An Interpretative Phenomenological Analysis of Punjabi Sikhs' Experience of Caring for a Relative with Dementia

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A thesis submitted in partial fulfilment of the
requirements of the School of Psychology, University of
East London, for the Degree of Professional Doctorate in
Counselling Psychology

November 2014

Module 12: Advanced Research Methods and Data Analysis

Abstract

This study explores the meaning of Punjabi Sikhs' lived experiences of caring for a relative with dementia. The Department of Health (DoH) recognises that people caring for a person with dementia (PWD) are the most vulnerable of all carers to experiencing psychological problems. Six Punjabi Sikh respondents were recruited and semi-structured interviews conducted. Their accounts were analysed using Interpretative Phenomenological Analysis (IPA). Three themes emerged from this analysis 1) Surface and Depth of Dementia: Confused and Transparent Awareness 2) I'm Stuck and Winded up in Dis-ease and 3) Still I Kept Going: Perseverance as Transcending Limits. These findings indicate that emotional, relational, social, spiritual and physical perceptions of dementia aetiology do not necessarily exclude understanding of dementia as an illness or prevent professional help-seeking or diagnosis. Participant accounts also indicated that personal meaning of caring for a PWD as dis-ease (or as involving limited support) can be transcended through engaging with Sikh specific spiritual concepts such as *Seva* and *Simran*. Caring in this context has been found to extend beyond the interpersonal to hold transpersonal meaning. Punjabi Sikh experiential understandings of such phenomena are demonstrated as being synergistic with Counselling Psychology's therapeutic relationship model. This connection provides scope for professionals to employ a broad conceptualisation of culturally sensitive phenomenological and transpersonal psychological support in this context. The thesis provides tentative guidelines for practice whilst indicating methodological limits to inform provisional suggestions for future research in this area.

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List of Abbreviations

AD	Alzheimer's Disease
APA	American Psychiatric Association
BME	Black and Minority Ethnic
BPS	British Psychological Society
DCoP	Division of Counselling Psychology
DoH	Department of Health
DSM	Diagnostic and Statistical Manual
GGS	Guru Granth Sahib (Sikh Scripture)
GP	General Practitioner
ICD	International Classification of Diseases
IPA	Interpretative Phenomenological Analysis
LHS	Left Hand Side
RHS	Right Hand Side
MMSE	Mini Mental State Examination
NCCMH	National Collaborating Centre for Mental Health
NICE/SCIE	National Institute for Health and Clinical Excellence/Social Care Institute for Excellence
NHS	National Health Service
ONS	Office for National Statistics
PWD	Person with Dementia
SA	South Asian
UEL	University of East London
UK	United Kingdom
US	United States
VD	Vascular Dementia
WHO	World Health Organisation

Acknowledgments

I am most grateful to God for being my life-line, for giving me the opportunity, heart, soul, mind and spirit to encounter Him in this research experience.

My sincere thanks to all the participants who agreed to take part in the study – and networked to support recruitment, without whom this thesis would not be viable nor meaningful.

The supervision provided by Professor Rachel Tribe and Dr Alison Macdonald helped me to recognise the resilience and autonomy required as a researcher. My deep thanks goes to Dr Miltiades Hadjiosif for his inspiration, encouragement and support in writing-up which was so invaluable. Thank you to all my peers and colleagues who have supported me on this journey.

Last, but most definitely not least, I am deeply grateful to Bebe for her spiritual outlook, Dad for demonstrating courage to think outside the box and Mum for modelling endurance in caring. Thank you to all my family and friends for your love, humour, encouragement and patience.

Chapter 1: Introduction

1.1 Preface

This chapter begins by outlining formation of the Punjabi Sikh Diaspora in the UK and how demographic changes and epidemiological issues highlight concerns for potentially increased demand of dementia care services in the future. Next origins of the study rooted in my personal and professional understanding, of the experience of caring for a relative with dementia, as a Punjabi Sikh are explored. This highlights the need to better understand distinct aspects of Punjabi Sikh caring experiences to support culturally sensitive psychological practice.

1.2 The UK's Punjabi Sikh Diaspora

In the north Indian state of Punjab compositions of Sikh Gurus (moral preceptors) biographical accounts between 1469 and 1708 are recorded in the Guru Granth Sahib (GGS) to support learning amongst Sikhs (students) (Singh, 2002). These writings have contributed to the continuity of the Sikh philosophical tradition amongst the Diaspora (Singh, 2002). The GGS states that ego-based living results in the disease of mankind and following God's will is the medicine (Singh, 1993). The Sikh tradition is monotheistic and egalitarian in nature emphasising the principles of *simran* (spiritual contemplation) and *seva* (selfless service to others) (Singh, 2002, 1993). Traditionally Indian society was categorised according to a hierarchical caste system, based upon occupation ranging from priests to 'untouchables' (Puri, 2003). The Sikh tradition actively worked to dissolve this iniquitous yet reified caste system through reformed systems based upon the concept of *seva*, such as *langar* (public eateries open to all castes) (Singh, 2002). More recently however, the British colonial system in India endorsed and exploited caste inequality through constructing a 'martial race' to advantage recruitment into the British Indian Army in the 1860's (Puri, 2003; Dirks, 2002, p.179). Since then, Punjabi Sikhs have migrated to the UK in several stages commissioned under Imperialist Rule as security auxiliaries and peddlers settling in Southall in preparation for world war two and post-war as unskilled male labour to aid industrial economic redevelopment (Singh & Tatla, 2006). Subsequently familial reunions marked growth of entrepreneurial and professionally aspirant middle-class migrants and British-born Punjabi Sikhs.

The UK's South Asian (SA) community is composed primarily of Bangladeshis, Pakistanis and Indians (Office of National Statistics, ONS, 2012a). The Indian community constitutes one of the most religiously diverse ethnic groups in the UK, comprising primarily of Hindus, Sikhs, Muslims and Christians (Babb, Butcher, Church & Zealey, 2006) and in 2011, the census recorded that 423,000 people identified as being Sikh (ONS, 2012b). Demographic changes in this population such as ageing alongside epidemiological issues have highlighted rising concerns about the future of dementia care in this community.

1.3 Epidemiological and Demographic issues

Despite BME communities comprising 14% of the UK's population in the 2011 Census (ONS, 2012a) specific authoritative estimates of dementia prevalence (total proportionate frequency of dementia within a population) for this group are lacking (Knapp et al., 2007). The prevalence of dementia in BME populations is, however, assumed to be similar to that of the UK general population (Knapp et al., 2007; Shah, Adelman & Ong, 2009). In 2008, Shah estimated the absolute number of cases of dementia in the older adult UK BME population was within the range of 7,270 to 10,786. According to Knapp et al., (2007) the prevalence of early onset dementia in the BME sector is thought to be 6.1% which is three times higher than in the UK's population as a whole, indicating a younger BME dementia profile

Proportionately higher dementia projection rates amongst BME communities compared to the general population have been partially attributed to the projected increase in incidence (new cases) of dementia in this population based on the large influx of SA migrants to the UK in the 1950's including Punjabi Sikhs, now ageing and entering the higher risk categories for developing dementia, (Knapp et al., 2007; Singh & Tatla, 2006; Lievesley, 2010; Rees, Wohland, Norman & Boden, 2010). Despite insufficient evidence indicating aetiological differences in the type of dementia prevalent amongst BME's, (Moriatry, Sharif & Robinson, 2011), the potentially interwoven relationship between religious practice, food and health amongst Indian Punjabi Sikhs has been suggested (Labun & Emblen, 2007), for example, some have thought that diabetes prevalence amongst older Asians may leave this group vulnerable to developing cardiovascular diseases such as vascular dementia (McKeigue, Shah & Marmot, 1991; Seabrook & Milne, 2004). Whilst clinical cardiovascular disease (such as stroke) has been indicated as a risk factor not just for VD but also similarly for Alzheimer's Disease (AD) (Gorelick, 2004) it is worth noting that common midlife physical health (vascular) risk factors, such as hypertension and diabetes have also been found to be associated with cognitive impairment in the British African-Caribbean population (Stewart, Richards, Brayne & Mann, 2001). Although a longitudinal study by Taylor et al. (2013), of African-Caribbeans, Europeans and South Asians in the UK, found that, both, low and high blood pressure in midlife were associated with cognitive impairment twenty years later and that no significant differences could be ascribed to ethnicity; this study comprised mainly of men and could not assess cognitive decline over this period. Indeed, firstly, although other studies found decreases in cholesterol and blood pressure levels in men (fifteen years prior to diagnosis or during follow up) as well as increase in blood pressure followed by decrease to be associated with the development of dementia; these associations are thought to reflect underlying dementia processes rather than dementia risk (e.g. due to build-up of amyloid deposits in areas of the brain regulating homeostasis or the consequence of pro-dromal dementia symptoms such as apathy) affecting blood cholesterol levels (Stewart, et al., 2009; Stewart, White, Xue & Launer, 2007; Mielke et al., 2010). Secondly, this seems significant to bear in mind when considering application of findings from the study by Taylor et al., (2013) to thinking about projected prevalence rates for BME populations who have demonstrated a younger age profile for dementia (high prevalence of early-onset dementia indicated earlier), since the study categorised midlife as ranging from 40 to 67 years. Whilst Taylor et al., (2013) acknowledge that their study focuses on late dementia, they also note that findings remain inconsistent across the literature, due to varying blood pressure measures, and the differences in treated and untreated changes in hypertension across studies. The next section shifts away from epidemiological issues to demographic changes in the UK's SA population.

Although SA households tend to be larger than the norm in the UK and Indians have been identified as the most likely out of eleven other BME groups to live in shared family households in America (Wilmoth, 2001) the size of SA UK households is becoming smaller, particularly amongst Hindu and Sikh families when compared with Pakistani and Bangladeshi families (Babb et al., 2006; Owen, 1996). Although recent findings have challenged the stereotype that SA's care for 'their own', (Katbamna, Ahmad, Bhakta, Baker & Parker, 2004, p.398) people are thought to be more inclined to care for a PWD if they live with them, and, or have kinship ties with them (Schulz, Gallagher-Thompson, Haley & Czaja, 2000). According to Milne & Chryssanthopoulou (2005), however, recent changes in family structures, such as the decline of extended families in UK SA communities (Atkin & Rollings, 1996) could threaten the BME community's traditional support networks, for example, in caring for relatives with dementia. Thus, despite low levels of service use in SA's possibly due to stigma around dementia (Seabrooke & Milne, 2004; Mackenzie, 2006) and suggestions that SA's not perceiving dementia as a medical disease can delay help-seeking (Mukadam, Cooper & Livingston, 2011) the above mentioned epidemiological and demographic issues seem to support researcher suggestions that an increase in the BME population will increase demand for such services in this community (Moriarty, Sharif & Robinson, 2011).

The DOH (2001) has recently prioritised a call for research in this area. Furthermore, an appreciation for better understanding cultural distinctiveness is reflected in the Division of Counselling Psychology (DCoP, 2005) guidelines which emphasise a need to consider cultural and social contexts in research to inform policy and practice. The NICE-SCIE National Clinical Practice Guidelines for supporting dementia carers, published by the BPS in 2006, highlight the importance of psychological therapy, including CBT, for people who may be experiencing psychological distress whilst caring for a PWD (National Collaborating Centre for Mental

Health, 2006). Despite psychological interventions indicating decreased symptoms of depression and anxiety in dementia carers (Brodaty, Green, & Koschera, 2003; Sorenson, Pinquart & Duberstein, 2002) the universal applicability of evidence-based psychological therapies appear questionable since the evidence tends to lack sufficient representation from BME participants (Hall, 2001; White, 2013). Despite a clear need for culturally sensitive support BME dementia carers (Adamson, 2001, Bowes & Wilkinson, 2003) the guidelines informing psychological practice for this population are limited (Gallagher-Thompson et al., 2003). These concerns were corroborated by my experiences.

1.4 Experiential origins of the thesis

My interest in this research originated from personal and professional experiences. As a British-born Punjabi Sikh I am aware that my various cultural identities have influenced the way I experienced caring for my *Bebe* (grandmother) with dementia and supporting others' caring for their relatives by facilitating dementia carer support groups.

From birth until early adulthood I lived with Bebe within an extended family setup. Thus I understood that providing for others beyond the immediate nuclear family reflected the Punjabi value of being co-resident within an extended system as well as Sikh spiritual ideas which I believe informed my family's caring ideology. This connective spiritual ethos helped me to manage the distress of caring as illustrated later. Although I think shared care helped disperse daily stresses of caring for Bebe's needs, I found Sikh concepts, particularly profound and useful when dealing with emotional difficulties in caring.

In caring for Bebe I used to pour oil in her hair, massage her scalp, hands and feet to help calm her agitation and one day I experienced her conveying to me that this could be our last goodbye. How? The depth of her communication through the conviction of her words, the listlessness of her body, how she touched my hand or her smile, I'm unsure. We shared a different kind of goodbye which involved some strange 'mutual knowing'; I remember purposefully turning to keep our gaze as I closed the glass doors behind me as we each took our turn to wave whilst pausing poignantly for the other, just in case. It turned out that this had been our last good-bye. For me this moment depicts the resonance of our connection – the parting experience was greater than the parts; it wasn't her loss of cognition but her spiritual presence that was important - I felt touched by who she was and who I was to her within this meaningfully wider system.

In this sense the pain of loss was eased by an experience of each other, beyond our ego selves in sight of our attuned integrative and relational essence through our *atma* (a Sikh philosophical concept of the soul which Sandhu (2004) refers to as the core of the person). Although I have found an agnostic approach (difficulty of 'scientifically' demonstrating God) helpful on occasion in therapeutic work with some clients and in this research process to help manage presuppositions, my personal experience as a Sikh can still influence the research process. As a client in personal therapy, however, I experienced spirituality to be a taboo subject, which may be argued as reflecting deeper issues within the profession as I have similarly felt pressured to adopt an agnostic approach as a trainee and thus shy from working with this in the therapeutic relationship with clients.

As an Assistant Psychologist working within an Older Adult Mental Health Service I facilitated Carer Support Groups for people caring for a person with dementia. I was struck by how professional presentations made to participants of the support group lacked cultural or spiritual competency. One Punjabi Sikh woman's experience of caring for her mother with dementia seemed steeped in emotional factors relating to religion. Although she did not consider herself a committed practising Sikh, i.e. baptised, she did endeavour to pray at *Amrit Vela* (early hours of the morning before sunrise) which Sikhs consider the 'ambrosial hour' to ease connection with God before the daily grind. A distinct aspect of her experience as a Sikh arose from the importance she placed upon praying at this time for her mother's dementia which conflicted with her need to remain vigilant to her mother's safety regarding disorientation to time and space. My search for literature on the meaning of caring for Punjabi Sikhs with respect to psychological impact and coping was of little avail.

1.5 Lead into Chapter Two

Despite the paucity of research into SA experiences of caring for a PWD specifically with respect to coping responses (Milne & Chryssanthopoulou, 2005) excluding a recent thesis by Jutlla (2011) on Sikhs, which is partially presented in Jutlla & Moreland (2009) there is no other research that specifically sets out to explore the lived experiences of Punjabi Sikhs in this context. The limited studies in this area means knowledge of this population comprises of the broader dementia care-giving literature within U.S. BME and the UK's SA populations. Studies with both communities will be reviewed in the next chapter from a Counselling Psychology perspective, before considering Jutlla's (2011) thesis. Chapter Two thus reviews the research frameworks informing existing studies which contextualise the core research question upon which my thesis has developed.

Chapter 2: Literature Review

2.1 Introduction

This chapter begins by defining salient concepts of dementia and care based terminologies (carer, caring and care-giving) within a cultural context. Subsequent sections will critique research and theory in BME, SA and Punjabi Sikh populations to identify epistemological and methodological issues of relevance to Counselling Psychology and how these have been addressed so far. Within these sections relevant frameworks are briefly outlined to help make sense of this field including the socio-cultural model of dementia care-giving (Aranda & Knight, 1997; Knight & Sayegh, 2010); the grounded theory of cross-cultural traditional and non-traditional care-giver ideologies (Lawrence, Murray, Samsi & Banerjee, 2008); and the grounded theory of Sikh migrants caring for a PWD in Wolverhampton (Jutlla, 2011). A rationale for the research question and aims of the current study concludes the chapter.

2.2 Defining dementia

The DOH (2009, p.15) classifies "dementia' within a biomedical system defining it as 'a syndrome which may be caused by a number of illnesses in which there is a progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves, which complicate care, and which can occur at any stage of the illness". The Dementia UK report by Knapp et al., (2007) documents a Cognitive Function and Ageing Study (CFAS) by the Neuropathology Groups of the Medical Research Council (2001) which indicated that the most widespread form of dementia when studied after death represented a mixed range of medical diseases (for example, a combination of Alzheimer's disease, VD, or disorders linked to prion, viral or toxic/metabolic issues or Huntington's disease). This means that clear cut sub-types of dementia as classified during diagnosis may not accurately reflect the precise neuro-pathology of dementia at the end-stage, though this discrepancy requires further understanding it brings the accuracy of current dementia diagnostic system into question (Knapp et al., 2007). Harding & Palfrey (1997) argue that the evidence supporting a theory of biological aetiology in dementia (on the basis of neuropathology) is not conclusive but limited since specific correlations do not establish causation and the evidence affirming genetic pre-dispositions does not indicate why this occurs. Although application of the medical model to dementia may be argued by practitioners as a way of aiding shared understandings to encourage access to support to manage uncertainty and the rate of neuro-cognitive deterioration using medication via services, there is no medical 'cure' for dementia (NHS choices, 2013) or cause to justify such dominance of the medical model in such mental health conditions (Wyatt & Midkiff, 2006; Summerfield, 2008). It is thus important to bear in mind that other models of dementia may exist since the medical model and evidenced based practice is not free of political, economic, moral, social and cultural contexts, since it is based upon assumptions, embedded in European, American and positivist cultures (White, 2013; Kirmayer, 2006; Kleinman, 1977). The dominance of the psychiatric model may link to the imperialist principles of such cultures which deem their specific values and standards as authoritative whilst imposing a sense of compliance from other cultures, implied when overriding allied models of health (Fernando, 2008).

Socio-historically Counselling Psychology having arisen from humanistic and existential traditions challenged the dominant influence of the medical and post-positivist models upon clinical psychology and acknowledges other models of health, illness and research paradigms as being equally valid (Strawbridge & Woolfe, 2003; Morrow, 2007). Kleinman (2000) suggests a fundamental anthropological idea, that culture strongly affects subjective understanding of illness, health and care. Thus cultural beliefs and values may influence the way indications or symptoms of dementia, such as wandering, confusion or forgetfulness, are perceived (Cox, 2007). Despite such acknowledgment, the World Health Organisation (WHO, 2012) has promoted universal adoption of generalising dementia as a biomedical syndrome using the International Classification of Diseases

(ICD-10) system, not just in the UK but globally (White, 2013; WHO, 1992). Evidence indicates that this perception may not be appropriate to apply across all cultures, with qualitative research highlighting, that some SA's in the UK may not attribute dementia to a biological cause but to God (Patel, Mirza, Lindblad, Armastrup & Samoli, 1998). In her recent grounded theory study of Punjabi Sikhs caring for a relative with dementia, Jutlla (2011, p.182, 3) study acknowledges the absence of an equivalent terminology for dementia in the Punjabi and other SA languages (Gunaratnam, 1997) and demonstrates how one Sikh expressed an emotional 'shock' based aetiology of dementia.

Globalising the biomedical interpretation of dementia as disease or interpreting perceptions of dementia based on any culturally different illness models other than the disease model of illness, as indicated by Mukadam, Cooper & Livingston (2011), may represent invalidation of diverse cultural models, assume imperialist or supreme authority over other cultural models and reflect cultural insensitivity. Indeed, Helman (1981) highlights that the pathological or medical disease model offers only one of a variety of illness models. Mukadan, Cooper & Livingston (2011) suggested that SA's not conceptualising dementia as an illness (i.e. spiritual, psychological, social perceptions of dementia aetiology) indicates lack of awareness and understanding of dementia as an illness and that this can impede help-seeking. Although this evaluation may be valid to some extent, this position could be considered to indicate an enmeshed conceptualisation of dementia within, what Fernando (2002) represents as, the western pathological psychiatric model of illness. Such a perspective could potentially risk drowning out and invalidating meanings of SA (including Punjabi Sikh) voices in research and practice, e.g. of social illness, spiritual illness or psychological illness, not just medical illness. Indeed, the most recent Diagnostic Statistical Manual (DSM) 5 focuses on neuro-cognitive deficits (American Psychiatric Association, APA 2013) and the Mini-Mental State Examination (MMSE) is largely focused on recognising cognitive impairments (Pangman, Sloan & Guse, 2000), rather than social-interpersonal behavioural changes. The issue of questionable cross-cultural sensitivity is not just relevant to research but has arisen in the context of professional practice in diagnosing dementia, for example in terms of validity of cognitive impairment screening tools which do not account for differences, in items of cultural specificity, language and education levels (Parker & Philip, 2004). Such issues have been addressed by the development of Punjabi, Hindi, Gujrati, Bengali and Urdu versions of diagnostic screening tools such as the MMSE to help validate diagnosis (Rait et al., 2000).

Kleinman (2000) critiques the rationale for assuming that the meaning of mental health perceptions, such as those of dementia, can be translated across cultures in the form of purely medicalised international classifications. This issue is particularly concerning and important to consider in the context of 'globalisation' of diagnoses, such as dementia, as a purely biomedical issue (White, 2013, p.182) despite academic perceptions that 'biological psychiatry' does not offer conclusive scientific evidence necessary for such mainstream presence in the field of mental health (Wyatt & Midkiff, 2006, p.132; Summerfield, 2008). According to Watters (2010) this leads to questions about how pharmaceutical companies may contribute to the health promotion of cultural difference in order to gain evidence for other cultural understandings of mental illness and paradoxically shifting these closer to western diagnoses and thus influencing traditional understandings to fit biomedical models (considered universal) in order to profit from them.

Recent guidelines on supporting people with dementia and those caring for them acknowledges the need to consider the social model of dementia in conjunction with the biomedical model. For example, according to the NCCMH (2006), in the Dementia NICE-SCIE guidelines published by the BPS, the social model of dementia recognises work by Marshall (2004) who highlighted that negative social understanding of the PWD imposes the meaning of dementia as a disability, specifically a social rather than inherent disability. Although the social model of dementia acknowledges the importance of cultural identity in dementia care, further research is required to better understand illness meanings of dementia for BME communities living in the UK, rather than restricting the social model to issues of social disability, for example, Milne & Chryssanthopoulou (2005) suggest possibly exploring the extent to which a cultural fusion of the Western model of illness with the ethnic psychosocial continuum of distress, may emerge. In Indian culture, the mind, body and social contexts are traditionally perceived as less separable than in the west and thus health and illness may be understood differently (Dash & Jounious, 1983; Kakar, 1984; Krause, 1989; Fernando, 2002), however; the DSM 5 having recently replaced the term dementia with major and mild neuro-cognitive disorder (APA, 2013), seems to shift or subtly impose thinking even further away from conceptualising dementia as a social issue towards the clear and unequivocal biomedical labelling of dementia. This highlights the need for Counselling Psychology research carried out in the UK's diverse social context to take a phenomenological approach to enquiry (DCoP, 2005). On this note it seems important to consider conceptual issues pertaining to the study of, care, in those people caring for a PWD as they too may be culturally informed or imposed by western or modern institutional culture.

