, some spouses took the responsibility upon themselves to ensure their spouse continued to feel connected with their life (Jansson, Nordberg & Grafstrom, 2001; Perry & Connor, 2002). They achieved this through drawing on the past to establish a presence of their partners in the here and now, re-telling stories which described their spouse before the dementia and acknowledging their spouses' historical strengths and virtues. However, whilst continuity was highly valued by the participants within O'Shaughnessy, Lee & Lintern's (2010) and Robinson, Clare & Evans' (2005) study, spouses also expressed how difficult it was to foster a connection given that their partners had changed so significantly and they no longer were able to enjoy shared activities.

For some participants, a sense of continuity was related to their spouse's dementia progression. It was deemed easier to retain the marital essence when the spouse had first been diagnosed with dementia, however, as the symptoms became progressively more severe a sense of continuity eroded (Hyden & Nilsson, 2015; Walters, Oyebode & Riley, 2010).

### *Change in relational dynamics*

The theme of equality was present in some form in all eleven studies. For some, equality was a concept which had all but disappeared in their relationship as the caregiver spouse took on more responsibilities (Quinn, Clare, Pearce & Van



Dijkuizen's, 2008; Robinson, Clare & Evans, 2005). For others, equality had diminished due to the lack of communication, love and reciprocal affection shown by their spouse with dementia (Quinn et al., 2008; Shim, Barroso & Davies, 2012).

Participants also recounted the ways in which gendered roles within their marriage had changed considerably. For example, women in Quinn et al's., (2008) study had now assumed the role of head of the household which was typically their husband's role.

For some participants, the increased dependence and reliance their spouses showed toward them was unwelcomed, begrudged and thought of as "needy child behaviour" (Shim, Barroso & Davis, 2012, p. 12) and being stuck to them "like a piece of glue" (Quinn et al., 2008; pg 10).

Conversely, participants in a few studies also stated that despite changes in gendered roles and lack of verbal communication, they still felt the concept of equality was very much still present in their marriages (Jansson, Nordberg & Grafstrom, 2001; Robinson, Clare, Evans, 2005).

### *Impact on self*

Participants in all eleven studies reflected upon the impact of dementia and caregiving upon themselves. For many, the term "caregiver" was congruent with how they felt their identity had evolved from one of wife to a professionalised caregiver (Brown & Alligood, 2004; Jansson, Nordberg & Grafstrom, 2001; O'Shaughnessy, Lee & Lintern 2010).

A lack of personal time was also a negative impact of dementia caregiving that many participants expressed (O'Shaughnessy, Lee & Lintern 2010, Quinn et al, 2008). Participants explained that caregiving was a time consuming and tiring responsibility which left them with little energy to engage in activities they previously found enjoyable (Sherman & Boss, 2007; Walters, Oyebode & Riley, 2010). The giving up of old activities not only contributed to a sense of sadness but participants also explained that their strong identity was gradually diminishing day by day (Quinn et al., 2008; Robinson, Clare & Evans, 2005).

A dilemma participants reflected upon was between meeting their own needs whilst also being mindful of their spouses' needs (Molyneaux et al., 2012 O'Shaughnessy, Lee & Lintern 2010). This often led to feelings of guilt, self-criticism as well as a sense of bitterness at having their own needs neglected (Quinn et al., 2008). Participants also alluded to a sense of overwhelming depression, grief and sadness in light of their spouses' dementia (Molyneaux et al., 2012 O'Shaughnessy, Lee & Lintern 2010, Quinn et al., 2008).

### *Coping*

There was great variation in the coping strategies participants described in helping them tolerate changes in their spouse. A strategy outlined in several studies was that of avoidance (Quinn et al, 2008; Sherman & Boss, 2007). Participants described various distraction techniques such as, ignoring their spouse, not thinking about the future and isolating oneself from social support as ways of counteracting the

hopelessness they felt about their situation (Molyneaux, et al., 2012, Quinn et al's., 2008).

Contrary to avoidance, participants in Perry and Conor's (2002) study described the active ways in which they jointly tried to cope with dementia with their spouses. For example, relying on their shared history enabled many participants to interpret current challenging behaviours in the context of their spouses past, this made it easier to know how best to respond. Similarly, participants also tried to reframe their thinking into conceptualising the challenging behaviours of their spouses as understandable (O'Shaughnessy, Lintern & Lee, 2010; Perry & Conor, 2002; Walters, Oyebode & Riley, 2010). Holding such compassionate and tolerant views enabled them to cope better with difficulties.

Participants also described the importance they placed upon identifying the retained abilities of their spouses. The reasons they cited for such a focus were two-fold, firstly it enabled them to maintain a connection with their spouse and secondly it afforded their spouse with a sense of agency which had a positive impact on their overall wellbeing (Perry & Conor, 2002; Walters, Oyebode & Riley, 2010).

For some participants, it was easier to start engaging in a grieving process as they believed their spouse was essentially no longer here (Walters, Oyebode & Riley, 2010). The anticipatory grieving was an important process for them as it helped them retain a memory of their spouse before dementia impacted them.

Participants in the Molyeneux et al., (2011) study highlighted a creative way of sharing the dementia experience through the couple exercising transparency and openness. Participants recounted ways in which they regularly sat together and talked honestly to one another about the impact of dementia on their wellbeing. The containing environment of their relationship allowed participants to share the “heaviness” of dementia without feeling judged or guilty.

### *Uncertainty*

Participants across all eleven studies expressed a degree of uncertainty about their spouses, dementia and their future. Many participants expressed feeling unsure whether their spouse was the same person or different. The unpredictability of dementia (especially in the earlier stages) meant that at times they felt reassured when their spouse exhibited completely normal behaviour but then quickly felt shocked when their spouse done something out of the ordinary (Hyden & Nilsson; 2015; Walters, Oyebode & Riley, 2010). To counteract feelings of uncertainty participants described two distinct processes. For some, avoiding thinking about the future helped protect them from feelings of anxiety which accompanied uncertainty (Jansson, Nordbery, & Grafstrom, 2001; Sherman & Boss, 2007). Whilst, others sought medical reassurance from GP’s and memory clinics as a way of exerting better control over their situation (Brown & Alligood, 2004; Robinson, Clare & Evans, 2005).

Participants also expressed uncertainty about their future, whilst they all accepted the inevitability of death they felt particularly unsure about the trajectory the dementia would take and how their spouses symptoms would worsen (Hyden & Nilsson, 2015).

### *1.5.1.3 Methodological appraisal*

#### *Recruitment*

In terms of recruitment, the Walters, Oyebdoe and Riley (2010) and Brown and Alligood (2004) study demonstrated novel strategies through recruiting participants from charitable organisations as opposed to solely medical institutions, as is typically the norm in dementia related research. This may have potentially allowed for alternative non-medicalised discourses and experiences to emerge.

#### *Sample*

The participants in all the studies were predominately Caucasian and there is little critical exploration of the implications of such homogenous samples. Furthermore, no study outlines whether concerted efforts were made to recruit a more ethnically diverse sample.

#### *Credibility*

In terms of the credibility of the analysis, Walters, Oyebode and Riley (2010) exercised methodological rigour through recruiting two researchers to carry out coding and further checked the final themes with psychologists who work with older adults to ensure resonance. The credibility could have been further enhanced through carrying out member checks with spouses. Walters, Oyebode and Riley (2002), Quinn et al., (2008) and Perry and Conor (2002) demonstrated a good use of participant quotations to better elucidate the themes and allowed for the findings to be rooted in the accounts of the participants.

### *Reflexivity*

Brown and Allgood (2004) demonstrated rigour through exercising researcher reflexivity and continually reflecting upon their own assumptions and their impact on the research process. The absence of such reflexivity in the other studies is a serious flaw and undermines the reliability of the findings.

### *Terminology*

A key weakness in many of the studies was use of the term “carer”. The participants were positioned as “carers” from the outset of the study and repeatedly asked about their caregiving experiences. It would have been useful to explore the resonance of this term with the participants first, in failing to do so, it could be argued that the researchers have colonised the experiences of the participants with their own research agenda. Only the study by Quinn et al., (2008) was mindful of using medical words such as dementia and Alzheimers. The terms carer and caregiving were only used if the participant mentioned them first in order not to prime their experiences through the researcher’s lens.

### *Data Collection*

Very few of the studies explain how the interview schedule was devised, nor do they state if the interview schedule was adapted in light of emergent findings. A key pitfall of all the studies was the lack of exploration of the cultural, political and social contexts of the participants. An absence of such exploration makes it difficult to interpret the findings in their unique context and one could mistakenly try to generalise them across inconsistent contexts.

### *Researchers position*

Another key point of interest for the author of the present study is navigation of dual roles in research. The data in the Quinn et al's', (2008) study was collected by a clinical psychologist. However, there is no discussion of the intricacies involved in conducting interviews whilst holding two different positions and whether any clinical psychology assumptions had to be suspended in the data collection process.

#### *1.5.1.4 Conclusion of Literature Review One*

The literature review thematically analysed the evidence base pertaining to spousal experiences of dementia. Given that informal caregiving by spouses occurs in the privacy of couples' homes this review helped elucidate some of the strategies employed by spouses to make sense of dementia. In addition, this review also highlighted the complex emotional responses which dementia caregiving evokes.

Yet, the review also identified methodological inadequacies in the research material, therefore calling into question the reliability and clinical contribution of such findings. Notwithstanding the above points, each study does highlight the importance for continued research in to how wives (predominant carers) understand dementia within their husbands.

#### *1.5.2 Literature review Two: Dementia within South Asian communities*

The rise of dementia within South Asian communities is unprecedented, with upwards of 25,000 individuals with a diagnosis, and potentially thousands more undiagnosed cases (House of Commons All Party Group on Dementia, 2013).

Through the identification of suitable literature this review aims to critically examine the evidence base and gain an in-depth understanding of how dementia is conceptualised by South Asians (Appendix C). It is particularly concerned with unearthing the role of culture and religion upon how conceptualisations and knowledge of dementia are formed. This is an important line of enquiry as governmental policies (e.g. NICE, 2006) dictate that to provide culturally competent dementia care, it is imperative to explore the impact of religious and spiritual beliefs.

Whilst the present study is concerned with gaining a deeper understanding of Punjabi-Sikhs specifically, very few studies exist exploring this group singularly. Therefore, for the purposes of gaining a thematic understanding, this review will incorporate literature across South Asians more generally. The implications of homogenising cultural groups will also be addressed.

#### *1.5.2.1 Search strategy*

Similar to the previous literature review, the research question was divided in to three component parts; “South Asian”, “dementia” and “conceptualisation”. Synonyms for each term were then attached to the search string (see Appendix C for complete search string). For the term ‘South Asian\*’ Van der Veer’s (1995) geographical definition was adopted and the following countries were included in the search; India, Pakistan, Nepal, Sri Lanka, Afghanistan, Bangladesh, Burman and Bhutan. Limiters excluding far Eastern countries such as China and Japan were added. The most common religions in these countries were also added to this search string as existing



research has shown religion, race and ethnicity are used interchangeably within research.

Dementia diagnostic categories were used to compile a separate search string and synonyms of the term “conceptualisation” were added together to form the final search string.

Each string was searched for independently, and then merged together, to form a complete search string (Appendix C for search string and results generated). The databases searched were, CINAHL Complete, MEDLINE with Full Text, and PsyArticles as these were thought to contain the most relevant health, social care, psychological and medical journals. Similar to the previous literature review, only articles published post 1980 were included in the review in order to focus specially in more psychological and social elements of dementia.

Of the results generated, the author imposed the following inclusion criteria:

- a) The study recruited individuals who identified themselves as South Asian.
- b) Only empirical studies were included
- c) The paper explores dementia specifically and not related co morbid conditions.
- d) Participants were adults over the age of 18.
- e) Articles were published in English

### *1.5.2.2 Results*

Eight articles were deemed suitable for inclusion in this research review. All eight papers utilized qualitative methodologies to explore the knowledge and experiences of dementia within South Asian communities. Three of the papers focused solely on South Asian communities (Bowes & Wilkinson, 2003; Jutlla, 2014; Mackenzie, 2006; La Fontaine, Ahuja, Bradbury, Phillips & Oyebode, 2007), whereas the other four (Jolley et al., 2009; Turner, Christie, & Haworth, 2005; Lawrence, Murray, Samsi & Banerjee, 2008 and Adamson, 2001) assessed South Asian, Afro-Caribbean as well as Caucasian communities. Key findings and study characteristics are presented in Appendix D.

The thematic analysis revealed four core themes which ran across all seven studies; views about ageing, understanding and awareness of dementia symptoms, community perceptions regarding dementia and finally how to treat dementia. These themes will be discussed in greater detail below.

#### *Views about ageing*

Participants all described the aging process predominantly from a physical health lens, citing ailments such as blood pressure as a significant concern. The La Fontaine et al., (2007) study found themes of loneliness, isolation and lack of care also featured heavily in the participants' views of ageing. Memory difficulties were rarely mentioned by participants and when alluded to within the La Fontaine et al., (2007) study, participants did not attribute memory changes to dementia but inevitable ageing. Mackenzie (2006) identified a strong theme of fear of ageing amongst South

Asian carers. This fear developed from an uncertainty regarding dementia. It is important to make a distinction here that, the participants in Mackenzie's (2006) study felt the term dementia incited fear and not ageing per se. Fear was not a common theme amongst the other studies in which the term dementia was not readily introduced by the researcher. This finding opens an important debate, whether terms such as dementia and Alzheimer's should be imposed from the outset of research and risk potentially biasing the participants' accounts or whether, participants should be allowed to freely express their experiences without having terms incongruent with their culture thrust upon them.

#### *Dementia awareness*

In a study by La Fontaine et al. (2007), awareness of dementia amongst participants was assessed through vignettes. Participant explanations about the vignette did not allude to dementia. Instead, individuals cited social exclusion, familial tensions and physical ailments as explanations for the presentation outlined in the vignette. Similar findings have been identified by Turner, Christie & Haworth, (2005), in which dementia awareness amongst South Asians was considerably lower than their Caucasian peers.

Spiritual and religious explanations were also a feature across the papers. For example, negative religious attributions, such as punishment from God, were used as providing context for dementia related symptoms (Mackenzie, 2006). Yet, cross-generational differences with regard to religious attributions are not explored in such studies.

The authors in seven of the eight studies (apart from Jutlla, 2014) homogenize the experiences of all participants and present the findings as generalizable to all South Asian religions. In reality, as shown in the Jutlla (2014) study there are distinct ideological and cultural differences between South Asian religions such as Sikhism, Islam and Hinduism and to assume that religious explanations of dementia are the same across all three is reductionist. For example, Mackenzie (2006) cites supernatural explanations such as magic spells and jins as religious causal factors for dementia however, such supernatural explanations are entirely incongruent with the ideology of Sikhism and more commonplace in Islam and Hinduism. The trend of homogenizing of South Asians into one collective group in western research further highlights the need to explore specific cultural and religious groups separately.

Participants in the Adamson (2001) and Jutlla (2014) study used biographical narratives to help make sense of the changes they noticed within their relatives. Within the Jutlla (2014) study participants particularly focused on the migration history of their relatives and predominately conceptualised the changes they experienced as indications of cultural isolation, social exclusion though living in a host country and oppressive practices such as racism by majority groups. Similarly, participants in the Adamson (2001) study thought about the losses endured by their relatives such as bereavement, loss of employment and loss of mobility as contributing factors for the disorientation and memory losses they observed. These themes are distinct from those in the other six studies and this may in part be due to the authors' openness to explore the experiences of the participants as opposed to

judging and quantifying the participants understanding of dementia against a pre-set standard of guidelines.

It is also worth noting the way in which the authors present their findings. For example, Jutlla (2014) and Adamson (2001) endeavour to understand participant experiences within their frame of reference, without an imposition of dementia terms. Whereas studies by Bowes and Wilkinson (2003); Mackenzie, (2006); Jolley (2009) and La Fontaine et al., (2007) conceptualise the participants' responses as a lack of awareness and understanding of dementia. They go on to suggest that participants from BME communities would benefit from formal training about the causes and treatment options for dementia. As such, these studies adopt a positivist stance toward dementia, in which it is seen a concrete construct and do not allow for explorations as to how ageing related changes can be conceptualised in alternative more culturally congruent ways.

#### *How to treat dementia*

South Asian participants reported a lower awareness of the available treatments for dementia in many of the studies (Jolley et al., 2009; Turner, Christie & Haworth, 2005). Turner, Christie and Haworth (2005) found that medication and biological treatments were taken up by Caucasians more so than South Asians. Instead, support from family member and the wider community was thought to be the ideal treatment option (La Fontaine et al., 2007). Biographical narratives and understanding were cited by participants in Jutlla's (2014) study as the best frame through which to support individuals with labels of dementia. These findings highlight that South Asian communities draw upon less formal and medicalised services to assist them

with relatives. However, participants did express an interest and need for culturally sensitive support in the NHS (Jolley et al., 2009; La Fontaine et al., 2007).

### *Community perceptions of dementia*

Adamson (2001) reported that medicalized terms such as dementia and cognitive loss evoked panic and a fear of stigmatization within South Asians. This was expanded upon by Lawrence et al., (2008) who found stigma to be the predominant reason for individuals not seeking professional and clinical support. Healthcare professionals echoed similar sentiments in the Bowes and Wilkinson Study (2003). Participants in the Bowes and Wilkinson (2003) study highlighted some of the relational difficulties present in eliciting support from friends and family. A feeling of shame and judgement prevented individuals from seeking such support, leading to feelings of isolation. This is an interesting finding as it contradicts the notion that South Asians “look after their own” (Lawrence et al., 2008). Such beliefs often prevent health care services from developing culturally sensitive treatments.

#### *1.5.2.3 Methodological appraisal*

##### *Data Collection*

In order to avoid potential interviewer bias, many studies (Adamson, 2001; Lawrence et al, 2008) utilised a topic guide to help structure the interview process. However, caution must be advised to prevent strict adherence to the schedule from limiting and influencing the participants’ accounts.

Conducting the interviews in individuals’ native tongue was a focus of many of the studies. However, Adamson (2001) utilised translators in the interview process. One

can argue that the utility of translators may be undermined by the potential for stilted exchanges and the introduction of the translator's own assumptions which masks the true voice of the participant (Squires, 2009).

### *Reliability*

Positivists often critique qualitative research on the grounds of trustworthiness, as traditional quantitative evaluation frameworks do not apply to qualitative research (Lincoln & Guba, 1985). Qualitative researchers are therefore faced with the task of implementing strategies to enhanced the reliability and validity of their studies. Scrutinising negative cases (e.g. data not consistent with main theory) is one such strategy utilised only by Adamson (2001). Through using emergent models to explain negative cases, trust in findings is enhanced (Denzin & Lincoln, 2005).

Coding bias can be eliminated through using inter rater coding (Glesne & Peshkin, 1992). Yet, this strategy was only adopted by Lawrence et al., (2008). It was also only this study (Lawrence et al., 2008) which provided a detailed account of the data collection and analysis process. This calls into question the methodological credibility of the other studies.

### *Reflexivity*

The researcher should also look to reflect upon and analysis one's relationship with the study (Bickman & Rog, 2008). Yet, this was not a feature in any of the studies examined. The prospect of researcher bias can therefore not be discounted. The adoption of snowball sampling techniques in the Adamson (2001) study also creates

the prospect of homogenous and aligned attitudes and experiences of dementia amongst participants.

### *Recruitment*

Recruitment difficulties were eluded to in all studies. Future research may wish to alleviate such issues through dialogue with South Asian Patient Public Involvement Panels (PPI). Such partnerships are able to assist in developing culturally sensitive research processes. (INVOLVE, NIHR 2015).

#### *1.5.2.4 Conclusion Literature Review Two*

The literature review thematically analysed the evidence base pertaining to dementia awareness in South Asian communities. Levels of dementia awareness differed across all studies. It can be argued that this is in part due to the way in which the researchers framed their research, studies which privileged a biological understanding of dementia found South Asian participants to have limited understanding. Whereas studies more exploratory in nature found alternative conceptualisations of dementia such as social exclusion, migration history and personal biographies. Poor cultural understanding within professionals was cited as a key factor keeping South Asian communities away from formal services. Therefore, services such as the NHS need to ask questions about how to make their care more attuned to the needs of the changing cultural landscape within the U.K.

#### *1.5.3 Overall conclusion*

The two literature reviews helped shed light on important areas within dementia related care, culture and caregiving experiences. However, inherent within both



reviews were a multitude of unexplored and unanswered questions. For example, a trend to homogenise South Asian communities and frame religion and culture synonymously may have overshadowed critical findings. Indeed, wider systemic thinking about external as well as more relational dynamics would benefit an exploration of spousal caregiving too. With these questions in mind the focus of the current study is outlined below.

### 1.6 Aims of the present study

Upon closely analysing the existing literature base, the author noted several gaps in research, with these in mind the present studies aims to:

- Explore conceptualisations of dementia, specifically within a Punjabi Sikh population.
- Explore the extent to which predominant biomedical explanations of dementia are congruent with the values, virtues and experiences of Punjabi Sikhs.
- Explore the experiences of those who tend to provide the most informal caregiving in Punjabi Sikh communities, wives.

### 1.7 Key points covered in this chapter

- The construct of dementia has undergone many psychological and social paradigm shifts, as evidenced by the emergence of psychological theories such as attribution theory and Kitwood's (1990) idea's about preserving personhood.

- More recently, social constructionist theory has started to question the validity and consequences of using dementia diagnostic labels upon individuals, carers and society more generally.
- Spousal caregiving in dementia is a deeply complex emotional, relational and social experience. Current literature suggests that spouses draw upon both internal and external resources to navigate feelings of uncertainty and changing identities.
- South Asian communities draw upon less formal and medicalised services and instead understand age related changes such as memory loss through a prism of religion, personal history and relational dynamics.
- The following chapter will provide a commentary on the chosen methodology to begin exploring the aims of this study.

## **2 Methodology**

This chapter begins by briefly outlining the researcher's epistemological position. This exploration helps the reader ascertain the theoretical congruence between the methodological design and the research questions. The proceeding section contains a critical overview of Grounded Theory (GT) and outlines the rationale for employing this approach. Issues of rigour in qualitative research are also explored in relation to GT. Researcher reflexivity is also explored in this chapter. The latter sections of this chapter outline the recruitment process, data collection and analysis procedures.

### **2.1 Research paradigm**

This section outlines the conceptual and philosophical context in which the current research took place. The purpose of this section is to orientate the reader to the epistemological, ontological and methodological assumptions of the researcher in order to help ensure that the design of the research is consistent with the author's concept of reality and truth (Mills, Bonner & Francis, 2006).

An ontological position refers to the researcher's relationship with the reality of their study (Ponterotto, 2005). Ontologically speaking, realism and positivism both view reality as objective, independent of one's experience, while pragmatism and relativism regard reality as subjective. The author of this study adopted a relativist position as she believes that there are multiple realities and that the researcher themselves participates in the construction of that reality.

Epistemology refers to the philosophy of knowledge, specifically how we have come to 'discover reality' (Ponterotto, 2005). Within research, epistemology can also refer

to the relationship between the researcher and the participant (Ponterotto, 2005). Quantitative research assumes a positivist epistemological position, in which the emphasis is placed upon objectivism and the researcher and participant are positioned independent of one another.

The current research aligned with the notion that reality is influenced by the context of the situation, for example the individual's experience, socio-political environment and the interactional space between people. It is within this realm that reality is constructed. Therefore, this piece of research was conducted within a framework of social constructionism.

The focus upon the unique experience of the individual and how it is constructed within the inter-subjective, social and political space makes it different from interpretivism, which focuses on individual meaning making. Social-constructionism occupies a relativist position and therefore is congruent with an emic position with regards to cross-cultural research. It is important to highlight the difference between social constructionism and constructivism, two terms, which at times are interchangeably used, but hold different underlying assumptions. Constructivism frames knowledge as being constructed within the mind of each individual (Glaserfeld, 1995). In contrast, social constructionists argue that knowledge is co-created between persons (Gergen, 1999).

## 2.2 Rationale for a qualitative approach

The voice of the participant is privileged within qualitative methodologies which, is in contrast to quantitative research that, often imposes predefined assumptions driven by the research agenda. (Gergen & Gergen, 1999). The qualitative approach is particularly important when conducting cross-cultural research, as often westernised and euro-centric psychological frameworks cannot readily be applied to all cultures (Ember, Ember & Peregrine, 1998).

Furthermore, qualitative methods are valuable in exploring less researched psychological domains (Smith, 2011). Whilst a small number of qualitative studies have been conducted exploring the caregiving experiences of South Asian individuals, there has been limited research on understanding the conceptualisations of dementia within spousal relationships in the Punjabi Sikh community. Given the exploratory aims of this research, a quantitative methodological framework was viewed as likely to obscure the individual's personal perspectives (Patton, 1990). The researcher selected Grounded Theory as the most suitable method and source of analysis and data collection.

## 2.3 Grounded Theory

Grounded theory (GT) aims to examine individual experiences, meanings and social processes, and produces a theory based on such perceptions (Glaser & Strauss, 1967). Central to the GT methodological approach is its focus upon the inductive processes through which data is collected and analysed. An inductive approach allows the researcher to immerse oneself in the data as opposed to condensing the data in to pre-

existing theoretical frameworks (Glaser & Strauss, 1967). Glaser and Strauss (1967) purport that the emergent theory is able to be contrasted against existing literature and theory. Only then can discussions take place as to how the new theory contributes to the existing understanding of the phenomena being explored.

Glaser and Strauss (1967) propose several rigorous methodological steps to guide GT research. Firstly, they highlight the importance of concurrent processes of data collection and analysis, and specifically propose that analysis be conducted after individual pieces of data are obtained. Therefore, meaning making starts from the very start of data collection and codes and labels are developed to describe each segment of data. The codes and labels also inform the theoretical sampling and support the means of further recruiting participants on the basis of findings. These codes are further developed conceptually and form the building blocks from which a grounded theory is developed (Charmaz, 2011). Theoretical saturation is achieved when no new categories are discovered (Glaser & Strauss, 1967).

To facilitate the development of categories, the constant comparative method is advocated, which entails constantly comparing codes and labels across and within individuals. (Glaser & Strauss, 1967).

### 2.3.1 Charmaz's version of Grounded Theory

GT has undergone many revisions since its development by Glaser and Strauss in the 1960's. Inherent within GT as a whole is an epistemological continuum. Whilst earlier approaches sought to discover an objective truth and were more closely

aligned with positivist epistemological positions, more recent developments in GT have sought to situate the approach along more social constructionist lines.

Charmaz's (2011) social constructionist GT (CGT) approach offers an alternative to more classic GT approaches and seeks to understand how the participant and researcher engage in the co-construction of knowledge. Charmaz (2014) places a critical spotlight on the original forms of GT and argues that it assumes a distancing relationship between participant and researcher. Furthermore, she asserts that the researcher in classical GT approaches is elevated to an 'expert position' who aims to introduce objectivity to the research and in doing so brings to the research process issues of relationality. Without explicitly exploring such relationality issues the classic GT researcher risks developing artificial theories void of context and their own assumptions.

Charmaz (2011) instead promotes a non-hierarchical relationship between participant and researcher, in which the interactional space between them is critically examined and the researcher's own assumptions made clear. This positions the researcher as part of, rather than external to, the ongoing study. (Charmaz, 2014). The critical exploration of the researcher's impact on the research occurs through a continual reflexive process and documented in memos and discussions with supervisors. In contrast to classic GT approaches, Charmaz's (2011) version of GT is concerned with developing understandings which are tentative, and specific to the context in which they were explored, as opposed to developing generalizable theories (Charmaz, 2014).

The research aims of this study were to explore the process of conceptualising dementia within Punjabi Sikh spousal relationships. Therefore, constructionist-GT is well suited to this exploratory process as it allows for the researcher to examine the mechanisms of attribution and conceptualisation whilst also ensuring that the researcher's own assumptions are clearly explicated (Morse, 2009). Furthermore, existing theories of conceptualisation and attribution based on Western ideas of dementia may mask the nuances and subtleties of Punjabi Sikh perceptions.

Within GT approaches Charmaz's (2014) social constructionist version was deemed most suitable for this research given its close epistemological alignment with the beliefs of the researcher. In this research, Punjabi Sikh wives are expected to attach different cultural meanings and understandings to their spouse with dementia. Such understandings may be outside of the realm of Western models of dementia caregiving and therefore a methodological approach which privileges the unique social and personal context of the participant is favourable.

#### 2.4 A brief note on other qualitative methodologies

Whilst it is beyond the scope of this research to provide a detailed comparison of all qualitative methodologies, the following section aims to outline a popular qualitative approach and further discuss the choice of CGT in over this alternative methodology.

The Interpretative Phenomenological Analysis (IPA; Smith, 2011) approach is concerned with individuals' lived experiences, and the meanings they attach to these. Inherent within IPA is a researcher approach that focuses on interpreting the meanings behind what participants have reported. This is viewed as inconsistent with



the author's beliefs about who 'holds the knowledge' in research relationships. IPA supports a position in which the researcher is given freedom to understand the data through their frame of reference alone. The neglect of a mutual meaning construction process in IPA is another reason for why a CGT was chosen. In research, which is concerned with how carers from a minority culture ascribe meaning to their caregiving experiences, it seems inappropriate to elevate a western trained psychologist/researcher to hold the power to interpret the participant's voice. Such skewed power differentials within the research process may potentially mimic the power differentials experienced by minority carers within service utilisation in the U.K. IPA is also not concerned with the construction of a theory. Given theory construction is an aim of this research, IPA is a redundant methodological choice.

## 2.5 Quality assurance in qualitative studies

Positivists often question the trustworthiness of qualitative research, perhaps because quantitative evaluative criteria cannot be applied as seamlessly to qualitative research (Lincoln & Guba, 1985). However, several checklists exist specifically for the evaluation of qualitative research. However, as suggested by Yardley (2000) one must exercise caution and not simply make quality assurance a tick box exercise at the end of the research. Rather, commitment to rigour and best practice must be inherent throughout the whole research process. Outlined below are several key areas which have been afforded attention from the outset of this study.

### 2.5.1 Researcher reflexivity

The social constructionist approach proposes researchers be an integral part of the research. Charmaz (2014) therefore stresses the imperativeness for adopting a position of reflexivity. As such, the researchers' own context, subjective experiences and how they present themselves to participants must be continually reflected upon to enhance the transparency, accountability and general trustworthiness of the research. Particularly in CGT, where the emphasis is on the joint construction of meaning it is imperative that one can deconstruct any emergent theories and delineate the views of the researcher from that of the participant. To neglect the researchers, frame of reference and impact upon the research would mean limiting the theoretical sensitivity of the research (Nightingale & Cromby, 1999). Within a CGT research framework, such reflections typically take the form of memos and reflective journals and therefore documenting personal biases and discussions with research supervisors was integral (see Appendix E).

Throughout the research process, the author was particularly reflective of the implications of being an 'insider' and carrying out research within her own Punjabi Sikh community. Through a shared ethnic identity, the author cultivated good relationships with potential participants and tailored the research process to meet the unique cultural needs of the individuals. For example, being a practicing Sikh, equipped the author with an innate respect and compassion for the local Sikh community and hence granted her easier access to the temple to advertise the study. Participants were able to ask questions in Punjabi about the study and a number of participants cited ease of communication to be a key reason for participating in the research. This is particularly important as Bowes and Dar (2000a) found that there

was often distrust within South Asian communities about participating in health-related research. Indeed, Suwankhong and Liamputtong (2015) also found that a shared ethnic identity helps promote stronger relationships which is key to an exploration of cultural experiences.

However, 'insider cultural research' is not without its flaws. The author was particularly mindful of the fact that being a native Punjabi speaker may lead to her attributing her own personal meanings to the data collected and assume this to be the 'correct translation'. For example, in one interview a participant spoke about hoping for "chardi kala", the author translated this to mean personal joy and contentment, as was the author's personal understanding of the term. However, later in the same interview the participant explained that "chardi kala" to her meant a sense of contentment with God. Similarly, one participant began to describe the Sikh baptism ritual of drinking "amrit" (holy nectar) however, because the author believed she held an in-depth understanding of cultural and religious practices she did not explore this further and potentially stunted an important area of exploration for the participant. Indeed, Suwankhong and Liamputtong (2015) warn against 'insider' researchers becoming "insufficiently curious" and encourage researchers to temporarily suspend their personal cultural understandings in order to better obtain richer descriptions of the participants' experiences.

Systemic processes within families, diversity and cultural processes are of great interest to the researcher. The researcher has also developed a critical approach to cross cultural research and the heavy reliance upon Euro-centric theories to describe and explain distress in cultures other than the ones in which such theories were

derived. Such an approach may have influenced how the researcher not only read literature pertaining to the construct of 'dementia' but also the probes used in the interview process may have favoured themes linked to more spiritual non-medicalised explanations of dementia.

Another aspect continually reflected upon during the interviews and analysis stage was the dual status of the researcher as a Trainee Clinical Psychologist and principle researcher. The impact of the two roles on the way in which the researcher conducted the interviews has been particularly focused upon in the reflective journal (see Appendix E for excerpt). Whilst the researcher was aware that a certain degree of rapport would need to be built between researcher and participant to facilitate an in-depth exploration of experience she was also mindful that given her status as a trainee psychologist such a process may at times be experienced as therapeutic.

### 2.5.2 Relationality

Relationality is concerned with the power differentials inherent within researcher and participant relationships (Hall & Callery, 2001). Given the close alignment between the researchers personal and professional beliefs and systemic ways of thinking the concept of power was given focused attention.

It is especially important to consider issues of relationality in the current study given the complex positioning of the researcher as from both within and periphery of the community from which the participants were recruited. Whilst identifying as a Punjabi Sikh, participant's may have privileged the researcher's position as a Trainee Clinical Psychologist thus 'othering' her from their experience. Furthermore, the

added dimensions of age and gender added complexity to the concept of power within the research relationship. The researcher was curious and reflected within supervision whether her young age meant that she was positioned in a way by participants to protect her from the difficult aspects of their experience. Equally, being a female and interviewing other females may have led the participants to share more, due to a perceived similar frame of reference.

Participants may also have been elevated to a higher power position as they were all referred to as 'aunty ji' during the interviews, a respectful term of any female elder of the community. Connoted with this term are many implications of power linked with age and wisdom and may give rise to assumptions such as a need to protect a younger generation from the difficulties of older age or a higher spiritual level of thinking not to be disclosed with younger members of the community for they have not acquired spiritual maturity.

### 2.5.3 Grounding in examples

To increase the transparency of the study, it is important to present excerpts of data to illustrate the research process. With the aid of interview transcripts and research memos, it is hoped that the reader is better able to appreciate the development of emergent theory (see Appendix F). Quotations from participants are also presented within this report to add richness to the emergent themes.

#### 2.5.4 Providing credibility checks

Credibility checks, such as discussions with research supervisors and experienced qualitative researchers, enabled further validation of the model.

A ten minute sample of transcript from three separate interviews was also translated, coded and reviewed by a Punjabi speaking qualitative researcher. The qualitative researcher had a substantial background in Punjabi teaching and carrying out research. The level of agreement between the researcher and external consulting researcher was discussed in supervision.

Participants who took part in the focus group at the beginning of the study were again consulted in the latter stages to carry out member checks and ensure that the model was largely congruent with their experiences. This is an integral part of GT research as it provides further credibility to the findings (Corbin & Strauss, 1990).

#### 2.5.5 External validity

A criticism often directed at CGT is the paradox that given the construction of meaning unique to a specific context and specific interaction between participant and researcher to what extent can any model to emerge be generalizable to a wider context? Elliot, Fischer & Rennie, (1999) propose a potential solution for this paradox which involves the researcher outlining from the outset the level of understanding they intend to achieve from the research. Within GT, there are two types of theory; substantive and grand. These two theories differ on the emphasis placed upon the ability to generalise. Substantive theory, which is what the study

aimed to develop, provides an understanding of experiences grounded in a specific time as well as social and cultural context. Grand theory instead looks to generalise findings across all contexts (Corbin & Strauss, 1990). Setting this distinction out from the start of the research is important as it allows both the reader and researcher to reflect on the scope and transferability of the findings.

## 2.6 Ethical Issues

The University of Essex Research Ethics Committee (Appendix G) has provided ethical approval for this research. The following section outlines how important ethical topics were considered.

### 2.6.1 Informed consent

To obtain informed consent, an information sheet was sent to eligible participants. This contained details on the processes and ultimate aims of the research (Appendix H). The individual participants also had the opportunity to discuss any concerns or questions with the researcher before consenting to participate (Appendix I). Each was also informed that their participation was independent of any ongoing care or support being received from external agencies. Furthermore, participants were told of their right to revoke consent at any point during the research process, and six months following the research dissemination. Before the research interviews started, the researcher ensure written consent was received from all participants.

### 2.6.2 Confidentiality

The researcher ensured that each participant was aware of that data gathered was confidential and anonymous. It was an integral part of the research process, as previous studies have identified such issues as being a major barrier to BME individuals participating in research (Bowes & Dar, 2000; Seabrooke & Milne, 2009). In cases where excerpts will be used from the interviews participants will be assigned pseudonyms and no identifiable information will be reported

### 2.6.3 Distress during/following interview

Before the commencement of the interviews participants were made aware that they could disclose as little or as much information as they felt comfortable with. Participants were advised they could request breaks as frequently as they needed during the interviews and were not obliged to answer every question.

In the likely event that the sensitivity of the topic area evoked upset and distress, participants were provided with information of relevant support organisations. They were also advised that they could terminate an interview at any time.

## 2.7 Recruitment

To recruit Punjabi Sikh wives the researcher circulated adverts within Sikh voluntary, religious and community organisations. Snowballing recruitment techniques were also employed. Given the researchers familiarity within the local community concerted efforts were made not to recruit from the researcher's immediate network.



Interested parties who contacted the researcher were given an initial questionnaire to ensure that they met the inclusion criteria for participation and an information and consent form were sent to them to complete. Interested parties were also given the option of contacting the researcher to discuss any element of the study before consenting to participate.

To keep in line with core GT principles, the recruitment of participants was conducted in phases. This iterative approach to data collection ensured the researcher could identify data or research gaps, which in turn informed the adaptation of the interview schedule as well as theoretical sampling.

Charmaz (2011) proposes the benefits of interviews undertaken in the home setting to allow for a more 'naturalistic' environment in which participants can safely recount their experiences. Equally however, participants were also provided with options of community settings in case they felt privacy would not be afforded to them at home. Of the eleven interviews eight were held at home and the others in the local Sikh Gurudwara (temple).

### *2.7.1 Theoretical saturation*

The researcher adopted theoretical sampling methods to achieve a level of theoretical saturation, in which research categories were not enhanced by the introduction of new data. The current research did not aim to strive for complete theoretical saturation, but aimed for theoretical sufficiency as it is argued to be a more flexible and attainable alternative to saturation (Charmaz, 2011).

## 2.8 Participants

In recruiting participants, the researcher adopted the below criteria:

- Participants should be aged 18 years and above. There was no upper age limit applied.
- Identify as Punjabi Sikh
- Female spousal caregivers of person diagnosed with dementia
- Husband has received a formal diagnosis of dementia
- Had been supporting a husband with dementia for a minimum period of six months.
- Not have a co morbid chronic health condition (e.g. diagnosed depression), as it may add additional complexity and mask the caregiver's conceptualization of dementia specifically.

### 2.8.1 Participant Characteristics

A total of eleven participants took part in the study. They were all recruited from the same geographical area in the South of England. Participant characteristics are outlined in Table.1. An area which was not captured in the initial questionnaire was sense of religiosity in participants. Participants were not asked whether they were baptised (Amritdhari) or not (Sejadhari) and the implications of this are discussed in the critical review section of the discussion.

To maintain confidentiality, all quotations have been anonymised and personal and identifying information has been removed or altered. Participants have been assigned pseudonyms to further protect confidentiality.

**Table 1. Participant Characteristics**

	Demographic Information	Number of Information participants (n=11)
<b>Age</b>	60 -70	1
	70 - 80	8
	80 – 90	2
<b>Ethnicity</b>	British	0
	Indian	0
	Panjabi Sikh	11
<b>Religion</b>	Sikh	11
<b>Number of years in the UK</b>	30 – 40	0
	40 - 50	4
	50 – 60	5
	60 – 70	2
	70 +	0
<b>Number of years married</b>	30 – 40	0
	40 - 50	3
	50 – 60	6
	60 – 70	2
<b>Primary language</b>	English	0
	Hindi	0
	Punjabi	11
	Urdu	0

## 2.9 Data collection

### 2.9.1 Preliminary interview schedule

The researcher produced a preliminary interview schedule (Appendix J). This was based on the researcher's knowledge of the Punjabi Sikh community and literature pertaining to caregiving experiences within BME communities. The interview schedule was not intended to narrow the line of enquiry but rather, provide a preliminary framework to begin an exploration of constructions of spouses with dementia. The schedule started with structured questions such as age, number of years living in U.K and route to getting a dementia diagnosis in order to acclimatize the participant to the interview process.

### 2.9.2 Piloting the interview schedule

A focus group consisting of three Punjabi Sikh female spouses caring for an individual with dementia were invited to discuss the preliminary interview schedule. The focus group took place at a local Sikh Temple. The focus group looked to examine the research questions, and highlight any viewed as inappropriate or culturally irrelevant. Likewise, participants were encouraged to suggest areas of enquiry the researcher had not yet considered. The recruitment of BME participants has been identified as particularly difficult in cross-cultural research, as many individuals believe that research aims do not explore pertinent or relevant issues for them (Bernal & Castro, 1994). Therefore, it was important to ensure that the lines of enquiry in the interview schedule resonated with the participants. Furthermore, the focus group was a useful exercise in ensuring the questions were easy to understand

and that the questions were not heavily loaded with complex psychological constructs.

The author made preliminary notes during the focus group and elaborated upon these notes upon watching a video recording of the group afterwards. The author chose not to employ a specific methodology such as thematic analysis to analyse the data in the interest of time but also because the focus group was deemed to be an adjunct to the research study, simply designed to inform the main research interviews.

The focus group was highly critical toward the initial interview schedule, particularly toward the terms 'carer' and 'dementia'. Participants stated that the schedule focused too heavily upon the term dementia without allowing for potential participants to express alternative conceptualizations for the changes they experience. Furthermore, participants expressed that terms such as 'carer' and 'caregiving' should be avoided as these do not accurately portray their experiences, instead they suggested terms such as 'supporting' or 'living with'.

Participants also commented that the questions focused too heavily upon the internal experiences of the wives and the spousal dyadic relationship. They highlighted an important cultural observation that for many woman of that age and cultural cohort, talking about their marriage would be considered a taboo. Therefore, they recommended that the line of enquiry be extended to incorporate a more systemic exploration of the impact of wider family and community factors upon experiences and meanings attributed to dementia.

Taking on board the feedback from the participants, the researcher ensured that each research interview began with drawing a cultural genogram and a system ecomap with the participant. Whilst traditional genograms focus on the depiction of familial relationships, a cultural genogram adds to this through also illustrating the impact of culture, religion and migration upon the individual's relationships with family as well as outlining helpful/unhelpful systems around them (Harding & Laszloffy, 1995).

The collaborative genogram drawing was considered important on two fronts. Firstly, it was hoped that it would allow participants to ease in to the interview setting through focusing on information readily accessible to them and secondly, it was hoped it would introduced a wider familial focus, thus allowing for a more systemic exploration of dementia experiences. To protect the confidentiality of participants, the researcher is unable to provide an example of a cultural genogram completed with a participant.

### 2.9.3 Adapting the interview schedule after interviews

The preliminary interview schedule was adapted considering the feedback from the focus group and utilized for the first two interviews with participants. The schedule was subsequently further adapted following successive stages of interviews. This was a crucial part of the data collection process and in line with principles of theoretical sampling as advocated by Charmaz (2011). Charmaz (2011) argues that theoretical sampling in grounded theory research does not solely have to mean searching negative cases and interviewing numerous participants until the data is no longer enriched by new information. Rather, theoretical sampling, in particular interview adaption, should aim to guide the line of enquiry in light of tentative emergent themes

in order to further elucidate and illuminate categories. Thus, highlighting the importance of data analysis occurring in parallel to data collection.

For example, following the initial two interviews, the themes of intergenerational difficulties became increasingly prominent, therefore, in order to better understand the role of such difficulties this was added to subsequent interview schedules. As interviews progressed, participants also spoke of social inequalities and through adding this to the interview schedule, the researcher was able to progressively clarify such inequalities to mean racism, ageism and colonialism. Adapting the schedule allowed for increased precision and clarity in differentiating between processes and categories.

In addition, the style of questions also adapted in light of ongoing dialogues with participants. It was noted by interview four, that participants were keen to bring in the voice of their husbands as well as exercise curiosity about the role of discourses upon their understanding of dementia. Prior to interview four, questions had tended to be linear in nature, they implied an inherent cause and effect. For example a linear question asked in interview two was, why do you think your husband is experiencing these difficulties? However, in interview four this had been adapted to a more systemic circular interactional question (Evans & Whitcombe, 2016), when your husband becomes confused how do you think it impacts your son? How does this subsequently impact your husband? The latter question allowed for participants to describe the interactional processes involved in their experience of dementia not only with their husbands but their wider system.

#### 2.9.4 Interviews

The researcher conducted the interviews in Punjabi. It was deemed important to conduct the interviews in the participant's first language to facilitate a deeper and richer data gathering process.

Eight interviews took place in the participants' homes. Whilst it was hoped that the familiar surroundings would help foster trust and cooperation. The author noted that during the initial home interviews some participants expressed a reticence to explore sensitive topics in the presence of their daughter-in laws and/or children. Moving forward, the author ensured that the participants were asked on the telephone beforehand whether they would like the interviews to take place at home or in a different environment. Three participants stated that whilst they would prefer they were interviewed at home but would like for the author to ask their relatives for privacy during the interview as they felt anxious to ask their family themselves.

The remaining interviews took place in a private room in the Sikh Gurudwara. The implications of this setting are explored further in the discussion chapter of this thesis. The interviews each lasted between one to one and a half hours, and were recorded on a Dictaphone.



## 2.10 Data analysis

### 2.10.1 Transcription

The researcher transcribed all interviews herself to ensure she was fully immersed in the data and in turn facilitate a deeper understanding of the participants' experiences (Charmaz, 2011). As the interviews were in Punjabi, transcribing was also done in Punjabi. It was important to not to skip to the translation stage straight away, as meaningful data could have potentially been lost too early in translation. The data analysis process is depicted in figure 1.

**Figure 1. Data Analysis Process**



### 2.10.2 Initial coding

The next stage was extremely important and involved the researcher reading and re-reading the transcripts carefully and understanding each word intently. Charmaz (2006) states that initial codes form the skeleton of research upon which to build the body of analysis and therefore this stage should be carried out with precision. Data was analysed sentence by sentence and as such, particular words started to stand out for the researcher. These words are what Fredman (2004) coins 'rich words' and are what formed the basis of the initial codes. As advocated by Charmaz (2014) these 'rich words' were coded using actions as opposed to theoretical labels (see appendix

F). This helps to ensure the researcher stays close to the data, and that the subsequent theory is grounded in the participant's experience as opposed to pre-existing theories. For example, one participant spoke about experiencing her husband as "the same and yet sometimes different", this could have been coded as "fluctuating behaviour" however, this code seemed emotionally removed from the wife's personal experience and felt too 'clinical' in its essence. Therefore, an 'in vivo' code (the verbatim terms used by participants) "he's different and yet the same" was assigned. In vivo codes have been shown to facilitate meaningful category naming, and are a way of communicating the participants' experiences more accurately (Charmaz, 2011).

### 2.10.3 Focused coding

The next stage of coding was also done in Punjabi and involved synthesizing the initial codes into emergent themes. The Punjabi translation of the codes is shown in Tables 2, 3 and 4. During this stage the researcher thought of two key questions; how big should a theme be and what constitutes a theme? The researcher took on board recommendations by Braun and Clarke (2006) who propose that researchers should exercise flexibility and allow for themes to freely emerge as opposed to constricting them to a certain number of codes.

When thinking about what constitutes a theme, the researcher's aim was to look for repeated patterns of data within the initial codes. This was achieved through manually writing each initial code from all the transcripts onto individual pieces of card. These were then all searched for repeated phrases and meanings. Whilst this process may seem archaic when compared to more complex computer data analysis packages, it allowed the researcher to immerse herself even deeper into the data whilst also

reflecting on her decisions and their underlying assumptions to group the codes the way she had.

The cue cards outlining the initial codes were constantly compared with each other and tentatively grouped together until solid categories began to form which could account for larger segments of data (Charmaz, 2011). This stage of the analysis was more subjective in nature than ascribing initial codes and therefore the researcher wrote about her decisions for grouping in a reflective journal.

#### 2.10.4 Theoretical coding

The different levels of coding are depicted in table 2, 3 and 4. The final stage of the analysis involved looking through the focused codes and begin to understand the relationship between them all. A careful selection of focused codes were then elevated to analytic categories and sub categories. Similar to the previous stages of coding, the theoretical codes also emerged through the data rather than overlaying pre-existing labels upon the data. The purpose of the theoretical codes was to ‘tell a story’ of the data as opposed to produce a grand theory designed to predict or explain all experiences within this community.

Table 2. Wives' responses theoretical Codes

Theoretical codes	Focused codes	Examples of initial codes
ਰਸੀਦ ਕਰਨਾ	ਉਹ ਇੱਕੋ ਜਿਹਾ ਲੱਗਦਾ ਹੈ, ਪਰ ਫਿਰ ਵੀ ਵੱਖਰਾ ਹੈ	<ul style="list-style-type: none"> <li>ਉਸ ਦਾ ਸਾਰਾ ਕੁਝ ਬਦਲ ਰਿਹਾ ਹੈ (Acknowledging full extent of changes)</li> </ul>
	He seems the same, yet different	<ul style="list-style-type: none"> <li>ਕੋਈ ਚੀਜ਼ ਪਹਿਲਾਂ ਵਾਂਗ ਹੀ ਹੈ (Something isn't quite the same as before)</li> </ul>
Acknowledging	ਮੈਨੂੰ ਵੀ ਵੱਖਰਾ ਲੱਗਦਾ ਹੈ  I feel different too	<ul style="list-style-type: none"> <li>ਮੈਂ ਇਸ ਬਾਰੇ ਪਹਿਲਾਂ ਸੋਚਣਾ ਨਹੀਂ ਚਾਹੁੰਦਾ ਸੀ (I didn't want to think about it before)</li> <li>ਸਾਡਾ ਰਿਸ਼ਤਾ ਡੂੰਘਾ ਹੋ ਗਿਆ ਹੈ (relationship deepening)</li> </ul>
ਸਮਝਨਾ	ਸਿੱਖੀ ਮੇਰੇ ਲਈ ਇਸ ਨੂੰ ਸਪਸ਼ਟ ਬਣਾ ਦਿੰਦਾ ਹੈ  Sikhism makes it clearer for me	<ul style="list-style-type: none"> <li>ਇਹ ਤਬਦੀਲੀਆਂ ਤੁਹਾਨੂੰ ਵਾਹਿਗੁਰੂ ਦੇ ਨੇੜੇ ਬਣਾਉਂਦੀਆਂ ਹਨ (Getting closer to God)</li> <li>ਵਾਹਿਗੁਰੂ ਦਾ ਹੁਕਮ (Gods will)</li> </ul>
Understanding	ਸਾਡੀ ਜੀਵਨ ਕਹਾਣੀ  Our life story	ਜਦੋਂ ਤੁਸੀਂ ਸਾਡੀ ਜ਼ਿੰਦਗੀ ਬਾਰੇ ਸੋਚੋ ਤਾਂ ਬਦਲਾਅ ਆਉਣੇ ਹਨ (Changes make sense in context of our life story)

	<p>ਜੜ੍ਹਾਂ ਦੀ ਤਰਸ</p> <p><i>Yearning to return to our roots</i></p>	<ul style="list-style-type: none"> <li>ਪੰਜਾਬ ਵਿਚ ਜੀਵਨ ਅਤੇ ਯੂਕੇ ਵਿਚ ਜ਼ਿੰਦਗੀ ਦੇ ਵਿਚ ਬਹੁਤ ਵੱਡਾ ਫ਼ਰਕ ਹੈ (<i>So much difference between our life in the UK and India</i>)</li> <li>ਸਾਡੀ ਰੂਹ ਪੰਜਾਬ ਵਿਚ ਰਹਿੰਦੀ ਹੈ (<i>Our soul is in India</i>)</li> </ul>
	<p>ਪਰਮੇਸ਼ੁਰ ਸਾਡੀ ਸਹਾਇਤਾ ਕਰਦਾ ਹੈ</p> <p><i>God helps us live</i></p>	<ul style="list-style-type: none"> <li>ਪਾਠ ਕਰਨਾ ਆਪਣੇ ਜੀਵਨ ਨੂੰ ਸੌਖਾ ਬਣਾਉਂਦਾ ਹੈ (<i>Praying and enacting religious values helps couples live through changes</i>).</li> </ul>
ਜੀਨਾ Living	<p>ਸਾਡਾਪਨ</p> <p>Staying us</p>	<ul style="list-style-type: none"> <li>ਇਕ ਦੂਜੇ ਦੀ ਦੇਖ-ਭਾਲ ਸਾਡਾ ਰਿਸ਼ਤਾ ਡੂੰਘੇ ਬਣਾ ਦਿੰਦਾ ਹੈ (<i>looking after one another makes our relationship deeper</i>)</li> </ul>
	<p>ਕੀਮਤੀ ਵਾਸਤੇ</p> <p>Valued connections</p>	<ul style="list-style-type: none"> <li>ਸਾਡੇ ਨੇੜੇ ਅਤੇ ਪਿਆਰੇ, ਹਰ ਚੀਜ਼ ਨਾਲ ਸਾਡੀ ਮਦਦ ਕਰਦੇ ਹਨ (<i>People that we trust and value help us in different ways every day, practical and spiritual support</i>)</li> </ul>