2.3 Defining care based terminologies

Use of the term, *carer,* is considered contentious by some researchers due to issues around misunderstanding amongst professionals and lack of individuals' ability to personally identify with this phrase (Molyneaux, Butchard, Simpson & Murray, 2011; Afiya Trust, 2008; Henderson, 2001). The terms carer and caregiver are both used in defining those individuals providing informal family care as well as professionals employed to provide formal care (Afiya Trust, 2008). The term informal carer may be ascribed to an individual who provides family members or friends needing support, due to ageing, disability or chronic illness, with; 'unpaid care, ranging from round-the-clock tending to occasional acts of assistance' (Offer, 1999, p.469). From such broad definitions, study sampling can fluctuate depending on various dimensions, (O'Connor, 2007) such as the type of caring relationship, co-residence or quantification of care. Despite such diverse dimensions relating to the level of care involved, Tennstedt, Crawford, & McKinlay (1993) suggest that living with the person being cared for is more important than the relationship type, in the care-giving outcome of psychological well-being. This is thought to relate to a sense of immediacy of contact, being a critical dimension in the level of care involvement particularly in the end stages of dementia when a greater amount of time and responsibilities of caring are thought to emerge (Boaz & Muller, 1992; Penrod, Kane, Kane & Finch, 1995). Furthermore, the Afiya Trust (2008) wonder whether variations may also exist in how some people may be more willing to care in particular cultures. In this context it is worth noting that although the belief that SA's are keen or able to care for family, this idea has been challenged (Katbamna, Ahmad, Bhatka, Barker & Parker, 2004) and SA reports of not identifying with the term carer may be better understood perhaps in the context of findings that suggest this community may instead have a tendency to perceive caring for a relative with dementia as a normal or expected part of kinship relationships, familial duty and obligation (Townsend & Godfrey, 2001; Adamson & Donovan, 2005). Thus within SA communities, non-residence and non-kinship caring for the PWD could represent a different type of involvement or experience from a person caring for a relative with whom one is co-resident and in a kinship relationship with.

From a cultural perspective, the term carer may add another layer of confusion when attempting to make sense of Punjabi Sikhs' caring experiences. Research by Jutlla (2011) found Punjabi Sikhs caring for a relative with dementia 're-positioned' themselves between being a carer and caring in the context of their kinship relationship. This may link to her methodology in that she sought to explore the impact of the carer role whilst interviewing participants in Punjabi as well as English, and that there is no correspondingly accurate term to represent carer in Asian languages (Gunaratnam, 1997). Whilst evidence suggests that SA's do not identify with the term carer suggestions have been made that in discussing cross-cultural translation of terms explanation is more important than 'changing words' (Townsend & Godfrey, 2001; Afyia Trust, 2008, p.5). Considering service utilisation of the term carer, an explanation and acceptance of the terminology amongst SA's despite non-identification with the term, would require a change in cultural 'concept' or ideology (Heaton, 1999; Afiya Trust, 2008, p.5) and could possibly indicate a form of institutional racism. Attributing non-identification with the term carer to SA's on the basis of cultural specificity or institutional racism, however, would limit understanding of potentially wider cultural issues in the post-modernist sense, regarding service-related political and economic agendas, such as those suggested by Dean & Thomson (1996) or Netto (1998) further below.

Molyneaux et al., (2011) compiled a range of evidence that non-identification with the term carer has been demonstrated in various contexts, such that this phenomenon may be recognised as not being restricted to BME populations, and found the term to negatively impact the identity of the people being cared for and caring (including those caring for a PWD) and they challenge the movement for 'universal adoption' of the term (p.422). Their review of these findings support those of Dean & Thompson (1996) and possible negative impact of this service-driven terminology upon people's experiences of caring and the processes involved is indicated in the section below. Potentially wider cultural implications for the conceptualisation of dementia care-giving are considered in section 2.6 in noting the context of complex hybrid cultures in the UK evidenced through cross-cultural research by Lawrence, Murray, Samsi & Banerjee (2008) who differentiate traditional from non-traditional caring ideologies more universally.

Dean & Thompson (1996) argue that service implementation of the term carer has transformed the concept of care; from a phenomenon pertaining to a 'verb' to that of a 'noun'. Their suggestion that the action of caring (as a verb) has become a 'role' or a 'position' (noun), of carer, which objectifies and detaches people from their traditional kinship relationships is confirmed more recently by O'Connor (2007, p.166) to be experienced particularly in service contexts. This shift in perceiving caring in the context of the previous kinship relationship to that which emphasises people as carers can create unnecessary interference and detachment in the relational experience of caring, since the process of emphasising the carer role (especially as burdensome) over the previous relationship can 'undermine' the person being cared for whilst potentially disrupting how the people caring perceive themselves (Calderbank, 2000, p.530; Harding & Higginson, 2001). It has been argued that the term 'carer', which originated in the context of questioning social norms in which women obliged caring, (Fine & Glendinning, 2005) shifted perceptions of caring from those that emphasised caring as moral choice to caring as imposition of responsibility (Dean & Thompson, 1996). Dean & Thompson, (1996, p.151) suggest that paradoxically de-emphasising the option to care contextualised a conceptual shift in the perception of caring so that it became ‘fetishized’. Through the process of ‘refamilialisation’ (modifying familial dependency by transferring responsibility of care to services) and the subsequent ‘recommodification’ (normalisation of the informal ‘carer’ as a ‘commodity’ to ‘reverse public expenditure’) informal caring has been ‘ideologically distorted’. They argue that this later political and economical move of services has pressured individuals towards the moral obligation to care at home, without offering appropriate supportive options, thus isolating people who are caring. The term carer has, indeed, been considered ‘a socio-political construct’ in that it lacks focus on ‘feelings and relationships’ limiting deeper understanding of the phenomenon of caring (Netto, 1998, p.223). This point warrants defining and contrasting the concept of caring from the similar terminology of care-giving.

According to Morse, Solberg, Neander, Bottorff & Johnson (1990, p.1) caring may be considered from several epistemological perspectives each of which emphasises different aspects of caring as, ‘a human state, a moral critical or ideal, an affect, an interpersonal relationship’ as well as an intervention. Ory, Yee, Tennstedt & Schulz (2000, p.6, 7) define care-giving as ‘a dynamic process that unfolds and changes over time’ and ‘evolves from pre-existing social expectations and obligations’ based on research such as that by Stoller, Forster & Duniho (1992). Pearlin, Mullan, Semple & Skaff (1990, p.583) differentiate care-giving from caring by considering caring as the ‘affective component of one’s commitment to the welfare of the other’ whilst care-giving is viewed as the ‘behavioural expression of this commitment’.

2.4 Defining Dementia Care-giving

Ory, Yee, Tennstedt & Schulz (2000) define the hallmark of dementia care-giving as the need to provide supervision and cueing, in response to the behaviours of the PWD, to aid activities of daily living. For illustrative purposes, imagine a person bewildered by time and space when out walking; s/he may require supervision and cueing to reduce risks associated with wandering and becoming socially disinhibited (such as undressing in public whilst lost alone). The cognitive and behavioural style of managing these aspects of care may depend on the focus of care and preference of one's interaction with the PWD which may range from 'facilitating and balancing' to 'advocating and directing' (Corcoran, 2011). There is an established evidence base that indicates the impact of dementia care-giving upon personal, social and financial levels (Schulz, O'Brien, Bookwala & Fleissner, 1995, Milne & Chryssanthopoulou, 2005). Although these different levels may be interlinked, the level of depersonalisation involved in the use of terminologies such as carer and care-giving in research prioritises behavioural rather than affective expressions, it seems appropriate then in a Counselling psychology study to understand the affective or personal aspects of dementia care-giving.

2.5 BME Dementia Care-giving theory and research

The National Collaborating Centre for Mental Health (NCCMH, 2006) documents research findings which suggest that people caring for someone with dementia are vulnerable to suffering from high levels of stress, burden, guilt, isolation or other psychological problems such as depression and anxiety (Brodaty, Green & Koschera, 2003; Sorensen, Pinquart & Duberstein, 2002). Despite this negative impact, research also evidences positive affect, satisfaction, well-being, role gain, rewards, gratification, mastery, growth and meaning in dementia caregiving (Connell, Javenic, & Gallant, 2001). The majority of multi-cultural studies tend to be carried out within the dominant positivist/post-positivist paradigm (Ponterotto, 2010). Dilworth-Anderson, Williams & Gibson (2002) highlight evidence of the prevalence of this framework in BME dementia care-giving literature with research being primarily informed by predetermined models. According to their review, much of the BME dementia care-giving research in the U.S. uses quantitative methods to measure psychological constructs such as stress, using standardised scales. Measuring scales can be limited by predetermined responses, preventing research from capturing the multi-dimensional depth, richness and complexity of personal meanings of psychological phenomena relevant to dementia caregiving. Furthermore, these methods are imposing and closed rather than open to recognising potentially different cultural meanings that BME people may personally experience in dementia care-giving. For example, in the Zarit burden interview, the concept of burden is based primarily on findings from ‘white’ carer populations (Zarit, Reever & Bach-Peterson, 1980) meaning that it lacks cultural sensitivity and additionally takes a structured approach to interviewing. Furthermore, most models guiding the hypotheses informing BME dementia care-giving studies do not explore issues pertaining to race, ethnicity or culture (Dilworth-Anderson, Williams & Gibson, 2002). The socio-cultural stress and coping model proposed by Aranda & Knight (1997) which suggests that cultural values influence care-giving, including dementia care-giving is a clear exception.

The model suggests that cultural values may influence the stress and coping process in dementia care-giving at several points, not just through coping behaviours of use of family support but also cognitive appraisals of the situation are thought to be accorded to the emphasis placed on values such as familism (a family form of collectivism), and thus are considered pivotal in determining whether and how the situation is experienced as burdensome (Aranda & Knight, 1997). Similarly, others suggest that cultural perceptions of dementia can influence how care-giving is perceived, how the caring relationship is experienced and impacts upon well-being and approach to management of difficulties and help-seeking behaviour depending on the specific culture (Cox, 2007; Janevic & Connell, 2001). Other themes in BME dementia care-giving research relate to duty and reciprocity as well as coping via spirituality or religion, social support and the use of care-giver appraisals as coping resources (Dilworth-Anderson, Williams &, Gibson, 2002). The revised socio-cultural stress and coping model (Knight & Sayegh, 2010), however, suggests there is only limited support for the hypothesis that cultural values, specifically familism, influence the appraisal of care-giving as burdensome. Instead they suggest that burden is part of a core common process of stress and coping across cultures, dependent upon the demands imposed by the PWD’s behaviour and hypothesise that cultural values function only through mediating the availability, use, choice and nature of coping styles and social support, i.e. considering cognitive dementia appraisals part of coping.

Contrary to the revised model, however, studies of African American descriptions of dementia care-giving as favourable rather than burdensome (Farran, Miller, Kaufman, & Davis, 1997) exemplify the potential fallacy of the core common framework. It appears the reductive nature of the revised model, limits an understanding of other possible meanings of dementia care-giving and how caring may be experienced in different cultures. This highlights how quantitative research that relies on hypotheses based on positivism and ethnocentrism can fail to capture other potentially significant aspects of the meaning of the experience of caring for a PWD. For example, a population based survey conducted by the 10/66 Research Group (Prince, 2009) aimed to address methodological issues prevalent in population-based research into dementia in developing countries. They indicated that dementia may be an unseen problem in India and have responded by promoting awareness in the media. This problem may be explained, however, by quantitative findings from a study by Emmatty, Bhatti, & Mukalel (2006) which reported low burden in dementia carers in India, though, how this may be experienced, remains little explored. This study analysed answers to open-ended questions through quantitative analysis which limited understanding the meaning of experiences of individual carers without supplementing such knowledge through qualitative analysis. Indeed, Knight & Sayegh (2010, p.10) acknowledge that they have been unable to understand why African Americans caring for a PWD report less burden than in ‘white’ populations and that such understanding requires a move from ‘speculative discussion to scientific exploration’ as cultural values affecting care-giving are specific to cultural groups. They suggest this is where qualitative research can help identify which cultural values may influence the stress and coping process.

Extrapolating the above US post-positivist evidence-base to understanding the experiences of Punjabi Sikhs caring for a relative with dementia is limited for several reasons. Firstly, BME groups tend to be studied according to universal dementia caregiving models, whilst being poorly represented in ‘universal’ studies which lack cultural conceptualisations or models, meaning this research tends to lack cultural relevance or sensitivity (Connell & Gibson, 1997; Dilworth-Anderson, Williams & Gibson, 2002;). Additionally, the majority of BME dementia care-giving and interventionist studies are US based, and thus primarily focus upon dominant BME populations such as African-Americans, Latinos, Hispanics and Asians, indeed, the model by Aranda & Knight (1997) is based on studies with the Latino population. Moreover, the American Asian population is not comprised primarily of South Asian descent but those with Chinese, Filipino, Korean and Japanese origin and such prominence is reflected in U.S. dementia care-giving studies (United States Census Bureau, 2010; Ishii-Kuntz, 1997) which limits comparability with UK South Asians primarily of Indian, Pakistani and Bangladeshi origin (ONS, 2012a). A quantitative approach may be considered premature or assumptive when researching a topic in a relatively uncharted population, such as SAs caring for a PWD and Creswell (2009) suggests that qualitative research is important when the topic of study has not been addressed with a particular group of people, in which the variables are unknown and whose experiences have not been considered in existing theories. This warrants exploration of the UK SA qualitative context of dementia caregiving to better understand issues pertinent to the study of Punjabi Sikhs and how these have been addressed so far in the literature.

2.6 Making sense of SA experiences of caring for a PWD

Despite reported levels of distress and isolation appearing readily amongst SA’s as in ‘white’ caring communities and even being experienced similarly these aspects of caring may also potentially be experienced and communicated differently (Atkin & Rollings, 1996; Milne & Chryssanthopoulou, 2005; Adamson, 1999). Despite this understanding, no studies to date appear to have specifically set out to explore the experience of caring for a PWD amongst SA’s with a commitment to phenomenological enquiry focused on better understanding the psychological meanings of experience. Rather, studies tend to focus on noting social issues such as gender stereotypes, filial or family issues, patterns of shared care, lack of access to services or isolation from community life (Townsend & Godfrey, 2001; Bowes & Wilkinson, 2003) with little in-depth exploration of psychological issues such as coping responses or processes in SA approaches to care (Milne & Chryssanthopoulou, 2005).

Although studying these areas has helped to better understand the experiences of caring amongst SA's, shared patterns of care, for example may however, also involve conflicts around the locus of care as well as complex financial disputes which could involve more complex psychological or affective experiences which have not yet been explored in depth. Townsend & Godfrey's (2001) and Bowes & Wilkinson's (2003) studies primarily sought to understand the experiences of those caring in the context of better understanding the needs of the PWD and barriers to accessing provisional amenities, thus taking a service policy perspective rather than exploring what is of phenomenological significance to those caring on a deeply personal level, e.g. to aid coping. Research suggests that SA's may not consider dementia's cognitive and functional difficulties important, perhaps to avoid services as a way of protecting themselves from dishonouring the family (Katbamna, Bhakta, Ahmad, Baker, & Parker, 2002) through fear that stigma and shame could lead to rejection from the community (Mackenzie, 2006). These findings highlight the importance of social approval and fulfilling expectations amongst SA's, however, how this may impact upon well-being has not been little explored.

Lawrence et al., (2008) developed a grounded theory of specific caring attitudes, amongst three ethnic groups of SA, black Caribbean and white British individuals caring for a PWD. Their use of a wide ethnic sample meant improved understanding of how cultural convergences between ethnic groups can be evidenced in attitudes to caring. They categorised peoples' accounts of their experiences according to traditional or non-traditional caring ideologies. Those with a traditional ideology perceived caring as natural, expected and virtuous, whilst non-traditional caring ideologists experienced caring as unnatural, conflicting with expectations and lacking virtue. These ideologies were found to cut across ethnic groups, thus identifying implications for how individuals may be better supported by services according to one's caring ideology rather than ethnic or cultural group. For example, they suggested encouraging the value of the carer role to non-traditional ideologists or reassuring people with traditional ideologies of the need to take time for themselves through respite.

These findings highlight the potential influence of acculturative processes upon the caring phenomenon in SA's in the UK, but also suggest that white British traditional ideologies may also be open to influences or promotional impositions of modern UK service culture. Dean & Thompson (1996, p. 149-156) suggest the 'ideological shift' in how caring is perceived minimises the moral essence of caring as a choice whilst emphasising burden, through pressure from services, since when care has been returned to the family anticipations may conflict with personal hopes. In some respects this profile seems to overlap with the 'non-traditional caregiver ideology' suggested by findings from Lawrence et al., (2008, p.241) which involve putting 'life on hold', with 'caregiving positioned negatively', feeling 'too burdened to fight' or sensing an 'absence of rewards from the caregiver role'.

In considering the issue of acculturation, the concept of convergent care-based ideologies across cultures identified by Lawrence et al. (2008) supports Hinton's (2002) argument, which contests the mainstream conceptualisation of culture; that people within a particular ethnic group similarly adopt the same values. This highlights that specific caring ideologies cannot be generalised to fit the whole range of people within a particular BME group such as SA's. Despite the need to acknowledge the potential acculturative effect upon caring ideologies of Punjabi Sikhs living in the UK, it may be premature at this stage in the research development, to base sampling criterion upon categorisation such as that suggested by Lawrence et al. (2008). Researchers highlight the need to be sensitive to differences between communities from the same country (Fernando, 2002; The Mental Health Foundation, 2002) in dementia care-giving (Milne & Chryssanthopoulou, 2005). Thus Lawrence, et al. (2008) research focusing on identifying inter-cultural issues detracts from the need to take into account the heterogeneous nature of the UK's SA population of carers.

Despite convergent characteristics of the Sikh community with other SA communities there are divergences according to spiritual and cultural practices and behaviours informing health choices (Nayar, 2004). Trans-cultural models of counselling note that distinct religious belief systems can aid understanding of traditional healing and cultural helping styles which may be used to develop culturally sensitive interventions (Sandhu, 2005; Arthur & Stewart, 2001; McCormick, 1998). Mukerjee & Gangul (1984) suggest such differences between Hindu and Sikh world-views are reflected in their divergent helping styles in child rearing. Their study observed Sikh mothers using a method that was considered more controlling or 'active' than the 'detached' passive approach of Hindu mothers. They suggest these differences in the practice of child care represent differences in the Sikh and Hindu traditions. Although these findings were based upon objective measurements rather than subjective experiences of caring, philosophical differences may be further exemplified by the Sikh approach to care for sick children, which is considered to be less ritualised than in Hinduism with potential implications for managing bioethics (Campbell, 2006; Gatrad, Jhutti-Johal, Gill & Sheikh, 2005). This illustrates the usefulness of differentiating between Hindu Punjabi and Punjabi Sikhs when studying the experiences of Punjabis, since knowledge of whether or not such diversity impacts upon the lived experience of caring for a PWD is lacking.

With the partition of India and Pakistan during Independence in 1947 Punjabi's may identify with either Indian or Pakistani nationalities whilst Pakistanis tend not to be Sikhs but to primarily practice Islam (Babb et al. 2006). Bowes & Wilkinson (2003) explored SA experiences of caring for a PWD by interviewing Pakistanis and Indians. The researchers noted how being Muslim affected how one family's experience of caring was founded on the obligation to care being perceived in an 'explicitly religious sense' based upon reading of the Qur'an (p.389). The same family found their difficulty with hygiene issues relating to their relative's incontinence negatively affected their ability to pray. Similarly, a study by Lawrence, Samsi, Banerjee, Morgan & Murray, (2011, p.47) indicated how being Sikh or Christian informed a constituent part of how some people who were diagnosed with dementia described helping others; as part of being a 'good Christian or a good Sikh' – which clearly relates to religiously or spiritually informed ideas of morality around caring. Although Bowes & Wilkinson (2003) study highlights the potential for psychological conflict to exist between religious ideas and the demands of caring for a PWD, whether similar obligations or experiential conflicts exist for Punjabi Sikhs remains unexplored in research. These findings affirm the importance of defining purposive homogeneous sampling criteria as exemplified by Jutlla (2011) though she defines her sample as Sikh rather than Punjabi or Punjabi Sikh.

2.7 Understanding Punjabi Sikh experiences of caring for a relative with dementia in the UK

Jutlla (2011) explored twelve Sikh Diaspora accounts of caring for a relative with dementia in Wolverhampton, with a particular focus on how migration and personal histories including those of British-born descendants, could influence their experiences of caring. The use of a biographical narrative and grounded theory approach emphasised how participants told their story to generate explanatory theory with the aim of identifying patterns of dementia care. The thesis explored the influence of various contextual issues upon the caring experiences of Sikh migrants. These contexts included participants' reasons for and experiences of migration, their experiences of living and engaging within a Sikh community in Wolverhampton and the different roles and positions they held according to social norms within the family.

Jutlla's (2011) use of positioning theory (Milband, 1971) meant she sought to explore how participants assumed rights and duties within the caring experiences according to local and wider social contexts such as family, temples and service support, either in their countries of origin or transition, including the UK and Punjab. This meant that the focus was on the social reality of the participants narrating their stories, such that the phenomenological meaning was only considered with respect to how participants were positioned in their stories, for example, as carer. Seeking explanation within the grounded theory yet narrative approach with a focus on social phenomena meant that much of the phenomenological meaning although validated was drowned out by the social reality of the narrators by focusing on the theoretically driven research questions in her analysis. For instance, although Jutlla (2011) claims that her central finding was that Sikh experiences of caring involve a ‘complex and continuous (re)positioning between the caring role and their relational role to the cared-for person’ (p.2), the core tenet of this theme, is a ‘positioning’ between the roles as carer and relative; a concept which is clearly grounded in her use of ‘positioning theory’ since participants have not used this terminology although she does demonstrate how this finding is drawn. Her analytic approach to the data thus prioritises the theoretical above the phenomenological. The importance of phenomenological inquiry when researching cultural and social contexts within the UK’s pluralistic society is emphasised by the DCoP (2005).

The sociological specificity of Jutlla’s approach helped improve understanding of the diverse implications of migration within the dementia caring experience. For example, she demonstrates how various changes within traditional cultural norms regarding gendered roles within the family including responsibilities, expectations or restrictions can highlight ambivalence and conflict, culminating in idealised perceptions, of pre or post migratory support as a form of psycho-social coping or strain in caring. Considering the sociological focus of Jutlla’s study it is not surprising that her findings expand upon cultural norms prevalent in the SA literature, however, it would be difficult to read the findings as being Sikh-specific. Her only reference to explicitly Sikh values being of significance in participant accounts relate to two brief descriptions of not accepting home-help or withdrawing the use of day care, due to concerns that the staff may drink alcohol or due to the PWD’s inability to communicate Sikh Baptist dietary restrictions whilst not trusting staffs’ cultural competence in this matter. It is important to consider, however, the lack of further insights or knowledge into Sikh perceptions of caring, may relate to Jutlla’s use of specific research questions being focused upon Punjabi cultural ideas or social norms rather than Sikh philosophical tradition.

Jutlla's (2011) use of the term 'Sikh culture' (p.87, p.211) is misleading since it amalgamates and confuses Punjabi cultural ideologies with Sikh religion without noting their clear divergence on issues regarding gender (in)equality, which is significant considering her thesis is founded upon exploring 'discourses within the Sikh culture about gendered roles and division of labor'. Punjabi culture could be seen as assuming formalism through observance of socially reified positions of gender or caste stereotypes rather than meaning, which the Sikh spiritual worldview challenges rigorously (Singh, 1988). The Sikh tradition is rooted in a democratic approach to reforming cultural and spiritual practices which espouse equality based upon 'mutual co-existence and cooperation' (Singh, 2008, p. 33). The origins of the Sikh tradition in Punjab stem from the Gurus challenging Indian and Punjabi formalised gendered norms in the context of dominant Brahmin society (the upper caste religious authority) who manipulated the populations' naive faith, by endorsing misogynistic cultural practices of *sati* (burning women once widowed), female infanticide and child marriage under the guise of religion through the caste or elitist system (Singh, 2008; Singh 1988; Shanker, 1994). This highlights the clear differentiation between Sikh and Punjabi values. Sandhu (2009) similarly differentiates the Punjabi and Sikh perceptions on alcohol (mis)use, with the former through the GGS prohibiting use regardless of gender whilst the latter grossly sanctions and exploits alcoholic indulgence amongst men to maintain male identities of Sikh heroism. This oppressive blurring of identities served the Punjabi purpose of sustaining excessive farming labour demands during harvests or maladaptive coping with stress (Sandhu, 2009). This confusion may explain why some researchers such as Jutlla (2011) consider little distinction between the traditions and mislabel Punjabi culture or nationalism as Sikh culture.

2.8 Interventions for members of BME communities caring for a PWD

Katbamna, Baker, Ahmad, Bhakta & Parker, (2001) have developed team guidelines to better support SA carers based upon review of the literature and the Afyia Trust (2002) highlight examples of good practice guidelines for working with BME carers. Despite these recommendations explicating management of pertinent issues through better communicating information in a comprehensible manner, coordinating teams to raise awareness of roles in the family as well as recognising cultural and religious beliefs; they did not detail or focus guidelines for developing psychological interventions for specific subsets of these communities. Gallagher-Thompson et al. (2003) reviewed guidelines on how to tailor psychological interventions for individuals from BME communities caring for a PWD. Their evaluation highlighted that despite an established evidence base of the stress experienced in this caring population, there is a corresponding paucity in the literature base informing the development of strategies for how to culturally tailor psychological interventions sensitively. Any guidance on culturally competent interventions that have been developed in their review can only be regarded as culturally relevant for specific ethnic groups of dementia carers, namely African Americans, Hispanic/Latino Americans, Cuban Americans and Mexican Americans. Their conclusion confirmed the main argument of my thesis, that better understanding of nuances in caring amongst other underrepresented and poorly understood ethnic minority groups, such as Punjabi Sikhs, is required to learn how to effectively assist health and management of potential difficulties which may arise within this experience. They underlined the urgent need to continue research in this area in order to better support psychological practice through informed recommendations.

2.9 Summary of Rationale for the Research Question

This chapter has reviewed a vast body of literature to examine epistemological and methodological issues pertinent to the field of dementia care-giving within a cultural context, including definitions, theory and research. This has provided a useful evidence-base from which to argue that a qualitative approach may be deemed most appropriate for further study of Punjabi Sikhs lived experiences of caring for a PWD. The review demonstrates how the use of heavily positivist paradigms can engage culturally insensitive methods which prioritise dominant Western cultural conceptualisations. Through qualitative approaches, the research may seek rich, complex and nuanced knowledge of specific BME values which may be important in this experience. Although positivist findings from BME and SA literature helped identify the need for study in Punjabi Sikhs in the introductory chapter, the advantages that comparative cross-cultural qualitative research has fostered, through gaining first person accounts of the experience of caring, is also evident through being open to personal meanings. This section highlighted how individual caring ideologies helped understand psychological needs to aid development of guidelines for support, though this focus on the cross-cultural may have overshadowed cultural differences since recommendations did not link to BME communities specifically. This smaller body of literature indicates the need to note the potential influence of acculturative forces and service frameworks upon experiences of Punjabi Sikhs living in the UK's modern hybrid culture, whilst conversely highlighting how such focus may detract from the need to recognise the SA community as heterogeneous and in need of being studied at a more homogeneous level.

Defining Punjabi Sikhs as a homogeneous group and approaching analysis of accounts accordingly may help make sense of potentially convergent understandings gained from idiosyncratic perceptions which characteristically contextualise the meaning of experience. More specifically, there is a need to acknowledge that despite evidence of low levels of service contact amongst SA's, that over time, Punjabi Sikh caring ideologies are likely to become increasingly exposed to and thus influenced by UK modern or western realities and thus experiences, in particular the experience of relatives receiving diagnostic impositions of dementia as a biomedical entity. Thus it is important to remain open to learning about the experiences of people whose relatives have received a formal diagnosis of dementia. Cultural sensitivity may be demonstrated from the outset of research through openness to potentially diverse yet relevant frameworks outlined in the review, rather than superimposing these upon the research question, to capture personal meanings based in lived experience.

There is a clear gap in understanding whether, and if so, how, Sikh spiritual values are important to the experience of caring for a PWD, considering Jutlla's (2011, p.211) focus on Punjabi cultural norms under the guise of 'Sikh culture'. Despite this acknowledgment, it is critical at this early point in the research trajectory not to impose this dimension of spirituality or religion upon the research question, by phrasing it as an exploration of religious coping. Instead keeping the question open, respects Jutlla's findings, that Sikh values may not be important to the experience but should this dimension hold meaning for Punjabi Sikh experiences, it should be evidenced as arising from their accounts without prompting. The literature has indicated a need to explore phenomenological accounts of how caring is experienced with respect to embodied personal understandings, which appear to have been marginalised in BME research as have psychological meanings.

The study of the phenomenon of caring for a relative with dementia has not been addressed in Punjabi Sikhs in a way that openly seeks understanding of what dimensions, other than migration, geographical location and specific roles might be important within this populations' experience. Thus other unknown and potentially distinct aspects of this population's experience have not as yet been considered in helping to inform existing theories and psychological interventions in the field. This issue may be addressed by exploring and gaining descriptive and interpretative knowledge where personally lived and well-informed experiential understandings of the phenomenon can be interpreted against theory at later stage in analysis for the advancement of Counselling Psychology Practice Guidelines for supporting those in distressing contexts and better understanding those in health. The thesis thus explores the following research question:

What is the meaning of Punjabi Sikhs' lived experiences of Caring for a relative with dementia?

This question, is inherently open to tentatively exploring what is personally meaningful (i.e. significant) within participants' lived experience of caring, both positive and negative. The primary aim is to consider how idiographic and phenomenological understandings of experience may embody converging aspects of experience, characteristic of being Punjabi Sikh. The next chapter considers IPA as the most appropriate methodology in this pursuit and how this will be applied in this study to answer the research question to meet the aims of the thesis.

Chapter 3: Method

3.1 Introduction

This chapter begins by defining my epistemological position as a researcher since this informs my theoretical perspectives and in turn has influenced the qualitative nature of the methodology chosen (Lyons & Coyle, 2007). This exploration helps evaluate whether the research question is being addressed using the most appropriate methodology. The latter sections of this chapter outline the methods of sampling, data collection and analysis, as well as reflexivity.

3.2 Research Paradigm and Design_Framework

3.2.1 Epistemological position

My epistemological position assumes that an external reality beyond one which is socially constructed by discourse can exist. I recognise this reality is imperfectly accessible due to subjective perceptions and hermeneutic interpretations of reality. There is an inherent assumption in my research question of the validity of multiple subjective realities. This indicates a subjective and inter-subjective epistemology in which knowledge is co-constructed thus highlighting an interpretivist/constructivist paradigm underpinning interpretive knowledge production whilst seeking an insider-perspective. Thus I recognise the importance of reflecting upon my role in the research process, by noting the interpretative concept of the double hermeneutic. My aim of gaining an empathic/insider-perspective on the meaning of carers' experiences is evident in my research question. This implies that I consider carers' embodied thoughts and feelings to be accessible via language and lean towards the critical/emancipatory paradigm whilst remaining firmly anchored in the interpretivist/constructivist paradigm since I have not extended emancipation to the point where participants shape the research question or add a layer of respondent validity (Ponterotto, 2010). Giving voice in this way fits with IPA (Larkin, Watts, & Clifton, 2006) and suggests that my epistemological position falls within the interpretivist end rather than constructivist end of the interpretivist/constructivist paradigm and IPA seems a suitable methodological approach to answer my research question.

3.2.2 Methodology

IPA's emphasis on inter-subjectivity in knowledge production is influenced by symbolic interactionism which fits with my transactional epistemology as I recognise both participant and researcher in sense-making. IPA is considered useful when a paucity of research exists by acknowledging a link between participants' thoughts, feelings and their verbal accounts (Smith, 1996) which fits my assumptions. Furthermore, IPA notes that as researcher, I make interpretations, when making sense of participants who are making sense of their experiences, through a double hermeneutic (Smith, Flowers & Larkin, 2009). This perspective is informed by Heidegger's hermeneutic phenomenology which assumes that individuals will inevitably experience different parts of reality according to their unique socio-cultural lens (Smith et al., 2009). Phenomenology acknowledges an epistemological connection with empirical subjective reality such that external reality interlinks with understanding subjective experiences (Willig, 2008). IPA aims to develop idiographic analysis from a homogenous sample of participants' accounts of their experiences at a significant point in their life, such as care-giving before examining shared meanings.

The exploratory and open nature of my research question offers participants scope to share experiences meaningfully important to *them*. A data collection method, which enables participants to discuss the topic and allows the researcher to probe unanticipated insights i.e. open-ended interviews, would fit well with this approach. Consistent with this view, my interview schedule asks minimal questions rather than imposing many questions as the latter would represent a more structured interview, and a leaning towards the post-positivist paradigm (Ponterotto, 2010). IPA is argued as an appropriate methodology that is consistent with my research aims in addressing the research question.

3.3 Sampling Framework and Participant selection

3.3.1 Selection and Recruitment of Participants

IPA is characterised by homogenous sampling and purposively selecting a small and limited number of participants enables rich elucidation of the research question in order to justly and transparently represent each individual voice in the narrative (Smith, Flowers & Larkin, 2009). The rationale for selecting people who identify as Punjabi Sikhs and who are or have been co-resident with a relative who has received a diagnosis of dementia has been set out in the literature review. Non-relatives were excluded as it was considered they are less likely to be co-resident and sufficiently expert in the qualitatively experiential nature of caring that may arise from kinship relationships i.e. same level of commitment, duty or stigma issues as a relative. To prevent the bias effect of homogenous sampling being too specific, it was considered that the sample criteria should not exclude by specific caring or other population based demographics other than those relevant to ethics – in this case relating to care age vulnerabilities, i.e. individuals under 16 and over 85 years of age. Given the paucity of studies in this area of research, it was likely that these selection criteria would provide both convergent and divergent experiences and perceptions of caring for a relative with dementia. Considering that participants were expected to have a diagnosis, it was thought that recruiting individuals through medical channels might skew medically dominant ideas so recruitment was aimed towards other services as well as cultural and spiritual networks.

Ethical approval was obtained through the university ethics committee originally to study the coping processes of SA’s as this appeared to be the obvious gap in the literature. Upon deeper critique of the literature application was made to the university to amend the scope of the project by changing the focus to that of Punjabi Sikhs and opening up the research question, which was again approved (Appendix A and B).

Participants were invited to take part in the study through various means. Advertisements (Appendix C) were placed in community shops, centres and temples in areas known by the researcher to have high concentration of

Sikhs, such as Southall, Birmingham, Slough and Leicester. Advertisements were also displayed in communal areas of voluntary and charity Carer and Dementia Support Organisations including Asian Day Centres and branches of the Alzheimer's Society throughout the London area. An advertisement was published in the local Ealing Dementia Concern newsletter. Whilst response to adverts was nil two formal carers who did not meet the criteria did respond through this method. The researcher attended Carer Forum Meetings in a local Asian Day Centre. Only one participant was recruited through this method. Once initial contact was made with members within two Gurudwara (Sikh temple) community networks in the South East of England, however, a process of chain referrals or snowball sampling generated the sufficient number of participants using word of mouth. This proved to be the most fruitful avenue of recruitment. Two male respondents or potential participants were not interviewed due to one having expressed indirect interest via the snowballing network without providing a telephone number upon follow-up. The other informed me that his father (the PWD) had recently passed away and considering the recency of bereavement this would not have allowed sufficient time to process his grief which may have thus dominated and complicated his account of caring, whilst being deemed unethical.

3.3.2 Participant Description

Six Punjabi Sikhs took part in the study, two of whom were men and four women, with ages ranging from 33 to 75 years. All had cared for their relative for a minimum of three years with only one having cared part-time for that whole duration. Three participants shared accounts retrospectively and three were still caring at the point of interview. Both men were the only spouses, three of the women were daughters-in-law caring for either their mother or father-in-law and the other her grandmother. Only two participants specified knowing the medical aetiology of their relatives' diagnosis, as Alzheimer's Disease and Frontal-Temporal dementia. Only one participant was British born with English as her first language, whilst the rest migrated directly from Punjab for work, marriage or with their families as children. Three of the participants had retired, one was unemployed and two part-time employed. All but one participant lived within an extended (albeit minimalist) family set up. These demographics are outlined in the table below.

Table 1 – Participant Descriptors

Name	Diagnosis	Relationship with PWD	Time Caring (yrs)	Type of Caring	Account Type	Age	Migrant Status	
Sukhdeep	AD	H	4	F	C	65	M	
Dilraj	DM	H	7	F	C	75	M	
Parminder	DM	G	8	P	R	33		B
Akashpreet	FT	D	1 ½	P & F	R	37	M	
Gurveer	DM	D	7	F	R	62	M	
Harshdeep	DM	D	5	F	C	55	M	

Key

Alzheimer's Disease (AD)	Husband (H)	Current (C)
Fronto-temporal (FT)	Daughter-in-law (D)	Retrospective (R)
Dementia (DM)	Granddaughter (G)	
Full-time (F)	British-born (B)	
Part-time (P)	Migrant (M)	

3.4 Data Collection

3.4.1 Design of materials and Interview preparation

A semi-structured interview guide was prepared in accordance with guidelines suggested by Smith, Flowers & Larkin (2009). The focus was on allowing questions to be informed by broad areas of psychology noted in the literature review, such as perceptions, stress, positives, coping and support which would address the research question relating to experience of the phenomenon. More specifically these areas involved understanding dementia development considering dementia is a progressive entity, what it is like caring day to day which aimed to understand the lived aspects of experience, if difficulties or positives are mentioned how these are understood and managed or supported, if at all, and whether and how any of these may relate to their identity as a Punjabi Sikh.

After practise interviewing with a colleague, a pilot interview was conducted with Sukhdeep, transcribed and analysed – though not all questions were asked as many were already answered and seemed repetitive. The initial interview schedule (Appendix D) was then refined (Appendix E) following consultation with the London IPA group who advised the pilot interview still be used in the thesis since the participant highlighted the desire to share their voice in research. Revisions to the interview schedule included, reducing the number of questions as some seemed superfluous, integrating synonymous questions and recognition that participants may find questions directly asking the meaning of the phenomenon confusing - so these were re-phrased. The use of prompts was included more generally rather than specifically so the interview could be adapted to specifics of the participant experience i.e. to use the questions as a guide rather than heavily structured script. For example, a recommendation was made by the IPA facilitators to only prompt discussion of certain areas if participants did not themselves share such information as this might suggest it is not necessarily significantly meaningful to their experience. This approach helped minimise imposition of my assumptions (through closed or leading questions and thus overly-structuring the interview) giving participants scope to share what was specifically meaningful to them so that any findings, e.g. which do relate to carer terminology, diagnosis, cultural and spiritual issues would hold more weight. Similarly the facilitators mentioned that some questions may not need to be asked at all as the participants may well answer the questions organically through their descriptive responses to the first few questions or questions may not be asked chronologically (reiterating my experience of the pilot study).

It was agreed that interviews be conducted in participants homes considering the demanding nature of caring, for their convenience to facilitate a comfortable and familiar setting within which caring takes place. Participants were asked to make arrangements for their relatives care for the duration of the interview (two hours including time to go through issues of consent and debriefing) to minimise disruption and concerns around safety of the PWD. All participants had other family members in the house during the interview, which did on occasion interrupt the interviews as noted on transcripts.

3.4.2 Procedure

Prior to interviews taking place, all participants were asked to read the information sheet describing the study aim and procedures (Appendix E) and complete and sign the accompanying consent form (Appendix F). Interviews lasted on average between 60 and 90 minutes and were audio recorded. Participants were reminded of; their right to withdraw, e.g. by letting me know if they felt overwhelmed and wanted to stop the interview, that the purpose of the study was not therapeutic, and of how information would be used.

Questions regarding demographics were asked without the recorder on to ease participants into making the transition from informal conversation to formal interview. Participants were encouraged to ask questions and raise concerns before final permission was sought to start recording which prompted me to remind participants that they are experts on their experience of caring and that there are no right or wrong answers to ease them into formal questioning. Participants were provided time to debrief after interviewing which included leaving the information sheet with details of my contact details and those of the university as well as carer support contact information. All participants were given pseudo-names to keep anonymity, brief reflexive impressions were noted immediately post interview and interviews transcribed according to Smith, Flowers, & Larkin, (2009) to facilitate immersion in the data.

3.5 Data Analysis and validity

3.5.1 Data Analysis

Analysis using IPA as suggested by Smith, Flowers & Larkin (2009) began with a detailed reading and re-reading of transcripts whilst listening to the recordings to enable examination of each case individually. This process generated initial notes recorded on the left hand side (LHS) of the transcript followed by exploratory notes indicated on the right. This facilitated paraphrasing of ideas, contradictions, as well as consideration of salient ideas and abstracted psychological notions, feelings and contextual issues. The next stage involved relating these ideas to one another (and transferring them to the RHS) so that emergent themes could be identified (on the LHS) whilst still visually checking against the transcript (in the middle column) (Appendix H) before collating some emergent themes hierarchically or more organically to develop a list of sub-ordinate themes per participant prior to cross-analysis (Appendix I). Comparisons of individual emergent or sub-ordinate themes were then made across the corpus of transcripts, which generated a clustered list of sub-themes (Appendix J). This stage involved consideration of shared and divergent meanings and re-coding again hierarchically or organically to do justice to the material. For example, the themes ‘mind occupation’ and ‘dementia as blockage’ were re-coded by incorporating quotes into describing engulfment in a broader sub-theme of accumulative psychological stuckness. These were then organised into overarching master themes which represented the corpus as a whole as demonstrated in the narrative. A table which included quotes characterising each sub-theme helped structure master themes whilst simultaneously ensuring credibility was maintained by minimising temptation to overly abstract themes to fit pre-determined theoretical positions, through thematic analysis such as emotion-focused coping. Finally themes were considered against more formal theoretical perspectives tentatively, presenting one possible way in which to organise the meaning of data.

3.5.2 Validity

Various checklists exist for the evaluation of validity in qualitative research, however, (Smith, Flowers, & Larkin, 2009) suggests that such an approach can become prescriptive and dismissive of subtleties in qualitative work. They suggest employing guidelines set out by Yardley (2000) offering assessment criteria focusing on the principles of sensitivity to context, commitment to rigour and transparency to coherence as well as impact importance. These can be appropriately applied to IPA alongside, an audit trail (Appendices H-J and Table 2).

3.5.3. Researcher Reflexivity

In IPA it is important to consider the researcher's subjective experience and how this may subsequently construct meaning with participants. Reflexive sections throughout the thesis demonstrate reflections of my various identities as researcher and potential impact of that other positional experiences may have had upon the research process at different stages. Ongoing reflective discussions with my Therapist, Research Advisor and Supervisor helped understand, manage or value potential influences rather than dismissing researcher bias.

My training at UEL in a Psychology Department distinguished for its critical approach to psychiatric diagnostic categories along with historical positioning of Counselling Psychology influenced my take on literature, though this seemed more difficult during analysis. This may be due to my previous professional positions informed by positivist ideas from which underlying anxiety about challenging dominant theoretical positions emerged during theme formation (see Personal Reflections in the Discussion). Discussion in the London IPA group not only noted how this conflict also became evident in designing my initial interview schedule but reflected upon this general tension between post-positivist and constructivist approaches in Counselling Psychology trainings at this point in time, which helped normalise and trust my movement through this process and was encouraging.

In Research Supervision, reflexive discussions of my position as a Sikh and native Punjabi speaker helped me recognise potential overlaps in shared meanings with participants and to think about how to manage this. This potential bias was managed during data collection by asking participants to unpack personal meanings of shared cultural or spiritual terms, such as *seva*, since these could hold different meanings for each participant from my own.

In remaining mindful of my previous caring relationship with *Bebe*, and the possible impact of this experience upon the research I engaged with person centred and psychodynamic personal therapy during the research process. In therapy I reflected upon how I could minimise disclosure of my own experience of caring for a PWD to my participants through my own meta-communication, to encourage positioning them as experiential experts although this may still have occurred, none of the participants asked me about this. Personally processing my own feelings, helped develop awareness of the importance of embodied meaning through meta-communication, which helped me probe deeper in interviewing (see Discussion on Commitment and Rigour). Also processing loss in caring for *Bebe,* in therapy during data analysis helped overcome my experience of stuckness in the transcripts which resonated with me, as did my experience of the professions reluctance to acknowledge spiritual issues, which helped me empathise and critique constructively (see Discussion on Personal Reflections).

Reflections in therapy also helped me to make sense of, process and separate my own thoughts and feelings associated with my personal experience from those of participant accounts in order to understand how their voices interacted with mine to form an Interpretative and phenomenological focus. For example, my Research Advisor made me aware of how my account of caring was more positive than that of participants. I realised this might be due to being a transient carer, i.e. I intermittently cared for *Bebe* when I visited my parents at home, and did not have to deal with the same difficulties that my parents did, thus my initial set of themes seemed relatively negative. Reflexive discussion in Therapy helped me to consider and make sense of this difference, as I wondered whether this reflected my attempt to compensate for my more positive experience of caring by over-empathising with participants' negative experiences. These reflective processes helped me re-balance my approach to analysis and theme formation by developing Theme Three more clearly and articulating it as a positive theme with less emphasis on human helplessness and service failures as a separate sub-theme by developing deeper analysis and noting participant transcendence of interpersonal limits and loss of the PWD, by merging these.

Chapter 4: Results and Analysis

4.1 Introduction

Analysis of interviews began by grouping ideas emerging from each participant's account of experiencing and making sense of caring for their relative with dementia. The process of analysis developed towards group level themes to form abstraction of the entire sample's experience. This analysis identified three Master Themes informing the narrative presented below.