Table 3. Systemic responses theoretical Codes

Theoretical Code	Focus Codes	Properties of the codes
ਸਾਰਿਆਂ ਦਾ ਪਾਰਵਾਓ Systemic response	ਮਨ ਦੇ ਬਾਹਰ Ignoring	<ul style="list-style-type: none"> <li>ਬਾਕੀ ਇਨਾ ਦੇ ਹਰਕਤਾਂ ਚੈਖਦੈ ਹਨ ਉਨਾ ਡੀ ਜਜ਼ਬਾਤ ਨੇਹੀ. (Others ignore husband's emotional changes and focus on outwardly behaviour)</li> </ul>
		<ul style="list-style-type: none"> <li>ਬਾਕੀ ਹਰ ਕੋਈ ਇਨਾ ਦਿ ਹਡ ਬਿਤੀ ਨੇਹੀ ਸਮਝ ਦੇ (Others ignore personal experience of husband)</li> </ul>
		<ul style="list-style-type: none"> <li>ਜੋ ਰੀਹ ਗੀਯਾ ਉਹ ਨੇਹੀ ਵੇਖਦੇਹ (Others ignore husbands' retained abilities and focus on lost capabilities)</li> </ul>
ਸਾਰਿਆਂ ਦਾ ਪਾਰਵਾਓ Systemic response	ਗਲਤਫ਼ਹਿਮੀ Misunderstanding	<ul style="list-style-type: none"> <li>ਬਿਮਾਰੀ ਬਾਰੇ ਸੋਚਣੀ (Disease narrative)</li> </ul>
		<ul style="list-style-type: none"> <li>ਗੋਰੈ ਦੀ ਸੋਚਣੀ (Re-colonization through western ideals)</li> </ul>
		<ul style="list-style-type: none"> <li>ਸਾਡੀ ਜ਼ਿੰਦਗੀ ਦੀ ਕਹਾਣੀ ਬਾਰੇ ਕੋਈ ਨਹੀਂ ਸੋਚਦਾ (Lack of life story appreciation)</li> </ul>
		<ul style="list-style-type: none"> <li>ਹਰ ਕੋਈ ਡਾਕਟਰ ਹੈ (Quick to 'problem solve')</li> </ul>

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ਸਾਰਿਆਂ ਦਾ ਪਾਰਵਾਓ ਰੋਕਣਾ  
Denying  
Systemic response

- ਕੋਈ ਵੀ ਸਾਡੇ ਬਾਰੇ ਨਹੀਂ ਸੋਚਦਾ  
(Ignoring the person)
  - ਉਨ੍ਹਾਂ ਨੇ ਸਾਡੇ ਤੋਂ ਦੂਰ ਹੋਣਾ ਸ਼ੁਰੂ ਕਰ ਦਿੱਤਾ ਹੈ  
(Distancing self from the person through defences (physical and emotional distance))
  - ਉਨ੍ਹਾਂ ਨੇ ਸਾਨੂੰ ਬੁੱਢੇ ਅਤੇ ਪਾਗਲ ਹੋਣ ਦਾ ਲੇਬਲ ਲਗਾ ਦਿੱਤਾ  
(Labelling – ‘demented’, ‘senile’, ‘old fool’)
  - ਉਹ ਬੁੱਢੇ ਹੋ ਜਾਣ ਤੋਂ ਡਰਦੇ ਹਨ ਤੇ ਪਰ ਉਲਟਾ ਇਸ ਨੂੰ ਸਾਡੇ ਉੱਤੇ ਲਾ ਦਿੰਨ ਦੇ ਹਨ  
(Projecting own fears and insecurities about death and endings on to person with label of dementia)
-

Table 4. Resistive responses theoretical Codes

Theoretical Code	Focused Codes	Properties of the codes
Resistive responses	ਮੋਢੇ ਨਾਲ ਮੋਢੇ Standing shoulder to shoulder	<ul style="list-style-type: none"> <li>ਜਿਨ੍ਹਾਂ ਨੇ ਇਨ੍ਹਾਂ ਮੁਸ਼ਕਲ ਸਮਿਆਂ ਨੂੰ ਦੇਖਿਆ ਹੈ, ਅਸੀਂ ਇਕੱਠੇ ਖੜ੍ਹੇ ਹਾਂ (Solidarity with others in a similar position).</li> <li>ਸਾਂਝੀ ਪਛਾਣ (Collective identity fostered)</li> </ul>
	ਜਿੱਦਾਂ ਹੁੱਡਾ ਮੈਂ ਤਾਂ ਬੋਲ ਦਿਨਦੀ ਹਾ (Not being afraid to call a spade a spade)	<ul style="list-style-type: none"> <li>ਸਿੱਖੀ ਦਾ ਅਪਮਾਨ ਕਰਨਾ ਅਤੇ ਬਜ਼ੁਰਗ ਦੀ ਬੇਇੱਜ਼ਤੀ ਹਰ ਜਗ੍ਹਾ ਹੈ ਇਸ ਗੋਰਾ ਚੀਜ਼ “ਡਿਮੇਨਸ਼ੀਆ” ਵਿਚ ਵੀ (Calling out inherent racism, ageism and colonialism within labels such as dementia)</li> <li>ਤੁਸੀਂ ਡਿਮੇਨਸ਼ੀਆ, ਡਿਮੇਨਸ਼ੀਆ ਕਾਇ ਜੰਡਹਿ, ਪਰ ਇਹ ਸਾਡੀ ਗਲਤੀ ਨਹੀਂ ਹੈ, ਜਦੋਂ ਅਸੀਂ ਬੁੱਢੇ ਹੋ ਜਾਂਦੇ ਹਾਂ ਤਾਂ ਇਹ ਵਾਪਰਦਾ ਹੈ (Shedding oneself and husband of blame associated with labels).</li> <li>ਮੈਂ ਇਹ ਗੋਰ੍ਹ ਅਤੇ ਉਨ੍ਹਾਂ ਦੇ ਲੇਬਲ ਡਿਮੇਨਸ਼ੀਆ 'ਤੇ ਵਿਸ਼ਵਾਸ ਨਹੀਂ ਕਰਦੀ, ਮੈਨੂੰ ਪਤਾ ਹੈ ਕਿ ਉਮਰ ਦੇ ਨਾਲ ਇਹ ਗੱਲਾਂ ਹੁੰਦੀਆਂ ਹਨ. (Challenging western discourses and retaining alignment with cultural values)</li> </ul>



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<b>Resistive responses</b>	<p>ਅੱਗੇ ਦੇਖਣ ਲਈ ਤੁਹਾਨੂੰ ਪਿੱਛੇ ਦੇਖਣ ਪੈਂਡਾ (Turning to the past to help with the future)</p>	<ul style="list-style-type: none"> <li>▪ ਸਾਨੂੰ ਬਹੁਤ ਸਾਰੀਆਂ ਮੁਸ਼ਕਲਾਂ ਦਾ ਸਾਹਮਣਾ ਕਰਨਾ ਪਿਆ ਹੈ, ਅਸੀਂ ਭਾਰਤ ਦੇ 1947 ਦੇ ਵਿਭਾਜਨ ਨੂੰ ਵੇਖਿਆ ਹੈ ਕਿ ਅਸੀਂ ਪਰਿਵਾਰ ਨੂੰ ਵੱਖੋ-ਵੱਖਰੇ ਦੇਸ਼ਾਂ ਵਿਚ ਪੁੱਤਰ ਭੈਜੇ ਹਨ, ਅਸੀਂ ਬਹੁਤ ਸਾਰਾ ਵੇਖਿਆ ਹੈ ਅਤੇ ਅਜੇ ਵੀ ਜਿਉਂਦੇ ਹਾਂ, ਅਤੇ ਸਾਨੂੰ ਬਹੁਤ ਕੁਝ ਵੇਖਣਾ ਸਾਡੇ ਅਤੀਤ ਤੋਂ ਸਾਨੂੰ ਤਾਕਤ ਮਿਲਦੀ ਹੈ</li> <li>▪ (Recognising own personal strength in dealing with past difficulties and channelling this to deal with current difficulties.)</li> <li>▪ ਤੁਸੀਂ ਸਾਡੇ ਗੁਰੂਆਂ ਦੀਆਂ ਕਹਾਣੀਆਂ ਅਤੇ ਉਹਨਾਂ ਦੀਆਂ ਮੁਸ਼ਕਲਾਂ ਦਾ ਜਾਣਦੇ ਹੋ, ਇਹ ਕੁਝ ਵੀ ਨਹੀਂ ਹੈ. ਅਸੀਂ ਹੁਕਮ ਵਿਚ ਰਹਿੰਦੇ ਹਾਂ, ਜਿਵੇਂ ਕਿ ਪੰਜਵੇਂ ਗੁਰੂ ਨੇ ਕਿਹਾ ਹੈ... ਤੇਰਾ ਕੀਆ ਮੀਠਾ ਲਾਗੈ ਹਰਿ ਨਾਮੁ ਪਦਾਰਥੁ ਨਾਨਕੁ ਮਾਂਗੈ</li> <li>▪ (Recognising cultural and spiritual history to help with current difficulties)</li> </ul>
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### 2.10.5 Translation

Once codes had begun to become more conceptual in nature it is at this point that they were then translated in to English. Difficulties arose during this stage when exact translations in to English could sometimes not be made and therefore the researcher felt some categories were distant from the voice of the participant.

### 2.10.6 Memo writing and constant comparative analysis

Guided constant comparisons of the data directed the theoretical sampling of the participants. Furthermore, the constant comparison allowed for changes to the interview schedule to be made in light of emergent theories. Memo-writing was an important step throughout the data collection and analysis stage as it allowed for the researcher to actively be involved in the early generation of categories and thus inform higher levels of abstraction (see Appendix K).

### 2.11 Key points covered in the chapter

- Social constructionist Grounded Theory was deemed to be the most suited methodology to explore the research questions. It allows for the researcher to examine the mechanisms of attribution and conceptualisation whilst also ensuring that the researcher's own assumptions are clearly explicated.
- Participant recruitment and the fostering of good relationships was thought to have been aided by the researcher identifying herself as someone from within the same community.
- Concerted efforts were made to ensure data collection and analysis were carried out in Punjabi in order to stay as close as possible to participant experiences.
- Memo writing enabled the researcher to make transparent her own assumptions throughout the research process.

### 3 Results

This chapter outlines the key findings which emerged from the research conducted. The begins with a graphical representation of the emergent model which then is expanded upon with a detailed overview of each theme. Participant quotes are included in each theme to further illuminate the participants' experiences.

#### 3.1 Findings

The emergent model is divided in to three distinct yet, inter-related processes, the wives' responses, systemic responses and resistive responses. Incorporated within each process are several theoretical codes as well as focussed sub-codes (see Table 2, Table 3, Table 4 and Figure 1).

During data analysis, the researcher wished to ensure that proximity was continually maintained with the data. With that in mind, it was important to use verbatim participant quotes to label the focused codes (e.g. he seems different and yet, the same).

Furthermore, the theoretical codes were also labelled using gerund based phrases, words which end in -ing. Using labels such as acknowledge-ing, understand-ing, liv-ing, deny-ing, misunderstand-ing and ignor-ing, helped to further highlight the active and dynamic nature of the processes for the participants. During the interviews participants were keen to highlight how their experiences were continually changing and being shaped by systemic, cultural and religious encounters and it was hoped that the labels capture such fluidity.

### *3.1.1 The wives' responses*

This process relates to the ways in which the wives related to their husbands as well as well to themselves. It is comprised of three processes, acknowledging changes, understanding changes and living with changes. Inherent within each process is a further description of the themes which further illuminate that process. Whilst the diagram in Figure.1 graphically depicts the processes to be linear, the participants in fact explained they fluctuated continuously between all three processes.

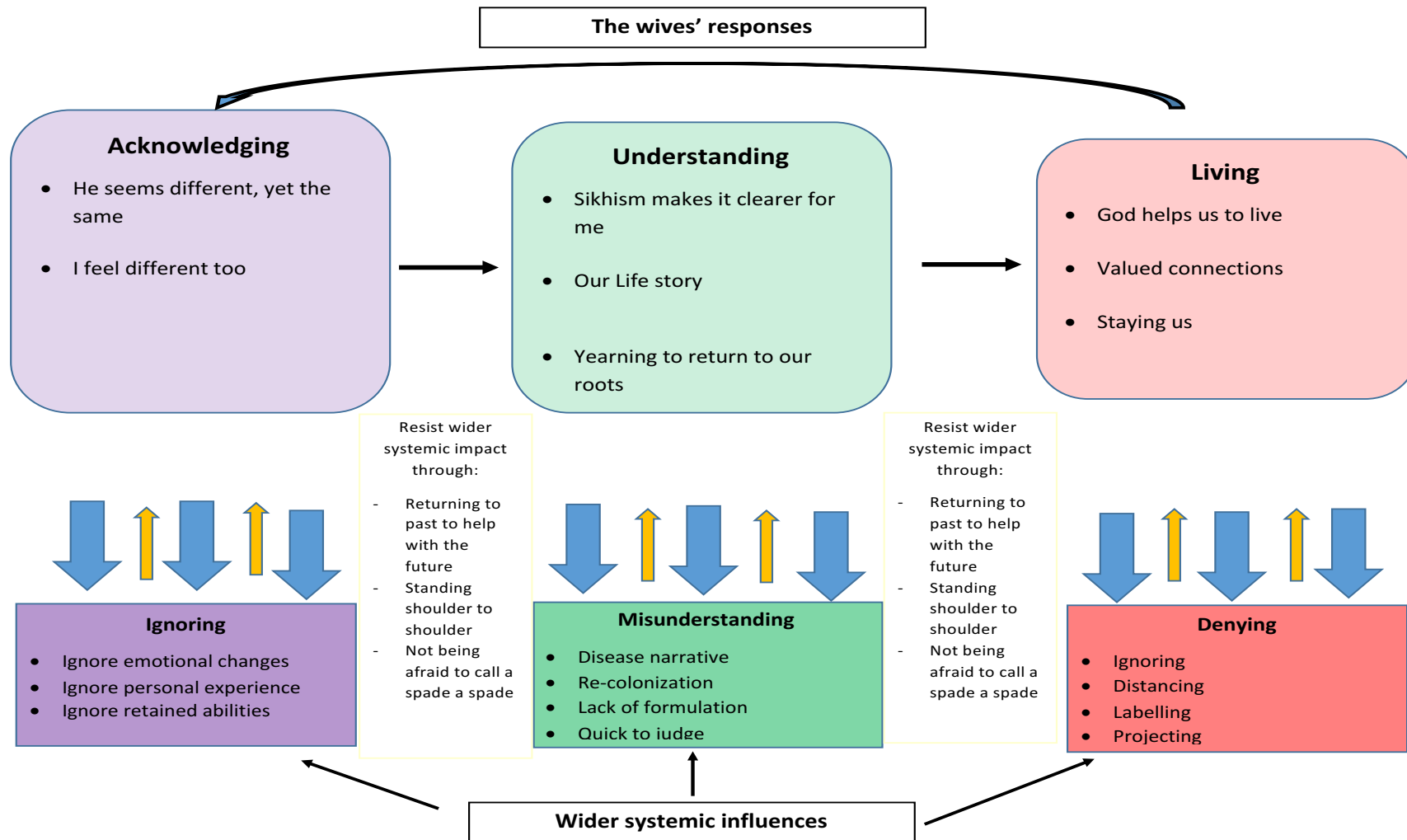
### *3.1.2 Systemic responses*

This process outlines the way participants experienced wider systemic factors to counteract their own response. Figure 1, depicts this “push and pull” dynamic through the use of arrows between the wives’ and systemic responses. The figure does not fully capture the impact of such systemic responses as the weightings attributed to each systemic response differed between participants.

### *3.1.3 Resistive responses*

The final process captures the way in which the wives attempted to resist the systemic responses imposed on them and their husbands.

Figure 2. Theoretical model of Punjabi Sikh wives' experiences of living with a husband with a label of dementia



### 3.2 The wives' response: acknowledging

This theme refers to the multiple ways in which the participants acknowledged the changes within their husbands. This category is divided into two categories. The first category captures the type of changes the participants first noticed in their husbands. The second category captures the more intrapsychic element of the wives' experiences, and highlights the changes the participants began to acknowledge within themselves.

#### 3.2.1 *He is different and yet, the same*

Interviews began with each participant reflecting upon the various changes they had first noticed within their husbands. The participants did not solely focus on one specific element. Instead, they acknowledged changes in their husbands' physical health, emotional wellbeing, spirituality, social life and investment in the marital relationship.

One of the first areas that all the participants reflected upon was a change within the marital relationship. Each were also keen to highlight that, whilst these changes were subtle, they were only noticeable to them.

*"I can't really explain it...it was very small things at first, small things that no one else would even realise...I noticed them straight away though. When you live with someone for 40 years you know them better than yourself. He became, ummm, less interested, he didn't look at me the same way, I knew something was different then"* (Charan Kaur).

Yet, participants were keen not to solely focus their reflections upon the changes they experienced. Each was also forthcoming in presenting narratives of retained abilities. For every domain that they noted a change, they equally provided an example of a retained ability.

*“He can’t really go shopping on his own anymore, he gets a little bit confused about the route.....but when it comes to paying for things he’s still there trying to haggle with the shopkeeper! Typical Indian man! (laughs). (Surinder Kaur).*

Focusing on the retained abilities was a key element of the narratives the participants presented. When asked about the importance of this, the women provided many explanations. For some women, the focus on retained abilities served to remind them that their “husband was still there underneath all the confusion and sadness” (Jaspal Kaur) and that they were “not alone in their journey in to old age.” Some participants explained that retained abilities signified a resilience within their husbands which they found admirable, and which in turn tapped in to their own resilience and enabled them to understand and live with the changes.

*“I know he’s struggling, I could tell from day one, I noticed it straight away.....everyday he tries harder to deal with it all, how can I give up then, I bounce off his strength and perseverance” (Jaspal Kaur).*

Participants also explained that the impact of the changes they noticed varied in severity, depending on the context. Participants recounted a similar pattern whereby

the intensity of the changes were more prominent in unfamiliar environments. They attributed this to the sense of comfort the husbands experienced in their presence.

*“My son told me that his dad started crying the other day when he took him shopping. I know he wouldn’t cry if we went together, he feels comfortable with me” (Balwant Kaur).*

*“If we go somewhere where we used to go a lot he’ll be fine, but I know he gets upset and confused in new places now. I try to make sure I go with him to unfamiliar places” (Satwant Kaur).*

The participants focused heavily on such changes in the emotional wellbeing of their husbands. In contrast, changes in memory were largely absent in the participants’ accounts. Indeed, memory changes were dismissed as being unnoteworthy, whereas emotional changes were deemed to be concerning.

*“We’re all going to forget things aren’t we, but I wasn’t prepared for the sadness and sinking heart. He cries a lot now...he never once shed a tear before, never.” (Kashmiro Kaur).*

*“I look at him sometimes and think where has his happiness gone? Why is his soul so sad? He’s still the same man, just with a sinking heart” (Jaspal Kaur).*



### 3.2.2 *I feel different too*

The participants did not solely focus changes within their husbands. Each was also open to exploring and discussing the changes they had experienced in themselves, in relation to their husbands. The participants all described a similar emotional process which began with a deep-rooted sense of denial toward the changes. Participants recounted noticing subtle changes, but then immediately dismissing them or attributing them to their own old age:

*“One day I noticed that he couldn’t remember the names of his friends, I ignored it. A week later, he couldn’t remember the name of our grandchildren, again I ignored it. I didn’t want to think about him forgetting, I thought it’s just me being an old fool”.* (Balwant Kaur).

The participants explained that the denial stemmed from a position of *“Petrifying and paralysing fear”* (Kashmiro). The women explained that they felt extremely scared at the potential that their husbands may eventually fail to remember them. Whilst some participants did not elaborate on the feelings of fear, others developed this narrative and explained that the sense of fear was coupled with feelings of selfishness. They clarified this link through giving examples:

*“I thought oh God! One day he will forget my name and who I am, then who will I have left in this world? My parents are dead, my friends are all dying, my children don’t really care, he is all that I have, I can’t lose him too”* (Joginder Kaur).

The feelings of selfishness were therefore rooted in a fear of being left alone. The women all recounted a deep sense of connection with their husbands and a strong sense of dependence upon them. Whilst they spoke about the equality of their relationship, they highlighted the difference in their gendered roles and linked this with a fear of losing their husbands:

*“We have always been equal in our relationship.....But, we do have different roles in our marriage. I’ve always looked after things at home whilst he was always in control of financial matters and official things. I started thinking what will happen if he forgets to do those things....I don’t have any idea how to go and get a pension, I don’t even know where the bank is, I can’t even speak a word of English!” (Satwant Kaur).*

The participants also frequently reflected on the process of being interviewed. For many, it was the first time they had spoken about their own feelings with anyone. The process of sharing feelings about their husbands evoked further difficult emotions within most of the women.

*“I feel so bad for saying these things, I can’t believe I was so selfish only thinking about my own needs. I’ve never said all this out aloud before” (Charan Kaur).*

The need to keep their personal feelings a secret highlighted the dilemma most of the participants faced on a daily basis. Specifically, the need to balance their own needs with that of their husbands, families, and wider communities had provided little

scope, or opportunity, to express and reflect upon their own feelings. Whilst an exploration of the processes which restricted the women from reflecting on their personal feelings is beyond the scope of this research, many of the women did note that sharing personal feelings was something that they had not been acclimatised to before. Many described it as an alien experience, absent within their cultural upbringing.

The wives further described that, as the changes became more prominent, they moved from a position of denial to experiencing feelings of frustration and anger. The participants were not as forthcoming in sharing examples of their anger and frustration, and instead wished to move to the next stage in their emotional process. However, one wife commented on how her sense of frustration developed:

*“I thought he was making it up you know, like he wanted attention or something. I would get so angry with him just sleeping on the sofa all day..I told him to stop asking me the same thing ten times! I feel so ashamed I treated him like that” (Baksho Kaur).*

Baksho Kaur further elaborated that her anger and frustration stemmed from a position of uncertainty. She described how the changes had slowly “crept” up on the family and she felt “lost” as how best to make sense of what was happening.

Moving forward, the wives explained that their anger and frustration quickly subsided, giving way to increased connectedness. This process was again driven by a

sense of anticipatory grief of losing their husbands. This resulted in the women feeling an increased desire to spend more time with their husband and becoming even more attuned toward their needs:

*“I felt like one day he will forget everything and join his soul with Waheguru.....it became really important for me to spend as much time with him as possible before that happened” (Surinder Kaur).*

The increased connectedness between the wives and their husbands evoked feelings of specialness and purposefulness within some of the participants. They explained that with old age they had gradually began to lose their sense of worth and felt they were no longer needed by their children or by society. Noticing the changes, and increasing dependency from their husbands, made the women feel that they had a purpose in life again, with their underutilised caring capacity and role gradually re-emerging.

*“The more changes I noticed the more we became connected. Odd isn’t it. I can’t explain it.....I knew I was the only one who really understood him, it felt nice to be needed so much again” . (Joginder Kaur).*

### 3.3 Systemic response to acknowledging

The systemic response which the participants experienced to counteract their process of acknowledging was ‘ignoring’. This category portrays the ways in which the

participants experienced the system around them to be ignorant or dismissive of the changes in their husbands.

### *3.3.1 Ignoring*

This category outlines some of the initial ways in which ‘others’ noted and/or ignored certain changes in their husbands. The participants were unanimous in terming wider systemic influences, such as their children, extended family and wider community as ‘the others’ or ‘them’. The reflections shared in this category are very much positioned as ‘us versus them’. The participants continually reflected on how their personal experiences differed to the more dominant reactions they encountered in ‘others’.

One of the key reflections shared amongst the wives was that whilst they were able to, and wanted to, remain attuned to the retained abilities of their husbands, there was a pattern of ‘others’ being quick to dismiss or ignore such retained abilities.

*“You know...I knew from the very start that he was still the same man, the way he looked at me and the way he still done his morning prayers, but my children kept telling me I was being stupid..... They spoke like he was gone for good or something” (Satwant Kaur).*

The response to such reactions to their husbands varied amongst the wives. Whilst some focused on their emotional response to this experience, others offered hypotheses to better understand the dismissing pattern of others.

The majority of the emotional responses were aligned to feelings of frustration and anger. However, upon further exploration, housed within the anger was a deep sense of sadness.

*“Tell me young child, why do his own flesh and blood act like this? It angers me so much. I want to shake my son and say to him ‘look your dad is changing, please help me’, but all he does is ignore us both” (Kashmiro Kaur).*

Three wives also noted that whilst they initially felt angry that ‘others’ were not aware of the subtle changes in their husband, they paradoxically also felt relieved. The sense of relief came from feeling they ‘had more time’ with their husbands before ‘the others’ started offering their own explanations and solutions to help. The experience of being the only person to acknowledge the subtle changes in their husband increased the sense of connection these wives felt with their husbands.

*“I know I said I was angry, but...(whispers) I am also a little bit happy they don’t notice how he is changing. You know why I’m happy (laughs) because it means it’s just me and him at the moment, no one to tell us what to do, it’s just us (smiles).” (Kashmiro Kaur)*

A lack of care was central amongst the hypotheses formulated by the wives to explain the dismissal/ignoring pattern. This explanation was predominately directed at their own children, but some wives also extended it to incorporate the wider family and

community. The shared consensus in all accounts was that the lack of care stemmed from individuals' being too immersed in their own lives to care about their husbands.

*“I know people are so busy these days.... but that shouldn't stop you caring for those around you should it? Care is missing in the modern day souls”*  
(Baksho Kaur).

The participants were keen to highlight the differences in their acknowledging experiences, with the ignoring/dismissing practices of 'others'. A key difference the wives noted was the propensity of 'others' to solely focus on negative behavioural changes, and yet completely dismiss or ignore the more subtle emotional changes in their husbands. They framed this process as an intentional and conscious choice 'the others' made:

*“They think I don't know what they're doing, silly old woman they think! I know they deliberately talk only about the bad things he does, like wet himself or get the wrong bus. They never once mention his silent tears or the sadness in his soul. I'll tell you young child why they do this.....the behaviour they can blame on him or on anyone else but the sadness in his soul.....they know they have a part to play in that.”* (Kashmiro Kaur).

Similarly, other accounts shared by the participants mirrored the above emotional denial process. The participants believed the denial of feelings was a conscious attempt by 'others' to protect themselves from the potential reality that they were somehow implicated in the changes in a person with a label of dementia.

Whilst the wives initially spoke of ‘the others’ ignoring the retained abilities of their husbands, they also began extending it to how ‘the others’ also ignored/dismissed their own personal visceral responses. All the wives noted that ‘others’ showed a lack of interest in wanting to indulge in self-reflection. They contrasted this to their own experiences, of how over time they had begun to reflect upon their personal responses to their husbands, and how this had been central to developing a better understanding and empathy toward the changes. Again, the lack of self-reflection observed in ‘others’ was coupled with a sense of frustration and anger.

*“Why don’t they just stop and think for two minutes? It angers me. Ask themselves, how do I feel when Daddy Ji doesn’t get out of bed in the mornings, how do I feel when Daddy Ji becomes scared of the dark? If they just spent two minutes thinking about how they felt they might show the same consideration for their dad, don’t you think? (Kashmiro Kaur).*

#### 3.4 The wives’ response: understanding

After acknowledging the changes within their husbands, the participants increasingly began to provide frameworks for how they attributed meaning to these changes. Their frameworks for understanding the changes ranged from focusing on the individual, to thinking about how wider societal discourses may also account for the changes.



### 3.4.1 *Sikhism makes it clearer for me*

Spiritual explanations were frequently cited by participants to help attribute meaning to the changes in their husbands. Changes in memory were explained in the context of the husbands forging a higher and deeper connection with Waheguru. The participants sung hymns from the holy Sikh scriptures to enrich their explanations.