Table 2 represents sub-themes constituting these Master Themes. The first Master Theme entitled *Depth and Surface of Dementia: Confusion and Transparency* indicates participants' confusion in developing awareness of the meaning (something serious) and purpose (questioning why) of dementia and yet clarity about dementia as a surface expression of emotional neediness or underlying relational pain that has a spiritual function. The second Master Theme *I'm stuck and Winded up by Dis-ease* represents the psychological sense of being stuck or uneasy in caring which accumulates to manifest more substantial blocks or dis-ease at either the bodily or identity level. This sense of stuckness reflects either participant experiences of lacking choice in caring, stemming from cultural ideas, or restlessness or uneasiness relating to the relentless demands of the PWD. Theme Three is entitled *Still I kept going: Perseverance as Transcending limits*. This theme captures participants sense of perseverance, help-seeking and support, as well as transcending limits to interpersonal support, which for some includes seeking transpersonal support from God or connecting with the transpersonal nature of caring. The emphasis is on interpreting the phenomenological meaning of experience, in essence, amongst the group. Quotes from all participants contributed to each sub-theme, some of which are illustrated in the narrative below.

Table 2: Table of Themes

Master Theme	Sub-theme
1. Depth and Surface of Dementia: Confused and Transparent Awareness	1a) 'It's gone on top': Surfacing Awareness of Something Serious
	1b) 'This thing' : Difficulty Real-ising or Naming Dementia
	1c) 'Why it happen?' vs Spiritual Purpose of Dementia
	1d) 'Oh!' Dementia as Emotional Neediness: Reflects Underlying Relational Dis-ease
2. I'm stuck and Winded up by Dis-ease	2a. 'I've got to': Engulfed by Dis-ease of Culturally Entrapped Caring
	2b. 'A storming time': Psychological Dis-ease in Caring 'Winded up' as another Dis-ease
3. Still I kept going: Perseverance as Transcending Limits	3a. 'I'm strong': Self-Agency
	3b. Determining 'What I need: Transcending Barriers to Interpersonal Support is 'not right'
	3d. Transpersonal Essence of Care, Help-seeking & Support

4.2 Master Theme One Depth and Surface of Dementia: Confused and Transparent Awareness

This Master theme is comprised of the four sub-themes indicated above which represent Punjabi Sikhs' perceptions of dementia. In sub-theme 1a confusion represents participant attempts to understand changes in their relatives' presentations whilst normalising these. In the early stages surfacing awareness that something is wrong escalates unexpectedly with high level emotion (shock) pre and post-diagnosis. Sub-theme 1b captures the deeper, almost indescribable representations of and difficulty in realising, remaining aware of or naming dementia. Participant confusion is further signified in sub-theme 1c questioning the purpose of dementia which appears unfathomable whilst transparency in the purpose is paradoxically perceived as having spiritual meaning, which for some participants includes clear spiritual meaning for caring. Sub-theme 1d encapsulates the transparency in participants' understanding of and expression of dementia as being unmistakably aetiologically rooted in, or on the surface manifesting as, relational pain.

4.2.1 Sub- theme 1a) 'It's gone on top': Surfacing Awareness of Something Serious

This sub-theme begins by highlighting participants' experience of initial confusion or gradual dawning of something being wrong which is normalised before starkly lucid awareness of dementia as something serious emerges.

Sukdheep and Akashpreet's accounts indicate surfacing awareness of dementia as a diagnosis, being delayed, whilst Parminder emphasised a gradual process of dawning awareness:

"By the time we come to know about it (diagnosis), it's (dementia) gone on top" (Sukhdeep)

"Test, test, test, no results coming" (Akashpreet)

For Akashpreet and Parminder the experience of escalating awareness of dementia as a note-worthy condition was dismissed due to attributing anomalies of relatives' behaviour to a relatively 'normal' phenomenon rather than something to be alert to. These extracts illustrate how a gentle rising in awareness was experienced as confusing:

Parminder

"At the beginning you would just think it was just the same as anybody else – just forgetting.... later on you realised...it was something a bit more serious; there was something to it"

Akashpreet

"Dad is just pretending to be honest, we just thought that... because dad was a very authoritarian man...these are just his normal habits"

"So we got confused for these habits"

"He started having accidents... toilet in his you know trousers...because Dad was such a proud man...he always used to say to my husband 'You are my only son, you have to look after me'... Like Indian people, they want their sons to be with them and all...We used to laugh at him – 'Dad, don't test us, we will be there... but he was 'Now you aren't going to look after me"

"We didn't know that these kind of....diseases really existed"

For most participants as illustrated by above accounts, difficulty in discerning dementia from normality seemed to relate to their lack of knowledge of dementia as a medical disease. Nevertheless, Gurveer's account in contrast indicates that despite prior knowledge of dementia she similarly experienced gradual awareness of dementia development due to lack of familiarity:

"I understand when...I saw it in the news...but it was, when my father-in-law had it...we are getting experience about this, that's what the dementias are"

"Because I'd never seen this sort of things before, I didn't know it can be like this"

The shift from gradual to sudden escalation of awareness involved inescapable insight into the seriousness of dementia, both pre and post-diagnosis. Participants describe experiencing an onslaught of awareness that seems unexpectedly outside of their control.

"She'd say something odd, that didn't make sense...That really raised the alarm" (Parminder)

"We weren't informed much (by the doctors)....and all of a sudden the bombshell was dropped, 'Oh, he's got front temporal dementia" (Akashpreet)

"It's a real shock" (Sukhdeep)

"Unexpected things....her memory has gone sick, now she can't speak. We never, never, never thought in life she lost her voice" (Dilraj)

In sharing their experiences of developing awareness of dementia participants portray a sense of shock. Parminder's metaphor of the alarm signalled a hazard that seems poignantly amplified by Akashpreets's symbol of a bombshell shocking her into awareness. These metaphors portray a threat of danger, such as possible paralysis. Indeed, this after-shock ricochets into Master theme two, where Akashpreet and Dilraj portray a sense of fear/danger and deadness of feeling in their descriptions of caring for a PWD, respectively. The tremor and unnerving echoes of such unexpected surfacing awareness of dementia as a serious issue or medically diagnosed dis-ease are also reflected in the following sub-theme. It may be interpreted, that in this link between sub-themes 1a and b, participants seem to be distancing themselves from the deeply penetrative repercussions of shocked awareness (1a) of the power of dementia as a controlling or overbearing entity, by not naming dementia as a disease, which appears to make 'it' more real (1b).

4.2.2 Sub-theme 1b) 'This thing': Difficulty Real-ising or Naming Dementia

Developing awareness of dementia as something confusing and yet clearly serious seems to represent outstanding personal meaning for participants which is indescribable. This sub-theme captures that tense experience in having developed a deeply penetrating understanding of dementia as powerful and identifiable yet not fully expressible on the surface. Despite acknowledging the diagnostic terminology of dementia participants gave an indication of the difficulty in learning of the name, or in naming the experiential quality of what was happening for them in their making sense of what was happening to their relative as indicated in their rudimentary representations of dementia, below, as a 'thing' or 'it'. This highlights how participants underlying knowing or awareness of dementia as something serious may re-surface, through naming 'it', thus recognition of a real or progressively deteriorating condition that takes hold of (or happens to) their relative can be a challenging experience whilst holding deeply emotive meaning.

Sukhdeep, in recalling his experience of his wife being given a diagnosis seems more concerned for her state of being at the time of diagnosis than to the name:

"Dementia, Alzheimer's, whatever you call it"

"We see the doctor...specialist for brain...he told us 'this thing'.....at that time (being diagnosed) she (wife) wasn't that bad ... (Doctor) said 'it's (dementia) developing'."

It seems that labelling what was happening to his wife, as dementia in diagnostic or biomedical terms, did not do justice to his difficulty in experiencing or defining his wife as a person who's state of being was deteriorating through dementia and concern for her identity being overtaken by the progression of dementia. This clearly highlights issues beyond those of difficulty in acknowledging dementia as a medical disease, or lacking knowledge of medical language or articulation. Despite minimising medical language he is eagerly focused on identifying a way out of ***this*** dis-ease. It is this personal meaning which takes precedence beyond any other meaning of dementia, whether biomedical or otherwise that has been imposed upon his personal understanding of concern for the powerful incurability of dementia.

"I said any cure? He (Doctor) said 'no cure for that"

Akashpreet's perception of dementia as something serious is experienced as more than concern but fear, of maintaining awareness of dementia as a deteriorating condition such that at times it almost appears to have become unbearable to name:

"*I feel that it's the very, very scariest thing that anybody can go through"*

"We still didn't like admit it to ourselves that...these stages are going to come"

In Parminder's case, dementia is described as an entity of real yet indescribable proportions. Her witnessing the PWD's disorientation to time and place (hallucinations) as an embodiment of dementia, exemplifies her inability to name or realise this depth of dementia awareness or to face it on the surface of awareness as a real or substantial entity.

"It (hallucination) was really the thing"

Harshdeep's account indicates her understanding of dementia as an inherently unknowable power that imposes upon or takes possession over her mother-in-law:

"This thing (possibly taken over by anger) happens to her"

Although Gurveer, reports acceptance of dementia as a diagnostic entity, she still does not name dementia in her description instead similarly characterises dementia minimally.

"*Well er, after that (receipt of diagnosis) we took it"*

The next sub-theme demonstrates further experiences of difficulty in making sense of dementia, albeit clarity.

4.2.3 Sub-theme 1c) 'Why it happen?' vs Spiritual Purpose of Dementia

This sub-theme reflects participants paradoxically challenging the purpose of dementia which seems difficult to fathom, yet ascribing spiritual meaning with clarity. Some participant descriptions highlight questioning the purpose of dementia, either in practical (surface) or philosophical (deeper) terms whilst others such as Sukhdeep challenge the purpose of dementia indirectly by questioning caring for a PWD.

"Why wasn't she understanding you?...Why do you keep coming upstairs? Why do you keep bothering me?" (Parminder)

"Why is she doing this to us?" (Harshdeep)

"You look at the person going...deteriorating day by day....and you die everyday...the person is there...the physical body is there but he is not there...why did Dad have to go through this? At least if...leg cut or had an accident....at least he could communicate...even a child can cry when he's not well...but this...scared" (Akashpreet)

"Why he's got this sort of thing, you know why?...He didn't harm anybody and so why did he come into this term?" (Gurveer)

Despite Parminder and Harshdeep's accounts indicating at times, ability to differentiate the PWD from their behaviour and not defining their relative accordingly, they also seem to experience victimisation and confusion in their pragmatic questioning of dementia. Akashpreet's wondering and attempting to make sense of dementia seems steeped in personal pain of losing a sense of herself in losing the PWD and brings fear. For others questioning is illustrative of a worrisome or ruminative type of thinking which is linked to feeling bad, depressed or scared. For Dilraj and Sukhdeep the deeper level of questioning appears profoundly linked to an unsound rationale warranting dementia or caring, respectively, as a karmic punishment for earlier misdeeds which conflicts with their lived understanding of personal morality. This experience of confusion, injustice or disappointment in making sense of dementia and caring as karmic punishment seems to clear up when karmic perceptions are seen to have spiritual purpose according to God's Will.

Dilraj

"Why this happened? When I feel bad about her I just keep thinking what she done wrong, she got this punishment...she got all this sickness, what she done? Just then I said 'Oh, that's God's will"

"I don't know what she's done wrong in her life that she got this problem...according to me...she never done any wrong to anyone"

Sukhdeep

"Why, why it happen to me? What did I do wrong?...where I went wrong? That's where I feel depressed....Why God punish me? I don't know...I haven't got any answers for this"

"I say whatever, alright, thank God whatever it is"

These excerpts indicate participants' nuanced and complex psychological processes in making sense of dementia in spiritual terms. I.e. when considered solely in negative karmic terms that the purpose does not make sense and it can impact negatively upon well-being, whilst embedding karmic understanding within wider spiritual beliefs about the source of dementia or caring as a karmic response from God seems more acceptable or having more meaningful purpose.

Complexities in spiritual understanding of dementia are further demonstrated in Harshdeep's enmeshed understanding of dementia with caring but in contrast to the above, she indicates a more neutral stance in her perception of the karmic understanding of dementia with clearness rather than confusion around the purpose. Meanwhile, Gurveer focuses on the transparently positive aspect of karma, being integrated with her understanding of God as an omniscient and omnipotent being, whereby she focuses on the reward of caring rather than dementia directly.

Harshdeep

"*She can't look after herself so it's sort of karma that I'm in this situation. If it wasn't (karma of two people being intertwined), she wouldn't have this condition... so you understand me? ... If it wasn't in my karma, she wouldn't be in this situation, I wouldn't be looking after her like I do now*"

Gurveer

"If you care for somebody...God is up there looking and so He knows what you're doing, bad things or good things"

"If you do something for somebody it will come to return on you"

Parminder perceives spiritual purpose in relation to caring by understanding dementia as offering her a divine opportunity to face the challenge set by God to care for her grandmother:

"*Try to be understanding in terms of my faith that it's like a test for us, and God gives us, er family members.... to act out our responsibilities as a test...to make sure that we...fulfil our duties*"

Parminder's spiritual perception of dementia links with a relational responsibility in caring for the PWD's needs as a duty. The next sub-theme highlights participant perceptions of relational/emotional needs of the PWD.

4.2.4 Sub-theme 1d) 'Oh!' – Dementia as Emotional Neediness: Represents Underlying Relational Dis-ease

This sub-theme indicates how despite participants' having relatives with a medical diagnosis of dementia, they all described dementia beyond a biomedical entity, albeit as a *dis-ease.* Dementia is perceived as having underlying or etiological roots in relational pain or manifesting on the surface as emotional neediness or relational pain, reflected in some participants' expressions of "Oh!"

Dilraj perceives dementia onset as amassing from accumulative physical, emotional and relational ills whilst Akashpreet similarly attributes relational dis-ease or emotional upsets relating to familial, personality anger issues.

<u>*Dilraj*</u>

"She (wife) developing (dementia) after the stroke...because she's diabetic....afterwards my son, he got diabetes... kidney failure...when she heard that she is more worried about him...she go in a shock... gone sick there (India) she got shock....saw him in hospital, all the machines on him, she got more shock...after a couple of months she got another stroke.... effect on her memory...slowly"

<u>*Akashpreet*</u>

"(Father-in-law) was a very proud man... he got loss....the person tricked him. He didn't like that...a close relative.... that aggressed him...I think he was struggling with his emotions inside... He found...to move on with that chapter very hard...I think that triggered a little bit of his behaviour"

"I've started to research on the whole family...(husband's) granddad had Parkinson's disease...his uncles...their sons have the same symptoms... same characters...relating to each other... they cannot control their temper...I used to wonder.... they all do this thing, which is not normal... go up very, very angry, very, very angry and then calms down, and says sorry. Which was very unbalancing.... 'no, this is not right'... when I try to question, they say 'no we are all like that, we are fine, this is how my dad used to be, this is how our granddad used to be'...a very abnormal way of losing temper....all of a sudden"

"I used to feel angry when my husband lost his temper...he panics and he, you know, doesn't calm down... but since I saw dad develop dementia I've started to understand... his character is this way... underlying health condition... they are ignoring it. It's like people.... with ADHD and the parents don't want to admit it. We can see the child being hyper and the child being not a normal person....parents they say 'no, our son is fine. It's just his natural character'.... something that occurs in his blood"

The majority of participants highlight their relatives' emotional neediness.

"Hold her hand...all the time...like a little baby" (Sukhdeep)

"He gets up at night...says 'Oh! I want to go home'...we'd just wander around the house and then his mind got settled down" (Gurveer)

"A typical day...she start saying 'I want to go home" (Harshdeep)

"She'd almost reverted to a, a childlike state" (Parminder)

Harshdeep and Parminder also describe dementia as manifesting highly emotive and traumatic relational dis-ease stemming from earlier life losses and inability to move forward from this anguish.

Harshdeep

"Oh! My sister died and nobody told me' and her sister died, I think my husband doesn't even know her, because he's saying to her, you know, that happened a long time now. 'No, it happened recently, I had a letter from India and you didn't tell me', and she just get angry with us"

Parminder

"She'd often... start knocking... three or four times in the night... get up an hour later after you'd settled her... yelling...at the top of her voice... "Somebody call the police!"

"She'd wake up...say things like 'I had a baby sleeping next to me and it's been taken away; where is my baby?' ... reverting back to her younger years when she, when she had um my aunties and uncles as babies...have to settle her down

In participant accounts, disease is not just evidenced in perceptions of dementia representing the PWD's earlier experiences of relational *dis-ease* but also an uneasiness or *dis-ease* in the participants' personal experience of caring for the PWD within a cultural context as demonstrated in the next theme.

4.3 Master Theme Two – I'm stuck and Winded up by Dis-ease

Theme two is comprised of two sub-themes, 2a) entitled *'I've got to': Dis-ease of Culturally Entrapped Caring* and 2b) '*A Storming Time': Psychological Dis-ease in Caring 'Winded up' as another Dis-ease*. Sub-theme 2a encapsulates how participants' experience caring as stuckness or *dis-ease* from a sense of being entrapped by a lack of choice in caring through cultural norms or expectations to care. Sub-theme 2b represents participants accounts of accumulative psychological uneasiness or restlessness associated primarily (Akashpreet's was also heavily informed by cultural/familial pressure) with the relentless demands of caring (for example, persistent fear, despair, guilt or anger) which seems to wind up in the body or negatively affect participants' sense of self.

4.31 Sub theme 2a) 'I've got to': Dis-ease of Culturally Entrapped Caring

All participants indicated a sense of no choice in their perceptions of caring, informed by diverse cultural expectations and norms which indicate dis-ease. This understanding of caring as cultural entrapment links to community stigma (Parminder) culturally conflicted yet expected filial piety (Akashpreet) and familial positioning (Gurveer). The dis-ease seems to be weighted by isolation and concerns around stigma not just from the community but via the Temple (Sukhdeep) and Governmental contact (Dilraj) or karmic necessity (Harshdeep).

Parminder

"It (caring) was kind of one of those things that was thrust upon you and you had to cope with at the time"

"In the Indian community, in the Sikh community, it's almost frowned upon... if you send your elderly relative away to be looked after, because it's as if you can't be bothered, or you don't want to take on that, that, those chores and that responsibility"

Akashpreet

"The thing with Indian families is that the community comes in between. You know there is a pride and there is a honour there."

"We dare not...say 'No, we're not doing this (caring)"

"But this is where it all clashes.... western culture... we have to ...put ours foot down and say 'no, this is injustice'...conflict between the culture and the western culture".

Gurveer

"There is no one around and so I know I've got to be doing it"

"Why didn't they (sisters and brothers in-law) share it (caring)"

"(Husband) say "don't worry, we've got to look after him...we are the eldest," you know, I think you know the Indian rules"

"I think... that it (being the eldest) doesn't matter"

Sukhdeep

"So if I don't do it, who else will do? So she's my wife... I can't leave her alone, so it's not very nice but life goes on"

"I'm stuck... go to the Gurudwara (Sikh Temple) you know she can't sit down, so it's embarrassing for me... what can I tell you (laughs) honest?"

Dilraj

"I've got to init. Nobody else can"

"I'm stuck...I've got to look after because she's my wife...it doesn't matter whether I enjoy it or not... it doesn't matter what I feel"

"The government saying "you'd better look after her at home....they're not giving any help"

Harshdeep's account indicates a nuanced meaning to lack of choice or entrapped caring. She refers to having some choice despite perceiving caring as an imperative albeit a moral one (imposed by karma). This paradox thus appears through her spiritual rather than cultural perception of caring as a pre-determined experience which offers scope for caring to be viewed positively or freely rather than the uneasiness or dis-ease of forcing herself to comply.

"This is my karma. I'm in this situation to look after her so there's no way I can say "I can't do it". Whether I do it willingly or force myself, so I have to do it... so it's better to do it willingly than forcing myself"

The next sub-theme indicates further psychological dis-ease in caring which accumulates and has an impact upon the body or the self.

4.3.2 Sub-theme 2b) 'A storming time': Psychological Dis-ease in Caring 'Winded up' as another Dis-ease

This sub-theme represents caring as an experience of being stuck in repetitive cycles or storms of negative emotions, which accumulate, in caring for the demands of the PWD (or cultural stresses- Akashpreet) to the point at which the body or sense of self, become dis-eased. Participants' accounts suggest that this experience of dis-ease in caring is experienced as being 'winded up' or amasses as a physical blockage or other bodily problem. Participants' descriptions convey a psycho-somatic transition in dis-ease almost as a sense of being consumed by highly emotive aspects of caring. Participants indicate psychological dis-ease (negative emotions of caring such as fear, despair, anger and guilt) accumulating and infiltrating in different ways.

Some participants indicate psychological disease of caring as negatively impacting upon identity (Gurveer, Parminder and Akashpreet).

Akashpreet's excerpts highlight the accumulative dis-ease in caring rising as a dangerous tornado which engulfs and penetrates her-self to defile the core of her caring identity as bad or not good enough as she describes the bleakness of no escape:

> *"Every little, little, small thing,(mother-in-law) like 'Oh...you haven't done this, you haven't done that"*
>
> *"One small little issues were clustering together to make a big massive problem...on the heads of us"*
>
> *"My mother-in-law made it (caring) into a big a big issue...created, made such a big thing about it"*
>
> *"Going back, is really, really like scary, scary, scary time... me and my husband we lay, lay at night and thinking how are we going to cope?"*
>
> *"It was very hard. I mean I felt that I am letting my family down. I felt at one time that 'I'm not good enough for them'. I went through depression, because first I hadn't produced an heir to their family and now I'm blamed that we are not helping enough... I was thinking 'where am I going wrong?'... I was doing the best of my ability....I couldn't think of doing a better way... because then I would be losing my future, my own children there, I had to think about...my parents back home...I am the only child...too much going on in my life. It was quite a storming time."*
>
> *"We were like...made villains out of it"*
>
> *"We had no definition for becoming, how to become (good) unless we stand there 24 hours on the head, which was, as human nature was find hard for us to do it."*

Parminder indicates the struggle of preventing the storming chaos or insanity of her experience of caring from infiltrating into her-self:

> *"She'd be shouting all sorts of nonsense... walking in and out of the room constantly...knock on the door three, four, five times in an hour...this could go on for hours... you'd get so frustrated... you'd try to be sympathetic.... lose your temper... but there was enormous guilt.... It was difficult (not to lose temper)...and also sort of have a bit of sanity to your own self... you can't really describe it... just that as if there was no excuse to shout at her"*

Gurveer's metaphor of being wound up depicts her experience of dis-ease as being coiled into a tightness that squeezes and consumes more than her mind; her- self:

‘”I (as a daughter-in-law) shouldn’t be doing these sorts of things... changing his nappies”

“You’ve been winded up, your mind’s been all winded up”

“I get angry because...I couldn’t get proper sleep”

For Harshdeep and Sukhdeep psychological dis-ease of being winded up or on edge is illustrated as a manifestation of physical dis-ease of the blood bubbling up or being depleted. Harshdeep’s angry imagery may reflect an attempt to compensate for the blood already drained from her body (reflective of her anaemic deficiency) to stimulate a rush of blood or life-force in the hope of caring without dis-ease.