*"Having been smeared with the dirt of pride, the world suffers in pain. With faith in his name all egotism is destroyed" (SGGS 1231) (Charanjit Kaur).*

The theme of egotism and attachment to material things was central to the participants' spiritual explanations. They explained that as with most individuals, their husbands too had become consumed by wanting to accumulate material wealth throughout their life (to the detriment of their relationship with Waheguru). The recent changes in their memory and wellbeing highlighted the irrelevance of such things.

*"He was always trying to work out how to make more money, how to get the best business deal. I guess none of that matters to him anymore, he knows that we came to this earth empty handed and one day we will return empty handed. Instead, we need to work on our relationship with Waheguru, that's why he doesn't concern himself with irrelevant conversations anymore" (Kamaljit Kaur).*

Relatedly, participants hypothesised whether the recent changes in their husbands were in fact a spiritual message from Waheguru. Yet they overtly rejected the notion

that the negative changes, such as disorientation and low mood, were a form of punishment. Rather, they framed the changes as a reminder from Waheguru to re-evaluate one's life.

*“we both became quite greedy....we needed a sign from Waheguru to put us back on the right path” (Balwant Kaur).*

Participants strongly believed that the confusion, memory loss and disorientation was a way of Waheguru preparing individuals for the inevitability of death. They reflected on what meaning 'death' had for them, and explained that they did not think of it as 'a true end', but rather, as a way of merging with Waheguru.

*“We come to this world as a little baby, unaware of the atrocities happening around us. Waheguru protects us....similarly when our time comes to leave this earth and merge with him once more he protects us...he takes away our awareness of the meaningless and trivialness of this world and prepares us for more spiritual pastures” (Udham Kaur).*

#### 3.4.2 *Our life story*

Thinking about the unique life story of their husbands was an important backdrop for the participants to better understand the changes they experienced. Participants explained that this was the initial way they started making sense of the changes. They preferred to think about the individual life events of their husbands, as opposed to generic and universal biological explanations of change. The participants believed

that reviewing their husbands' lives and *'looking for clues'* was the most accurate way of understanding their particular changes.

*"How can you just say the chemicals in his brain aren't working? That doesn't tell you why he screams every evening, only I can tell you that....he has always hated the dark, it reminds him of when he was imprisoned by Pakistani forces when he fought in the Indian Army...the doctors can't tell you that". (Jaspal Kaur).*

*"You need to think about what has this man been through, what's his story....otherwise, you'll just misunderstand everything he does" (Satwant Kaur).*

*"He used to be a bricklayer, real hard manual labour you know. This work took its toll on my husband, since then it became harder for him to go out and meet friends or go to the temple. You tell me if you spend all your time at home, will you not become a little bit sad? It makes sense he is the way he is". (Surinder Kaur).*

The participants explained that when they first experienced the changes it evoked a multitude of emotions within them, namely uncertainty and anxiety. Furthermore, due to language barriers they felt unable to research the changes or seek advice from professionals. This in turn triggered the participants to reflect on what it was they

already knew about their husbands and use this valuable knowledge to make sense of what they were experiencing.

*“I’ll be honest, I didn’t know what was happening. He became so disorientated and confused. I didn’t know who to ask, so I just trusted my gut instinct! We have shared a whole lifetime of stories, they told me everything I needed to know.” (Balwant Kaur).*

The participants reflected that through drawing on the personal histories of their husbands, they felt empowered to resist the dominant explanations surrounding memory loss and ageing.

*“The more they tell me it’s all in his head, the more I tell them stories about him.” (Kashmiro Kaur).*

The women also reflected that their unique position as ‘the wife’ meant that they felt it was their duty to ensure everyone around them knew their husbands’ stories. The participants recounted the various different ways they shared this with other people, in order to help them better understand the changes.

*“His sister rung from India and started getting angry that he wouldn’t talk to her....! He’s obviously forgotten her because she never contacts him. I wrote her a long letter. I wrote about how he always relished being head of the family, but the fact his family no longer made an effort to talk to him meant he became quite isolated and sad....it really helped to write his story” (Charanjit Kaur).*

*“When no one listens, I sing...I sing old farming songs, to remind them about their father’s farming background. He’s a hard worker, he just doesn’t have any jobs to do anymore, that’s why he sleeps all day” (Baksho Kaur).*

*“When I read a bedtime story to the grandchildren, I deliberately make sure that I weave in parts of their grandad’s story. I really want the children to respect their granddad, and not just think he’s a grumpy old forgetful man” (Joginder Kaur).*

### 3.4.3 *Yearning to return to our roots*

This category refers to the way in which participants believed the confusion and disorientation their husbands experienced stemmed from them missing their Indian heritage and roots. Participants explained how factors such as financial concerns and deteriorating physical health had prevented them from visiting their ‘motherland’. Participants evocatively narrated stories of their time spent in India, and explained how their husbands’ disorientation and confusion had arisen when they stopped visiting India.

*“We used to go every winter to our Punjab, the winter sun in India is so special, cures all manner of ills. He would love spending time there, he’d sit for hours with his friends, playing cards and drinking tea.....we don’t do this anymore....his heart...our heart...aches to go back.” (Jaspal Kaur).*

Many participants also reframed the behaviours that they observed in their husbands as not being indicative of a physical or mental illness, but rather, as a conscious strategy to feel a sense of home. Specifically, participants formulated the behaviour they witnessed as a form of re-enacting life back in India.

*“Other people think he is losing his mind when he asks about his friends who have long since died....he just misses them and doesn’t know how to think about them without believing they are still alive.....some stupid people tell him his friends are dead, he doesn’t understand and gets angry” (Kashmiro Kaur).*

*“He wakes up every morning and puts on his Indian clothes. He thinks he is going to the farm....when you miss something so much you have no choice but to bring it to you. Then when he realises we’re in England he gets so confused.....I comfort him” (Baksho Kaur).*

The participants expressed a mutual fear of losing their own connection with their Indian rituals and customs. However, whilst they had opportunities to share stories with their friends, and watch Indian TV soap dramas, their husbands had no outlet to reminisce about India and resist the dominance of western influences in their family. Therefore, talking repeatedly about their earlier memories, and mistaking people for old friends, was an important way of staying in touch with their culture.

*“I miss home a lot but I can watch these Indian dramas on the TV and still stay in touch with the latest fashion trends (laughs). But for him it’s harder.*

*He can't pick up the phone and call his friends for hours, can he? His anger comes from feeling trapped in a culture which doesn't belong to him"* (Udham Kaur).

*"Our kids and grandchild chatter away in English. I don't mind because I understand little bits of it, but he doesn't understand a word. He feels so lost and disconnected from our Punjabi culture. That's why he walks around singing non-stop, or asks the same questions about his village. He's afraid of losing his culture"* (Satwant Kaur)

Narratives of old age were also interwoven in these explanations of cultural loss. The participants explained that old age brought with it an inevitable sense of anxiety, fear of death, grief for lost friends and loneliness. Thinking about happier memories in the comfortable setting of India was a way of tolerating these difficult feelings.

*"When he first started getting confused about where he was, I was scared and thought he had gone mad.....it clicked to me then that his best friend had passed away three days ago. This was his way of consoling himself, thinking about happier memories in his motherland"* (Basksho Kaur).

*"When a tree or plant starts to weather away, and all its pretty flowers and leaves fade, all it has left is its roots to rely upon. That's what he's doing, staying close to his roots"* (Joginder Kaur).

### 3.5 Systemic response to understanding

The systemic response which the participants experienced to counteract their process of understanding was ‘misunderstanding’. This theme portrays the ways participants experienced the system around them to wrongly attribute explanations of cognitive deterioration and physical brain damage to the changes in their husbands.

#### 3.5.1 *Misunderstanding*

This category describes the incorrect explanations the participants believed ‘the others’ had used to label their husbands. The participants highlighted the ways in which they believed these explanations were derogatory, inaccurate and, most importantly, had obscured the essence of their husbands.

Participants also believed the ‘others’ had subscribed to a discourse which propagated that the changes were due to mental or physical causes. The participants expressed that they first heard these explanations within the family context, from their children. They explained that whilst their children were typically slower to notice the changes in their husbands, once they did acknowledge them, they viewed the changes through a medical lens.

*“He didn’t even notice at first that his father was so upset and lonely. The only thing he ever did notice was when his dad started making a mess in the bathroom. He didn’t once try and talk to his father and ask what was*



*wrong...the first thing he said was I'm taking you to the doctors you crazy old man (starts crying)" (Joginder Kaur).*

A few participants referred to the term dementia, but did so in a mocking and rejecting manner. They explained that they heard this term from a medical practitioner and had little understanding of what it truly meant, but knew that it was an inaccurate explanation of their husbands' presentation.

*"This dee-men-ching thing, what is it? I told my son to stop using the stupid word for his dad. Since he heard the doctor say it, he won't stop using it, he even tells his poor dad, 'oh dad, you have dee-men-ching'" (Joginder Kaur).*

*"They dragged me along to this doctor's appointment where the woman asked my husband some stupid questions and said that he had something wrong with his brain. They said they couldn't give me any medicine for it and that it will get really bad. I was so angry that day....what does she know about his life history, she hasn't a clue what my beloved husband is going through. Obviously, there isn't any medication for loneliness and heartache (shouting) (Jaspal Kaur).*

During the interviews, the participants explained where their reticence toward medical based explanations had stemmed from. They all believed that medical explanations were reductionist and obscured the unique characteristics of their husbands. The participants shared the multitude of emotions such explanations had

evoked within them. For some participants, they felt a sense of anger and frustration, primarily toward the people posing the explanations, but also at themselves for not being able to assertively counteract the explanations. For others, they expressed their sadness at the way in which their husband had been reduced to a single inaccurate label, and how the unique essence of their husband was violated.

*“Whenever I hear dementia on the news, I feel like I want to hit the television!! I hate this word, it sounds like a disease, a really horrible disease” (Kashmiro Kaur).*

Another explanation the participants rejected was that the changes had been self-inflicted, and could have been prevented. These explanations were again predominately proposed by their children and/or medical professionals. These explanations were again accompanied with feelings of anger and upset.

*“The doctor said “Mr Singh, you should have looked after your health better, not eaten so much sugar and fried food, you wouldn’t be in this situation today!” How can this be??? He is missing his motherland, that has nothing whatsoever to do with his diet, how dare they blame him for all this” (Kamaljit Kaur).*

*“My granddaughter said to him the other day that he should exercise more because it will help his memory. No I thought...what will help his memory is meditating on God’s name and helping him visit India” (Balwant Kaur).*

Participants had definitive ideas about why the ‘others’ misunderstood their husbands. The key reason every participant cited was the dominance of western ideology and a re-colonizing process.

*‘We came to this country with hardly anything. We are really grateful for everything this country has given us but, ummmm, how shall I put this.....the West are very good at pushing their culture and their way of living in others’ faces aren’t they?! It mean they get to be the king of world as usual whilst the rest of us....ummm, paupers I guess.’ (Kashmiro Kaur).*

Participants openly recounted their own personal experiences of the colonisation of India. For many, the colonisation of India had a lasting impact on their sense of self and subsequent self-positioning in Western society. Participants were able to outline a clear link between their experiences of living under British rule and living as migrants.

*“We’ve always had to do what they tell us to do, it’s been this way for nearly five or six generations, I am tired of it. I need to hold on to our culture a little bit tighter....if I let go then they will rule us again wont they....that is why I am not going to just swallow their language with their big fancy labels. I’m going to resist it this once thank you very much” (Satwant Kaur).*

Participants voiced their concern that the ‘dementia label’ was simply another subversive attempt of the Western world to further subjugate other cultures. For some participants, the British colonial rule over India marked an oppressive movement which, however subtle and nuanced, was still prominent in their everyday lives.

*“The British Raj isn’t truly over is it. For me, my experience, our experience of this whole dementia thing is just a perfect example. Doctor says your husband has dementia, I tell him I disagree because we don’t have this thing in India in our village. He says I need help coming to terms with it, that I am denying it. One big whoosh (waves arms one side to another), he pushes my culture away and tells me to trust his culture. Ha ha (laughs), if we don’t resist they will rule us once again” (Surinder Kaur).*

Another source of misunderstanding the participants cited was the others’ propensity to term their husbands’ behaviours as ‘attention seeking’. The participants noted that whenever their children or medical professionals were unable to make sense of their husbands experiences, they resorted to labelling it ‘attention seeking’.

*“We went to see a specialist because my son said we needed help ‘sorting dad out’. The women told us that every time my husband shouts or makes a mess in the bathroom, it’s because he is attention seeking. The best thing to do, she told us, was to ignore him, like he is some sort of naughty child. I’m shaking with anger as I tell you about it” (Baksho Kaur).*

The participants expressed their anger at the way in which such explanations were derogatory to not only their husbands, but to them as a couple. The participants experienced the ‘attention seeking’ explanation as a personal attack on their role as a wife, and as a crude misrepresentation for all that they did for their husbands.

*“When my daughter in law tells me that my husband is just being an attention seeker, I get so angry. It’s like she is saying I am not giving him enough attention, that I am failing as a good wife. My whole life I have tried to be a good wife and when they say this I feel like it was all for nothing” (Jaspal Kaur).*

### 3.6 The wives’ responses: Living

The category of living refers to the various ways in which the participants adapted to the changes they experienced in their husbands. It signifies the next part in the process, after understanding the change and attributing meaning to them. There is some overlap in the ‘understanding’ and ‘living’ categories as, inevitably, the way in which the participants understood the changes impacted the ways in which they lived with them.

Participants were keen to differentiate between ‘living’ with the changes and ‘reacting’ to the changes. They conceptualised their own behaviour and emotions to be centred around ‘living’ with changes, as they highlighted the active ways in which they tried to maintain a sense of life and not allow the changes to dominate the way in which they went about their daily life.

### 3.6.1 God helps us to live

This theme refers to how the overarching ethos of Sikhism translated into feelings of connectedness with their husbands, and how daily difficulties were navigated through reflecting on the key principles of Sikhism; equality, self-less service and compassion. Each participant noted the impact of Sikhism and spirituality in defining their experiences of living with someone with a label of dementia.

Many participants highlighted that thinking of their husbands in equal terms enabled them to retain a sense of connection with them despite the ongoing changes in their outwardly behaviour and mental state.

*“I know he is going through a lot of changes. One minute he is screaming, and the next he is wetting himself, that doesn’t mean I think he is any less human or that he is any less my husband. Waheguru ji taught us the importance of treating everyone with dignity and compassion. I will continue to do this until the day I take my last breath.” (Satwant Kaur)*

Similarly, participants voiced the importance of ensuring their husbands experienced, and felt a sense of, equality in the relationship.

*“There is no point in reciting hymns if you are not going to enact them. My Guru Nanak taught me to call everyone noble, none is lowborn: there is only one potter, God, who has fashioned everyone alike. So, I make sure I continue to tell my husband everything about the family, that I still involve him in*

*important decisions, that I still respect and love him. It's in moments like this that I feel the most connected with him" (Baksho Kaur).*

Participants were also keen to criticise the dominant societal narrative about illness and 'madness', and highlight how equality should prevail.

*"I treat him as my husband, the man who has always loved and protected me. I am not suddenly better than him just because he is not able to think clearly or because other people call him mad. We are the same soul still" (Udham Kaur).*

The reciprocal nature of equality and connection was privileged by many participants as the bedrock of a Sikh marriage. They highlighted how, while roles previously shaped by gendered beliefs had evolved and changed, the constant thread of equality remained.

*"He always treated me as his equally we always done different things in the marriage....he would look after the finances and I, the home and children, but these roles were always seen as equally important. He ingrained it into our children the teachings of Guru Nanak that both men and women are equal. The roles have changed now in our relationship. He looks after the grandchildren, whilst I ensure the finances and everything is in order. We are still equal". (Kamaljit Kaur).*

Many participants were also keen to highlight the equal contributions their husbands continued to make to the marital relationship despite not being able to uphold their previous responsibilities. There was a sense of how embodying the Sikh spirit of equality made it easier to think about contributions in equal terms.

*“I can’t really have a proper conversation with him anymore, I can’t rely on his brilliant advice of how to deal with tricky family situations anymore, but as our religion teaches us, when a tree stops bearing fruit it still gives you shade. In the same way his presence alone is the biggest contribution he makes to our marriage”. (Joginder Kaur).*

When describing daily acts of living, participants were keen to reject the label of being ‘a carer’. The connotations they ascribed to the carer label were incongruent with their Sikh values, namely that of sewa (selfless action) and simran (contemplation):

*“I do not understand this term carer. I am not paid to do this, it is not a job, I am not coming from outside. I am his wife, and more importantly, I am a Sikh. Our Gurus taught us the importance of selfless action. For me, I understand that to mean that I do all that I can to ensure my husband lives a happy fulfilled life, and that we continue to have Waheguru in the centre of our marriage” (Satwant Kaur).*

Participants further described how their application of sewa offered them contentment and the possibility of fostering a closer karmic connection with Waheguru.



*“I do not want or expect anything in return. I am not hoping God will see my actions and grant me a special place in heaven. I do these things because I know it is right, I know it is the moral thing to do” (Kamaljit Kaur).*

For some participants, there was an initial deep sense of frustration and uncertainty around the ongoing changes exhibited by their husbands, which lead them to question their faith. Yet, many also cited their faith, namely contemplation and meditation, as the vehicle for allowing them to accept the changes, and act in a way most congruent with their values and beliefs.

*“Don’t get me wrong, when he wet himself the first time, the second time, and the tenth time, I thought he was being lazy, I thought he was maybe trying to spite me. I asked God why he was putting me through all this, I am 79 myself, I couldn’t cope with all this. With time, I began to meditate...I reflected and I contemplated, Waheguru showed me small signs, like my husband singing me my favourite song, that enabled me to realise that this was still my husband, he was not lazy, he was just ageing. Waheguru taught me that more than ever my husband needed me now” (Surinder Kaur).*

### 3.6.2 Valued connections

This sub-category encompasses the ways in which the participants ensured that their relationships remained connected to valued people, rituals and places. Connection within the marital relationship was also a strong narrative to emerge and therefore was placed within its own sub-category of ‘staying us’.

As highlighted within the ‘understanding category’, one way participants conceptualised the changes they experienced in their husbands was believing that they were ‘yearning to return to their roots’. Therefore, participants described ways in which they actively tried to foster a deeper connection to their Indian heritage, with the hope of trying to alleviate their husbands’ anxiety and sense of confusion.

*“I asked my son...no literally begged my son, if we could get some Indian TV channels...I said I would pay for them out of my pension.....it’s great now.....we watch the Indian news together every morning and evening. He sits up straight and puts his glasses on and really enjoys listening to the current affairs of India” (Jaspal Kaur).*

The act of storytelling was an important activity the participants highlighted in ensuring their husbands remained connected to India. Specifically, the women linked the process of storytelling to their collectivist culture. They explained that storytelling had always been a strong part of their culture growing up in the village, and was important to continue even whilst in England.

*“We would sit on the rooftops after dinner in the monsoon humid heat, it was magical, the whole village would get together on our rooftop. My father-in-law was an amazing story-teller, he would have you engrossed in minutes. The stories were beautiful...all set in Punjab. I still remember every one of his stories. Every night after we have prayed, I re-tell these stories to my husband. He’s engrossed as ever....it’s not quite the rooftops of Punjab but it still reminds us of home.” (Baksho Kaur).*

*“We never had this internet business when we were young, the only way to keep ourselves entertained was to share stories. When I got married..I was so young...only 16, every night I would cry because I missed home....My husband would soothe me to sleep by telling me traditional Punjabi stories. When I first noticed his memory worsening I started asking him to tell me those stories again, he loved it, we loved it. It gave him a sense of purpose again, that he was soothing my soul..I loved it because he felt connected to home. (Kamaljit Kaur).*

Yet embedded within the narrative of helping their husbands live fulfilled lives was an undercurrent of ‘struggle’. Participants reflected on the various ways they often struggled to foster the important connections both for their husbands and themselves. The predominant struggle, outlined by most participants, was having sole responsibility for bringing alive a lost culture, and strengthening important relationships. Participants spoke about feeling as if they were the last link to India and only they could help their husbands reminisce. However, the participants were keen to highlight that the sense of responsibility was not burdensome in anyway. They felt it was their ‘duty’ as a ‘good wife’ and ‘good Sikh’.

*“They don’t know anything about my Punjab...they [children] have only ever been twice! How can they talk about what it used to feel like to pick cotton from the fields in the sweltering heat...or what it felt like to dance in the first monsoon rain? Only I can help him re-live these precious memories.... that’s*

*a huge responsibility you know.... what if I forget these memories? We'll both be lost" (Kamaljit Kaur).*

Participants also recounted the difficulties they encountered in trying to 'remain true' to their Punjabi identity whilst living in a host country. They spoke about the 'race' to keep alive their own culture, before it became too enmeshed and fused with a Western cultural framework.

*"Some days I really really struggle....I keep telling my grandchildren to speak Punjabi at the dinner table so that their Dada can understand...but all they can speak is English." (Udham Kaur).*

*"We started celebrating Christmas when the grandchildren were born....it's good don't get me wrong, you should always adapt to your surroundings...but what it means is that we no longer celebrate Diwali or Vaisakhi at home. No wonder why he feels sad and homesick" (Joginder Kaur*

In order to share this responsibility, participants recounted the ways in which they subtly recruited their family members to help their husbands strengthen connections to valued voices.

*"The next generation and the generations which follow have so much to learn from us....they need to hear our stories before we are gone...it's not the same reading them from the pages of a book....that's why I ask my grandchildren to ask their Nana about his life in the village or what it felt like escaping*

*Pakistan on the midnight train when the partition happened.....not only do they get to learn valuable lessons from him, but he also feels like he is a part of the family,”* (Surinder Kaur).

As well as trying to alleviate the anxiety they observed in their husbands, participants reflected that nourishing these connections with India also served a self-indulgent purpose. Many of the participants spoke about feeling alone due to the changes in their husbands, and explained that their culture enabled them to regain a sense of identity which they felt was gradually deteriorating in the absence of having another individual to keep it alive. Participants explained that their sense of identity was relationally constructed, primarily through interactions with their husbands. In the absence of coherent communications, the participants experienced a sense of ‘lostness’ which was also alleviated through similar strategies and gave them a sense of strength which they were then able to draw upon to help cope with difficulties.

Whilst in the main part, participants focused on the strenuous relationships in their life (‘the others’ and trans-generational conflicts), they were also able to highlight small groups of important individuals whom they valued. These groups of individuals came from various parts of the couples’ lives and were deemed integral in helping them live a fulfilled life.

*“One of the first things I noticed was that he was scared to go out...I decided to take him to a safe place...our local Sikh Gurudwara...he was a different man when he was there...he was so chatty with everyone. The Sikh community are such an important part of his life. The Gurudwara is such an important*

*place for him....no matter what the weather, I make sure we go there three or four times a week” (Udham Kaur).*

*“There is a place in town where the old Punjabi men all sit on benches and have a little catch up.....he didn’t know the men well at first but after talking to them for five minutes he realised his cousin’s aunty’s niece’s daughter is married in the same village as one of them (laughs). You put two Punjabis in a room for five minutes and they will find a connection (laughs). I take him to see these new friends regularly. I do the shopping whilst he natters away about Indian politics. (Kashmiro Kaur).*

One of the key factors all the participants highlighted in these individuals was their ability to hold a non-judgemental view of their husband, and by extension, them as a wife.

*“What feels so nice when you go the Gurudwara is that these old familiar faces aren’t judging you, they know you are doing the best you can. They try really hard to make things comfortable for him, they really make him feel valued. (Charanjit Kaur).*

### 3.6.3 Staying Us

This subcategory encompasses the various ways the participants tried to maintain a sense of ‘us-ness’ within their marital relationships. As highlighted within the ‘acknowledging’ and ‘understanding’ categories, the participants encountered several

changes within their relationships. Participants initially highlighted feeling lonely and a sense of 'loss' at not being able to converse with their husbands. However, they adapted to this change by communicating through other means.

The use of touch as a communication tool was highlighted by many of the participants. Participants were initially reluctant to elaborate on using touch as a means of communication due to it being thought of as a taboo subject to talk about amongst Indian women. However, as interviews progressed, and trust and rapport were established, the women began sharing examples.

*“We don’t really talk as much as we used to, he hardly talks to anyone. He’s really struggling with being lonely I think.....every evening I rub oil in his hair...just like his mum used to when he was younger. It’s like magic, whenever I touch him, he is happier. Also....(laughing shyly) it makes me feel like we are still a couple (hides face with headscarf). (Kashmiro Kaur).*

*“He loves it when I give his feet a massage, I think it makes him feel special, which he really is, I just want him to feel loved” (Baksho Kaur).*

Participants expressed how, although the verbal communication had decreased between them, as a couple they had both developed a heightened ability to converse using non-verbal methods.

*“The other day my son shouted at me because (pauses) over something really silly and my husband came over and sat next to me on the sofa..... we have a*

*connection, he feels my pain and sorrow and I..I feel his. He could tell I was upset, he just knows..... He looked at me as if to say “Joginder Kaur it’s ok, I’m here with you, I’m protecting you.” He said so much...without saying anything.” (Joginder Kaur).*

A dilemma many of the participants recounted was how to ensure their husbands still maintained a sense of independence whilst also ensuring their needs were met. The participants described various instances where they felt an urge to intervene when they saw their husbands struggling with a task, but refrained in order not to embarrass them. Relatedly, they also reflected on how difficult it was to balance acting as an advocate for their husbands with their desire to ensure each could exercise their own decisions. Participants were specifically asked how they negotiated such dilemmas, and how they were still able to privilege their husbands’ choices and sense of agency. Participants unanimously explained that to retain a sense of ‘us-ness’, they knew it was vital to ensure their husbands’ identity and sense of self was maintained and not overshadowed or coloured by the hopes and wishes of others.

*“If we go out with friends, I make sure I let him answer questions. I don’t want to end up being his voice for him. He is still a person! Not an empty shell like others want to make you think he is. His soul is still beautiful and gentle” (Charanjit Kaur).*

The concept of reciprocity was key in all the participants’ reflections. Whilst participants highlighted all that they did for their husbands, they also narrated stories about how much their husbands were still able to contribute to their marital



relationship. The experience of reciprocal love and compassion was one of the key factors in 'staying us'. In addition, the mutual love and compassion between the couples was highlighted by the participants as one the main factors for ensuring their own sense of wellbeing and protection from exhaustion and low moods.

*"Please don't just think it's me who does everything for him, cooking, cleaning.....he does so so much for me. Whenever I wear a red outfit (laughs) he looks at me lovingly and makes me feel like the most beautiful women. He knows how much I love cooking and he still appreciates my cooking by asking for seconds every night. It's the little things he does which he knows mean so much to me."* (Kamaljit Kaur).

Participants were asked how the sense of reciprocal care and love was maintained in the face of unpredictable behaviour and uncertainty. Whilst some participants attributed it to their strong marital relationship, others thought it was the changes themselves which made their husbands feel an increased sense of love toward them.

*"We've always had a connection, like our Guru's have told us, we are one soul in two bodies. We have been through many difficult times, we'll get through this together as well"* (Udham Kaur).

*"He always loved me, but didn't perhaps show it so overtly. But more recently he's able to show me in more obvious ways.....I think the changes have brought us closer together. He feels scared at how quickly he is changing,*

*that's why he tried to hold on me to, I'm the only constant thing in his life"*  
(Jaspal Kaur).

Collective reminiscing and sharing stories was a key part of 'staying us' for the participants. The participants all highlighted different ways in which they reminisced with their husbands. Whilst some wives preferred going through old photo albums together, other participants tried to use all their husbands' senses to evoke memories.

*"This probably sounds really silly, but I have been using the same soap for the last thirty years and I know it gives him a sense of familiarity when he is close to me. I saw him smelling my head-scarf and smiling the other day.....it's so special the way our senses hold on to memories."* (Satwant Kaur).

*"We have a few photos from our wedding day that I know he loves looking at....when he has had a really bad day, I bring out the photo album and ask him to tell me about the photos. He never forgets the story behind each picture and that makes me feel so close to him"* (Balwant Kaur).

For many participants, the sense of connection with their husbands was further fostered by keeping in mind their relationships' unique strengths. Participants explained that throughout their marriage they had developed a mutual understanding of the values and dreams which bonded them, and equally, an awareness of the factors which could lead to rifts. This understanding was highlighted as key to

ensuring participants maintained a sense of ‘us-ness’, as it allowed the wives to navigate unpredictability by utilising their collective resources, and avoiding factors which were known to negatively impact their relationships.

*“Humour has been in our relationship since day one! (laughs) The day he saw me on the wedding day, he lifted my veil and pretended to faint (laughs). We have never gone a day without laughter since. When I sense he is angry or sad I try to make him laugh. It makes things feel like things haven’t changed” (Jaspal Kaur).*

### 3.7 Systemic response to living

#### 3.7.1 Denying

The category of denying refers to the overt and subtle ways in which the participants experienced ‘others’ denying their husbands a fulfilled life. The participants focused on the language others used when talking about their husbands, how they had been more reactive than adaptive to the changes, and the ways in which the individuals had created a physical and emotional distance between themselves and the participants’ husbands. Participants also reflected on the underlying processes they believed were at play which gave rise to the denying behaviours of ‘others’.

Many of the reflections centred around how people in society had reacted to their husbands, and the negative impact this has caused. Participants expressed their upset and confusion at how their ethos of equality and compassion was not mirrored by everyone in society.

*“We went to the local shops and my husband started shouting because he felt unsafe as it was getting dark outside. Everyone started staring...children started mocking him....women started passing dirty looks to him. Why could they not just try to understand? He could be their dad, granddad, uncle...they wouldn’t do the same to him would they? When he went back home he said he didn’t want to go back to shops ever again.....they took away the one enjoyable activity we still did together (cries). (Joginder Kaur).*

Participants also emotively reflected upon the various social racial abuses they experienced throughout their life, but that this had only become worse in older age. Their collective experience of racism hindered both the wives and husbands’ ability to carry out enjoyable activities and live an enriched life.

*“I don’t know what it is, do we stick out like even more now that we are grey and wrinkly? People think it’s completely acceptable to shout P\*ki at us or tell us to go back to our smelly motherland....worse since this Europe Brexit thing. We used to be strong and be able to brush it off before, but now.....I’ll be honest, it means we don’t get to go out much.... I’m scared one day they will hurt us physically.....it makes him worse when we sit at home all day.”*

(Surinder Kaur

One of the key ways in which the participants noted ‘others’ denying their husbands’ personhood was through language. They explained that the Punjabi language was very nuanced and even the smallest of changes in language communicated big

themes. Participants reflected on the ways in which they noticed people in their lives use the past tense to refer to their husbands.

*“it’s the little things I notice ....the other day a man at the Gurdwara introduced my husband to his relative who had come from India...he said...this is Mr xxxx and he used to be such a funny man, his jokes were hilarious.....I replied back and said you should hear his jokes now! They even funnier and dirtier!! (laughs). He’s not dead you old fool, no need to talk about him in the past tense”* (Baksho Kaur).

Participants also noted that certain people in their lives had stopped even asking about their husbands. They reflected on the impact they believed this had on their husbands’ wellbeing.

*“He could be standing right in front of them and they won’t even ask him how he is, they think he is just a skeleton...just imagine how he must feel, it must wound his soul so much, might even make him want to give up living.”*  
(Udham Kaur).

Another experience the participants highlighted as being ‘denying of life’ was the lack of reciprocity in the way ‘others’ spoke about their husbands. They contrasted this to the strong sense of mutual appreciation they had for their husbands.

*“My daughter in law told me the other day that she had cooked for my husband....her tone was so angry and bitter....as if she had done something so huge and deserved a prize or something. I felt like saying to her, don’t ever*

*forget all that that old man has done for you, the free babysitting, the thousands of pounds he has given you, the moral support when your dad passed away. They are so quick to forget everything...not me though, I'll never forget". (Surinder Kaur).*

Coupled with the lack of reciprocity was a conceptualisation of their husbands as burdensome. The participants mentalised the impact of being thought of as burdensome.

*"If someone thinks that you are a burden, after a while you stop asking for help. After a while, you will just stop talking and sharing your feelings, and finally, you will just stop living" (Kashmiro Kaur).*

### 3.8 Resistive responses

The final part of the theoretical model outlines the resistive response of the participants to counteract the systemic responses they experienced from 'the others'.

When describing the various ways participants experienced 'others' to ignore, misunderstand and deny their husbands, the participants also recounted another narrative which ran in parallel to the perceived oppressive actions of 'others'. This process was the act of resisting the power of the wider systemic influences. The process of resisting was described along three main strands, 'turning to the past to help with the future', 'not being scared to call a spade a spade' and 'standing

together, shoulder to shoulder'. However, before detailing each strand, it is important to further deconstruct what the participants meant by 'resisting'.

Whilst there is no direct translation from Punjabi to English for the actual word the participants persistently used, the closest synonyms are 'resistance', 'fighting back' and 'going against the grain'. The language used by the participants portrayed an active ongoing resistive process which was prevalent in all contexts of their life.

Upon conducting three member checks of the final grounded model, the participants initially expressed their uncertainty toward the term 'resistance'. They explained that inherent within the term was a 'negative and almost deviant' element which did not accurately portray what they perceived their actions to be doing or communicating. However, upon detailing the intricacies of the model as well as increasing the number of participant quotes the participants felt increasingly comfortable that the use of the term 'resistance' in this research context did not communicate 'hostile or abusive acts' but rather, it portrayed a more nuanced process. The member checks also iterated the importance of highlighting the 'hopeful and protective' element of the resistance and framing it as a process for 'wanting to achieve something different, something better' (Sukhmani Kaur).

### *3.8.1 Not being afraid to call a spade a spade*

An important form of resistance shared by the participants was the naming of the oppressive processes against their husbands as well their culture more widely.

Participants explained that, ‘not being afraid to call a spade a spade’ was one of the earliest forms of resistance they practiced and was imperative for providing the ideological basis for other forms of resistance later.

*“before anything else my child, you need to open your eyes and see what is happening around you, if you blink you will miss all the little ways they are trying to control you. And then.....once you have seen it....ask your heart what is it....don’t be afraid....just name it. That’s exactly what I done....I saw the way they all treated him, like he was worthless.....I asked my heart....it spoke loudly.....Ageism (shouts). They all discriminate against the elderly. Once I realised this, it made it so much easier to resist all the other ways they tried to control us grey folk. (Harpreet Kaur).*

The naming of oppression was construed as a form of resistance by the participants because without unearthing the processes which negatively positioned their husbands and by extension them, participants had begun to internalise a sense of blame as well as shame.

*“I used to think the doctor was right, maybe his diet was to blame for all the difficult things he was experiencing....I was to blame.....maybe I didn’t look after him properly....cook the right foods. Gradually though, I started realising what the doctors and nurses were upto....they wanted to feed us their westernised labels and tell us how to start living....it was colonizing us all over again, ruling over minds and bodies again. When I realised this I shed the heavy burden or blame I was carrying around. (Satwant Kaur).*



Participants explained the challenges they faced in ‘calling a spade a spade’, namely that of ‘others’ saying that they were in denial. Participants explained the ways they overcame this argument.

*“When I told my children that I thought the doctor was being racist, that he wasn’t listening to my explanations.....they all laughed and told me I was crazy like their dad. I could have shut up and listened to them....no! (shouts). Instead, I just... I allowed myself to feel everything more and I realised that I wasn’t wrong. My heart was telling me that the doctors laughed at me when I spoke about God and India” (Basksho Kaur).*

Participants described the various ways that ‘naming a spade a spade’ helped them to resist what they perceived to be oppressive acts.

*“When my son shouted at me and told me we had to put their dad in a care home, I shouted back. I told him he was trying to control us...that he had no respect for the elderly....that he had lost any remnants of his Punjabi heritage. That shut him up” (Kamaljit Kaur).*

*“I asked his sister the other day why he continually spoke about her brother in the past tense....I even said (laughs) is it because you feel guilty you have done nothing for him and it’s easier for you think of him dead? I felt so powerful when I said that!....I’ll tell them all how I see it (laughs). (Jaspal Kaur).*

### 3.8.2 *Turning to the past to help with the future*

A key part of the research dialogue with the participants was to further understand the ways in which they challenged and resisted the dominant discourses. Highlighted within each of the participants accounts was an exploration of their own unique historical context as well an appreciation of the historical context of Punjabi Sikhs.

Participants spoke emotively about the hardships they faced in their own personal lives, however, they did so to demonstrate their unique values and resources. They made parallels with their previous hardships and current difficulties with ‘others’ and how they utilised their learning from the past to help with the current situation.

*“When I first got married, my mother in law didn’t really like me much, I wasn’t pretty enough for her son. I used to feel so upset about this and spend hours writing letters to my mum. One day I decided to stop crying and just kill her with kindness. Kindness is so contagious...she had no choice but to do the same to me. I think about these times a lot when my children or people that we know aren’t kind to my husband, I just kill them with kindness. That’s the best response to these fools.” (Balwant Kaur).*

Participants keenly shared important life lessons they had learnt from wise figures in their life such as their grandparents and parents. These life lessons formed a strong basis for enabling the participants to go against the dominant grain.

*“My father always told me to be different, he taught me to be a lion in a world full of goats. I was the first woman in my village to go to college.....this*

*has been such an important life lesson for me....when people laughed at me for talking to my husband as if he was a still a real human being or when my children tell me to put him in a care home, I remember that I am a lion and I will not follow what all these people tell me to do like some sort of weak goat”* (Harpreet Kaur).

Sikh history and Punjabi cultural stories also formed a strong basis for how the participants could resist the impact of dominant systemic factors. Participants all referred to Sikhism’s turbulent history against oppression. Drawing upon this historical memory was cited by all participants as an important source of strength that they drew upon every day. Many participants referenced a need to stand up to oppression in similar ways to their ancestors hundreds of years ago. Retrieving their historical religious narrative to endure adversity helped them foster hope. Strength and resilience was rooted in religious stories they read in the holy scriptures. These stories help give meaning to present events and shape idea’s for how to conceptualise and deal with things.

*“Our tenth Guru gave us Sikh’s all the same middle name, Sikh women all have Kaur as their middle name meaning warrior princesses’ and men were bestowed with the name Singh, a roaring lion ...I make sure I fight for what I believe in, I believe in dignity and compassion not care homes and stupid dementia labels”* (Satwant Kaur).

Balwant Kaur similarly connected with her Sikh history to explain how she fights back the derogatory comments aimed toward her husband by people in society:

*“they call him old, foolish, stupid, crazy....during these times I bring up the image of our fifth Guru, Guru Arjan Dev Ji. I think about how he sat on a hot plate with fire underneath, he endured that suffering for us, so that we didn’t have to convert to Islam....if he can endure that suffering for us....I can endure the upset they cause us and resist the names they call him”*

Many of the participants recounted personal stories of monumental times in Sikhism’s history and highlighted the resources they gained from it. Most the participants had a direct experience of being displaced during the 1947 partition of India and this monumental historical event had left a lasting memory for all. Kashmir Kaur spoke about her feelings of “hopelessness and despair” as a young teenager being made to flee her home in what is now known as Pakistan. However, she vividly recalls her grandfather telling her to reframe her thoughts and remember that ‘*where there is Waheguru, you are never alone*’. She frequently draws comfort from this holy scripture; “*when I am alone at night and my children’s father is awake next to me feeling unsettled I remember that just like when I moved home hundreds of miles away, I am not alone on this night, my Waheguru is watching over us and will guide us*”.

Another historical event monumental for Sikhs was the genocide of ten thousand Sikhs by Indian prime minister Indra Gandhi in June 1984. Many of the participants referred to this event as a source of strength and justice. Harpreet Kaur lost many family members at the Golden Temple during this event and she explains that the memory of this event helps her cope with adversity in current events.

*“ us Sikh’s have not had it easy, for hundreds of years many have come and tried to wipe us out, we have not, we have stood stronger, I remember this when I feel weak, I remember that as a religion we are tough and we cannot be defeated, so tell me child, what is one bad day?”* (Harpreet Kaur).

### 3.8.3 *‘Standing shoulder to shoulder’*

Resistance was rarely spoken about as an individual endeavour, participants were forthcoming with examples of collective resistance. Again, participants differentiated between the notion of collective resistance built on hope versus collective rebellion designed to instigate anarchy and chaos.

*“We’ll sit together and drink cha (tea) and talk about how our sons and daughters are desperate to make us change our ways....bleach us of our colour and heritage....make us white. We’re hardly planning protests and marches (laughs)”* (Charanjit Kaur).

Sharing stories of coercion and subjugation fostered a strong feeling of affinity with other oppressed people. The participants spoke about the importance of sharing experiences as it not only helped them feel less alone but also further fostered their own resilience and courage. For many participants, the sharing of stories was reminiscent of their experiences in Punjab, when an ‘individual’ problem was never deemed as such and the community would congregate together to offer support and guidance.

*“There was a big tree in the middle of the village, every evening the whole village would meet there. Under the evening shade of the tree, a villager would share their woes....it was no longer just their woes but it became our collective woe. Similarly today, I sit with women at the Gurudwara and talk about my husband and my struggle to keep my culture alive in a family which is so set upon diluting it....the women share similar stories.....we feel connected and united. I go back home feeling stronger and able to assert myself. (Jaspal Kaur).*

Participants explained that the process of collectively resisting dominant discourses and practices gave them a sense of energy and motivation to change the status quo.

*“When I tell my neighbour about the ways people misunderstand my husband’s behaviour and how they do not allow him to live happily, she tells me about similar stories she has heard from her friends....I do not feel alone. When I realise that other wives are going through similar things....trying hard to preserve their husbands’ essence, I become even more motivated to go against the grain and stick to what I feel is right.” (Surinder Kaur).*

*“Standing shoulder to shoulder”* and demonstrating collective resistance was an important process the participants wanted the ‘others’ to witness. For some participants, it was important for ‘others’ to appreciate that they were not alone and therefore any attempts to subjugate or coerce them would be met with collective force and resistance. For some, a show of collective resistance built on hope was important

for society to witness and change their negative misconceptions about groups of Indians being devious and violent.

*“Recently there was a fayre in our local town, a few of us decided to put up a stall to promote our culture. We made some food and played Punjabi music. We wanted others to see how inclusive and united we were....I’m sick of people equating brown people with being terrorists. If they see we’re a united and compassionate bunch of people maybe they will stop falsely judging us....It might make it easier for me to take my husband to town without getting evil looks from people”* (Harpreet Kaur).

### 3.9 Key points covered in the chapter

- The wives’ experiences of living with their husbands was not described as an individual isolating process but rather, participants explained the various relational and societal influences which shaped their experience.
- Whilst the graphical depiction of the wives’ experiences may be linear, they all expressed the circular process in which their responses interacted with that of those around them in a dynamic fashion.
- A thread of connectedness and reciprocal caring ran through all the categories and highlights the relational element of ageing within this community.
- A strong focus upon culture, religion and heritage underpinned all categories and provided the foundations upon which the wives made sense of, lived with and dealt with societal challenges because of changes in their husbands.

## 4 Discussion

This study sought to explore the experiences of Punjabi Sikh wives in living with a husband with a label of dementia. Specifically, this study aimed to identify the meaning the wives attributed to their experiences. This chapter will provide a summary of the findings and then discuss these in relation to existing theories and literature. Novel findings to emerge from this study will also be discussed and their contribution to the field of Clinical Psychology will be outlined. The chapter will conclude with personal reflections from the author as well as a critical analysis of the research process.

### 4.1 Overview of Findings

Many of the theoretical codes emerged to explain the processes implicated in attributing meaning to the experience of living with a husband with a label of dementia. The first process, the wives' responses was further divided into three processes; acknowledging changes, understanding changes and living with changes. A distinct second process outlined by participants was the perceived systemic responses of others. These were divided into, ignoring, misunderstanding and denying. The last process, resistive responses was also divided into, standing shoulder to shoulder, not being afraid to call a spade a spade and turning to the past to help with the future.

Whilst many of the emergent findings from this research are consistent with existing studies, highlighting the shared elements of spousal experiences between cultures, it also provides new and specific insights into the experiences of Punjabi Sikh wives. It is these issues that are the predominant focus of the discussion that follows. The



findings are intended to support and inform ongoing and future engagement with such communities.

## 4.2 Acknowledgment

### 4.2.1 He's different yet the same

Participants felt their unique position of having a close relationship with their husband was what enabled them to acknowledge changes before others. The findings from Perry and Conor's (2002) study support this emergent model, which found, wives believed themselves to hold 'interpretative expertise' which enabled them to be better attuned to changes in their husband. This cross-cultural similarity highlights the universality of intuitiveness as an important foundation in spousal relationships globally.

However, novel to this present study is a further exploration of *how* wives believed themselves to hold this intimate knowledge of their husbands. Participants in the current study provided spiritual narratives in allowing them to foster such intuitiveness. The participants' spiritual narratives provide an additional layer of complexity which is rarely specified in Western literature pertaining to spouses and dementia. A study by Stuckey (2003) explored the role of religion and dementia in Jewish and Christian spousal relationships but found that wives turned to religion as a coping strategy to ease the burden of loneliness and emptiness. These findings differ somewhat to how religion was utilised in a more explanatory manner for the Sikh wives in this study. This highlights the need for increased research exploring the unique spiritual experiences of all religions as one cannot homogenise the role of religion across all cultures.

Whilst, many studies which explore spousal experiences of dementia mainly centre around the negative changes exhibited by husbands (Quinn et al., 2008; Robinson, Clare & Evans, 2005; Sherman & Boss, 2007), a novel finding to emerge from this study was a consideration of retained abilities in their husbands and how such capabilities were preserved. Whilst the study by Perry and Conroy (2002) outline the various ways women recognise and support preserved competencies within their husbands, there is little exploration in the study of *why* wives focus on their husbands retained skills and personality traits.

For some wives in the present study, enhancing their husbands' strengths was a protective strategy, designed to defend them from thinking about the magnitude of the losses shown by their husbands. Such reflections can be thought of from a psychoanalytic lens in which, it has been posited that a strong preoccupation with the positive aspects of oneself and others is a defence mechanism, intended to guard against knowing oneself and others truly (Sadavoy, 1991). Indeed, psychoanalytic ideas regarding the structure of one's conscious and unconscious fears is largely consistent with the way in which the 'mind and soul' are described within Sikh holy scriptures (Singh & Tatla, 2006), thus further enhancing the credibility of the aforementioned hypothesis.

Participants also proposed that thinking about the retained elements of their husband fostered curiosity as to why particular traits were preserved and allowed them to retain a sense of continuity in their husbands' identity. Such reflections are synonymous with literature pertaining to narrative therapy, in which central to the therapeutic process is exploring 'unique outcomes', actions which move away from the dominant discourse surrounding the person and a consideration of what values or

virtues underlie such actions (White & Epston, 1990). Both Sikh ideology and narrative therapy share strong postmodern foundations (Bhokal, 2014) and therefore it is no wonder that the participants in this study gravitated toward making sense of changes through the prism of critical curiosity. This further highlights the need to explore the unique ideologies of each cultural/religious group and adapt and match therapeutic models accordingly.

The way in which participants looked beyond their husband's behaviour and tried to understand their inherent emotion instead is consistent with strategies advocated by Kitwood (1997) for enhancing the personhood of individuals with diagnoses of dementia. The findings from this study also fuel the argument that the NHS has become too consumed with challenging behaviours exhibited by dementia patients and warns against anti-psychotic drugs being readily used to treat negative symptoms. The findings suggest that more emphasis should be placed on collaboratively trying to understand behaviours which challenge (James & Jackman, 2017). Key psychological techniques such as clinical formulations can greatly aide with this.

Another unique finding from this present study was the way wives thought about their husbands' wellbeing in a holistic manner as opposed to focusing entirely on memory loss. Whilst existing literature does mention emotional wellbeing as an important factor considered by spouses, changes in cognitive capacity is still predominantly the main lens through which people notice changes. One potential explanation for *why* the participants in this study thought more holistically about their husbands' wellbeing may be related to the ideology of Sikhism. Counter to most western discourses about dementia, Sikhism challenges the notion of dualism and does not draw sharp distinctions between mind, body and soul (McLeod, 2000). Instead, it

advocates for Sikhs to adopt the notion that they are non-dual multifaceted forms and that one's soul connects these various forms together (Singh, 2008), thus again highlighting the centrality of religion and spirituality in the wives' experiences.

#### 4.2.2 I feel different too

Participants recounted the ways in which they initially chose to overlook or deny the changes they started noticing in their husbands. Similar feelings of denial were also mirrored in the accounts of the wives in studies by Brown and Allgood (2004) and Hayley, West, Wadley, Ford, White, Barrett & Roth, (1995). In fact, the process of denial and minimisation of dementia related changes in spouses has been well documented in the work of Veroff (1981) who, coined the term 'survival denial' to explain the process of denying and ignoring age related changes in spouses to navigate problems deemed too difficult to handle.

Central to the exploration of changes in themselves, the participants also focused upon their changing identity as an individual, wife, and their role in society. Counter to existing research in which wives have typically thought of changes in identity through a prism of loss of self and overwhelming burden (Quinn et al., 2008), the participants in this study did not feel a loss of identity but rather a continuation of their role as a Punjabi Sikh woman which, felt different yet rewarding nonetheless.

For many, caring for their husbands gave them a sense of purposefulness which with growing age they felt had begun to diminish. These findings support Phillips' (1957)

social role theory in which he proposes that with growing age the elderly begin to experience a loss of social rank and this can give rise to feelings of despair and hopelessness. He too suggests that society has a responsibility to recognise the continual contribution the elderly make and celebrate their uniqueness.

The cultural disparity between the findings in Western studies and those outlined in this study are important to unpick further. The women in this study spoke about feeling different but still framed this change positively, this may in part be due to their reticence toward the carer label. Through dismissing being a carer and living by the Sikh values of compassion and selfless service, the women may have been able to conceptualise their new feelings as simply a continuation of a different part of their soul as ascribed in Sikh scriptures. However, religion aside, from a more cultural perspective the strong patriarchal make up in Punjabi communities may have made it harder for the women to voice their discontent with their new caring context. The present study did not tease apart the respective roles of religion and culture, as both exert very different influences upon individuals and as such this is an important avenue for future research.

#### 4.2.3 Systemic Response: Ignoring

The wives shared that whilst they wanted to remain attuned to the retained abilities of their husbands, 'others' were quick to dismiss or ignore preserved competencies. This finding is in keeping with patterns of behaviour outlined in Kitwood's (1997) Theory of Malignant Social Psychology (MSP), in which individuals with labels of dementia are ignored, ridiculed and abused through social interactions. The various MSP

practices such as mockery, punishment and ignoring observed by the participants against their husbands further reinforces Kitwood's (1997) notion that the wellbeing of an individual is not just internally driven but rather, socially constructed. The importance stressed by the participants on the social construction of wellbeing challenges the dominant perspective that diminishing cognitive capacities make individuals with dementia beyond help and cure (Grossman, Bergmann and Parker, 2006). These findings also serve to remind society to be mindful of how interactions uphold or devalue the personhood of those with dementia diagnoses.

Whilst Kitwood (1997) hypothesised that malignant patterns of social interaction arose because people with dementia are seldom visible or acknowledged in society, the participants in this study proposed an alternative hypothesis. They suggested that the propensity for others to ignore their own emotional experiences and that of the person with dementia was an unconscious attempt by them to protect themselves from the reality of their own inner fears.

Whilst very little is written about the role of defence mechanisms in dementia caregiving specifically, parallels can be drawn with the work of Sinason (1992). Sinason (1992) described a similar defensive demeanour in relatives and professionals caring for individuals with a label of learning disability. She argues that, the tendency for healthcare professionals to infantilise marginalised individuals such as those with a learning disability is an unconscious drive designed to shield the self from the painful exploration of the parts of themselves deemed too difficult to process. She elaborates on this hypothesis through giving examples of modern health

care practice in which there is a strong emphasis on behavioural monitoring as opposed to a deeper exploration of emotional experiences of patients.

Extending Sinason's (1992) central hypothesis, one could argue that the denial of visceral emotional experiences and that of the person with dementia witnessed by the participants is an attempt by 'the others' to shield themselves from inner conflict but also potentially existential thoughts regarding death and ageing.

### 4.3 Wives' Response: Understanding

#### 4.3.1 Sikhism makes it clearer for me

Numerous studies cite the importance of religion as a coping mechanism for caregiver burden and stress (Wright, Pratt & Schmall, 1985; Regan, Bhattacharayya, Kevern & Rana, 2013). However, the present findings provide a unique contribution to the research field through evidencing the role of religion and spirituality in *understanding* and framing age-related changes. The threads of religion and culture are weaved throughout the participants' accounts and further solidifies the argument that dementia needs to be explored through the unique cultural lens of each individual and their family.

The few studies which do explore religious constructions of dementia in South Asian's frame such religious understandings as punishing, folklore or superstitious (La Fontaine et al., 2015; Turner, Lawrence et al., 2008). The fact these findings differ to the positive narrative in the current study leads one to question whether the reporting of such spiritual explanations in Western medical and psychology journal

articles truly reflects the stories of the participants. One could question whether western ideas about the incongruence between religion, medicine and psychology potentially bias the reporting of findings.

The role of religion and spirituality in BME research relating to dementia is not novel in of itself, however, when religious influences are considered with regard to conceptualisations of dementia they are done so in-conjunction with cultural attributions. It can be argued that culture and religion are often fused together as concepts due to their mutual influence upon each other, thus making it difficult to ascertain whether a participant's views are driven by culture or religion (Saroglou & Cohen, 2011). Rarely have studies homed in specifically on the influence of religion alone. The findings from the present study are therefore unique in highlighting the specific influence of religion on understanding dementia more clearly.

#### 4.3.2 Our life story

The participants in this study explained that in the absence of proficient English language skills and lack of engagement with popular British culture meant that they could only rely on their joint stories to make sense of changes in their husbands. Therefore, connecting with their joint life story was an adaptive strategy participants were almost forced to adopt due to socio-cultural factors. This differs from existing literature on life story work, for example, Perry and Connor (2002) also found that wives drew on the past to establish a presence of their husbands in the present, but, done so because they hoped it would give an illusion that nothing had



changed. These subtle cultural nuances between studies seemingly exploring the same topic area of spouses and dementia require further amplification and exploration as they have very important clinical implications.