Harshdeep

“I get annoyed, I get angry...she gets annoyed.and starts saying stuff...I just have to put up with it”

“She forgets but I don’t”

“I feel like pulling my hair..., but I can’t do that”

“She just follows me... It’s annoying but I just have to block it out... but she is there...knocking on the door, open the door and this and that”

“She just comes back in here and sits down, and I come back...she seems like nothing happened, but where I’m still feeling angry...it’s (holding on to the anger) not good for my health”

“It’s like a circle... if I say I’ll be better tomorrow and if she’s agitated and annoys me, I get angry, it’s like a vicious circle”

“I became very anaemic with the stress”

Sukhdeep

“You can see how it affect me (emotional pause); in the night time... I put her to bed...any little noise I wakes up, she...get up (pause) and then that’s like my life and like my health”

“I’m stuck... depress...I can’t leave her alone for a minute”

“You’re blocked...unwind”

“It’s a (sigh) feel uneasy... feeling is uneasy (hands moving restlessly)”

“Everyday, I’m stuck... I got a blood pressure, due to her otherwise I’d be fit now”

For others the psychological dis-ease of needing to remain alert in the relentlessness of the caring experience is described as amassing a less dramatic yet physical dysfunction in the form of fatigue or immobility, drained of vigour and rest to the point of lost feeling or becoming drowned in feeling. The majority of participants also made reference to the night-time despair or lack of sleep in contributing to this sense of no escape.

Dilraj

"I mean at the end of the evening when I sit there, I, it's the body not working properly (laugh)... my body running out...I can't move from the chair, so I feel tired because at night I can't sleep properly. When she get up I get up quick"

"I'm frightened in case she fell over...one time she...fall down, nearly five minutes she is unconscious"

"For me it's, I got to hold her now. I hold her all the time. I won't let her do again. I make sure I hold her back.. If I bring her back, I walk in front so she can't fell over on the front. When she go up, I hold her from the back, so that's, I makes sure she don't fell over anymore. That's the problem"

"So I'm so restless I can't sleep properly because worrying only if she get up, she fell over and might hurt, having more problems, so that's why my health going down... I stuck with her that's why I say my feelings dead, I can't, I don't think anything else"

"I stuck with her (pause) so need to think anything glorious. That's the end of the story."

Parminder

"Multiple occasions, after you'd told her... very difficult having to get up out of bed...each time once you're ...in a deep sleep....and explain it all again to her....It's very kind of disturb, disruptive to your night's sleep... three or four, five days in a row, it could get quite exhausting and just, just be in a state of despair"

Despite a sense of such stuckness in the hypervigilance of caring for the PWD's relentless demands, the next theme demonstrates how participants also described a capacity to transcend their personal and interpersonal stresses, some of which arose through help-seeking or in receiving interpersonal support. Although some stresses or limits are further described in master theme three the purpose of presenting them here is to contextualise participants' sense of perseverance in transcending these.

4.4 Master Theme Three. Still I kept going: Perseverance as Transcending Limits

This Master theme is comprised of three sub-themes reflecting the personal, interpersonal and transpersonal transcendence over difficulties within the caring experience. Sub-theme 3a*) I'm strong: Self-Agency* illustrates persevering in caring through a sense of personal strength which facilitates capacity for autonomy over difficulties, for example, through describing personal traits such as being maternal, resilient or diligent. This includes examples of transcending the sense of caring identity being engulfed by negative emotion reported in Theme Two and seeing past dis-ease of caring is reframed with contentment and for some links to spiritual processes strengthening identity. In 3b) *Determining 'What I need': Transcending Barriers to Interpersonal Support is 'not right'*, persistence in caring is indicated as participants continue to seek and, or accept support albeit difficulties in this process, which helps to determine their unmet needs or helplessness experienced in recognising the limits of interpersonal help in caring. Sub-theme 3c entitled *Transpersonal Essence of Care, Help-seeking, Support* symbolises the transpersonal essence of caring, by moving beyond the limits of the personal helplessness or lost attachment relationship with the PWD, or to support others in the community to develop awareness of dementia. The majority of participants also describe seeking or espousing the need for transpersonal support, through prayer, hope or reverence for God, to cope with personal difficulties in caring, to manage difficulties experienced through help-seeking or transcend limits to human or interpersonal support within their experiences of caring for the PWD.

4.4.1 Sub-theme 3a) 'I'm strong': Self-Agency

The majority of participants explicitly personalise strength in depicting their capacities to care for the PWD. Accounts of coping with caring as the engulfment of dis-ease, involve perceiving caring as perseverance, based upon personal determination and resilience developed through experience of overcoming previous adversities. For some participants this involves reframing negative experiences through personalised reciprocation of care received from the PWD prior to dementia onset or recognising the personal meaning of gratitude indicated by the PWD whilst caring.

Sukhdeep's resilience is indicated in his descriptions of hardiness developed through migrant experiences. Similarly, Akashpreet indicates personal resolve in her endurance with caring despite additional burdens she experienced as a daughter-in-law. Gurveer's account highlights how she has accrued a strong heart to care based on her earlier experiences of caring for her grandson with cancer.

Sukhdeep

"I'm strong minded I can cope...when I came to this country... I had many hardships, so I can take these things... nobody to turn to...so, I said 'I can cope for a while"

Akashpreet

"It was quite stressful... I had gone through myself as a daughter-in-law quite a few things... which I didn't have to...but still...I just kept going"

Gurveer

"It's a bit of a long story because I had a grandson and he had cancer and so that's from where we got a bit stronger and stronger. We looked after him for years"

Although not explicit, Harshdeep's description of autonomy in reframing caring as a choice is owned and personalised as a purposed strength to ease the dis-ease of caring to benefit her well-being. Dilraj highlights the necessity in maintaining a positive spin on his negative experiences of caring through acceptance and contentment. Dilraj and Parminder indicate how perceiving caring as a reciprocal relationship with the PWD also aids contentment to overcome the loss of personal hopes and strain in caring.

Harshdeep

"I do it willingly not to get stressed about it or think about why do I have to do it...do it and it's a lot better for me so I don't get stressed out"

Dilraj

"I stuck with her.... but still, I'm happy she's alive and I'm looking after her. So I think in my mind it's okay what happened to me, is happening....I

keep myself like that [happy] I am happy I look after her. What I can say? Feel bad? (Slight laugh)...she's my wife, my good companion so that's why I feel happy. It's okay. It doesn't matter the things I've not done my life"

Parminder

"I'm not saying it wasn't a burden at all, but it was. We were happy to assist her because she had helped us as we were growing up...helpless as babies and she'd almost reverted to a, a child-like state"

Strength of character can also come from within the experience of caring for the PWD. Parminder and Gurveer refer to the strength of their personal characteristics being maternal in nature and amenable to caring. Carrying on from her earlier mentioned strengthening process in caring (mentioned above) Gurveer describes a further enrichment process in her character developed throughout her caring for the PWD. Parminder described how caring for her grandmother allowed access or repositioning back to the personal attachment relationship with her prior to the dementia, albeit momentarily, in which caring is spiritualised or consecrated enabling a new level of bond which encouraged contentment in caring.

Parminder

"It was disturbing of a personal nature...upsetting...memories that she had of you had been erased"

"Part of our relationship disappeared altogether...with her dementia"

"Washing her hair and then handing her the soap to wash herself...preparing her clothes... there would be moments when she'd remember you (clears throat) and she'd be so grateful and realise what you're actually doing for her and be so happy....she had someone to look after her....kind of mutual ...happiness on both sides.....I think (pause)...bonding"

"I remember times when I'd helped with her...shower and having a bath (tearful) and (pause) she'd be so grateful and she'd bless me (pause) repeatedly because she'd felt so happy that she'd had a grand-daughter to look after her and I felt happy that I was able to , I felt very happy...to return the acts of kindness she'd shown us...she would sometimes get really distressed in the shower...calm her down and say 'don't worry everything will be fine' and she'd appreciate it...I did enjoy it...when I realised she appreciated it...it kind of developed a different closeness for us"

"I did quite enjoy it [caring] because I, I'm quite a maternal person"

Gurveer

"It's always in my heart....I can take care... I know how to be lovable and take good care (pause)"

"I'm a very strong person and now I'm strong but I wasn't before, since my father-in-law. After that I just got stronger and stronger"

Akashpreet and Sukhdeep also highlight how their spirit of hope for a dementia cure upholds their will to persevere in learning more, though Akashpreet describes fear around this, a proactive and responsive approach is evident.

Sukhdeep
"Touch wood, she's not that bad for a while, it could be bit worse years time, so might, might some medicine comes out. They are trialling you know all these things comes out... the other day on the telly, they said they should drink coffee, so we started giving her coffee now (slight laugh) (R: um). So, anything comes out, I try"

Akashpreet
"I've seen Dad's (PWD) habits and I see my husband's habits relating together. It's scaring me more... I've started to love my husband more... I'm protective about him (husband) now. Every time he is like 'Oh, no, no, no!' I panic"

'I'm studying...every minute of him (husband)... "Why is he getting angry?... and how it (the anger) takes him?" And I know now when he gets angry. I know. I mean, before I would get angry myself, and answer him back... but now I know... it is his nature"

The next sub-theme builds on this sense of persevering but focused in relation to formal and informal support, by transcending barriers to help-seeking or appreciating support despite inadequacies.

4.4.2 Sub-theme 3b) Determining 'What I need': Transcending Barriers to Interpersonal Support is 'not right'

This sub-theme represents the sample's acknowledgment of limits to familial and service support, and how these concerns have been pursued through consistency in help-seeking or continuing to accept help despite unmet needs remaining. This experience seems to develop resolve of what they do need with conviction as some participants articulate that unmet need is ‘not right’.

Despite Sukhdeep experiencing setbacks in help-seeking for his wife (whereby his GP minimised his concerns and denied him constructive help) he continued to persevere (resorting to travel abroad) with this avenue until his wife finally received a diagnosis.

> Sukhdeep
>
> *“Doctor didn’t do anything she just said, ‘there’s nothing in the medical...in the NHS”*
>
> *“I did try it (GP’s ad hoc Ayruvedic herbal advice)...didn’t help her...brain...nothing constructive so the year after we went to India....see specialist for the brain”*
>
> *“So people comes on here they go on about pension credit...but money is not good to me, what I need (emphasised), help...if she goes (day centre)...be better for me”*

Considering all these set-backs, Sukhdeep highlights how even unhelpful offers of support are pursued and hindrance to diagnosis does not limit transcendence of obstacles to perseverance in caring.

Despite Akashpreet’s acknowledgment of medication being unable to cure dementia, she perseveres and highlights her experience of injustice in her perseverance for early intervention on an interpersonal level (help-seeking for her concerns/recognition of signs of dementia in her husband) being rejected by the NHS.

> Akashpreet
>
> *“The Doctor said there is no medication for him (Father-in-Law)...that can cure him”*
>
> *“I am nagging him (Husband) to go and see a Doctor. He went and...then I feel that NHS is not doing enough here, it’s not right...this thing (experience of dementia as she perceives it – Relational pain/familial/personality issue) has made me aware now (of need to seek early preventative support through emotional management)”*

For Akashpreet this sense of ‘it’s not right’ is also appropriated on an interpersonal level by standing up to her mother-in-law, not just in help-seeking but transferring care to her mother-in-law despite the cultural pressures and persevering with seeking help for herself and from formal carers.

Akashpreet

"That (pastoral care from employer) is what...kept me going... that is what made me stronger day by day...I feel a much stronger person today...confident ...with myself that I don't feel any bad'... It's alright to think about yourself it's not a crime"

"I took a stand...Now you (mother-in-law) have to pick up the responsibility, because all these years I have I have done everything for mum. I have never complained, and now, you, a little bit of responsibility is that you stay with dad. We can give you one hour or something, but not 24 hours, you can't go out in the morning and come back in the evening, go with your daughter and all around. No, this is not going to happen, because you are saying everything, your son has to do everything - the son has to do, no, mum. That is not the right mentality (pause, sigh)"

"Slowly, mum started to understand"

"We tried to get help (from social services) but we were refused because they said 'this is the only best help we can give you (day service)' because Dad's got property"

"We can afford it (full-time formal carer) there (in India) because we couldn't certainly afford one here (in England)"

Despite a whole array of negative experiences of service support, including concerns of basic needs not being met Dilraj determines his need for practical night-time support remaining unmet.

Dilraj

"They (respite) said 'she not eat anything today'...you've got to grind her food...still they put sandwich.....you've got to feed her...that's why she...health going down"

"If somebody help me...to look after her at night, I can sleep properly"

Harshdeep and Parminder determine a need for advice and to be heard. They describe usefulness of phenomenological support (being understood) accepted from formal carers, despite making a formal complaint about carers and already being in receipt of emotional support from family (Parminder) or difficulty in acquiring this from family (Harshdeep). Parminder also indicates a reverence, and trust that Doctors will inform her of available support (as does Sukhdeep further below) in managing helplessness.

<u>Parminder</u>

"I felt very helpless, because we didn't know what else to tell her"

"If there were any other sort of things that you could do to assist, I mean I'm sure the Doctors would have made us aware"

"We (family) were counselling each other... just to have somebody else to talk to and they (family) understood fully what we were going through"

"Having the outside help of professional carers helped us to understand....having that extra support to know that the burden wasn't just on us"

<u>Harshdeep</u>

"I couldn't talk to anyone even in the family, that how it was affecting me"

"(With Carers assistant)....I let it all out and cried. She understood maybe made a me a bit more understanding, somebody to talk to"

The majority of participants highlighted limits to the medical treatment which Sukhdeep generalises as human helplessness including interpersonal helplessness and Dilraj's acknowledgment of these limits to medical help, prompts him to seek transpersonal support, which leads into the next sub-theme.

<u>Gurveer</u>

"He was on medication but you know there's nothing we can do"

<u>Sukhdeep</u>

"Everybody tried to help, but nobody can do anything really...doctor, can't do anything who else can do it...no treatment"

<u>Dilraj</u>

"They (Doctors) they simply said they can't do anything...no medicine can do anything, they give her medicine but they not affect memory function – the brain and calm down...that's all"

"Even doctors say well, only pray to God now...she get better"

4.4.3 Sub-theme 3c) Transpersonal Essence of Care, Help-seeking, Support

This sub-theme represents participants' accounts of caring, help-seeking and receipt of support as being transpersonal in essence beyond personal or interpersonal endeavours of perseverance indicated in the first two sub-themes. In this way the personal caring relationship is repositioned within the wider humanitarian or spiritual understanding of community care. This highlights how participants perceive caring beyond the attachment relationship with the PWD at a transpersonal level or seeking transpersonal support through prayer based upon perceptions around the limits of human endeavours (described in the previous sub-theme) through reverence for God's omnipotence and omniscience.

The following excerpts illustrate how transpersonal care involves the Sikh spiritual concept of *seva* being applied in a way that transcends perceptions of care in terms of the attachment relationship to aid caring either for the PWD (Sukhdeep, Parminder and Akashpreet) or other carers in the community (Sukhdeep). Perceiving caring beyond the personal (Transpersonal essence of caring) does not involve depersonalisation of care for the PWD but paradoxically can reflect a more significant spiritual meaning (of benevolence) to their understanding of caring.

<ins>Sukhdeep</ins>

"So I'm a religious person... do seva....somebody can ah gain on it"

"My mean (of seva) is...what I experience, If I knew it a little bit early...she (wife) might be in a treatment before, she might be a bit better"

'It (seva) could help somebody...to make any difference...like a social worker"

Parminder describes how her application of *seva* offers contentment in applying a Sikh principle to her caring experience. Contentment or Ease is also a Sikh principle.

<ins>Parminder</ins>

"Our religion teaches...to assist others in times of need.... Seva... applied to… help in…a Gurudwara…. the concept was originally...aimed towards homeless people...but... always making sure that people...are.....looked after... so I, I kind of apply that principle and I enjoyed looking after my grandmother...a service...to God, in terms of my grandmother....being a being who needed help so I...saw it in that sense"

Akashpreet indicates the need to transcend cultural misunderstandings of Sikh principles. Although she does not explicitly use the term *seva* she highlights the importance of Sikh egalitarian principles, such as showing the way with love and *simran* (by reflecting on the word). Akashpreet indicates her meaning of caring as enabling an emotionally corrective relational experience, similar to Parminder in sub-theme 1d and 3a or Gurveer in 1d.

Akashpreet

"I look at faith in a different way than they (parents-in-law)"

"I don't believe in going to...Gurudwara (temple)... looking at people....it's about studying, it's about principles. It's about what Sikhism expects... you have to read the gra, the Holy book (GGS) and then you have to follow those principles. There's no point saying 'Oh, I'm a Sikh' and...not doing things in the...proper way... in that process (Sikh Baptism) they forget...how are they. Are they honest? Are they kind? Are they understanding?..They forget all these principles"

"Sit and read the whole day...but they won't understand what is that book asking you to do? They won't follow those"

"I follow one thing... if I'm honest throughout my whole day...I've been a proper Sikh....which is hard...to maintain, because....we come under the pressure of....not doing things the appropriate way, because the politics around us is in everywhere....the different path because the whole.... community is following that and that's where we question...'are we....strong enough to stand by our principles?"

"Keep patience I started to keep calm... explain...by showing some good, being a good role model...rather than answering back, it's better to change the way by love... So I would show my patience, I would say 'No dad, it's all right, don't worry about this...Make him feel that yeah, he's on the top of the world...at the same time, show him that 'No, no Dad, this is... wrong'....in a very calm way"

Gurveer's account also captures her experiencing the Sikh concept of *simran*, which supports caring for the PWD indirectly through embodied self-care in prayer and reflection that infiltrates her identity and her body as she spends time relaxing and acting in accordance with her perception of God's omniscience and omnipotence.

Gurveer

"God is...looking and so He knows what you're doing, bad things or good things...we got to keep nice, stay calm and look after people"

"If you read the books...our Paahts (prayers)....it can relaxes in your mind and so you can understand what's in this world... if you believe in your God.... that...helps you"

"I just go into my deep Paaht (prayer)'"

"Deep into your body... then you just don't know where you are, just relaxed....like a yoga...I used to do it after a couple of days"

"It (deep prayer) helps me quite a lot while I was looking after my father-in-law. That's what it (spiritual embodiment of prayer) carries on me"

"I start getting stronger and stronger from inside"

"My heart's...my sister-in-law....she said 'well, because our dad's doing these sorts of things I'm getting scared away quickly'...But I don't know what comes in me"

Similarly Sukhdeep and Dilraj seek support through God in prayer and submitting to His will which embodies hope.

Dilraj

"Pray to God. He might do something good, she get better"

"I will leave up to God now when nobody else can help"

Sukhdeep

"I'm a religious person...I sit down there (temple) where there is a paaht (prayer) going on...bit quiet - don't think anything else there...pray to God, that's all"

"I pray...God give me a strength, make her bit... I can't do anything on this...I say whatever happened, alright thank God whatever it is (dementia) so I'll do it (care) as long as I can"

The next chapter discusses further analysis of themes in relation to the literature.

Chapter 5: Discussion

5.0 Introduction

This chapter begins by discussing how the results help address the research question. The aim is to determine how participant meanings may be further made sense of in context of theoretical frameworks and research pertinent to the field of Counselling Psychology. This discussion aims to help me develop tentative Guidance for Professionals to support Punjabi Sikhs' psychological needs in a way that may be appropriate to support thinking about the usefulness of the meaning of caring for a PWD identified in this study. Next a critical review of the thesis examines the validity of findings according to good practice guidelines for qualitative, IPA research. Examples of good practice are demonstrated, including outlining the thesis' original contribution to counselling psychology research and discussion of my personal reflections. Finally methodological limitations of the study are considered and addressed with recommendations for future work.

5.2. Discussion of research findings in relation to the research question

The research question asks '*What is the meaning of Punjabi Sikhs' lived experience of caring for a relative with dementia*?' This section aims to determine how each of the master themes contributes to this understanding, using extant literature to help elucidate these findings and vice versa. Occasionally, the meaning of participants experiences of the caring phenomena are discerned through exploring how themes overlap.

5.2.1 Discussion of Master Theme One- Depth and Surface of Dementia: Confused and Transparent Awareness

This theme recurred in several ways. The analysis showed that for Punjabi Sikhs in this study, making sense of dementia can involve surfacing awareness of something being wrong or serious. These understandings seemed to be described as a gradual dawning or more explosive escalation in awareness as well as being associated with feelings of confusion and shock in moments of insight, respectively. Participants seemed to normalise confusing changes or minimise dementia terminology pre and post diagnosis. An IPA study by Quinn, Clare, Pearce & van Dijkhuizen (2008) conducted with people of white European descent caring for their spouse with dementia in the early stages similarly found initial confusion and normalisation of dementia in carer reports. Those participants' also described resistance or reluctance to accept their relatives' diagnosis. Participants in the present study seemed to indicate similar reluctance or difficulty in naming dementia in both their pre and post-diagnostic accounts. In their descriptions, naming appeared to heighten realisation of the underlying power that dementia held for them in their personal meaning of dementia as an incurable condition. For one participant, even in her description of accepting her relative's diagnosis as a progressively declining condition, she did not mention the terms diagnosis or dementia. Another described resistance in confronting awareness of dementia as a diagnostic condition through fear and subsequent denial of the stages to come. The present theme suggests the possibility that these carers may have experienced resistance to accepting a diagnosis in attempts to manage deeper underlying anxieties about dementia from surfacing into awareness. Although these issues do not appear to be associated with being Punjabi Sikh specifically, other emerging sub-themes constituting this master theme do seem to lend themselves towards the general literature indicating culturally and spiritually specific ideologies around dementia. Mukadam, Cooper & Livingston (2011) equate psychological, social or spiritual perceptions of dementia within the SA community to non-belief of dementia as an illness which significantly and negatively hinders help-seeking. The present study elucidates some nuanced meanings emerging from some Punjabi Sikh experiences which suggest this academic position may be assuming a biomedical vision of dementia, which may be considered to reify institutional racism.

Some participants' descriptions of confusion around the purpose of dementia, which focused on the unfathomable or profound sense of karmic injustice may reflect the essence of the Sikh concept of Simran or contemplation, as participants experience confused attempts to make sense of the underlying purpose of dementia within a practical or spiritual framework of meaning. In questioning the karmic purpose of dementia and caring two participants reported feeling depressed or bad in their being stuck in worrisome or ruminative ideas about dementia as a karmic punishment, rather than a direct punishment from God. Psychological and meta-cognitive literature clearly considers rumination as an unhelpful process which involves dwelling on past events and negative concepts of the self or others which can negatively impact upon well-being. In the present study participants' confusion seemed to be described as suddenly clearing up through spiritual sense making in terms of perceiving dementia as God's will. Thus although Punjabi Sikhs' psychological sense making of dementia may appear to present a paradox of confusion yet clarity around the purpose of dementia, this duality may reflect more of a process out of confusion towards transparency through shifting from perceptions of dementia as karmic punishment to dementia as God's will in which spiritual purpose was found to be more acceptable. This is discussed further in the analysis of Master theme three. Other spiritual perceptions of dementia aetiology emerging from Master Theme one, included a spiritual karmic bond which is deeply embedded with and purposed for personal caring which may offer opportunity for karmic reward through caring.

Jutlla's (2001) findings of Sikhs did not indicate dementia being perceived as a spiritual entity, but rather as having relational or emotional aetiology. Jutlla's (2011, p.269) study noted 'shock' based aetiology was clearly articulated by one of the Punjabi Sikh migrants as stemming from pain of relational stress. She indicates that for the Sikhs in her study, dementia was not perceived as an illness but rather validates this through acknowledging this as 'triggered by stressful life events'. The findings from the present Master Theme suggest that such events may involve deeper psychological processes of trauma or relational pain involving loss or anger and thus perceiving dementia as a dis-ease, pain, distress or illness on a relational level may represent a re-processing of such events. Jutlla recognizes, however, the limited scope of her methodological focus in determining further understanding that dementia may hold for better understanding the experiences of caring for a PWD in SA's.