The process of assigning internal attributions (e.g. personality traits and life stories) to better understand their husbands' presentation contradicts Polk's (2005) hypothesis that internal attributions by caregivers are harmful. Whilst participants also provided external attributions for change (social inequalities and loss of role), the tentative way with which they proposed internal attributions suggests that attributing meaning to others is a far more nuanced process than what Polk (2005) may have suggested. The author hypothesises whether the reason for not assigning negative internal attributions (e.g. blame and attention seeking) to their husbands was also driven by the participant's strong allegiance with Sikh principles, namely compassion and tolerance.

A key differentiation between the emergent model and existing life story literature is the emphasis the participants placed on joint life stories. Much of the existing literature, about the use of life stories in dementia care, takes an authoritative stance of the person's life in which others are deemed 'experts' in their lives. This study presents an alternative more collaborative approach to the importance of life stories. Whilst many governmental initiatives (Department for Health, 2009) are advising carers and professionals to think about more person centered care, this study highlights that such an endeavor needs to be more relational but also more mindful of wider social factors impacting the individual's life such as migration histories. This is further supported by Jutlla's (2014) work on dementia and migration patterns in

Punjabi Sikh communities, in which she also highlights the importance of shared relational ‘stories’ and how they are even more paramount in making sense of dementia and age related changes than diagnostic frameworks.

#### 4.3.3 Yearning to return to our roots

The limited research which has been conducted with South Asian individuals has largely overlooked how oppressive experiences, social marginalisation and socio-economic disadvantage exert a strong influence upon dementia presentation. Whereas in the current study these were strong narratives in the participants’ accounts and areas which received increased attention. Jutlla (2014) similarly provides strong support for how the long-term impact of social inequalities can continue shaping one’s identity, to the extent that Punjabi Sikh communities may not wish to access more formal support based in Western frameworks.

From a liberation psychology perspective, the findings from the current study are wholly consistent with Martin-Baro’s (1994) work with marginalised communities. He argued that individuals who are already degraded in social hierarchies (e.g. minority ethnic populations) face further marginalisation and oppression when made to fit moulds of ‘acceptable behaviour’ which hold little cultural relevance for them. Indeed, participants in this study similarly expressed how a “yearning for [their] roots” was a form of escaping such marginalisation and oppression.

These findings are also consistent with Harding and Palfrey’s, (1997) notion that the structural realities faced by individuals from BME communities such as oppression and racism may also exert a strong influence in the course of dementing illness and

the caregivers' experiences. For example, they found that the African American individuals in their study experienced dementia symptoms which were persecutory in nature akin to their abusive experiences since arriving in the U.K. Participants in this study shared similar experiences in which they were publically ridiculed and physically and emotionally abused by racist individuals. Fox, Levkoff and Hinton (1999) argue that old age gives individuals the freedom to finally begin to name the persecutory actions of others. Therefore, in the context of the current study one can hypothesise that the desire to return to India through behaviours such as imaginary conversations is an attempt by the husbands to resist the oppressive attitudes and behaviours of society.

This is an important finding as according to western diagnostic frameworks such 'delusional' behaviour is seen as a form of psychosis and confirms a dementing illness, however, it negates the cultural experience of the individual. Therefore, professionals must exercise caution when diagnosing dementia related illnesses and exercise cultural curiosity.

One can also think of the self-soothing strategies witnessed by the participants within the framework of Terror Management Theory (TMT) (Greenberg & Arndtt, 2011). TMT purports that a major motivating factor for all human behaviour is an acute awareness of the inevitability of death (Greenberg & Arndtt, 2011). When faced with an existential threat the self-preservation instinct of individuals becomes activated and leads to behaviours designed to soothe oneself of death anxiety (Rosenblatt, Greenberg, Soloman, Pyszczynski & Lyon, 1989). Therefore, in relation to the current findings, one can argue that through social oppression, racism, ageism and

dominance of western ideology, the participants witnessed their husbands' cultural identity and self-concept being existentially threatened. Therefore, the desire to return to ones roots and the various manifestations of this such as hallucinating being back in India and having imaginary conversations with friends can be conceptualised as a buffer against an existential anxiety.

#### 4.3.4 Systemic Response: Misunderstanding

The dementia explanation was dismissed by all participants for it was felt it overshadowed the uniqueness of their husbands and positioned them as 'passive and powerless'. This asserts Foucault's (1970) notion that language is an extremely powerful social device which can have serious implications for how individuals think of themselves and their place within society. The participants' accounts of sadness and anger mirror Roberts' (2016) central thesis, in which diagnostic labels such as dementia were seen to have a detrimental impact on both individual and carer wellbeing.

Liberation psychology frameworks urge 'psy' professionals to deconstruct society's motives for using individualising labels such as dementia to explain social problems. Therefore, thinking about the current socio-political context in which this study was conducted, one needs to be curious how the label of dementia has a purpose in a politically uncertain, post-Brexit, austerity fuelled and increasingly racially intolerant society. Taking on board the participants accounts of racism and ageism, the researcher hypothesises whether dementia serves the needs of such a society through giving individuals a 'target' to blame and attribute such negativities to. For example,

post-Brexit the over 65's cohort were blamed for the outcome to leave Europe (The Independent, 2016), similarly the financial crisis within the NHS has also been blamed on an ageing society (Oliver, 2017) and therefore the elderly are increasingly being scapegoated in society and media. Akin to the participants' experiences, dementia may indeed be misunderstood as describing an 'individual illness' when in fact it a useful metaphor to describe the ills of society.

#### 4.4 Wives' Response: Living

##### 4.4.1 God helps us to live

Participants were particularly keen to highlight the various ways in which the overarching ethos of Sikhism enabled them to "carry on living" despite changes they both experienced within one another and their relationship.

The importance of spiritual guidance in caregiving has been well documented in dementia research. In such research, religion is predominately conceptualised as a resource primarily for the caregiver. For example, a study by Hebert, Dang and Schulz, (2006) found that religious beliefs and practices contributed toward better mental health for caregivers. Another study by Stolley, Buckwalter and Koenig (1999) found that dementia caregivers frequently used prayer and other religious activities as coping strategies for caregiver burden and to help soothe anticipatory grief of losing their loved ones.

A potential hypothesis as to why the participants in this study did not utilise religion as a protective factor against caregiver burden as cited in existing research is because the term ‘carer’ did not resonate with them. Participants actively rejected the term carer and its synonyms such as ‘duty’, ‘chore’ and ‘burden’ and instead thought about their daily experiences with their husbands through the lens of the Sikhs value of *sewa* (selfless action). This finding is particularly important in western clinical contexts and dementia related research in which spouses and family members are automatically positioned as “caregivers” without fully understanding or exploring the cultural and religious resonances for the individuals, the clinical implications of this finding will be discussed toward the end of this chapter.

When interpreting the current findings in relation to existing research and theory, one must be curious as to what has not been said or shared by the participants, in clinical practice this is often termed “thinking about the fringes” (Campbell & Draper, 1985). As discussed in the critical appraisal section of this chapter, there is a potentiality that participants were not comfortable in sharing the difficult elements of living with a husband who is experiencing difficulties or even exploring the negative aspects of religiosity. For example, in a study by Herrera, Lee, Nanyonjo, Laufman and Vigil, (2009) they found that religiosity was also thought about negatively by some caregivers. They identified “negative religious coping” as a theme which incorporated the ways in which religious actually inhibited caregivers from accessing support from external agencies and how religion actually created a further distance and split between couples in which one member was not particularly religious. These are important themes which require further exploration in future research.

#### 4.4.2 Valued connections

The narratives within this category highlight the reasons *why* participants engaged well with community resources as opposed to more medicalised health care services. Very few published studies have explored the relationship between community resources and South Asian families, instead an increased focus has been placed on stigma and shame within South Asian communities (Mackenzie, 2006).

Instead, the participants in this study shared hopeful stories of openness and close bonds with their friends. The disparity in findings between this study and others exploring service uptake in Asian families may be due to the way those studies have been framed specifically around the diagnosis of dementia. Participants in this study explained that they did not experience shame or stigma talking about their experiences with their community because they had rejected the term ‘dementia’ and instead, conceptualised the changes in their husbands as normal. Participants explained that if the study had asked questions specifically about the term dementia or depression then they would potentially feel ashamed and inadequate as these were culturally incongruent labels. These findings affirm Afuape’s (2004) argument that research enquiry must remain as close as possible to the experience of the participants. One such way to do this is to adopt the language and voice of the participant because as shown in this study the findings can differ significantly if ‘research language’ is imposed on participant experiences.

Participants also highlighted that their local community held all the knowledge, expertise and resources necessary to navigate any difficulties within their lives. The latter point especially, maps directly on to new and emergent community psychological approaches.

The premise of community psychology is that individuals, organizations, and communities gain mastery over their lives through collectively honing their shared resources (Rappaport, 1987). Such displays of collectivism were evident in participant's accounts of coffee mornings at the Gurudwara, the 'elderly bench' in town centre where elderly Sikh men congregate to share stories and religious hymn singing classes for the soul. As Afuape (2014) suggests, BME communities need to be trusted and congratulated on their unique ability to provide emotional and practical support without the help of 'outsider' professionals.

Whilst existing BME related research and policy has focused upon how dementia awareness ought to be increased in 'hard to reach' pockets of society, this study provides an alternative strategy. The positive benefits of valued connections for both the husband with a label of dementia and the wives demonstrates that services should perhaps help communities foster and cultivate their own unique resources as opposed to colonising their supportive strategies with culturally irrelevant ideas.



#### 4.4.3 Staying us

This subcategory encompasses the various ways the participants tried to maintain a sense of “us-ness” within their marital relationships. The use of touch was an important medium through which participants communicated love, affection, care most importantly marital connectedness. This is an important finding as it adds support to a growing body of literature calling for increased thinking around the embodied experiences of individuals with labels of dementia. The findings from the current study mirror Downs (2013) notion that, the rhetoric around dementia has been colonised with a fixation upon cognition, instead, the body should also be explored as an important medium for communication.

Collective reminiscing and sharing stories was a key part of ‘staying us’ for the participants. The process of story-telling is central within narrative therapeutic approaches, in which stories are thought to be the vehicle through which individuals give meaning to their lives (White and Epston, 1990). The current findings mirror existing research which shows that story-telling can have many positive benefits such as, better wellbeing, stronger relationships and less forgetfulness for dementia patients (Scherrer, Dayton and Spencer (2014).

Building upon narrative therapy related literature which predominately focuses on individual stories, these findings go further and suggest that reflecting on the reciprocal love within their relationship enabled the participants to feel stronger as a couple and better able to continue living life on their own terms. This is an important finding for healthcare professionals who should remain increasingly mindful that

'dementia patients' are part of a loving dyad and care plans should not negate the positive role of spouses. These findings negate the theme of individualisation which runs strongly through many government dementia policies (Department for Health, 2009).

#### 4.4.4 Systemic Response: Denying

The category of denying refers to the overt and subtle ways in which the participants experienced 'others' exercising power and denying their husbands a fulfilled life. Participants focused on how the label dementia evoked feelings of anger in them as it shadowed their husbands' unique essence. These findings echo Kitwood's (1990) sentiments, that 'dementia' should never dominate any description of an individual, for it is simply a label. The findings also strengthen Harding and Palfrey's (1997) argument that the dementia label is used by the powerful in society to further undermine marginalised individuals.

However, Fredman (2004) advises that power is a complex construct and one should exercise curiosity as to how systems exercise power. According to the participants in this study, they believed the younger generation tried to exercise power through imposing western ideology privileging medical discourses over cultural and religious explanations of age related changes. However, as this study did not explore the experience of the wider family the voice of the younger generation is absent and therefore it would be misleading to imply that such use of power was deliberate on their part. One could hypothesise however that the propensity for second and third generation Punjabi Sikhs to use dementia labels is due to their own powerlessness in adopting a dual cultural identity. A reliance on medical knowledge to counteract

cultural uncertainty and regain control has been similarly demonstrated in studies by Polk (2015) and Brown and Alligood (2004).

Similarly British born caregivers in Jutlla's (2014) study expressed they were not "just able to get on with things" (p.16) like the older generation. Instead, they resorted to different coping strategies rooted within *their* own frame of reference as opposed to norms of their older parents and grandparents. Indeed, Holmes and Holmes (1995) suggest that individuals assign illness attributions within their social, religious and cultural frame of reference. Therefore, what the participants perceived to be 'denying' behaviours of their children may in fact symbolise their attempts at understanding their father from within their dual-cultured context. This highlights the need for future research to explore how social and personal contexts shape inter-generational patterns of caregiving.

#### 4.5 Resistive Response

The term 'resistance' was conceptualised by the participants as an act which conveyed a sense of hope and protection as opposed to holding negative or hostile connotations. A more positive and hopeful portrayal of resistance has also been conveyed by Wade (1997) who reframes resistance to mean a creative act designed to preserve the identity of individuals.

Similar to the participants' positive conceptualisation of resistance, Afuape (2014) argues that whilst prevailing discourses in society will have one believe that

resistance is hostile and intent upon harming others, creative resistance encompasses the subtle ways individuals resist societal pressures.

Freire (2000) also provides a definition of resistance similar to that of the participants. He comments that one must explore the responses of the marginalised in society, because, inherent within each resistive response is an important value. Against this backdrop one can begin to understand the rationale for why the participants in this study actively avoided formalised dementia services. Whilst existing literature purports that stigma is the main barrier for South Asian underutilisation of services according to Friere's (2000) and Afuape's (2014) thesis one can reformulate this underutilisation of services to perhaps signify a subtle yet active form of creative resistance from the participants.

This re-formulation is particularly important as individuals from BME communities are increasingly labelled as "hard to reach" (Jutlla & Moreland, 2007; Seabrooke & Milne, 2004) and yet little effort or curiosity is afforded to whether such services are in fact not meeting the needs of the individuals they aim to serve. Participants in this study have urged services to respect their cultural values and instead of pathologising their resistance to mean "treatment resistant" or "avoidant", join alongside them to better develop culturally attuned services.

#### 4.5.1 Turning to the past to help with the future

Another strong narrative of resistance within each of the participants' accounts was an exploration of their own historical context and how this equipped them with the strength to cope with the uncertainty of their present situation.

These findings are closely aligned with those in Jutlla's (2014) study exploring the influence of migration patterns of Sikhs in caring for individuals with dementia. Both the present study and that of Jutlla's (2014) explore the impact of societal inequalities upon the manifestation of dementia related behaviours. As discussed earlier experiences of racial abuse and difficult migration histories are some of the explanations that participants presented for their husbands experiencing changes. Such findings further emphasise that, Punjabi Sikh individuals understand dementia to be a social problem and in turn this lends much needed empirical support for psycho-social theories of dementia (Cheston & Bender, 1999; Phillips, 1957).

Martin-Baro (1994) stresses the importance of helping marginalised individuals draw strength from their own struggles and that of their ancestors to endure adversity and hardship. The findings from the present study lend support to Martin-Baro's (1994) liberation psychology work that, retrieving historical memory helps individuals remain connected with their identity and help resist the influence of powerful subjugating discourses. The stories from their collective past and of their motherland were a powerful vehicle through which the participants resisted societies imposition of a debilitating narrative of their husbands.

Being a post-modern and social constructionist style of practice, it could be argued that narrative and liberation psychological approaches share a strong ideological basis with Sikhism. Both, emphasise the importance of collectivism in shaping one's identity and there is a strong drive within both Sikhism and narrative practice to challenge incongruent labels and unjust practices. The mirroring of the themes in this study with narrative and liberation approaches further highlights the imperativeness for clinical psychologists to ensure therapeutic practice is congruent with the values of the individual and family.

#### 4.5.2 'Standing shoulder to shoulder'

Resistance was rarely spoken about as an individual endeavour, participants were forthcoming with examples of collective resistance. The theme of solidarity has close resonances with the principles of collectivism advocated by Sikhism and as such,, many participants recounted historical stories of Sikhs gathering together to resist social oppression.

Furthermore, the findings from this study contradict the themes of stigma and blame often found to be synonymous with BME individuals and distress (Adamson, 2001; Mackenzie, 2006). Unlike the participants in Mackenzie's (2006) study, the women in the present study explained how talking to people in the local community actually helped her to better understand and support her husband. The divergences in findings between existing studies and the present research, further emphasises the need to explore cultural cohorts separately because for many of the participants it was their

specific Sikh background which enabled to share experiences with their community. The artificial homogenising of cultural groups leads to the risk of inaccurate reporting of findings.

However, it is worth considering why the participants in the present study found solace and hope in “standing shoulder to shoulder” with their community as opposed to experiencing them as blaming or judgemental. The roots for such differences may lie in Sikh ideology which, places collectivism and social justice at its very heart. The ways the wives utilised their collective resources to better support their husbands and retain both their own and marital identity highlights that for this cultural group, wellbeing is a social construct.

#### 4.5.3 Not being afraid to call a spade a spade

An important form of resistance shared by the participants was the naming of oppressive processes such as ageism and racism. The ways in which participants challenged GP's, nurses and their own children about the way they perceived them to undermine their husband shares strong similarities with the liberation psychology practices. The participants' reticence toward mainstream models of distress forms the basis of Martin-Baro's argument that, marginalised individuals carry the burden of society's ills through the labels and oppressive actions imposed on them by the most powerful in society.

Similar to the participants' resistive efforts, Martin-Baro (1994) states that marginalised individuals must be supported in de-ideologising and deconstructing their everyday experiences. Through placing difficult experiences under critical scrutiny, individuals can bring to light the ways in which society oppresses, silences and marginalises individuals. Indeed, this was apparent in how participants reflected on the meaning of the dementia label and rejected it as a form of ageism and western colonisation. This particular finding cannot readily be applied to other marginalised groups striving to de-ideologise oppression because the participants' age/wisdom and strong spirituality may have afforded them the freedom to name such oppression. An additional area of enquiry for future research would be to explore the most helpful contextual factors to help facilitate the deconstruction of oppression.

The findings from the present study extend Martin-Baro's (1994) thesis further and highlights the *impact* that naming oppression has on individuals. Specifically, participants experienced feeling a sense of "liberation" (Harpreet Kaur), "strength" (Joginder Kaur) and "pride" (Kashmiro Kaur) through dismissing the dementia label.

However, one must remain critical to the fact that the naming of oppression may not be an entirely positive experience for all. Two participants in this study expressed that noticing the racist practices of their neighbours left them feeling more helpless as they felt they lacked the resources to counter their prejudices. Fredman (2004) also notes that deconstructing oppressive practices is a delicate process which, if embarked upon rashly and in the wrong environment can lead to increased difficulties and poor wellbeing. Therefore, any clinical implications to arise from this finding



would need to be framed so that individuals are given a safe and supportive sphere within which to explore societal oppression.

#### 4.6 Critical Review

The present study unearthed new findings through focusing specifically on a cultural, religious and linguistic group which has not previously been researched. The findings from this study both equally challenge and support the existing literature base. However, this study is not without its methodological weakness, the following section acknowledges such limits and offers suggestions for addressing these.

##### 4.6.1 Sample

The recruitment of participants was focused within a certain county in the UK. Therefore, the findings are not presented as reflecting or representative of wider Punjabi Sikh communities across the country. Indeed, whilst critics of qualitative research may criticise such findings on their limited generalisability (Mays & Pope, 1995), it is significant to highlight that this research's aim was to develop a substantive theory grounded in the unique perspectives of a small group of individuals, as opposed to a grand theory accounting for the experiences of all Punjabi Sikh wives.

Whilst this study employed a highly defined sample and superficially may seem to be entirely homogenous in terms of religion, language and geographical area, there were still significant differences in participant experiences. A flaw within the present study

is that such differences, including migration history, socio-economic background, caste and religiosity, were not specifically explored in relation to care-giving experiences. Previous research has demonstrated a strong link between migration patterns and experiences of dementia care-giving (Jutlla, 2014). Furthermore, research has also shown that levels of religiosity within Sikhism, that is whether one is a baptised (Amritdhari) or non-baptised (Kesa-dhari) Sikh is a strong mediating factor in shaping how caregivers made sense of dementia (Uppal & Bonas, 2014). The lack of exploration of migration and religiosity may have potentially masked important nuances in the wives' experiences and therefore the aim of de-homogenising this cultural group was perhaps not entirely met.

The sample for this study was entirely recruited from a Gurudwara (Sikh place of worship). As such, inferences cannot be made with respect to individuals who do not frequent the temple, whose experiences may have unearthed divergent views on the emphasis of religion and spirituality in spousal care giving.

The stage and severity of dementia, as well as the period over which the wives had been providing support, also varied amongst the participants. This is viewed as a strength of the study, in that it provides an insight into the wives' perspectives across the dementia care-giving trajectory.

#### 4.6.2 Neglected perspectives

Perhaps the single most neglected voice in this research is that of the husbands with a label of dementia. Whilst the absence of this important voice is not unique to this present study, it does pose very important question for researchers as how best to

incorporate this important perspective into research. One can argue that, through researching caregiver and professional perspectives, such research is practicing a form of malignant social psychology and invalidating the experiences of those with labels of dementia.

However, therein also lies a problem, that of obtaining fully informed consent from individuals which may not cognitively be able to do so. A recent literature review by Cowdell (2006) explored the various ways researchers have tried to overcome the issue of neglected voices in dementia research. In a sample of 22 studies there were examples of how consent was conceptualised as an ongoing process, sought at regular intervals in the interviews as opposed to a one off procedure at the start of the research. Written consent was increasingly rejected by many of the studies in place for verbal and behavioural consent. Cowdell (2006) also concluded from the review of studies that if creativity is exercised by researchers, novel ways of data collection such as music composition, artwork and diary excerpts can provide an equally valuable insight in to the experiences of individuals with labels of dementia. This is an important consideration for developing future research ideas.

This study sought to focus on the experiences of wives specifically as research has shown they are the predominant caregivers in South Asian dementia caregiving (Bowes & Wilkinson, 2003; Lawrence et al., 2008; Uppal & Bonas, 2014) and this study also sought to explore the under-researched area of marital relationships in the Punjabi Sikh culture. However, one cannot shy away from the fact that much of the dementia caregiving in Punjabi Sikh families is also delivered by children, daughter/son in laws and extended families. The present study may have benefited

from an additional exploration of the emergent model and how well it represented the experiences of other potential caregivers. The aforementioned issues will be further considered in the future research part of this chapter.

#### 4.6.3 Style of questions

A particular strength of the research was the thinking surrounding the interview schedule. As highlighted within the methodology chapter, a small group of Punjabi Sikh wives were consulted about the present study. Their input specifically focused upon the interview schedule, highlighting that the original questions were linear in nature and centred too heavily upon the internal worlds of the wives. They highlighted the importance of ensuring the questions tapped into more relational aspects of marital experiences and that participants were given an opportunity to express their views about wider systemic factors impacting their experiences of their husbands.

This feedback was invaluable and prompted the author to think closely about utilising systemic therapy orientated questions to facilitate a wider more circular exploration of the wives' experiences. For example, the use of circular questions (who do you think is most affected by your husband's memory difficulties? how are they affected? How is it that society positions your husband?) prompted an exploration of familial and societal relationships and meanings attributed to memory loss. This in turn generated multiple explanations and stories in contrast to linear questions (describe the nature of the memory difficulties your husband experiences) which focuses more on the situation itself as opposed the *impact* of the situation.

Perhaps most importantly, the shift away from linear questions, questions which imply a cause and effect (why do you think your husband reacts like this when he is upset?) removes a pathologising spotlight from both the participant and their husband. Instead, it opens a space to think more widely about dominant discourses and as iterated by the participants imbued them with a sense of agency and was in stark contrast to the 'carer blaming' rhetoric they were frequently exposed to in their daily interactions with others. This allowed for the fostering of trust between researcher and participants, which is especially important given research on the mistrust amongst such communities toward such studies (Milne & Chryssanthopoulou, 2004).

#### 4.6.4 Interviews

The interviews may potentially have been shaped and impacted by numerous variables. The interviews were predominately carried out in the homes of the participants as a means of facilitating participation in the study and overcoming mobility issues. However, for six of the interviews, other members of the participants' families were also present in the background and this may have potentially restricted how much they felt comfortable sharing. In contrast, the home environment may have further enhanced the participants' sense of connection to their husband through being around photographs and their belongings.

Three interviews also took place at the Gurudwara, this may have also impacted the importance afforded to spiritual and religious explanations and/or hindered their willingness to share more difficult elements of their experiences for fear of karmic punishment.

#### 4.6.5 Language

One of the key strengths of this research has been the opportunity to carry out the interviews in Punjabi, as such, no participants were denied the opportunity to participate based on their English fluency. Given this group of participants had expressed experiences of marginalisation and social exclusion, it was especially important to afford them the experience of exercising their voice without the constraints of the English language (Patel, 2002). Indeed, previous research has shown that South Asian individuals tend to shy away from participating in research due to language barriers and uncertainty about the research process (Milne & Chryssanthopoulou, 2004). Therefore, concerted efforts were made to ensure the research process was clearly explained in Punjabi at every stage, with participants actively involved in the shaping of the research design and interview schedule. Conducting the interviews in Punjabi allowed for a more rich and nuanced account of dementia care-giving to emerge and contribute novel findings to the existing literature.

During the translation process concerted efforts were made to ensure the English translation remained as true as possible to the original Punjabi accounts of the participants. However, whilst many the Punjabi words used were translatable in to English, the English equivalent did not entirely capture the emotional and cultural complexities. These words were highlighted and during the member checks, participants were asked if the English translation was close to their experiences and modified accordingly. Member checks are an integral part of the qualitative research process and involved consulting group of three women who initially participated in the focus group at the start of the study. The emergent model was presented to the

women and discussions were held about the resonance of the model to their experience. The three women agreed that the model was a good fit for their daily experiences.

#### 4.7 Clinical implications

Exploring the experiences of Punjabi Sikh wives supporting husbands with a label of dementia provided significant insights. Whilst the findings of this study echo existing research highlighting the reticence of BME individuals, specifically Punjabi Sikh's do seek support outside of their immediate support network (Jutlla, 2014; Lawrence et al., 2008 Mackenzie, 2006), it also provides additional reasons for such restraint. In addition to the well documented barriers such as language, mistrust and unawareness, the present study brings to light issues of social inequality, racism and medical colonization as further barriers to service engagement.

The emergent model calls for clinicians and commissioning groups to re-think frameworks of support and practice more creatively and in line with the unique values and motivations of this cultural sub-group. The clinical implications outlined below are situated in the accounts of the participants, they reflect novel ways of working with not only clients from Punjabi Sikh backgrounds but also present ideas of how to work with difference.

Keeping in mind Martin-Baro's (1994) critique of traditional psychological research lacking societal relevance, the following clinical recommendations are designed to be attuned to not only the clinical but also socio-political context of the clients we work with.

#### 4.7.1 Rethinking psychological services

A key finding to emerge from this study was the participants' feelings of frustration when healthcare professionals focused solely on the behavioural aspects of their husbands' demeanour. Based upon such reflections clinicians should endeavour to adopt a holistic approach to assessment and intervention which considers a multitude of contexts other than just the individual context. Using frameworks such as coordinated management of meaning system (Cronen, Chen & Pearce, 1985) and Bronfenbrenner's Ecological Model (Bronfenbrenner, 1986), clinicians can extend their thinking beyond the individual and ensure that assessments take into account the various ways wider family, societal and governmental policies may impact the wellbeing of an individual.

For example, in the present study, a dominant category to emerge was how experiences of social inequality were strongly linked with the way in which the husbands presented with age related changes. Clinical psychology as a profession is increasingly being placed within a critical spotlight for the lack of social and political thinking it affords individuals (Fox, Prilleltensky, Austin, 2009). As evidenced in this study, the discipline's propensity to focus on symptom reduction and the individual alone is being experienced by clients as an iatrogenic factor, hindering rather than promoting their wellbeing.

Whilst a critical appreciation of the wider social influences upon mental wellbeing may be argued by traditional positivist psychologists as being beyond the scope of their practice, Martin-Baro (1994) contends that critical consciousness (extending



curiosity toward power imbalances within society) should be an imperative part of every 'psy' disciplines' practice.

#### 4.7.2 Importance of language

Participants in this study continually spoke about their reticence and anger toward certain labels such as 'carer' and 'dementia'. Participant's expressed their frustration of feeling silenced through such language and specifically re-experiencing the trauma of being colonized by western concepts. Decisions about language should not be made widely across all BME groups as for some being termed a 'carer' brings with it a sense of purposefulness (Mackenzie, 2006), rather, language should be carefully thought about on a case by case basis. Language is a powerful tool which can have serious implications for how individuals are positioned within society and how they experience services (Moane, 2003). Therefore, clinicians should continually engage in self-reflexivity and ask themselves questions such as; how am I being perceived by clients? Which discourses are impacting my practice with clients from minority backgrounds? How can I make these explicit to the clients and their families? Is my practice in any way further distancing the client and their family from the safety and familiarity of their cultural norms?

#### 4.7.3 Valuing family perspectives

The wives in this study repeatedly spoke of feeling 'silenced', 'misunderstood' and 'ridiculed' by services and yet evidently, they possessed rich and valuable information about their husbands. Given these findings, clinicians should ensure family members are given the appropriate space to discuss their concerns and in fact

consulted as experts in their own experience rather than assuming professional superiority over them. Clinicians should privilege the conceptualisations clients and spouses provide and attend particularly to the religious and cultural elements of their explanations.

#### 4.7.4 Cultural sensitivity

Determined efforts should be made to extend curiosity toward how Punjabi Sikh service users and families understand ageing and distress and which discourses govern their thinking. Western ideas about ageing and bio-medical models of distress should be lightly suspended in favour of cultural and religious conceptualisations more congruent with the values of the service users.

For example, participants spoke of their husbands being referred to mindfulness and reminiscence groups but these groups having no cultural relevance to their experiences. Given the emphasis on spirituality and collective story telling in the participants' accounts, clinicians can help families to think of more personalised ideas of help such as Simran (collective Sikh praying and meditation).

Participants in this study spoke about the sense of familiarity their husbands experienced when they sung traditional Punjabi folk music together. Therefore, reminiscence groups specifically tailored to cultural groups with an emphasis on, shared stories about the same country would facilitate more recollection and connection. Specific cultural groups would also enhance ones cultural and social identity more so than generic westernised reminiscence groups designed for a different cohort of older adults who grew up in completely different contexts.

#### 4.7.5 A true dialogue between families and services

One cannot deny the breadth and depth of experience held by clinicians however, this can be further supplemented by the experiences of carers and family members. Participants in this study expressed their feelings of embarrassment when doctors were perceived to mock their “lack of knowledge about textbook versions of dementia” and feeling coerced to “sit and listen to their medical explanations”.

Clinicians should endeavour to engage in a two-way learning process with spouses which has reciprocity at its heart. Mutual learning spaces should be set up in which true dialogue exists between professionals and family members and information is readily shared without conforming to typical power structures inherent within doctor-patient dyads. Spouses should be encouraged to educate clinicians about their cultural and social contexts and indeed such practices would be in line with Patient Public Involvement initiatives (Baggot, 2005).

#### 4.7.6 A safe cultural space for spousal reflections

Whilst initially reluctant to do so, participants did gradually begin to share personal reflections about the impact of supporting a husband with a label of dementia. Participants in fact expressed their relief at being able to express their personal experiences as barriers such as cultural norms and stigma had previously prevented them from sharing. Therefore, clinicians should think creatively about the best way to support spouses from minority backgrounds to have a safe space to explore and reflect upon their feelings toward caregiving. Clinicians should be particularly

sensitive to gendered and cultured ideas around emotional expression and not be quick to dismiss families for 'not engaging' or being 'hard to reach'. Clinicians need to be especially mindful of culturally adapting such reflective spaces for the unique needs of Punjabi Sikh spouses so that they experienced as safe, validating and curious about issues of difference and oppression.

Whilst individual therapeutic space may also be an option for some participants, given the emphasis on collective story-telling and collective resistance in this study a group format may be the most ideal format to begin with. Given the level of mistrust toward medical institutions, thought would need to be given to the setting of such spaces as well as potentially asking wives to help co-facilitate such groups to further quash power differentials experienced between carers and clinicians.

#### 4.7.7 What is not lost?

Whilst an assessment of cognitive, social and emotional changes is important, equally valuable is an exploration of retained abilities and resources. The participants in this study highlighted the oppressive and derogatory nature of conversations with healthcare professionals which focused solely on loss and degeneration. Spouses are well placed to help facilitate thinking about retained abilities and conversations should be reframed with professionals to prompt thinking about the values inherent within retained resources and how they can potentially help compensate for the changes experienced.

#### 4.7.8 Reciprocity

The concept of reciprocity was so key in the participants' narratives that it prompted the researcher to think closely about the lessons she learnt from hearing the participants talk about their experiences. The reciprocal reflections were shared with the participants at the end of the research interviews, the participants overwhelmingly responded that upon hearing such reflections they felt an increased sense of "confidence" and "pride in themselves". There is a strong drive toward reciprocal reflections in post-modern therapies such as narrative therapy (White and Eptston, 1990). Specifically, therapeutic letters and outsider witness practice encourage clinicians to share their personal resonances with client's accounts and highlight specifically how such learning will aid their future practice. Encouraging clinicians who work with older age clients to share their reflections with individuals and their families will provide an important and much needed paradigm shift in clinical practice which currently frames emotional expression as a one-way process. In addition, the sharing of such reflections would enable both clients and families to experience a much needed sense of agency which can at times be overshadowed through medical discourses and a reliance upon 'the expert' for advice and treatment.

#### 4.7.9 Intergenerational learning

A key finding in this research was that of the tensions which exist between first and second/third generation Punjabi Sikh's. The participants recounted numerous experiences of ageist attitudes, a pressure to conform to "newer shinier western ideas" and a lack of appreciation for the societal investment made by the older generation. Equally, participants expressed a lack of curiosity for learning about the demands

placed on their children growing up in dual cultures. Such tensions not only led to feelings of sadness and anger amongst the women but also directly impacted the wellbeing of their husbands.

Whilst creative initiatives designed to foster greater connections between different generations have been set up by the Alzheimer's Society (Alzheimer's Society, 2013), no such initiatives exist specifically within Punjabi Sikh communities. Unlike the spaces designed by the Alzheimer's Society an inter-generational learning space for Punjabi Sikh's would need to attend to the complexities of the older generation living in what they call a 'host country' and the younger generation not necessarily being able to find resonances with such accounts due to being born in the U.K. Curiosity could be forged between both groups through initially focusing on shared experiences such as racism and feelings of difference in a predominately White country. An inter-generational thinking space would hopefully allow both older and younger generations to have a mutual appreciation of the tensions faced by each and in turn bring together their collective resources and unique strengths to think of creative ways to help one another.

#### 4.7.10 Re-thinking policy

A key differentiation participants were keen to make in their accounts was the ways in which they actively adapted, resisted and responded to the changes in their husband as opposed to how they were personally impacted by them. Participants frequently cited the importance of focusing on the adaptation to change as opposed to impact as a way of asserting their agency and resisting discourses of passivity imposed on them by health professionals and younger generations. This is an

important finding for shaping the way in which policies pertaining to individuals with dementia and their families are researched, developed and disseminated. For example, within the National Dementia Strategy (Department for Health, 2009) the recommendations centre upon ‘early diagnosis, increased research to find a cure and safe use of medical interventions’ (NDS, page 4). These recommendations focus on the impact of dementia on individuals and imply a sense of passivity on the part of the individual who needs ‘medical interventions and cures’. The sense of agency demonstrated by the participants should be incorporated into policy recommendations calling for clinicians and families to work closely together to think creatively about living with dementia changes.

## 4.8 Reflections

### 4.8.1 Reciprocal reflections

In the spirit of social constructionist practice, there are many dialogues with the participants in this study which have moved me and which I hope to take with me in to various contexts of my personal and professional life. Whilst reflections of a reciprocal nature are not commonplace within research, they form a strong part of my clinical practice with clients. I have witnessed first-hand the power of sharing with individuals how their experiences and stories have had an impact on me and moved me to think about myself and society differently. One participant vividly described her experience of “a racist gaze” in the context of asking her GP for help. This expression struck me, it resonated with me on many different levels. I felt it in my stomach, the same way I had felt a sinking stomach when I too have been to see health professionals either for myself or accompanying my elderly parents. I recall

going to see professionals and feeling the ‘racist gaze’ of GP’s and nurses who didn’t believe what I had to say and/or who had totally misconstrued my culture. I remember recalling that it didn’t ‘feel right’ but always feeling uncomfortable and/or silenced to name the experience.

Therefore, I have been particularly moved by the way in which the participants in this study have named the unjust practices of those around them. I have learnt from them the importance of reflecting upon uncomfortable experiences within institutions and having an openness to name such experiences. For naming and unearthing the inherent unjust processes around us is I believe the first step in liberating oneself of the shame and feelings of inadequacy often imposed upon us by the most dominant and powerful in society.

Listening to the participants’ stories of migration, cultural loss and most importantly strength and perseverance has imbued me with a strong sense of curiosity about my own cultural heritage. Whilst I have always had a passion to learn about my own culture and religion, I have naively assumed an ‘expert position’ and believed my lived experience of being a young Punjabi Sikh woman has given me all the information I need to know. However, I now realise that I have so much more to learn, I wish to hear the stories of my ancestors and how their experiences of migration and living in a host country whilst trying to resist dominant discourses have shaped our family scripts. I am particularly keen to think about how my values of social justice may potentially be a learned experience I have learnt from my ancestors.



Through conducting the research interviews, I have increasingly thought about the way in which psychology as a profession at times contributes to power differentials through diagnostic discourses. I have specifically questioned the extent to which labelling and the non-questioning of system structures may feed into clients' distress and feelings of marginalization. Subsequently, these interviews have encouraged me to become more accountable to the potential iatrogenic effects of my psychological practice.

Being a minority ethnic Trainee Clinical Psychologist I have particularly struggled to hold on to elements of my cultural identity which do not readily conform to the western and Euro-centric theories of distress taught to me on the clinical doctorate. I have always attributed my silence of not challenging such discourses to a misconception that to challenge such theories one needs to be assertive and loud. As a quiet young woman who finds more solace in listening rather than talking, listening to the stories of participants has encouraged me to think about resistance and challenging taking many different (even quiet) forms. Learning about the ways the woman in this study have creatively resisted discourses about cultural inferiority has taught me that I too can exercise my voice in a creative way through engaging in forums and writing articles about my experiences on training as a BME woman.

#### 4.8.2 Process reflections

Reflecting on my position as a Punjabi Sikh Woman, my shared ethnicity with the participants may have brought with it a range of factors worth considering more closely. In many ways, I believe the shared frame of reference helped the research process, most notably regarding recruiting from what research calls a hard to reach

group. Whilst many researchers have argued that studying groups of individuals with whom one connects with culturally is a basis for effective research (Grewal & Ritchie, 2006), I have wondered what the potential drawbacks of ‘in group’ research could also be. For example, my shared cultural framework with the participants and perceived cultural similarities may have inhibited me from further exploring culture-specific participant experiences. Given the strong emergent theme pertaining to inter-generational conflict, I am also curious as to how I was positioned by the participants? Was I too thought of as a “naïve and ignorant kid” and if this was the case how did this impact on how much the participants felt able to share with me. Learning from this experience, in any future research I would endeavour to make naming of potential assumptions a key part of the research process.

In line with the social constructionist epistemology of this research, I endeavoured to frame this study as a “researcher–participant co-production of knowledge in which the division between researcher and subject was blurred, and control over representation was increasingly shared” (Gergen & Gergen, 2000, p. 1035). The decision to remove ownership of the research from the researcher and redistribute ownership with the participants was a conscious one. From the outset, I have been mindful not to further oppress a group of individuals who had shared experiences of being colonised by western concepts and ideas. My attempts at power re-distribution varied in their outcomes, whilst methodological considerations such as including a focus group to help design the interview schedule were successful, sharing my own reflections bordered on what pure qualitative researchers may call ‘data contamination’ (Lincoln & Guba, 1985).

Such scrutiny to democratize power imbalances may have at times led me to closely align myself with the participant. Whilst such an alignment can be a positive and a validating experience for participants, I now realize I may have inhibited my curiosity toward other parts of their story somewhat. In future research, as Fredman (2004) advises, I will try to extend my curiosity to all parts of the system as each facet holds equally important information

Initially I was reluctant to explore the inter-generational tensions which the wives described between themselves and their children. My thinking prior to conducting this research was heavily primed by existing BME dementia research suggesting that ‘they look after their own’ (Bowes & Dar, 2000). Personal reflections prompted me to realise that my thinking around cultural stereotypes of family networks being the sole source of support for BME groups was incorrectly aligned with dominant discourse. However, through research supervision and personal reflections I became increasingly confident in naming such assumptions and allowed myself to become more open to exploring such tensions within the accounts of the wives. Furthermore, it encouraged me think about how my position as a Trainee Clinical Psychologist working within NHS settings in which dominant discourses about “hard to reach BME individuals” stunted my curiosity into thinking more widely about systemic factors which may in fact make services hard to reach for BME individuals. This research experience has taught me the importance of reflecting on such experiences and thinking about the impact of how I co-construct meanings with participants.

#### 4.9 Future research

The novel findings which have emerged from this study can be further explored and form the basis of future research. In keeping with the systemic spirit of the emergent model, the current study could be extended by exploring the meaning and constructions of dementia from several different lens's. Given the participants repeatedly referred to the 'the others' as a dominant and oppressive force upon their wellbeing it would be useful to extend our curiosity to better understand the perspective of 'the others' Specifically, this may include interviewing the children of the individuals with labels of dementia and health professionals who see Punjabi Sikh's in their services. As highlighted in the personal reflections section, it is easy to become easily aligned to the most marginalised group of individuals, however, to better understand social experiences, it is imperative to exercise neutrality and curiosity and engage in meaningful dialogues with those positioned as holding the most power.

Participants in the present study exercised their agency and spoke of their resistive actions against dominant western ideas. Such creative resistance can also be utilised within research developed, specifically within a Participatory Action Research (PAR) framework. PAR is concerned with quashing traditional researcher/participant power differentials and instead positions participants as the active agents to design, conduct and disseminate research. An advantage of a PAR framework with Punjabi Sikh wives would mean they could further research area's which are pertinent to their own experiences and the dissemination of such findings could also be done in a creative way such as a short film, seminars or a collection of songs and poems. Dissemination in this way would allow for the findings to be readily shared amongst the community and may have more impact than an academic research report or journal article.

As highlighted within the limitations section of this research, the heterogeneity of the population was not adequately acknowledged or addressed. Therefore, future research may expand on the existing findings with an increased focus on migration history, marital attachment styles, caste, religiosity or even a different geographical area of the U.K.

#### 4.10 Conclusion

The present study, despite its limitations has, generated findings which support existing findings and theories. More importantly, it has also contributed novel findings to the under-researched field of Punjabi Sikh spousal experiences of living with dementia. The emergent theoretical model highlights the ongoing complexities Punjabi Sikh women face with regard to acknowledging, understanding and living with dementia related changes in their husbands whilst living in a host country.

The unique cultural and religious explanations provided by participants help conceptualise dementia from a different psycho-social angle than is traditionally done so in dementia research. Furthermore, the emphasis on the ethos and history of Sikhism in mediating understandings of dementia further highlights why it was important to research this cultural group specifically. Whilst participants recognised the practical and emotional difficulties faced with regard to wider systemic pressures such as, dominance of the biomedical model, fear of recolonization and racism, they also vividly portrayed accounts of resistance. This is an area particularly important to amplify for, it presents a new perspective of Punjabi Sikh women who, traditionally have been cast as passive in research and society more widely. The unique insights of

the participants have helped shape clinical implications which, if utilised will have important ramifications for health professionals, families and individuals with diagnoses of dementia, specifically within Punjabi Sikh communities.

#### 4.11 Key points covered in the chapter

- This research provides new insights in to how Punjabi Sikh wives conceptualise dementia differently to the dominant biomedical explanations so widely propagated in society.
- It adds further support to existing research which demonstrates that dementia caregiving in spousal relationships is not entirely a burdensome or isolating experience but can instead contribute to evolving identities and reciprocal care.
- The research lends itself to several easily implementable clinical initiatives designed to draw upon community strengths and celebrate difference.
- Future participatory action orientated research which places BME participants in the driving seat can help further elucidate unique cultural experiences and better shape clinical service provision.

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**Appendix A: Search string and inclusion and exclusion criteria for the literature review one**

**Table 5: Search terms, limiters and results**

<b>Databases searched</b>	<b>CINAHL Complete, MEDLINE with Full Text, PsyArticles</b>	
<b>Dates Searched</b>	<b>All years (January 1982 –April 2017)</b>	
<b>Search no.</b>	<b>Search Term</b>	<b>Results</b>
<b>1</b>	wife* OR “wive*” OR husband* OR spous*	<b>2,456,501</b>
<b>2</b>	“alzheimers disease" OR "vascular dementia" OR dementia OR “frontal temporal dementia” NOT cancer NOT depression NOT bowel NOT pain NOT palliative NOT "end-of-life"	<b>128,993</b>
<b>3</b>	Experience* OR understand* OR meaning* OR attribute*	<b>149,873</b>
	<b>#1 AND #2 AND #3</b>	<b>325</b>
	Duplicates removed	<b>266</b>
	Limit English Language, Adults, Humans	<b>185</b>

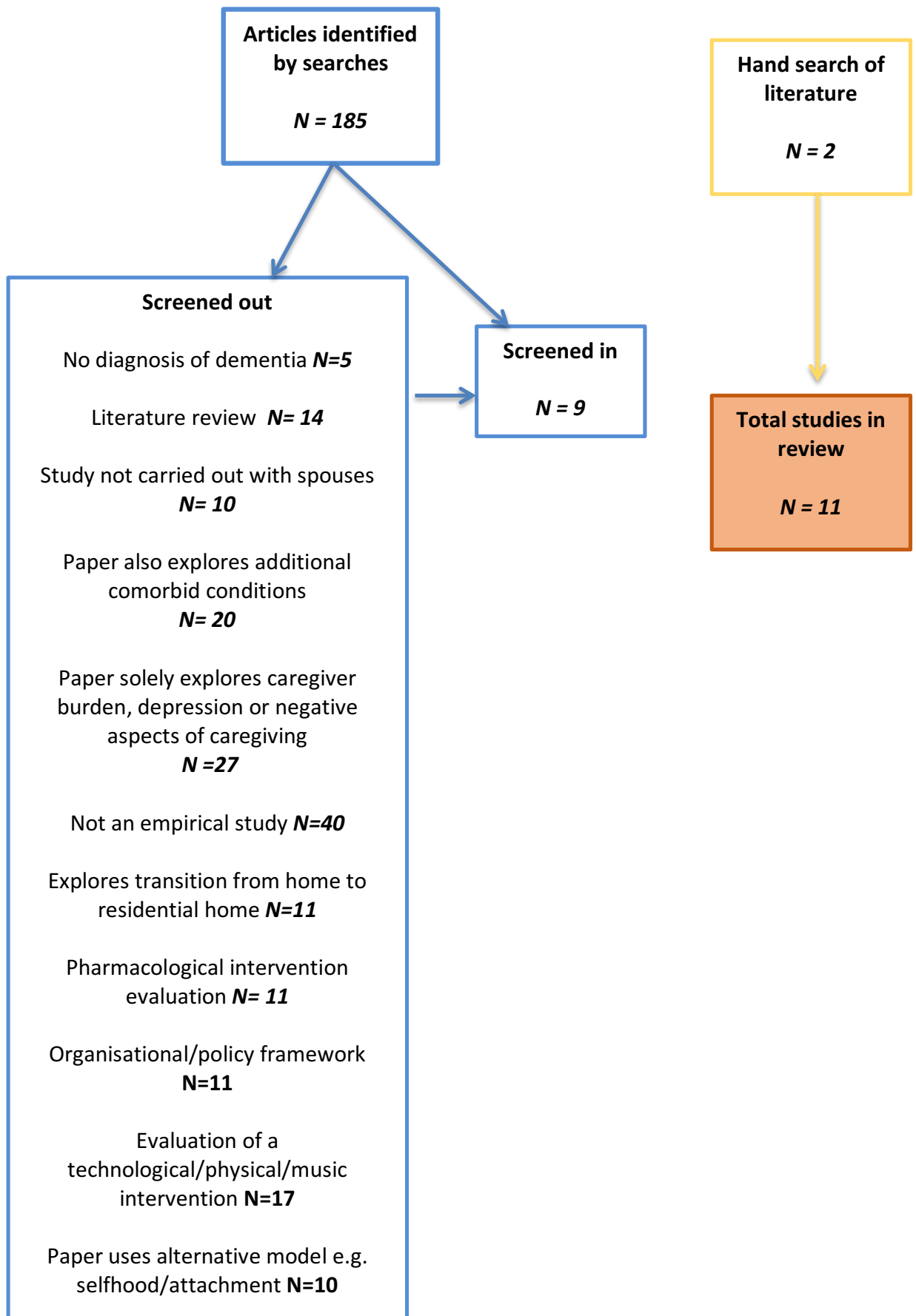
*Inclusion criteria*

The following inclusion criteria were applied in article selection:

- f) The study recruited spouses directly involved in the care of the person with dementia. For the purposes of the review, husbands were also included in order to provide context to the findings and ascertain gender differences within caregiving
- g) Only empirical studies were included
- h) The individual being cared for must have a formal diagnosis of dementia and no other comorbid conditions. This was applied because any comorbid conditions add further complexity to the caring process and may detract from the conceptualisation of dementia.
- i) Participants were adults over the age of 18.
- j) Articles were published in English



**Figure 2. Reasons for why the remaining studies were excluded.**



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**Appendix B: Study characteristics of studies included in Literature Review one.**

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Study	Sample	Design and analysis	Main Findings
Brown & Alligood, (2004)	11 Caucasian wives Aged 60 and above Recruited from memory clinics	Qualitative- semi-structured interviews with spouses. Grounded theory analysis	Spouses reached for external support as soon as realized something was wrong with partner. Actively sought diagnosis and medication to make sense of uncertainties. Relied heavily on medical professional support Physical and behavioural needs privileged and emotional needs downplayed
Hyden & Nilsson, (2015)	11 spouses Aged 57-60 Partner with dementia administered MMSE test	Qualitative – semi structured interviews with spouses and person with dementia	When spouse spoke about shared activities and sense of affection used the pronouns of ‘we’ to give sense of stable social unit. When spouses spoke of medical interventions and

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	Recruited from memory clinics		diagnosis referred to partner as 'you'. Medicalisation creates distance in couples
Jansson, Nordbery & Grafstrom, (2001)	8 spouses Aged 71-85 Recruited from memory clinics	Observational data collection and semi-structured interviews Grounded theory analysis	Doing activities together helped retain esse marriage Developed new roles which go against prev help gendered roles Ability to mentalise seen as unique marital not held by professionals Aimed to foster self-esteem and protect ma identity. Anxiety about inevitable loss and death

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Molyneaux, Butchard, Simpson & Murray (2011)	5 couples – 3 wives, 2 husbands Aged 72-84 Recruited from mental health clinics	Qualitative research- semi structured interviews Grounded theory analysis	Shifting identities – gendered roles changin self-identity eroded Preserving personhood – through affection reminiscing together and doing activities together. Sharing dementia – talking about emotiona responses together.
O’Shaughness y, Lee & Lintern (2010)	7 spouses, 5 wives, 2 husbands All white British Aged 59-86 Recruited from Alzheimer Society	Qualitative research – semi structured interviews IPA analysis	Lack of connection through loss of shared activities Tension meeting own needs and partner’s r Increased uncertainty about the future and dementia prognosis. Seek control of uncertainty through taking

			control over activities and avoidance of em
Perry & Conor (2002)	38 spouses recruited from mental health clinics	Secondary analysis of qualitative data.  Constant comparative data analysis	Maintain continuity important in marriage  Protecting spouse against incompetence  Preserve personhood of spouse through recognizing retained abilities.
Quinn, Clare,  Pearce, Van  Dijkuizen (2008)	34 spouses, 28 wives, 6 husbands.  MMSE administered to spouse with dementia	Qualitative research.  IPA data analysis  Interviewed by Clinical Psychologist	Don't know what is happening to spouse.  Changes in relationship – lack of equality a much dependence.  Not all plain sailing – no hope for future, bitterness and frustration with dementia spo

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Sherman & Boss (2007)	9 wives (7 White, 2 Hispanic) Aged 51-79 Recruited from medical clinic	Qualitative research design Grounded theory data analysis	Lack of help from wider family. Feeling alone with caregiving. Caregiving feels professionally Wider family lack curiosity of person. Spouses feel conflicted with retaining own identity while looking after needs of spouse. Taking increasing control over daily tasks (invalidating of spouse with dementia).
Shim, Barroso & Davis (2012)	21 spouses recruited from memory clinic	Qualitative research design Constant comparative analysis	Positive caregiver group – relished caregiving used life stories to make sense of dementia Negative caregiver group – defined all experiences as negative, felt professional n

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			spouse and focused on own unmet needs Ambivalent caregiver group – mixed emotions and difficulty accepting diagnosis.
Robinson, Clare & Evans (2005)	9 spouses, (5 wives, 4 husbands) Recruited from memory clinics	Qualitative research design IPA data analysis	Not quite the same person Noticed changes gradually but once acknowledged, sought GP support straight away Medication and diagnosis helped to make sense of changes. Depression and anxiety noticed in self Felt like a professional carer

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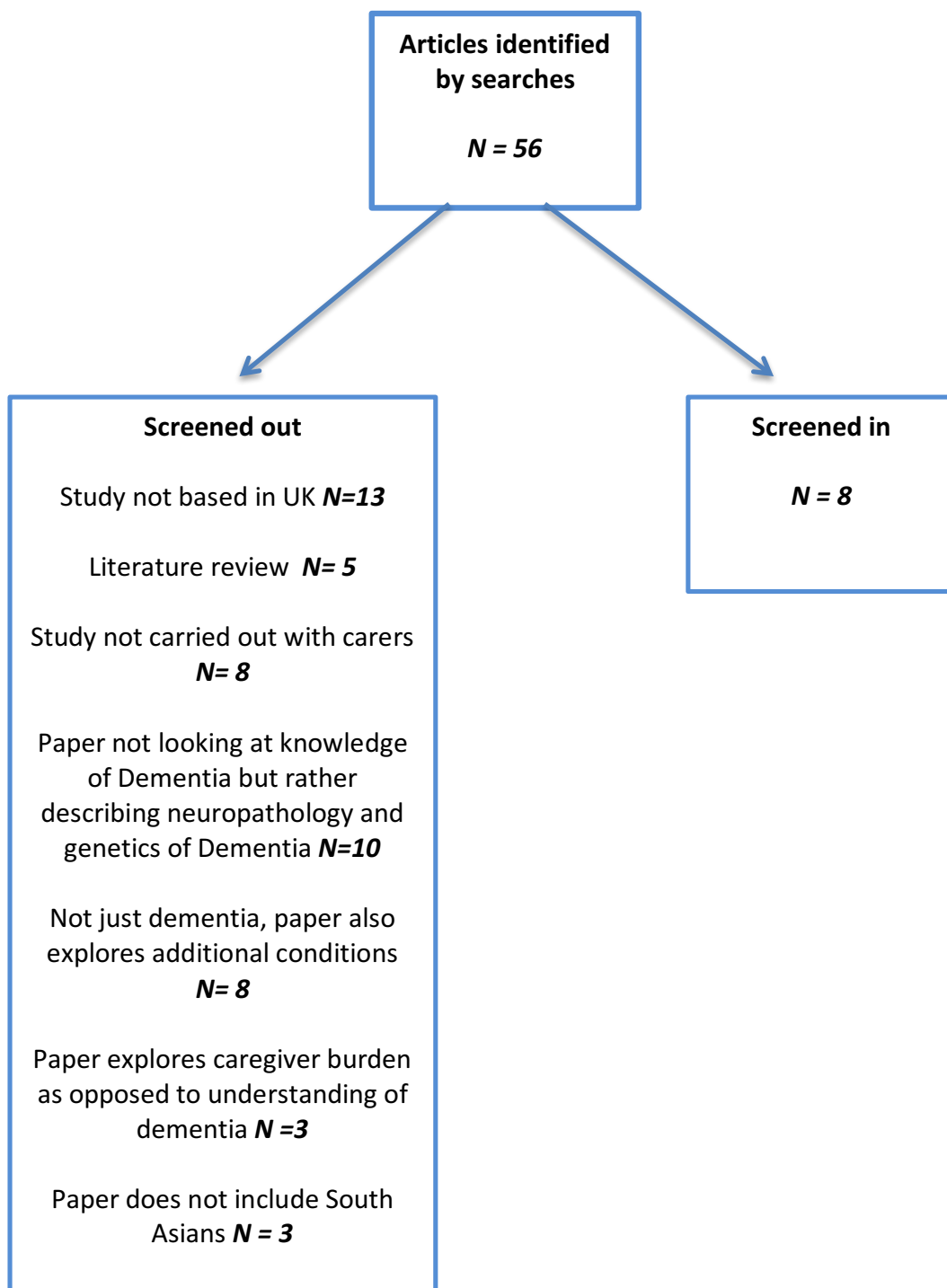
Walters,	6 wives	Qualitative research design	Uncertainty if same person or different.
Oyebode & Riley, (2010)	Aged 64-78	Grounded theory data analysis	Relational changes in marriage (lack of equality) Removing agency was a way of getting control overs situation. Hostile emotional response toward husbands – behaviour deliberate and controllable.  Person centered care more apparent earlier dementia diagnosis.