Finding relational meaning in the cause of dementia is a common theme in the literature representing SA experiences of caring. A recent study of SA's in Canada by McCleary et al. (2013) found participants attributed the early signs of dementia to personality whilst Uppal, Bonas & Philpott (2014) found similarly diverse perceptions of dementia amongst Sikhs aside from the biomedical disease variety in the UK, albeit not necessarily in the context of the lived experience of caring. This theme in the present study illustrates more nuanced understandings of how Punjabi Sikhs may understand the underlying cause of dementia in various ways, though primarily as relational and spiritual aetiologies. For example, relationally these were perceived as stemming from a personality issue relating to anger around loss that may reflect relational, familial or hereditary issues arising in the blood, or as stemming from accumulative shock from relational loss, stress and worry along with other physical health problems.

For the majority of participants' dementia was clearly perceived as arising from or being the expression of the PWD's painful losses of close relationships including angry responses to loss and manifestation of relational traumas associated with loss earlier in life or craving to return home. Jutlla & Moreland (2009) found one BME dementia carer's description of the PWD as being 'twice a child' represented the perceptions of many. According to the present theme participant ideas of relational cause of dementia are not necessarily separate from behavioural manifestation of emotional neediness or relational pains expressed by the PWD, (i.e. medically termed hallucinations, delusions or disorientation to place and time). This theme helps to consider how these two possibly divergent perceptions, of manifestation of emotional neediness (on the surface) and relational pain (underlying) aeitiology, can converge in that both sets of perceptions represent concern for the unmet psychological (emotional-relational) needs stemming from traumatic pains of the PWD. Some participants clearly articulated their understanding of dementia formation being linked to the PWD's relationally informed emotional pain remaining unresolved whilst others similarly shared observations of earlier unresolved relational pain from the PWD's earlier adverse life experiences manifesting in current presentations. Some participants' deep concerns for the incurability of dementia and others' concerns for negative impact of not caring upon well-being due to fear of karmic punishment or lack of opportunity for reward from caring well or living up to the test from God or karmic bond that necessitates caring well for the PWD, (i.e. the spiritual purpose of dementia being enmeshed with the personal meaning of caring warrants considering implications of this theme for dementia care for the PWD, to indirectly support well-being in Punjabi Sikh carers.

In considering dementia, Kitwood (1997) argues that relational life experiences may make it difficult for individuals to respond to social environments to the point that they can no longer maintain their usual adaptive sense of self. The present theme uniquely links participants' personal meanings of social, relational and emotional dementia aetiology in the present study with Kitwood's thinking and Miesen's (1993) ideas emerging from observing how people with dementia can become engrossed in past attachment relationships with their parents. This link suggests that carer perceptions of the PWD's emotional neediness may reflect the experiential replaying of earlier attachment based experiences of traumatic loss which remains unresolved for the PWD. In this context, Punjabi Sikhs perceiving dementia as stemming from years of exposure within attachment-based realities, in the context of significant others' inabilities to process or help them manage anger, as one participant suggested, may link to the ideas of Kitwood and Bredin (1992). They highlight scope for the potentially therapeutic impact of sensitive care-giving, by fostering meaningful activity or co-operation with the PWD's reality rather than the informal or professional carers reality. Miesen & Jones (2005) argue that dementia may be perceived as a 'trauma, a drama and a tragedy' whilst providing guidelines for how to set up a dementia café for carers and the PWD to help manage such experiential difficulties in caring for a PWD.

The Sikh model of the person, suffering and healing proposed by Sandhu (2004) suggests that karma is the consequence of accumulative or habitual behaviours, which can be intervened through taking personal responsibility for new 'cognitive behavioural impressions' (p.37). These ideas may also be relevant in considering further analysis of Master Theme Three, where participants' describe managing difficulties in the PWD's behaviour as opportunities for emotionally corrective experiences for the PWD. For example, by implementing Sikh principles such as 'showing the way with love', or by engaging with meaningful activity to help process the emotional neediness linked to relational pains or missing home, by connecting with the PWD's reality. These ideas can offer potential insights for how Counselling Psychologists may start to think about facilitating resolution of difficult emotions in the therapeutic relationship as part of early intervention or preventative work. This is significant when carers may anxiously seek help for the PWD, as indicated in Master Theme Three but feel unsupported this, or to think about supporting Punjabi Sikh carers in exploring how to implement sensitive dementia care alongside potential concerns they may have for their own karma, which is again potentially very meaningful, if they have developed 'bad' caring identities, as indicated in Master Theme Two.

In thinking further about the potential role that participant perceptions of anger or loss may have in being ascribed to dementia development, in the present theme, it may be useful to explore findings from other studies carried out in broader populations of men showing earlier signs of hypertension or depression. A study by Fuhrer, Dufouil and Dartigues (2003) identified the risk for developing dementia, amongst hypertensive men with depression, to be fifty percent greater than for men without hypertension. A study by Alexopoulos, Buckwalter, Olin, Martinez, Wainscott & Krishnan (2002) discuss findings which suggest that depressive symptoms may contribute to dementia aetiology long before dementia onset not just proceeding onset. They arguing that this thereby potentially acts as a risk factor as well as a pro-dromal symptom of dementia. In thinking about wider theoretical implications of this theme, Kitwood (1989) challenges evidence of the cause-effect linkage of both biomedical and social models of dementia, whilst Harding & Palfrey (1997) suggest that both models of dementia aeitiology are approximately equivalent in their evidence base. Harding & Palfrey present psychological theories which represent dementia aetiology as a 'defence mechanism to the threat of death or ageing, a reaction to traumatic events, a socio-demographic variable of age and gender, or relating to personality factors'. The socio-cultural context of dementia proposed by Downs (2000) suggests that the neuro-psychologisation of dementia by professionals and neglect of social and environmental issues may mean that potential opportunities for prevention of dementia development are missed. Summerfield (2008) argues that professionals need to help protect 'folk models' to prevent such cultural health or illness based perceptions as being otherwise classified unethically as 'ignorance' which in the case of dementia may be deemed as lack of knowledge or awareness as indicated by Prince (2009) in Chapter Two.

Despite participants in the present study having relatives diagnosed with dementia any perceptions aligning with the medical model did not dominate accounts and this Master Theme demonstrates psycho-social and spiritual perceptions of dementia in Punjabi Sikhs have not hindered the receipt of a diagnosis, albeit a medical one; as suggested by Mukadam, Cooper & Livingston (2011). It is important to bear in mind, however, that in the present study, although participants may see dementia as stemming aetiologically from or manifesting as relational dis-ease or pain, participants did not necessarily mutually exclude perceptions of dementia as a biomedical or hereditary disease. Rather, this theme supports the wider debate which questions the appropriateness of research and practice in elevating the level of dominance that the theoretical perspective of dementia as a medical entity. This indicates the need for Professionals to consider implications for the alternative treatment options for dementia becoming more marginalized in the future and more importantly potentially provides scope for invalidating the deeply personal meanings of Punjabi Sikh experiences of caring for a PWD. Both the biomedical and social models indicate potential for negatively impacting upon well-being, for example, by having potential to introduce stigma into the caring experience (Watters, 2010; Adamson, 2001). This theme which captures Punjabi Sikhs making sense of dementia through acknowledging depth and surface awareness in their experiences of caring for a PWD reflects the theories of Kitwood (1997). He rejected classical neurological theories of dementia for ones which are more inclusive of the social context of dementia development, by highlighting two vicious circle theories of dementia based on neurological impairment and psychogenic aetiologies. This balanced approach may be considered appropriate and useful to use in formulating valid support for Punjabi Sikh carers of a PWD.

5.2.2 Discussion of Master Theme Two – I'm stuck and Winded Up by Dis-ease

Although participants describe being stuck physically this theme encompasses the sense of being stuck and isolated psychologically and accounts of potential re-emergence of dis-ease in other ways. This dis-ease at the essence of the caring experiences indicated by Punjabi Sikhs here supports the findings of Jutlla (2011) who noted especially women's experiences of caring as indicating a sense of being trapped and isolated. Findings from the present study offer interpretative phenomenological understanding of Jutlla's theme of being trapped by noting stuckness, as having meaning beyond the social roles theory suggested by Jutlla. This stuckness was experienced by all participants not just women and further represented through emergent themes of dis-ease in caring, which involve perceived lack of choice in caring that arises from cultural pressures informing perceptions of caring as entrapment in expectations, as well as being 'winded up' through the accumulative restlessness (or uneasiness of being stuck) in caring for the PWD's relentless neediness.

Beyond Ory, Yee, Tennstedt & Schulz (2000) definitions of care-giving as requiring 'supervision and cueing', participants here reveal a sense of hyper-vigilance in attempting to meet the PWD's demands which contribute to the experience of restlessness. The BPS Response to the Dementia Strategy (2008) highlights that carers be provided the opportunity to choose if they would prefer to receive respite at home, whether this extends to night-time caring, however, is not discussed, though participants indicate that often it is this relentlessness which leads to experiences of despair or exhaustion cycling out of control. Psychological dis-ease is described as an accumulation, winding up or vicious circle of restlessness with the caring experience. The meaning of emotional dis-ease emerging from this theme represents feelings of uneasiness, fear, loss, anger, restlessness and guilt emotional disease which wind up in the mind, self or the body to the point of re-emerging as a different type of dis-ease. Indeed, participants interpret how restlessness or uneasiness in caring creates a state of stuckness, such as physical immobility as manifest in either physical dis-ease or uneasiness with their sense of self. Thus emotional dis-ease appeared to engulf either participants' sense of self or the body.

On the bodily level, this theme represents Punjabi Sikhs' vivid descriptions of how the constant demands of caring can engulf or entrap their bodies to the point of 'running out' and immobilising the body literally of feeling numb psychologically, depleting blood in the body manifesting as anaemia or winding up the pressure in the blood again literally manifesting as physical health problem of high blood pressure. Thus being engulfed by dis-ease indicates how participants reports of accumulative restlessness or distress in being stuck is analogous to participants literal metaphors of the self, body or blood embodying or mirroring their psychologically lived experience of caring as stuckness. Psycho-somatic meanings of dis-ease have not previously been identifiably reported in the experience of Punjabi Sikhs caring for a relative with dementia.

In the western cultural literature, BME perceptions of disease which link the mind, emotion and physicality, have historically at times been interpreted in derogatory terms. Psycho-somatic illness may be regarded as confusing by professionals who are accustomed to Western models of thought, even as malingering when people's reports fail to be categorised as purely emotional or physical entities. Indeed, counselling and psychotherapy researchers have previously interpreted affective somatisation experiences of BME's as an inability to verbalise or articulate psychological distress (Carothers, 1953). Moodley (2009) regards this type of meaning making as an 'ethnocentric' stance to understanding health which imposes and reinforces mythical assumptions that BMEs are incapable of expressing emotion. Some researchers have indicated that SA older people with depression, for example, are comfortable talking about depressive feelings when described more appropriately, e.g. as a sense of loss (Lawrence et al., 2006).

In the Psycho-somatic literature, affect has been conceptualised in physical terms amongst people of Punjabi origin, in the Punjabi model of emotional distress proposed by Krause (1989). This model indicates the importance of appreciating non-duality or unity between mind, body and self (in a social context) in bringing somatic meaning to how emotional pain may be experienced and communicated publicly by Punjabis as a ‘sinking heart’ (Krause, 1989). Krause suggests that according to Ayruvedic theory, Punjabi perceptions of sinking heart can be differentiated from worry and depression whilst the aetiology may be understood as arising from exhaustion in the physical body or a changing sense of self in terms of social failure. Krause suggests that Punjabi’s express emotional suffering through representing a unified and integrative relationship or embodiment of physical, emotional and social symptoms rather than separation. According to Indian Ayruvedic understanding, organs are perceived as stores of sustenance which moisten the all aspects of the person in a holistic sense, in which the heart acts as a central point for balancing the various physical, emotional and mental aspects of health involving the individual and social experiences of stress within a whole range of relationships, e.g. with the self or with God and thus holds possible moral implications due to fear of social disapporval (Dash & Juo Jounious, 1983; Krause, 1989; Kakar, 1984). Thus Kakar, (1984) posits that in India health can be represented as a cooperation between such pressures within the personal and the social context. The findings in this theme are consistent with this theory, but develop phenomenological understanding of issues of morality indicated below. These seem to link to participant descriptions of dis-ease in perceiving a culturally entrapped sense of caring responsibility and relate not just to Indian and Punjabi cultural ideas discussed above, but also to the Sikh specific spiritual models of suffering and healing as posited by Sandhu (2004) and Singh (2008).

Sikh models highlight that chronic disease results from inner unrest, perhaps such as the restlessness, uneasiness or dis-ease presented in this theme. This phenomenological experience of dis-ease in caring suggests a sense of illness rather than medical pathology of disease as may be considered in Western medicine, though symptoms of such disease seem to manifest. Sandhu (2009) highlights that although the bio-psycho-social model recognises the mind, social and body integration Sikh models also incorporate spiritual and existential perceptions. The disease from restlessness is thought to arise if one uses egoistic rather than spiritual principles to inform behaviour. In the present study this dis-ease embodies how participants experience being restless or uneasy when wound up or stuck in caring through cultural entrapment to care or demands of caring. Being engulfed by dis-ease lived experience of caring in this way, thus reflects not just cultural entrapment, informed by familial/community desires or egoistic pressures, but fear of social ideas pertaining to failure, such as honour and shame threatening to further engulf spiritual principles or approaches to care, as feelings become 'dead', despite attempts to remain content, as sense of hopelessness and helplessness endures through failed interpersonal connections, which for some stormed up perceiving the self as a social failure, to the point of choosing not to care due to conflicting caring ideologies. Sandhu (2009, p.31) suggests that the individuals 'psycho-emotional state or social environment..."triggers' or "activates" the genetic predisposition into an acute or chronic' problem.

Although Mackenzie's (2006) study highlights the issue of stigma in the SA's experiences of caring for a PWD, this theme demonstrates how psychological dis-ease from fear of stigma may be experienced so negatively almost as moral imposition of responsibility rather than moral choice, whilst others were able to perceive the paradoxical choice and no choice. The former may reflect the findings of Harding & Higginson (2001) and Calderbank (2000) but this theme opens up phenomenological understanding in which the caring relationship is complicated further by a sense of being stuck amidst the storm of conflicted experiences steeped in traditional and non-traditional conceptualisations of caring. This theme thus has potential implications for the suggestions made by Lawrence et al., (2008) of promoting the value of the carer role as an intervention for those with traditional caring ideologies. This interventionist approach may risk carers experiencing intervention as an intrusion if both ideologies are valued as indicated by several sub-themes and possibly further fuel feelings of alienation or isolation in the entrapment experience of caring. For example, in Lawrence et al., (2008) non-traditional perceptions of caring as 'putting life on hold', 'too burdened to fight' being unnatural, lacking virtue and conflicting with expectations which seem to link to participants descriptions of dis-ease in this theme of 'got to' whilst conversely in the next theme indicate an active yet autonomous stance to persevering with help-seeking.

Lawrence et al. attribute the former to traditional caring ideologies, and the latter to non-traditional. This highlights that perhaps caring ideologies cannot always be clearly delineated as Lawrence et al., (2008) suggest which could have implications for the universality of their interventionist approach.

The accumulative disease of being stuck in this predicament of choice and no choice may however, bring ease or contentment in caring, so that traditional and non-traditional caring ideologies could potentially co-exist within one's experience of caring and be deemed manageable if a spiritual focus is enabled this, as indicated in theme three, through re-framing lack of choice as willingness to care. These findings may link to those of Oliffe, Grewal, Bottorff, Luke & Toor's (2007) references to *seva* (selfless service) and *dharma dee kirat karnee* (self responsibility) in male health discourses and Laungani's (2004) reference to how valuing spiritual rather than material understandings enables the holding of inherent tensions. Indeed, Labun & Emblen (2007, p.147) found Punjabi Sikhs described how "sickness or premature death may provoke 'asking God why" as indicated in Master Theme one. One participant in their study reported "We have two pieces of mind. We thank Him as well as question Him. There are reasons for everything. But it's not our choice" whilst another added "(Health) is predetermined. (People) believe in predetermination by God. All Sikh abide under His will and get healthy under His will". Thus this theme when considered in the Sikh worldview, seems to demonstrate how phenomenological experiences of caring can lie at the ebb between themes, capturing the potential for participants to become further wound up and confused, powerless and question their experience to the point of becoming depressed through perceiving no choice, or transcendence of duality through unitary thought or being able to hold tensions in order to loosen the tightened wound up grasp of dis-ease on several levels, to ease up and unwind, through perseverance with transpersonal efforts beyond the limits of interpersonal stresses, whether from the PWD or societal/familial pressures.

5.2.3 Discussion of Master Theme Three: Still I kept going: Perseverance as Transcending Limits

This Master Theme highlights participants' accounts of moving beyond the limits experienced in caring. This includes persevering through difficulties by engaging an autonomous self-concept, pursuing identified needs for support despite attempts at help-seeking being denied by services through acknowledging these as 'not right' and transcending interpersonal limits to feeling supported by seeking spiritual support through turning to God, or the transpersonal essence of care.

Participants' descriptions of an autonomous self-concept in supporting their capacity for caring seems to expand upon the descriptions of Punjabi Sikh resilience in caring developed during migration as indicated in Jutlla's (2011) study. This theme shows experiences of having developed strengthened caring ideologies from earlier life adversities; having a strong heart through earlier caring experiences for a person with cancer, being a maternal woman or other broader personality traits such as diligence in caring developed through hardships as a carer, migrant or a daughter-in-law. A study of Punjabi Sikh perceptions of spirituality and health by Labun & Emblen (2007, p.144) identified the theme becoming 'spiritually strong' as being a benefit of religious practice which linked to the perception of health and becoming more adept in recovering from dis-ease. This understanding is consistent with participant accounts in the present study, for example, of embodied hope through prayer or understanding *simran* as a meditative empowerment process which embodied strength of the caring identity to support caring for the PWD. Such practice may potentially support a working through or transcendence of negative impact that cultural pressures identified in theme two may have upon defiling caring identity, particularly as a daughter-in-law. Jutlla's (2011) study reported findings of the negative impact of being a woman upon caring as a daughter-in-law, in the experience of caring for a PWD. The present theme develops understanding of how transpersonal perceptions of care and support may facilitate transcending difficult caring experiences through various psychologically nuanced examples of resilience gained through previous adversities experienced not just as a daughter-in-law. For example having overcome difficult experiences as a migrant or having already cared for others in distress, also acted to develop and strengthen caring ideologies or an autonomous self-concept enabling, endurance and perseverance in caring for a PWD further could also be further strengthened, e.g. for participant was clearly connected through spiritual practices.

A study by Greenwood, Hussain, Burns & Raphael (2000) highlight SA service users' expressions of disappointment in feeling unable to share concerns which may be understood from their perspective in mental health assessments. Those participants reported that their beliefs and commitments which influence the nature of their distress were not taken seriously; including lack of opportunity to explore the religious context of their experience and appropriateness of potential interventions. Theme three represents transcendence over negative experiences of help-seeking, e.g. through transpersonal means which are meaningful to participants and involve connection and trust in God. Mackenzie, Bartlett & Downs (2005) suggest that older carers have a tendency to seek spiritual rather than GP support in the first instance. In the present study, although both older carers did seek spiritual help directly from God this did not hinder formal help-seeking. One participant's perception of the medical model as limited was generalised as sense of human helplessness and pervaded his understanding of all forms of interpersonal support and prompted transpersonal help-seeking from God. Galdas, Oliffe, Wong, Ratner, Johnson & Kelly (2012) found Punjabi Sikh men following heart attacks perceived trust and prayer as equally significant or even more meaningful than medical support.

In the present theme negative experiences of help-seeking from through GP's involved invalidation of their perceptions of dementia, being minimised or rejected and thus negating early-help seeking and awareness and concerns of something being wrong with their relatives. These unmet needs raised feelings that 'this is not right' or prompted perseverance with further help-seeking. Although these findings echo those of La Fontaine, Ahuja, Bradbury, Phillips & Oyebode, (2007, p.605) whereby British Indian Punjabi perceptions of dementia, through focus-groups, indicated 'disillusionment with doctors' and a sense of 'exclusion from services', the present study demonstrates a capacity for Sikh ideas of caring to transcended barriers to help-seeking, albeit continuing to pursue help via the medical route. The BPS (2008) response to the Dementia Strategy suggests that despite the resource issues which may arise from offering a pathway to flexibly attend memory clinics so clients could pursue their own memory concerns by attending memory cafes which offer psycho-education including support for those struggling to get help from GP's. Alternatively, Punjabi Sikh experiences of injustice and unmet needs being identified in this theme despite persevering with help-seeking might be better addressed by promoting awareness of Counselling Psychology services which may be more receptive to their concerns, given that Manthorpe, et al. (2009) reported that people of BME backgrounds lack knowledge about the range of services which are available to them.

Adams (2007) and Morgan & Vera (2012, p.840) propose that there is scope for promoting awareness that Counselling Psychology services can work towards 'culturally responsive prevention' and education through advocating the phenomenological approach and emphasis of the therapeutic relationship in addressing issues of social diversity. Some participants in the present study described their appreciation of being listened to and 'understood' in receiving what may be considered ad hoc phenomenological support from formal carers, despite being either in receipt of a familial ear or more significantly when unable to talk or cry with family. This appreciation has been similarly illustrated in studies by Jutlla (2011) and Mackenzie (2006) suggesting that Punjabi Sikhs and SA's caring for a PWD welcome offers of emotional support made to them in their own homes. Indeed, the findings of a study by Clegg (2003) suggest that some SA ideas of cultural sensitivity seem to relate to valuing the nature of human relationships with an emphasis on 'respect, understanding, spirituality and dignity' – mostly consonant with the humanistic principles of Counselling Psychology, albeit common secularisation of Psychology.

Although the Sikh tradition has been minimally studied in the field of Counselling Psychology, (Sandhu, 2005) researchers have identified, that the UK Sikh population may be more religious than imagined by psychologists in the UK (Post & Wade, 2009; Bruce, 1995). A doctoral study by Thompson (2010) found that eighty percent of the Sikh community highlighted the importance of wanting their religious beliefs to be taken seriously by services, and the author advised Counselling Psychologists to acknowledge this. The present study supports this idea, in highlighting, that Sikhs consider spirituality a meaningful part of their experience of caring for a relative with dementia. This finding is counter to the impressions developed from Jutlla's (2011) study where spiritual issues appear marginal and solely limited to the practical (dietary) religious needs of baptised Sikhs. Indeed, although Jutlla (2011) stated that there is no Sikh specific concept of community care, the findings of the present theme indicate that *seva* is indeed a Sikh specific spiritual concept of community care and more importantly is meaningful in how some participants have made sense of and experienced caring for a PWD. Some participants described transcending their attachment-based caring relationship with their relative to a transpersonal caring relationship by application of the Sikh specific spiritual concept of *seva* or a wider humanitarian perspective of care or community care. *Seva* has previously been found in a study by Morajaria-Keval (2006) to have been useful in facilitating change amongst Sikhs with alcohol problems, albeit by acting as a practical 'distraction' or to 'eradicate sin by seeking redemption from God through service to others'. The latter reflects the application of *seva* as described in the present study or as an altruistic approach to caring, for the benefit of the PWD or the community.

This theme clearly indicated the important role of the Sikh faith, specifically faith in God and prayer. Prayer was also described as a meditative approach to well-being through integrating mind and body akin to the Sikh specific spiritual concept of *Simran* (contemplation or remembrance of God). Prayer exemplified this theme of transcendence and illustrated significance in how Punjabi Sikhs coped with difficulties in caring, by providing opportunities to relax, gain hope and be strengthened. Studies with SA's show spirituality, including karmic principles, can provide meaning and strength as a coping strategy for dealing with the distress of breast cancer and depression (Gurm et al. 2008; Hussain & Cochrane, 2003). Participants' accounts of support and coping in caring, in the present study tended not to relate to the concept of karma as much as they do to their expressed faith in God. For example, for men in the study discordance between personal and generic karmic rationales for dementia and caring as punishment were associated with worry and depression, however, these difficulties were justified and transcended though their faith and reverence in God's omnipotence and omniscience. Conversely, female accounts of caring as karma were framed more positively. Although the above mentioned studies were limited to women, other research, for example with Punjabi Sikhs demonstrates the importance of spiritual concepts such as God's will and karma in making sense of, and coping with alcohol difficulties in men, as well as common health issues (Labun & Emblen, 2007; Galdas & Kang, 2010; Morjaria-Keval's, 2006). Findings in the current study, however, illustrate some complex and potentially negative issues surrounding karmic sense making of dementia and caring as well as spiritual coping, in a way that has not previously been reported in discussion of Punjabi Sikh experiences of caring for a relative with dementia.

In considering the revised socio-cultural model of dementia care-giving developed by Knight & Sayegh (2010) Master theme three demonstrates that cultural values may need to be considered in conjunction with (or differentiated from) spiritual values. In this way, experiential conflicts between the two types of values can be recognised as being complex and nuanced in how they affect the nature of coping strategies being used. In the present study these spiritual values have been demonstrated to feedback and negatively impact upon well-being in perceptions of dementia or caring as karmic punishment or inform other spiritually informed coping strategies such as perceiving these as God's will. In broader dementia care-giving literature, Stolley, Buckwalter & Koenig, (1999) highlight that religious coping resources have been found to facilitate coping with stress whilst a study by Shah, Snow & Kunik (2002) suggests that religious beliefs can hinder emotional well-being due to difficulties in their relationship with God and be associated with increased burden and depression in those caring. In considering transpersonal care and support the findings of the present study highlight that religious issues could be addressed further to identify other nuanced and complex meanings in the wider field of informal care-giving as suggested by Herbert, Weinstein, Martire & Schulz (2006). In particular, discussion of this theme notes the need to consider how to support difficulties with well-being, experienced in Punjabi Sikhs through unhelpful spiritual or conflicted cultural/spiritual ideologies of dementia and care.

5.3 Reflective Summary of Findings

Whilst my research supports some existing evidence about perceptions of caring as duty or burdensome, and dementia as having relational or spiritual cause, it adds interpretative phenomenological dimensions to understanding of lived experience of Punjabi Sikhs by reporting, e.g. on how awareness of dementia as having relational or spiritual meaning can be experienced on deep and surface levels and experienced with positive and negative impact upon well-being. Despite co-constructed meaning of caring as transcendence, over the dis-ease of caring, help-seeking or support limits; perseverance still illustrates that relational dimensions in making sense of and experiencing coping (albeit transpersonal in essence) within the caring experience are important to them.

Punjabi Sikh perceptions of dementia seem diversely meaningful, and descriptions of both experiencing confusion and clarity in developing awareness of surface and underlying changes in their relatives' presentations including aetiology have to some extent been reported by other studies whilst some aspects offer more nuanced meaning. Spiritual understandings of dementia have been identified here as being potentially meaningful for how caring is understood by the Punjabi Sikhs in this study in particular, provide strengthening processes, empowering and embodying hope in the experience of possibly negative caring ideologies. Discussion of relational aetiologies of dementia has opened avenues for better understanding how some carers may approach dementia care for their relative. This thesis links Punjabi Sikh understandings of the social, relational and emotional aetiology of dementia with the social-psychological theories of dementia proposed by Miesen (1993) and Kitwood and Bredin (1992). Better understanding how Punjabi Sikhs make sense of dementia as relational dis-ease can bring meaning to the experience of caring by providing emotionally corrective or sensitive care for their relatives.

Findings indicate that certain dimensions of caring experienced as dis-ease may be difficult to manage, in particular emotional difficulties emerging as physical or identity level disease which may be difficult to make sense of according to Western models of health but more meaningfully using integrative or Sikh and Punjabi models of distress. The discussion highlights the potential for understanding Punjabi Sikh experiences of coping through theme three which captures the usefulness of spiritual understandings of coping through application of *seva* and *simran* to transcend difficulties and limits experienced in caring, help-seeking or interpersonal support.

Participant perceptions of dementia despite being experienced as confusing also present as being clearly perceived as relational dis-ease and spiritually sourced or purposed. This understanding seems to be similarly reflected in Punjabi Sikhs' meaning of their experiences of caring for a relative as being transpersonal-relational-emotional-psycho-somatic. This discussion left me wondering whether the interpretative phenomenological meaning of Punjabi Sikh lived experiences of caring for a relative with dementia for me in response to considering participant accounts in this study is as follows. That participant perceptions of dementia itself may be understood as arising from the painful memory loss of a previously lived experience of spiritually informed caring relationship (perhaps memory of a I-Thou caring relationship earlier in life). This dis-ease or loss of a fuller or more integrative sense of caring experience may be reflected in, participant understandings that the PWD's positive experiences of a caring relationship have been replaced by memory of I-It experiences and, or manifest physically as memory loss in dementia or other physical/caring identity dis-ease in caring according to the continuum of dis-ease described by participants. In this sense the loss of memory on the surface level in dementia or loss of physical or psychological functioning (argued in clinical psychology as being organic) may be understood by Punjabi Sikhs as embodying or re-playing painful I-it experiences. Experiences exposed to through automated culturally informed or spiritually impaired non-caring reactions from significant others including health-care professionals to earlier relational pains by focusing on physical-behavioural-cognitive level care rather than emotional, relational or spiritual level care, may be again re-lived in dementia or the experience of caring for a PWD and may accumulate or be wound up and become stuck over time, to become more chronic and detectable forms of medical blockages or disease categories.

These personal and interpretative meanings and possible implications of caring offer scope for psychologists to better understand how to support those in need, through employing the therapeutic relationship with Punjabi Sikh carers as will be indicated, in the following sections. This Discussion highlights the importance of preparing a set of recommendations that may be considered useful in supporting Punjabi Sikhs who may experience difficulties similar to those reported here, by making use of the psychological knowledge gained around negative and positive experiences in caring. Some suggestions have already been described above and the later section entitled Practical Implications considers more generic options for psychological intervention with Punjabi Sikhs through approaching culturally sensitive care at a transpersonal level. Guidelines for working with BME dementia carers, if psychologically focused are not specifically directed towards Punjabi Sikhs (Gallagher-Thompson et al., 2003) or are not psychologically focused but geared towards needs of SA carers more generally (Katbamna, et al., 2001).

The next section provides a few specific recommendations on how Counselling Psychologists may be able to start thinking about supporting Punjabi Sikh carers to care for relatives with dementia if running a Counselling Psychology service catering to this population or other health care professionals involved in such care. This is important given the conflicting nature of some of the sub-themes identified, i.e. between cultural and spiritual understandings of caring as spiritual purpose yet cultural entrapment. If caring is invariably experienced as psychological stuckness stemming from dis-ease of cultural entrapment such as familial duty or relentless demands of caring and as being spiritual or transpersonal in essence, for example, as *seva* or *simran* and can facilitate transcendence over difficulties experienced in caring, then this section considers what might be of benefit to other Punjabi Sikhs caring for a PWD. Wider applicability of such suggestions will need to be considered cautiously since speculative meaning here is not conclusive though informative and important to consider.

5.4 Tentative Guidance for Professionals Supporting Punjabi Sikhs Caring for a PWD

- **Defining Caring:** Acknowledging that Caring may be understood and experienced in different ways including holding spiritual or transpersonal meaning beyond the interpersonal attachment relationship. This is particularly pertinent in caring for a PWD where parts of relationship with the person or shared memories disappear.
- **Assist caring for PWD**: Recognising and exploring Punjabi Sikh perceptions of dementia may be different from the status quo. I.e. exploring relational pain aetiology of dementia may help to personalise dementia care, through connecting with the carers understanding of the specifics of the PWD's past traumatic relational experiences and thus emotional neediness (e.g. anger about loss) can be attended to in an emotionally supportive manner through the caring relationship not sole dependence on medication to reduce agitation. Discussing difficulties they may experience with empathising and supporting the PWD by reframing caring as *seva* or practicing *simran* to 'unwind' dis-ease which may be experienced in caring.
- **Transcending or reframing difficulties**: Exploring nuanced meanings of dementia and caring to transcend conflicts. For example, supporting people who find it difficult to differentiate between *Simran* (as contemplation of the purpose of dementia or caring) and worry or rumination potentially associated with confused unfathomable pre-determined understanding of dementia or caring as karmic punishment. Facilitating guided discovery to identify or re-frame negative spiritual meaning of dementia as negative karma; as God's will or more neutrally as karmic necessity or reward to help manage a sense of helplessness, stuckness or confusion. Facilitating empowerment of self-agency through exploring and connecting with strong caring identities developed at other stages in life to offer perspective to ease stuckness of caring as dis-ease (fear, guilt, anger, no choice) to possibly open access to perceiving caring as consecrated, contentment or gratitude.

- **Promoting prevention of Dis-ease in Caring**: Caring dis-ease accumulated through lack of choice from cultural/familial duty and relentless demands of caring could be validated and prevented by developing professional awareness of signs of relational-emotional dis-ease as being meaningful for Punjabi Sikhs. By validating psycho-somatic understanding of dis-ease through acknowledging an integrative approach to sense-making and attending to carers' relational pains to minimise progress towards identity or physical levels of dis-ease. Exploring spiritual values may identify ways of coping.
- **Sensitivity to wider health environments:** Offering training and collaboration with social and spiritual locale of the Sikh community through Gurudwaras and specialist BME and SA dementia carer support groups.
- **Re-branding the Concept of Memory Cafe**: I am aware that this community are not big coffee drinkers but rather fond of *chah* (milky Indian tea with masala). Re-labelling this service as 'Dementia *Chah Bhath* (Tea and a Chat) could promote interest. These may run in community centres attached to Gurudwaras to prompt accessibility. Facilitation of group discussions around difficulties which may be experienced in caring, for example, in managing unhelpful GP's. Making space for or signposting separate service for *Paaht* (Prayer) or *Simran (*as Reflective Contemplation as a scriptural study group) to facilitate understanding of idiosyncratic and convergent experiences of caring without judgment or Simran (as Integrative meditative Prayer, Yoga or Mindfulness) to aid relaxation or attunement with God.
- **Help-seeking as *Seva***: Individuals concerned about issues of stigma in attending a community group may be encouraged to view attendance of support groups as an application of *seva* through sharing experiential expertise of caring with those in need.
- **Promote Normalisation of Difficulties in Surfacing Awareness or Accepting Diagnosis**: Promotional education on dementia may include normalising feelings prior to diagnosis by acknowledging that awareness of something being wrong in the early stages may involve gradual or sudden insights. Noting that these processes can evoke confusion and strong emotion including shock or a sense of powerlessness over dementia. Processing resistance in accepting changes due to uncertainty about the

changes to come. Validating awareness of the relational and spiritual perceptions of dementia symptoms such as hallucinations, disorientation to place and time as being meaningful in context of the PWD's earlier relational/emotional and even social/moral/karmic life. Encouraging professionals to notify carers at point of diagnosis, of available support in assisting potential difficulties in making sense of diagnosis, including validating personal meaning of changes and fearful feelings.

- **Awareness of difference between culture, religion & spirituality**: Reimer-Kirkham (2009, p.407) notes culture as the 'shifting nature of shared systems of meaning' and importance of not stereotyping or. 'transposing fixed' traditional or non-traditional caring ideologies. Focus on implications of clients' spiritual values for their understanding of health and identity in the experience of caring, e.g. dementia or caring as karmic responses may reflect personalised understanding of earlier life experiences. Thus not stereotyping traditional institutional or orthodox religion as 'bad' or spirituality as 'good, new or contemporary' but focusing on spirituality as reflecting personal meaning.

5.5 Implications of Themes for the Practice of Counselling Psychology

The themes identified in this study may be integrated or considered within the definition of caring proposed by Morse, Solberg, Neander, Bottorff & Johnson (1990) as 'a human state' (of no choice or human helplessness), a 'moral ideal' (being spiritually intertwined with dementia), 'an affect',(of dis-ease), 'an interpersonal relationship' (stemming from the kinship or attachment relationship which can be transcended to a broader humanitarian or transpersonal level) and a 'therapeutic intervention' (an intervention with spiritual purpose). Participants accounts having alluded with this definition and thus provide support for applicability of this definition to the experiences of Punjabi Sikhs. This expands the definition of caring by indicating limits to perceiving caring as interpersonal and highlighting the transpersonal essence of caring for Punjabi Sikhs, and may be experienced as more supportive. This has practical implications for Counselling Psychology practice as suggested below.

Religious and spiritual coping has been mostly understood through the work of Pargament (1997). Although this framework despite being appropriate to Counselling Psychology in the context of the present study findings, according to Folkman & Moskowitz (2004) it is based primarily upon Christian populations in the U.S. employing mostly quantitative methodologies. Although theoretical Sikh spiritual model of counselling by Singh (2008), Sikh Life Stress (Sandhu, 2005) and Sikh Model of the Person, Suffering and Healing (Sandhu, 2004) have been developed with suggested implications for Counsellors, there is a paucity of evidence indicating whether or not these models are relevant or applicable for use in practice. Additionally, although some of the suggestions do attempt to link to western models of counselling, for example through existential philosophy and varying psychological concepts akin to the cognitive, behavioural, psychoanalytic, gestalt, feminist and humanistic traditions, some clearly require culturally specific knowledge, for example of 'popular traditional analogy to educate' (Sandhu, 2004, p.44). Although some participants in the present study, clearly indicate that their perception of caring highlights there is scope for applying the Sikh specific or culturally specified models of counselling, research, for example by Vallianatou, Leavey & Brown (2007), indicates that this could be difficult in practice. Their research supports findings from the present study which questions how the practicality of human helplessness stems from the medical model, as indicated by participant accounts of the lack of a 'cure' or way of implementing cultural sensitivity through training in cultural competency (or culturally sensitive models of counselling).

This raises the question of further research which needs to explore the potential for Counselling Psychology approaches not just in supporting Punjabi Sikh carers on the basis of cultural difference per se, but into learning more about and thinking about how to embrace and apply a relational psychological model of dementia aetiology and dis-ease in caring for the PWD as participants are clearly concerned about both (perhaps by considering earlier stages of intervention in the development of emotional problems). The Ayruvedic science of medicine takes an holistic approach (combining recognition of the spiritual, psychological and physical aspects of disease formation) which recognises unification rather than separation of the stages of illness progression (Dash & Jounious, 1983). For example, Professionals could become more aware of Punjabi Sikh sensitivity to earlier stages of disease identification at the more psycho-somatic level as participants have described in this study, rather than dependency upon detection of cognitive change, but valuing sensational bodily and emotional change.

In considering how to improve interventions then, La Roche (2005) highlights the challenging discrepancy between research and psychotherapeutic practice in the field of cultural psychology with the implication that they rarely inform one another. This is an issue that needs to be considered here, but also in future research and practice in this area, particularly in the design of research questions. Although the Sikh spiritual model of counselling proposed by Singh (2008) offers one way of integrating CBT with spiritual perceptions of the person, health, distress and illness, the study by Vallianatou, Leavey & Brown (2007) identified that Counselling Psychologists tend to reject formal training in cultural proficiencies. Whilst, their study highlights that existing cultural competency models can lack the coherence and scope for integration with specific therapeutic models, they address this issue by suggesting that there is potential to use cultural issues in the context of a sound therapeutic relationship. This approach indicates support for enabling breadth and depth in developing culturally sensitive interventions, without necessarily requiring prior cultural or spiritual knowledge of client needs, but enquiring about these sensitively through a respect for phenomenology and relational elements of interaction. In this sense, if clients are referred to a Counselling Psychology service, with concerns about a relative's relational way of being or other non-medical perceptions of dis-ease these could be validated not just for the carer but also those for whom they are concerned. Thus by being referred to work therapeutically with a Counselling Psychologist on the basis of their specialist training in understanding the underlying relational basis of psychological distress or dis-ease, professionals could act to prevent Punjabi Sikhs from experiencing set-backs in help-seeking. Instead of needs being relegated as untreatable psycho-somatic presentations of insignificance by medical professionals, this approach may facilitate the building of trust in service relationships. Indeed, Professionals who follow the dominant approach to dementia care adamantly or without awareness of other models may be considered as not listening to people's needs, and thus potentially undermine the relationship approach to professional and informal care-giving.

The Practical Skills Model of Multicultural Engagement proposed by Alberta & Wood (2009) offers a Counselling Psychology approach to cultural sensitivity which involves 'empathic communication', 'relationship building' with the client and the community and 'dinunital reasoning' which holds cultural tensions. The model also suggest consideration be given to cultural standards in practice to improve understanding of the world-view of the specific population and 'model management' to encourage therapists to reflect on learning from relational differences experienced during engagement, through use of the double hermeneutic.

The theoretical paper by Richards (2011) discusses aetiology and resolution of relational (alliance) ruptures (which could be applied to concerns about anger stemming from loss, for example, prior to what might be considered pro-dromal presentation of dis-ease such as dementia, by facilitating for example, the I-thou relationship with the client). Use of the transpersonal I-thou relationship concept in Gestalt Therapy emerges from the biblical perception of relationship with God and can be applied therapeutically within the interpersonal relationship between therapist and client (Harris, 2000). Cooper, Chak, Cornish & Gillespie (1993, p.72, 73) compare interpretation of the theological idea of 'love' within a human interpersonal relationship arising from having received God's love, with ideas of Buber who considered the capacity to encounter 'a higher spiritual presence' through an 'attentiveness, receptivity or responding' to the other's 'Being' within a caring relationship. Hycner (1990) and Clarkson (1997) have applied this latter conceptualisation to the therapeutic relationship. Cooper et al. (1993, p.73) contrast Buber's I-Thou attitude (of experiencing the other openly through love to confirm the other's 'Being' regardless of 'peculiarities') from an I-It attitude (of seeing the other as a confined and objectified 'thing' or category in which relationship is more akin to a side monologue than dialogic love). Friedman (2008, p.299) refers to confirmation as ‘experiencing of the other side of the relationship’ so the self is made ‘present’ or real in ‘between’.

In making sense of spirituality Harris (2000) cites Hycner and Clarkson as follows:

Hycner (1990, p.44); ‘talking about the “between” and mentioning “grace” places my thought explicitly in a spiritual context. By spirituality, I mean a recognition of a reality greater than that of the sum total of our individual realities, and of the physical and visible world. It is inconceivable to me to steep myself in a dialogical approach without recognizing a spiritual or “transpersonal” dimension. I feel more and more that in my best therapeutic moments I am present to, and sometimes the “instrument” of, some spiritual reality’.

And for Clarkson (1997, p.65); ‘The transpersonal relationship is the spiritual dimension of relationship in psychotherapy…It is about a kind of sacredness in the therapeutic relationship’.

Sandhu (2005) acknowledges scope for integrating gestalt ideas with Counselling in Punjabi Sikhs, by illustrating how role play in empty chair work to manage relational concerns aligns with the Punjabi Sikh model of managing life-stress. Illustrating the shifting nature of the I-It carer and I-Thou caring relationship in the present study has implications for Counselling Psychology Practice as indicated below. In drawing on transpersonal principles of the I-Thou relationship through concepts of the ‘between’, ‘grace’ or recognising reality as more than the sum of individual, physical and visible realities’ (Hycner, 1990, p.44) as well as the spiritual dimension or ‘sacredness’ in the caring relationship (Clarkson, 1997, p.65) further meaning of the varying aspects of participant experiences of managing difficulties within their caring relationships with the PWD can be developed for utilisation in therapy. The thesis interprets how the meaning of shifts from I-It to I-Thou parallel the transition from caring as dis-ease to caring as perseverance. This represents how burdensome carer based experiences in the context of the PWD or service relationships (I-It) can be managed by caring descriptions being depicted within their personal encounters with God in prayer to empower personal strength within the caring relationship or spiritual principle of love to provide corrective experiences for the PWD or even attempt to shift away from and overcome negative experiences of karma or service care relationships through turning to God (I-Thou).

It is also important to consider implications of how varying shifts in I-It and I-Thou within the caring relationship may be experienced in circularity between the PWD and the carer, perhaps in the scenario where one participant described being exasperated wanting to 'pull hair out' due to the relentless demands of the PWD, or in being condemned by the PWD replaying earlier painful experiences (of losing attachment relationships which were not managed or responded to appropriately through I-thou caring relationships at that time in the past when they were left feeling angered) onto the person caring for them now, who was also left angered in experiencing I-It. For another participant a shift in graciousness occurs in the relationship 'between' I-It to I-Thou towards the PWD. In managing experiences of past relationship hurts from the PWD in her struggles as a daughter-in-law (I-It) the participant makes a transpersonal shift into caring for the PWD as (I-Thou) through keeping patience and forgiveness enabling perceptions beyond individual, physical and visible realities, (e.g. of what she describes as the role of her father-in-law in her depression and his physical remnants as a person with dementia) by engaging with him on a deeper level of 'meeting' as a person, which enabled meaningful experiences of the new caring relationship in an attitude of I-Thou (focusing on lifting his spirit, employing a developmentally corrective approach to the caring relationship, by 'showing the way with love' and 'making him feel that he is on top of the world'). Another participant's uncaring and guilt ridden approach to the PWD's relentless behavioural demands indicated burdensome I-It positioning of the carer relationship, whilst accepting these 'peculiarities' as arising from the dementia not from her grandmother 'being a being'. This shift helped to experience the caring relationship in terms of I-Thou as a 'mutual happiness' when made 'present' again to the PWD's recognition and experienced a sense of 'sacredness' in the consecration of the caring relationship (I-Thou) despite having experienced being ‘personally forgotten’ or hounded whilst watching T.V. after work (I-It). These examples offer other implications for Counselling Psychologists to facilitate understanding and the significance of such patterns of varying shifts in the caring relationship with respect to I-It and I-Thou in order to encourage recognition of capacity to choose shifts, for example, for the benefit of the PWD or mutual benefit. Alternatively, further implications, for example, for people who choose not to engage with prayer or have difficulty experiencing spiritual encounters of a caring personal relationship with God, may include encouraging management of the qualitative shifts in the dementia caring relationship perhaps through experiencing a similar attitude of caring support within a professionally therapeutic relationship.