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**Appendix C: Excluded studies for literature review 2 exploring South Asian conceptualisations of dementia**

**Figure 3. Excluded studies for literature review 2 exploring South Asian conceptualisations of dementia**



**Table 6: Search terms, limiters and results for literature review 2, exploring South Asian conceptualisations of dementia**

Databases searched	<b>CINAHL Complete, MEDLINE with Full Text, PsyArticles</b>	
Dates Searched	<b>All years (January 1980 -June 2017)</b>	
Search no.	Search Term	Results
<b>1</b>	<b>"south asian" OR India* OR Pakistani OR "Sri lanka*" OR Afghanistan* OR Bangladesh* OR Bhutan* OR Bengal OR Sikh OR Hindu OR Hindi OR Muslim OR Nepal* OR BME OR "ethnic minorit*" OR Punjabi* OR Urdu OR Tamil OR Gujarati* OR Bengali* NOT American NOT Singapore NOT Japan* NOT Chin* NOT Taiwan*</b>	<b>131,864</b>
<b>2</b>	<b>"alzheimer* disease" OR "vascular dementia" OR "frontal temporal dementia" OR dementia</b>	<b>214,486</b>
<b>4</b>	<b>knowledge OR understand* OR conceptuali* OR awareness OR experience* OR perception OR belief OR perspective OR "make sense"</b>	<b>1,849,707</b>

<b>5</b>	<b>#1 AND #2 AND #3</b>	<b>72</b>
	Duplicates removed	<b>56</b>
	Limit English Language and Adults	<b>56</b>

**Appendix D : Study characteristics of studies included in Literature Review Two – South Asian conceptualisations of dementia**

<b>Study</b>	<b>Sample</b>	<b>Design and analysis</b>	<b>Main Findings</b>
Adamson, (2001)	30 carers  (18 African/Caribbean & 12 South Asian)	Qualitative – semi structured interviews Interview transcripts coded & themes identified.  Identified negative cases using constant comparative technique.	General awareness of dementia is low in South Asian carers (cite biographical narratives to understand dementia.) Theme of placing blame upon person with dementia.
Bowes & Wilkinson (2003)	11 service providers  4 South Asian carers	Qualitative – semi structured interviews with carers & service providers. Thematic analysis	Strong demand for services but limited uptake due to stigma. Limited knowledge & understanding of dementia amongst South Asian carers.
La Fontaine,	49 South Asians (all Indian)	Qualitative – focus groups	Little generational differences in views of ageing.

Ahuja, Bradbury, Phillips & Oyebode (2007)	aged 16-61 Recruited from religious and cultural centre's	Thematic analysis	Ageing perceived as a negative time by all. Dementia perceived to stem from physical and emotional difficulties and 'lack of love'. Strategies to cope include, medication, family self-help.
Jolley, Moreland, Read, Kaur, Jutla & Clark (2009)	10 South Asians 20 African 10 Caucasian	Discussion workshops Thematic analysis of discussions	Knowledge of dementia limited in all cultural all groups not only ethnic groups seemed to be
Jutla, (2014)	12 Sikh carers (9 women, 3men) (5 spouses, 6 intergeneration carers)	Qualitative design – narrative interviews Constructivist grounded theory analysis	Service use mediated by earlier experiences of and social inequality upon arriving in U.K. Participants drew strength and hope from exper

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			of migration and applied this to current difficulties experienced.
			Heterogeneity of Sikhs recognized with diverse migration histories impacting understanding of dementia caregiving.
Lawrence, Murray, Samsi & Banerjee (2008)	32 carers (10 Black Caribbean, 10 South Asian, 12 White British)	Qualitative – semi structured interviews. Constant comparative data analysis	Majority of South Asian carers possessed a traditional caring ideology in which they deemed professional help as a failure to fulfill carer responsibilities.
Mackenzie, J (2006)	39 carers (11 Pakistani, 5 Indian, 4 Polish, 1 Ukrainian).	Qualitative – semi structured interviews Data content analysed & organized into themes	Dementia explained using religious & cultural explanations inciting stigma & isolation in care

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Turner, Christie & Haworth, (2005)	96 South Asian (Indian, Pakistani, Sri Lankan)  96 Caucasians	Qualitative research – semi structured interviews  IPA analysis	In comparison to Caucasians, South Asian participants: <ul style="list-style-type: none"><li>- Dementia part of inevitable ageing</li><li>- Less overall knowledge about dementia and symptoms</li><li>- Unaware of treatments available</li><li>- More likely to rely on community and family support.</li></ul>
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## **Appendix E: Extracts from Reflexive Journal**

Charmaz's Social Constructionist approach views researchers as 'part of what they study, not separate from it' (Charmaz, 2006, p.21) and emphasise the importance of taking a reflexive stance. The researchers own context, subjective experiences and how they present themselves to participants were continually reflected upon to enhance the transparency, accountability and general trustworthiness of the research. Within a CGT research framework, such reflections typically take the form of memos and reflective journals to document personal biases and discussions with research supervisors. Below are three extracts taken from the researcher's reflective journal.

### **Extract 1**

I felt very moved today after conducting my first research interview with Joginder Kaur. Whilst I have worked with older adults in clinical settings before, the exchange did not feel therapeutic or even like a dialogue, it felt more like a one-way process, in which Joginder Kaur was put on the spot and I was simply there to 'extract' information from her for my own research agenda. I did find myself oscillating between a therapist and researcher role today and had to continually remind myself it would be unethical to start therapizing Joginder Kaur. Thankfully, the semi-structured interview schedule helped to keep me focused and on track. Moving forward, I will discuss this predicament with my research and clinical supervisors to better understand how I am still remain empathetic, curious, and compassionate whilst in a researcher role.



At times during the interview, I felt an embodied sense that Joginder Kaur wanted to share some more difficult experiences with me but for some reason felt inhibited to do so. I particularly noticed her bodily cues (holding her throat, deep breathing and looking away) when we briefly spoke about the relational difficulties with her daughter. At this point in the interview I did not feel comfortable highlighting what I had noticed, I will ask my research supervisor if it would have been appropriate to reflect on these embodied reactions to the questions with Joginder Kaur. Reflecting now, I too felt a dry throat as if I was unable to swallow or digest what it is that Joginder Kaur potentially wanted to tell me. I have been thinking about how I may have perceived by Joginder Kaur and how she may have potentially positioned me as her daughter. Her inability to articulate difficult feelings may have been a desire to protect me from her conflictual projections about her daughter. I will think closely about my position within the research interviews and how it possibility interferes/enhances the research process.

### **Extract 2**

Today I met with Baksho Kaur, from the outset I felt quite uncomfortable. She was mocking of my research equipment especially of my Dictaphone, suggesting that I was the one who had memory problems if I was unable to remember what she had to say in the interviews. My instant reaction was that of defensiveness and I feel I bombarded her with a highly-theorised explanation as to why I needed my notes and Dictaphone. This, I feel potentially ruptured the research process quite early on. From there onwards, Baksho Kaur was highly critical of my generation, especially Punjabi young people, claiming that they “knew little about their roots” and were “goats,

mindlessly following western idea's". Again, at these moments I felt quite defensive and wanted to prove my cultural competence through using complex Punjabi metaphors and idea's, however I refrained. Instead, I tried to reflect within the interviews, why it was that Baksho Kaur felt a need to position me in this way. One hypothesis I formulated was that the research interview was similar to her experiences of meeting with other health professionals, namely psychologists and GP's. These interactions had been difficult for Baksho Kaur as she had felt "ridiculed, powerless and mocked". I wondered whether her defensiveness toward me was a protective strategy against similar humiliation. After this point, I adopted an even more compassionate and curious stance to ensure I communicated to Bakso Kaur that *she* was the expert, not I. This helped significantly and I believe additional themes and experiences were able to emerge.

### **Extract 3**

I had a particularly difficult research supervision session today. I met with my two supervisors who provided their feedback about my tentative analysis of the transcripts. The theme of denial and incongruence kept popping up. They were particularly keen to think about why the participants in this study provided an "overly idealised and beautiful picture of caregiving". I felt myself feel a rising feeling in my stomach as well as a dry throat. I interpreted my embodied experiences to be communicating a sense of anger and frustration which I was unable to communicate. I wondered if this mirrored some of the experiences the participants highlighted, feeling constrained by western processes and having their culture misunderstood.

I felt frustration and anger because the interviews did not feel incongruent to me, I did not believe the participants were “saying one thing but actually meaning another”. The “idealised picture” the supervisors referred to, I believe was a manifestation of the participants’ religious values and historical virtues. At this point I felt an immense sense of pressure and responsibility to ensure I was able to do justice to the participants’ accounts and experiences and not tarnish or contaminate them with theories which held very little relevance for them.

Equally, I felt frustrated because I think “getting to the true meaning” of what the participants were trying to communicate was going against the epistemological and ontological stance of the research, I was not concerned with finding a true reality but rather with understanding how the participants constructed their felt sense of their reality.

## Appendix F: Interview transcript with initial codes and Punjabi translations

Researcher: Aunty ji tusi rangaa bareh kuch keh rehe si, meinu thoda hor das sakde oh is barch?  
Tusi keha ke dementia sirf kala aur chita lagda hai uproh par mein janana chaundi ah ke tuhnai  
kehre rang vikh de ne?

Researcher: Aunty ji, I'd really like to know more about the colours. You mentioned dementia  
being black and white on the surface but I am curious to know about what colours you see, the  
colours you experience in relation to it?

Participant: Putt, mein apne bacheya di pita ji kihna saalan di viyauni a, bahot bahot barsa de.  
Asi bahot kui vekhya akatheya ne, bahot kui seha asi akatheya ne. Jive Gurbani vich likya hai  
ke asi do jism par ek rooh a, vaakehve saadi rooh hun ek ho gai a. Hun tu aapi das putt mein  
kive apni rooh di gal sirf kaaleh ateh chiteh vich kara?

Jado saada viah hoya si mein bahot choti si, par meinu pehle din to ohne ne izzat diti, uhna ne  
kade vi meinu ehsaas ni dilaaya ke mein panj saal choti si uhna toh. Uhna ne mera saath ditta,  
uh ta rasoi vich aa ke vi mera saath dinde si jado sareh pind de kisaana di roti bana di hundi si.

**Thandi, Jasmeet K**  
Vekheya ekateh, seha akateh, (seen a lot and suffered a lot together)

**Thandi, Jasmeet K**  
Gurbani de vichaar, (turning to holy scripture to help make sense of changes)

**Thandi, Jasmeet K**  
Ek rooh hun, hoi a (they have become one soul)

**Thandi, Jasmeet K**  
Patti uhna di rooh a te bahot rang anal bhari a (talking in concrete black and white terms does not do her Soul (husband) justice)

**Thandi, Jasmeet K**  
Izzat mili, (feel respected by husband)

**Thandi, Jasmeet K**  
Saath mileya (always had husband's support)

Uhna di fooh saaf a, hanereh vich roshni dilaunde a oho. Sab kuj rang dinde a, asi bilkul khul mil jaande a pehla to hhi.

Mein galat na samji, gussa vi bahot karde ne oho, par sirf mehi aa jo uhno nu soot kar sakdi a. Bache kehnde ne ke pitta ji bajot badal gai ne, ke jive oh iteh nahi hun, jive uhna di battery kat di pevi a ja kuj. Par uhna ni nahi pata ke battery nu kive chalauna a, doorbeen je oh moran te oh vekh sakde ne apni pitta ji de saareh rang.

*Participant: young child.....I have been married to my children's father for decades and decades. We have seen so much together, we have experienced so much together. As our holy scriptures tell us 'we are two bodies but one soul'. Our souls have merged together, tell me young child how can I speak of my soul in just black and grey? .....(wipes tear from eyes)..... We got married and I was so young.....but from the very first day you know from day one he always respected me, he never treated me like I was 5 years younger than him. He supported me (laughs) he would even come to the kitchen and keep me company whilst I was cooked for the village farmers. He has such a pure soul, he lights up any darkness. His colours everything, we blend together so well. Don't get me wrong (laughs) he does have a temper as well (laughs)*

**Thandi, Jasmeet K**

Andhereh vich roshni (her husband is the light even in storms)

**Thandi, Jasmeet K**

Patti de Rang hajeh vi taaza hai (husband can still light up everything around him)

**Thandi, Jasmeet K**

Rishta mazboot hai kul mil (they have always blended together well, always had a strong relationship)

but I am the only one that can tame him (laughs). The children say dad has changed so much that....he isn't the same anymore....he just sits and looks out of the window....that as if he isn't here anymore... like his battery.... is going flat... or something. They just don't know what charges him up, they need to twist the tube, if they you know twisted it they would see all of their father's colours shining bright.

Researcher: Tusi meini das sakde o ke tuhanu ki lagda ke tuhade bacheh nahi vekh di tuhade pati vich jo tuhanu vikhda eh?

Researcher: *Can you tell me a little bit about what it is you think you see in your husband that your children don't.... what they may not necessarily see?*

Participant: Putt uhna ne ki vekhna? Oh ta uhneh a, jive oh hun uhno nu vekhna hi nahi chaunde, meinu samaj di a tu?

Participant: *(laughs) young child what will they see? They are blinded you know, it's as if...as if they don't want to see him anymore. Do you understand me?*

**Thandi, Jasmeet K**

Bacheh nahi vekhna chaunde (children don't want to see their dad properly anymore)

Researcher: Hunji aunty ji mein samaj di a, kis cheez nu uhneh a oh?

Researcher: Yes Aunty ji you are...what are they blinded to?

Participant: Mere bache uhneh a, uhna ne jaanke apne aap nu uhneh keeta. Ohna ne kaaleh chashmeh paayo ya fer sun nu vekhna ni phenda apneh pita ji te, apne himmat wale pitta ji the navaha di chadar vishahiyo ya. Jevah ah jeri demenjing cheeze ya eh kuj vi nahi ya tenhu patta . eh sirf ik chaddar ya jis nu apne pitta ji nu lakho sakhde ya, fir una nu sochna ni pehnda ehna deh bareh. Nigga teh Mun cho baar. Burie hushari ya , daso keh tusi teek ni and bas Khuli shooti , juh marji ghar wich karna karo. Sahibzadha ban janda raja. Par raja ta jeinda ya. Poar fir we ma ni chadar raehn dindi ma ta lakeh rakdi , befkoof na hoan. Tenu patta keh chooteh hundaya sadeh burjurga nu ah demenjing cheeze nai hundi si. Eh ta sirf gorehan neh baniyeh ah cheeze, eh sadeh leh nai ya . Meri befkoof nyaneh sab Khuj man lendh neh. Shayid Ehneh deh mulkh wich rendeh par meh enha deh befkoof asool nai mun nneh. Mein ta hukam nu hukam hi kahaava gi.

**Thandi, Jasmeet K**

Jaanke uhne (children have deliberately blinded themselves)

**Thandi, Jasmeet K**

Zehen ch bahar (ignoring their dad)

**Thandi, Jasmeet K**

Galan te naava de naal loko ditta (hiding dad in a veil of names and labels)

**Thandi, Jasmeet K**

Dementia loko dindi a (dementia label hides the true personality)

**Thandi, Jasmeet K**

Sochna nahi (don't think about dad anymore)

**Thandi, Jasmeet K**

Apne manmarzi layi kam (selfish reasons for using dementia term, to undermine dad)

**Thandi, Jasmeet K**

Gohreya ne banai hai, saadi li nahi (Dementia is not in our culture, devised by the west, not for us)

Participant: My children are blinded, they have deliberately blinded themselves. They wear these you know dark goggles so they don't have to see us and they cover their father, their amazing strong father in a veil of names and labels....this whole demenjing thing (laughs) it isn't anything you know. It's just a blanket you know like a veil to hide their father, and then you know they don't have to think about him, he becomes out of sight and out of mind. (laughs) it is very clever actually haha, tell him 'something wrong with you old man' and then...then you have free reign to do whatever you want in the house, the prince becomes the King but you know the king is still alive....(pauses). But I take that stupid stupid veil off! How foolish of them! You know growing up none of our elders had this demenjing thing. It is just something these white people have made up, it is not for us. My foolish children they just...they just accept it all. We might be living in their land but we won't...I won't just accept their stupid values, I will call a spade a spade.

Researcher: Acha phir tuhanu lagda a ke tuhade bacheh uhneh ho gai ne eh sab nawaan nal.....

*Researcher: So you believe your children are blinded by the labels they use to describe your husband.....*

Participant: Ha bas ehi!! Uhna vich pehla kuj vi galat nahi sigha jado uhna nu doctor de kol leke gai, meinu ta pata vi nahi si, meinu [dasseya] hi nahi ke doctor de kol kis gal karke leke ja re ne.

**Thandi, Jasmeet K**  
Dasseya kuj nahi (not being told anything by the others)



*Participant: yes exactly, there wasn't anything wrong with him when they took him to the doctor ji. I didn't even know...they didn't tell me what they were taking him to the doctor ji for....*

*Researcher: Tuhanu ki lagda tuhade bacheya ne vekheya ke oh doctor de paas gai?*

*Researcher: what do you think it is that your children saw that warranted a trip to the doctor ji?*

*Participant: Actually it was me who first noticed that he had begun to change, he was a little distanced distanced. But I knew why he was starting to live like this, you see he used to be president of the Sikh Temple, you know that young child? He was president of this place until 2016...15 years!! but........the elections happened he lost his role, it meant so much to him*

the presidency, it held so much value. That's why he is sad and lost now, he doesn't have anything of such value and status.

Sab to pehla vaise mein mehsoos keeta si ke oh kuj badal de pai ne, thodeh ukhre ukhre rehan lag pai. Par meinu ta pata si eh kyun es tara de rehaan lag peveh si. Oh hunna Gurudwareh de pardaun hundeh si tenu pata a? Oh 2016 tak pardaun rehe, 15 saal! Par chon toh baad, uhna da darza nahi reha. Uhna li pardaangai bahot ehmeeyat rakhdi si. Oh taahi ruseyp te gwache rehnde ne hun, uhn kol esi koi ehmeeyat ateh robh wali cheez hi nahi rehi.

**Thandi, Jasmeet K**  
Farak vekhna (Wife first to notice change)

**Thandi, Jasmeet K**  
Meinu ta pata hi si patni da darza (I knew exactly why – intimate knowledge gained through being a wife)

**Thandi, Jasmeet K**  
Zindagi di kahani (referring to his life story to make sense of changes)

## **Appendix G: Ethical Approval from University of Essex**

MISS J. THANDI  
21 BROOK ROAD  
GRAVESEND  
KENT  
DA11 8RQ

Dear Jasmeet,

**Re: Ethical Approval Application (Ref 15033)**

Further to your application for ethical approval, please find enclosed a copy of your application which has now been approved by the School Ethics Representative on behalf of the Faculty Ethics Committee.

Yours sincerely,

Lisa McKee  
Ethics Administrator  
School of Health and Human Sciences

cc. Research Governance and Planning Manager, REO  
Supervisor

## **Appendix H: Participant Information Sheet**

### **Living with husbands with a label of dementia. The experience and meaning of Punjabi Sikh wives.**

*What are the aims of this study?* This research aims to find out how Punjabi Sikh wives interact with their husbands who have a label of dementia. How do they make sense of their behaviour, diagnosis and emotions and what impact does this have on how they care for them. This research is not an assessment of the care that you provide but rather, it is hoped that this study will give Punjabi Sikh women a safe and non-judgemental space to shed light and reflect upon their experiences.

It is hoped that the findings from this research will help services have a better understanding of how best to help Punjabi Sikh families as well understand the strengths you exhibit when caring for family members with labels dementia.

*How will my information be stored?* The information you provide will be kept securely in a password protected secure computer file. Your information will be anonymised and any identifiable information will be stored separately from your responses.

*Do you have ethics approval?* This study has gained ethical approval from the University of Essex Ethics Committee. They have granted the research safe and ethical to participate in.

*Who is the researcher?* My name is Jasmeet Thandi and I am a Trainee Clinical Psychologist at The University of Essex. This research is being conducted as part of my Doctorate in Clinical Psychology. I am being supervised by (insert name here). Please feel free to contact (name) should you have any questions about the study itself or about me.

*What will the study entail?* If you consent to participate in this research, you will be asked to sign a consent form. The consent form will clearly highlight that your data will be kept completely confidential and that you are free to withdraw from the study at any point.

The study will consist of one interview lasting approximately 60 minutes in a location you choose. You will be asked questions about your caring experiences. If you consent to do so, the interviews will be audio recorded, to aid with data analysis at a later stage. The data will be anonymously stored onto a computer. You will be given a unique participant number and if you wish to withdraw your data from the study at any point please quote this number and your data will be destroyed.

*What will happen with my data?* It is hoped the findings from this research will be published in an academic journal as well as presented to local health and social care services. This will hopefully enable other individuals and services to have a better understanding of how South Asian carers make sense of dementia and how this impacts the care they provide to individuals with dementia. If you are also interested, a copy of the final report will also be sent to you.

Your responses during the interview will have no impact on the care and support you or your family member receive. This research is completely independent of any health service you currently receive.

Please do not hesitate to contact me should you have any further questions about the study.

Jasmeet Kaur Thandi

Health and Human Sciences Building

University of Essex

Wivenhoe Park

Colchester

Essex

CO4 3SQ

Signature

Date

## Appendix I: Participant Consent Form

This is a consent form to participate in the research titled:

**Living with husbands with a label of dementia. The experience and meaning of  
Punjabi Sikh wives.**

I, confirm that (please tick box as appropriate):

1.	I have read and understood the information about the project, as provided in the Information Sheet.	<input type="checkbox"/>
2.	I have been given the opportunity to ask questions about the project.	<input type="checkbox"/>
3.	I voluntarily agree to participate in the project.	<input type="checkbox"/>
4.	I understand I can withdraw at any time without giving reasons and that I will not be penalised for withdrawing nor will I be questioned as to why I have withdrawn.	<input type="checkbox"/>
5.	The procedures regarding confidentiality have been clearly explained (e.g. use of names, pseudonyms, anonymisation of data, etc.) to me.	<input type="checkbox"/>

6.	The procedures regarding audio recording of the interviews have been explained and provided to me.	<input type="checkbox"/>
7.	The use of the data in research, publications, sharing and archiving has been explained to me.	<input type="checkbox"/>
8.	I understand that other researchers will have access to this data only if they agree to preserve the confidentiality of the data and if they agree to the terms I have specified in this form.	<input type="checkbox"/>

**Participant:**

Name of Participant

Signature

Date

**Researcher:**

Name of Researcher



## **Appendix J: Preliminary Interview Topic Guide shared at focus group**

Context questions:

- When was your husband diagnosed with dementia? Can you tell me about the experience of getting a diagnosis?
- How did you first notice changes in your husband?
- How long have you been caring for your family member with dementia?

Reflection questions

The questions will then loosely follow the structure outlined below.

- How do you react emotionally and behaviourally (if at all) when your husband exhibits behaviour that challenges? What is your understanding of this behaviour?
- How have you understood the changes (if any) your husband has displayed since their diagnosis of dementia?
- Can you describe any periods you felt you were not able to provide the best care possible to your husband? (probes: what triggered this period, how did you feel? What do you think was the impact on your husband?)
- What particular strengths do you think you demonstrate when caring for your husband?
- How (if at all do you think your culture impact the care you provide for your husband ?
- What is your understanding of dementia and how (if at all) do you think it impacts how you provide care for your husband?
- How (if at all) have your interactions changed with your husband?

- What do you deem to be the most important aspects in the care that you provide for your husband?

Probes (to facilitate greater dialogue)

- What led to that
- How did that make you feel emotionally?
- What were your thoughts about that?
- Can you say a bit more about that

## **Appendix K: Example of research memo**

### Memo 1: Interview schedule adaptation – post interview 2

When asking Joginder Kaur about her experience of her husband getting a diagnosis of dementia, she focused a lot on how her husband must have felt at the time. In clinical psychology terms this would be referred to as mentalization. She seemed really keen to make him ‘come alive’ in the descriptions and stories she told about him. This is also very similar to Harpreet Kaur in interview one, who repeatedly referred to how her husband would be responding to similar questions.

Given the ethical barriers in recruiting individuals with dementia, given the participants want to actively involve their husbands in the recounting of their experiences, it might be useful to frame questions so that participants are given the opportunity to present ideas about how their husbands must feel. This appears to be an important part of the wives’ experience and process of meaning making and to exclude or silence such narratives would be unethical.

Therefore, the interview schedule will be adapted to include more systemic questions which tap in to how the participants believe their husbands also experience the world. This will be important to discuss in the discussion section that even in the interview process participants meaning making process would strongly aligned with that of their husbands.