Another account, highlighted how the shifting process between one type of I-Thou experience (on the receiving end from God) to another I-Thou experience within the caring relationship (of giving towards the PWD), was sourced through experiencing a deeply embodied personal shift in her sense of being met by a transpersonal presence or I-thou caring interaction with God. She described first experiencing an intra-psychic and encouraging physical presence in this caring relationship with God before noting how this essence (or I-Thou attitude of relational experience) shifted towards externally manifesting in her caring relationship with the PWD. She described how within her prayerful mediation periods, a sense of experiencing more than herself, led to experiencing a positive edifying process which strengthened her own positon (stronger sense of self within the mediation with God and being in an encounter of receiving), and clearly stated how this new position supported or strengthened her caring relationship with her father-in-law. Noting that this process may be considered in the theological understanding of an encounter with God in the I-Thou caring relationship, rather than the therapeutic interpersonal relationship as Buber described, may be empowering for such participants and has implications for how meaning of these shifts involve acknowledging and validating such autonomous experiences in practice.

The thesis also highlights the potential importance of recognising shifts within some participants’ I-It and I-Thou perceptions and experiences of caring relationships with professionals, such as Doctors. Participant accounts of this relate to shifts in experience of Doctors as ignorant when ignoring participant concerns about their relative and delaying diagnosis of dementia (I-It) to Doctors being perceived reverently as powerful beings despite acknowledging their helplessness e.g. 'if they (Doctors) can't do it, who can?' (I-Thou) facilitated turning to God and shifting all hope to this transpersonal relationship. Others reported experiencing additional strains in caring for their relative arising from the I-It relationships with care assistants or respite staff, who neglected the PWD's needs or carer complaints about practical concerns, yet shifted into more supportive caring I-Thou caring relationships when pains of the participant were met in respite 'being' available or just 'being' within the caring relationship with the Assistant enabled release of tears unable to be shed within the family. This interpretative understanding might have implications for training of formal caring relationships since practicing culturally sensitive Counselling Psychology in this way, one can start to facilitate various shifts towards transcending personalised perceptions of disease (e.g. from fear induced angry emotional responses possibly linking to perceptions of punishment from God or emotionally charged relational triggers or concerns of professional helplessness, loss of the PWD or entrapment in caring through the culture). This approach conveys potential for how the therapeutic relationship can act as an important tool in helping to develop calm empowering responses rather than automated agitated or restless reactions of dis-ease through transpersonal level of engagement within the I-Thou professional caring relationship on varying levels.

This level of cultural sensitivity alludes to what Richards (2011) refers to as returning to the phenomenology of empathy in place of the overpowering dominance of focus upon technical interventions or strategies espoused by CBT attempting to challenge clients spiritual ideas. The nature of such a relational approach becomes even more significant when clients have experienced prior service failures and thus potentially wary of or reluctant to embrace any therapeutic models according to their understandings of characteristically rigid IAPT versions of CBT. Indeed, Punjabi Sikhs in the UK are likely to be exposed to such models in upcoming years, however, relationally informed integrative approaches to CBT that are phenomenologically driven could provide scope to be culturally sensitive and thus offer scope for meaningful prevention and early intervention for people potentially perceiving their own or loved one's susceptiblity to developing dis-ease, whether of the underlying sort associated with disorders of the blood, identity, personality and relational dis-ease or surface level behavioural manifestations associated with neurologically or cognitively detectable representations of dementia. In summary these research findings from Punjabi Sikhs are consistent with wider research arguments which challenge the hegemonic position of the medical and cognitive model in the treatment and therapy of PWD and their carers' needs.

5.6 Critical Review

5.6.1 Assessment of validity

This section ascertains evaluation of the study's compliance with guidelines for good qualitative research by applying Yardley's (2000) criteria for assessing validity. Yardley names these principles; sensitivity to context, commitment and rigour, transparency and coherence as well as impact and importance. Smith, Flowers, & Larkin (2009) advocate using this approach in evaluating IPA along with an audit trail.

5.6.2 Sensitivity to Context

Sensitivity to the epistemological issues in the wider literature helped identify methodological issues and set the aim of minimising pre-imposition of theoretical frameworks upon the data. This meant the double feedback approach to enquiry was enabled. Sensitivity to the socio-cultural locale of the study is illustrated through addressing recruitment issues in accessing participants from minority populations. Despite difficulty enrolling interest through advertisements sensitivity to the context was required to facilitate closer and sustained engagement with important gate-keepers to access participants through personal invitation, by attending Asian carer forums and identifying cultural networks in the community through word of mouth. Sensitivity to context was also demonstrated through a significant level of personal commitment in attending closely to the data (indicted in Personal

Reflections) which Yardley espouses as the best example of sensitivity to context.

5.6.3 Commitment and Rigour

A significant level of commitment was required in attending closely to participants during data collection. During Sukhdeep's interview my commitment to the phenomenological psychological attitude, occurred through empathic attention to his meta-communication. This commitment raised my awareness of his restless fingers during his account of caring as stuckness. I acknowledged and questioned his hand movement– which revealed his sense of feeling 'uneasy' in caring or a synonym for dis-ease. Finlay (2008) refers to this rigorous approach in qualitative interviewing (becoming aware of shifts and exploiting these to gain richly verbalised expressions of how phenomena may be experienced) as the use of artistry and reflexivity in data collection. By engaging with his embodiments of meaning, informed inquiry, by probing deeper through noticing important cues from the participant to facilitate idiographic understanding. Reflecting on my assumptions of shared language meanings of *paaht* (prayer) in the initial interview with Sukhdeep, highlighted how I could miss opportunities to unpack shared understandings. Committed and rigorous practice involved applying the concept of *seva,* in my interview approach, to address this issue by asking participants prior to recording, to share their personal meaning of Punjabi words. This validated and opened up vivid descriptions, e.g. seva by Parminder.

5.6.4 Transparency and Coherence

Transparency of the research process is highlighted in various ways. Verbatim excerpts allow the reader to make their own assessment of validity through personally evaluating how grounded the themes are in the data and fairly participant ideas are represented in contributing to theme development. In this endeavour chapter three details sampling and recruitment procedures, justification for edification of the interview schedule; and interview and analysis procedures. The audit trail includes examples of emergent themes from initial and exploratory notes from a transcript, how super-ordinate themes developed from emergent themes, and collation of individual level super-ordinate themes from across transcripts formed overarching sub-themes and Master Themes, as well as interview guide and ethical documentation. The write-up is consistent with IPA demonstrating coherence, through the using the double hermeneutic, a core IPA principle, in reflexive sections throughout the thesis.

The next two sections consider the usefulness or importance (Original Contribution to Counselling Psychology) and impact (upon the Researcher in Personal Reflections) that this research can hold aside from the practical implications already discussed.

5.6.5 Original Contribution to Counselling Psychology

The present study contributes original, significant and useful knowledge of how some aspects of the Sikh tradition, which have been little studied in Counselling Psychology (Sandhu, 2005) despite the professions commitment to better understanding the pluralistic socio-cultural nature of the UK's society through phenomenological enquiry, can be applied (demonstrating impact and importance through practical implications) to bring meaning to better understand Punjabi Sikh experiences of caring for a PWD. Strawbridge & Woolfe (2003) highlight the importance of this approach in helping offer an alternative understanding from well-established pre-understandings, in this case for example, caring potentially signifying transpersonal not just interpersonal meaning. IPA has not yet been utilised in the study of Punjabi Sikhs caring for a relative with dementia. IPA and Punjabi culture share a value for embodied experience which has been useful in gaining in-depth access to emergent insights of how some people in this community may perceive and experience dis-ease in caring according to an integrative, broad spectrum model.

Findings that Punjabi Sikh perceptions of caring for a relative with dementia involves perseverance and seeking support through the transpersonal level of engagement extends the definition of caring as being interpersonal, which can be particularly significant in the context of experiencing dementia care-giving which involves recognising the pain of being personally forgotten by the PWD or part of the attachment relationship being lost. This research thus highlights potential usefulness of Counselling Psychology's relational approach to spirituality as being potentially culturally appropriate, through working with transpersonal concepts such as the I-thou interaction. I-thou may reflect the concepts of *seva* (spiritually informed humanitarian, community and even personal level care) or *simran (*similar to mindful yoga meditation integrating, reflective scriptural study or prayer with God). Although it has been documented that religion and or spirituality may hold particular significance for BME dementia carers, research has not previously identified this in terms of the meaning of religious or spiritual coping for Punjabi Sikhs specifically. More significantly, however, spiritual issues may raise concerns about karma as well as mediating anxiety and depression as well as conflicts with cultural caring ideologies and aiding coping, through the Sikh specific ideas of *seva* or *simran.* The thesis illuminates how positive caring identities may emerge from Punjabi Sikhs' accounts despite negative experiences of caring including defiled identities and disappointments in help-seeking through perseverance. The thesis contributes psychologically knowledge of psycho-somatic meanings of the lived experience of caring as dis-ease(s) and importance that Sikh specific spiritual values may have in transcending this experience, beyond the Punjabi cultural values that Jutlla (2011) identified in the experience of Punjabi Sikhs caring for a PWD. According to Gianakis & Carey (2008) understanding how to facilitate positive changes in those experiencing psychological distress, it is necessary first to explore the generic processes involved in the experience of positive changes in individuals without the support of psychotherapy prior to exploring effectiveness and optimisation of psychotherapy. This thesis highlights the relevance of social-psychological theories of dementia and caring in making sense of Punjabi Sikh understandings of relational pain aetiologies to provide sensitised emotional-relational support that may potentially have implications for their caring identities and emotional well-being and the PWD. These insights could inform explorative therapeutic processes and facilitate better nuanced complex relational experiences of Counselling Psychology practice in this population. Having considered the importance of this research I now consider the impact.

5.6.6 Personal reflections on the research process

Reflexivity recognises sensitivity to how my prior assumptions or experience may shape findings and vice versa. In order to consider researcher influences, making my personal and intellectual biases explicit at various stages in the thesis aimed to provide credibility to findings by noting the impact these may have had upon findings. Likewise, in considering the double hermeneutic, I also consider now how the analysis has impacted upon me personally and professionally. Although I did not use the term carer in communicating with participants to minimise imposition of the phenomenon upon data collection I have found this terminology helpful in the literature and discussion sections to ease communication with academics.

During data analysis, I became stuck in the data-set which I understood as emerging from over-empathising with participants' negative accounts. Initially attempting to distance and surface from personally identifying with descriptions of dis-ease in caring for a PWD I took a more critical stance which imposed theory on participant meanings whereby theme titles were less phenomenologically and more interpretatively framed. I learnt to manage this conflict of over-critical response to my over-empathic focus through tapping into participant descriptions of persevering with challenges and Counselling Psychology's emphasis on holding inherent tensions. With the help of supervision, this involved me connecting with Sikh concepts of *simran* (by meditatively contemplating my way out of the stuckness) through conceptualising my research function as *seva* (or selfless service) to my participants. This process involved working through my apprehension of challenging reified perceptions embedded through previously held identity as a positivist researcher. This process positively impacted upon my identity as a trainee Counselling Psychologist and Punjabi Sikh. In confronting and holding personal and professionally conflicted perceptions of dementia, caring and health I was able to develop themes in a more balanced way.

Whilst having previously uncritically allowed my deeply embedded theoretical impressions of dementia as a genetic disease to overlook the meaningfulness of emergent themes around relational pain and spirituality, due to apprehension about making unusual interpretations in the academic arena. I was holding on to commonly held dominant beliefs established through working as an experimental researcher in Gene Therapy and Assistant Clinical Psychologist carrying out neuro-cognitive tests for Dementia. Fortunately, therapy assisted me in re-connecting with the aims of Counselling Psychology rather than Clinical Psychology influences in the past, by noting that I was trying too hard to compensate for my personally spiritual outlook which facilitated an opening to challenge my concerns sensitively without resistance or pressure to conform.

Reflecting on these processes from a personally therapeutic perspective helped me approach analysis through a balanced hermeneutics of empathy (phenomenology) and suspicion (critique). I have thus become more critically aware of how underlying pressures of dominant psychological models of thought can still infiltrate my personal practice of Counselling Psychology research. Thus in becoming better able to reconcile such tensions in research personally and professionally, has helped me to think seriously about how I would work as a therapist with such a client group in order to support ideas for personalising psychological care. These research processes, findings and discussions have positively influenced my caring identity as a Counselling Psychology trainee who can meaningfully manage secular and spiritual tensions, which I mentioned experiencing in the profession, in the experiential origins of the study. This Interpretative Phenomenological Analysis has thus left me more confident about approaching spiritual meaning-making within the therapeutic relationship if working with Punjabi Sikhs caring for a PWD in the future.

5.6.7 Methodological Limitations and Future Directions

This section acknowledges methodological limits and offers some suggestions for addressing these. Although it may be argued that the discussion is heavily referenced and engages little with other phenomenological ideas, participant themes are very present and guide the discussion in order to infiltrate less phenomenological ideas of caring in the wider arena which could obscure findings of Interpretative Phenomenological Analyses which focus more on highly personalised discussion of findings. This is valid at this early stage, though future IPA studies in this area may benefit from the researcher personally engaging in discussion of other phenomenological findings.

Although lack of respondent validation and inter-rater reliability may be considered a methodological limit in the study, two peers confirmed that the findings seemed reasonably grounded in the data to ensure credibility of the narrative, and Mays & Pope (2000) highlight that respondent validation is limited as it minimises the meaning and value of researcher readings.

Having owned my perspective reflexively throughout the thesis, consideration of how this may have influenced the study (for example, whether it hindered or facilitated the extent to which participants shared information) requires discussion. It may be that my Punjabi Sikh background triggered impression management through fear of stigma or my professional stance as trainee or young female affected power dynamics. Alternatively, it may be that my experience of training in therapeutic interviewing and having placed participants as experiential experts on the topic provided them a validating environment in which to consider their experiences from various positions. This may have encouraged them to express their personal voice rather than the medical tone expected in conversations with health professionals. It is important to consider then, that this implicit influence may be reflected in the formation of themes which alluded to the bio-psycho-social model of dementia. Yet this approach may be considered valuable in the context of phenomenological psychological research in helping to better understand the contextual framework within which participants experiences are being studied.

It may be argued that having sought out participants, who identified themselves as Sikh in the purposive sampling process and my personal interest in the area of spirituality, may have inevitably influenced my analysis in finding spiritual aspects of caring as meaningful. Considering Jutlla’s findings of minimal spiritual influence and having allowed respondents to have decided whether or not they identified with being Sikh as well as keeping the research question open and interview questions semi-structured and non-specific to spirituality (other than as a prompt at the end of the guide), meant that this influence in the data collection process, was minimised. All participants introduced spiritual meanings during the interview without prompting and this is evidently important in making sense of each theme and validates their meaningful significance. A similar methodological approach could be usefully applied to better understanding caring for a PWD within other SA groups, from the Hindu Gujarati, Pakistani Muslim or baptised Sikh communities.

Although recruitment was initially opened up to largely Sikh populated areas, all participants in this study were resident in the South East of England, where the researcher lives. This is important to bear in mind in future study sampling, considering that one of the participants in Jutlla's (2011) study highlighted the potential impact that social (including local cultural) contexts can have upon how caring may be experienced. She suggested that Wolverhampton's 'village' milieu may foster a different type of mentality from those living in London and the surrounding areas (p.192). Despite purposive sampling the open inclusion criteria allowed diverse range of participant characteristics to be included, since no restrictions were imposed upon the sample demographics, e.g. according to the type of dementia, time or length of caring, carer relationship, gender, socio-economic status or practising religious status. Not overly restricting a homogenous purposive sample, however, is perceived by Meltzoff (1998, p.53) as a way of minimising potential 'biasing effects' which could result in 'narrowness of inbreeding'. Despite attempts to minimise such effects, the snowballing technique meant that daughters-in-law constitute half the sample making it more homogeneous than initially desired. This may have contributed to the more negative perceptions of caring, considering the possible derogatory or stereotyped hierarchical positioning of daughters-in-law in Indian families.

Other methodological limits relating to the sample demographic impacting on the data set include the need to consider how the meaning of caring for a PWD may be demarcated from that of caring for a person in general by delineating how these phenomena may overlap and differ. Although participants were not specifically asked to differentiate between experiences of caring for the PWD pre and post morbidity, many of the excerpts indicated examples specifying participants experiential responses to the PWD’s functional limits or commonly recognised behavioural manifestations of dementia, (such as caring for physical needs, activities of daily living, confusion, anger, disinhibited or challenging behaviours, disorientation to time, space or people, sleep disturbance, delusions and hallucinations) which helped clarify and differentiate between normal caring for the person pre-morbidly (or in context of generic or attachment based caring relationship) and dementia caring more specifically. The study findings still need to be considered with caution, however, in that attributing these meanings with certainty to the experience of dementia caring as opposed to caring for a loved one or anybody remains limited. Despite the overlaps of above stated manifestations of dementia with everyday random occurrences or conditions as described below, it is the relentless nature of the PWD’s behavioural and psychological needs and hyper-vigilant nature of caring described in participant accounts, as clearly demarcated in theme two, which fits definitions of dementia (associated challenging behaviours) and dementia specific carer roles (of supervision and cueing) and thus offers some level of differentiation between general and dementia specific caring experiences, e.g. with some participants noting differences between ‘normal’ and abnormal levels of challenging behaviour with agitation, aggression or anger. Nevertheless, the sampling criteria did not specify participant exclusion on the basis of other physical/mental health problems or needs of the person being cared for, such as brain injury, psychosis or personality disorder, thus meanings of care, say for a person displaying anger or fear due to delusions or hallucinations, cannot be assumed as necessarily differentiating from similar manifestations of a person with dementia.

Furthermore, it is important to recognise sample demographics in terms of the impact that past relationships and roles may have had upon the experience of caring for a PWD and thus the meaning of the current caring relationship in the context of dementia. The demographic profile was specific to those co-resident and in an attachment relationship with the PWD, meaning that that close proximity and attachment may play a role in how a generic form of caring might vary relative to specifically caring for a

PWD. For example caring for someone who is angry or physically aggressive (whether in the context of dementia or not) may be interpreted as caring for a loved one per se and in which the earlier relationship impacts upon present caring, e.g. through reciprocation of care for when they themselves have been angry in the past. Indeed, several of the transcripts described reciprocal care as rationale for caring for the PWD which may confound the meaning of caring identified in this thesis. Caring for the PWD as an act of returning care for having previously received earlier care from the PWD highlights how impact of the attachment caring relationship may be difficult to distinguish from dementia care in this demographic sample, from care informed by reciprocation indicating an overlap between caring for a relative due to dementia needs and caring as a filial attachment or concern towards the elderly, a spouse or parent-in-law who happens to have developed dementia. Despite the importance of reciprocation, this sample demographic being top-heavy with a particular attachment relationship of daughter’s-in-law however, may have impacted upon the dataset differently from a sample that may have been comprised primarily of children or spouses. Both spouses in the present sample described how this specific attachment relationship in itself necessitated perseverance in caring for their wives with dementia. The sample demographic having included two daughters-in-law that stopped persevering (gave up care) may thus have limited how far qualities of this theme three emerged with regard to perseverance, considering that one had a previously ruptured attachment relationship due to her father-in-law’s earlier life role in her depression and possibly her role in his dementia aeitiology. Conversely, a grand-daughter who experienced her grandmother as having provided maternal significance in her earlier attachment experiences informed a strong sense of reciprocity and ‘type of bonding’ informing perseverance in caring for her grandmother with dementia due to this positively impacting on the relationship compared to the relatively negligible attachments described by the daughters-in-law. Thus in a qualitative sense, this demographic representation of attachment relationships in dementia care may have either blurred or strengthened the meaning of the caring relationship by overshadowing the meaning of dementia care. Some participants discussed how perceiving caring as a female, maternal or resilient role, also offered rationale for perseverance in caring, particularly in terms of how they identified themselves within the carer role and could both reflect the perseverance required in meeting the relentless demands of dementia as well as caring capacities within any attachment relationship not necessarily limited to that of caring for a PWD.

Inclusion of both current and retrospective accounts of caring may have biased descriptions towards either more negative (loss) or positive (relief) stances. Thus the snowballing technique and keeping the sample open to aid recruitment and manage bias may have paradoxically biased the sample yet this approach did not prevent identification of meaningful convergent themes. Future research may consider these limits by exploring differences between retrospective and current accounts or employ even more homogeneous samples. Although non-relatives were excluded from the study, the finding that some Punjabi Sikhs may take a transpersonal approach to care (perceiving caring as seva) highlights the humanitarian essence of care beyond kin attachment in this community. Thus future studies of care with Punjabi Sikhs may not necessitate such exclusion criterion. Although narrowness of inbreeding in homogenous samples could be addressed by increasing sample sizes to draw in a wider range of experiences, this may not be appropriate for in depth qualitative studies, such as IPA. A grounded theory study which values theoretical saturation, could help address such concerns and explore in more detail the complex and potentially conflicted relationship between cultural and spiritual values informing caring ideologies.

The meaning of care in this thesis, has also been attributed to a Sikh spiritual framework, however, there is a need to recognise how the potentially blurring perception of culture and religion within the demographic sample may also impact on the meaning of caring for a PWD in this thesis. Indeed, in the present study the participants referred to experiences of karma, in both cultural and spiritual contexts, with the former imposing negative meaning for some participants, whilst the latter seemed to allow the same participants some reconciliation by shifting from conceptualisation of the I-It (dementia when judged by others in community as karmic punishment due to person's bad actions in past is uncaring or not justified) shifting to the I-Thou (caring as karmic punishment or opportunity is justified by God and is thus caring) caring relationship. For others karma was perceived more neutrally and perhaps highlights the scope for overlap and difficulty in being able to clearly demarcate the personal meaning of caring as deriving from spiritual or cultural impacts upon experience. Indeed, the concept of care as love (and similar to concepts of hope, trust or faith as indicated in the data) have been considered by some researchers such as Miller (1999) as spiritual concepts but which are also clearly embedded within our everyday culture, which makes spiritual capacity accessible to all human beings. This difficulty in sifting out the cultural and spiritual impact upon how caring for a PWD may be experienced and made sense of is especially important to consider in studies of Punjabi Sikhs, given the academic understandings of religion and culture in this field appearing blurred, for example with Jutlla (2011) conveying these as relatively indistinct. Whether or not this impact may be more indistinct in India due to colonial oppressive influences or more relevant to the UK due to the diaspora holding on to spiritual values remains unknown and future studies may seek to explore such complex impacts of culture and religion upon the meaning of caring for a PWD, in this context, in more detail by clearly delineating such entrenched phenomena in the sampling, exploratory and analytic stages of research in this area.

For such reasons, the drawbacks of the sample size require further reiteration in that, the claims made here cannot be generalised to either the Sikh spiritual or Punjabi cultural populations, caring for a relative with dementia whom they are co-resident with, since the focus of this study was to identify the essence of the meaning of caring for a PWD from a small sample of respondents which was deemed to be sufficient in size, such that would allow a reasonable level of analysis to ensure that both idiosyncratic and convergent meanings could be developed. The main purpose of using a sample size of six, was to gain deeper understanding of issues at the cost of gaining wider understanding, without restricting size to the point of lacking capacity to note convergence or enlarging size to the point of losing depth, in order to develop descriptive and interpretative knowledge that could stimulate and enrich future thinking in the context of clinical practice and future research in this field. Although a single case study may have offered even deeper idiosyncratic understanding than a sample size of six, this allowed sufficient understanding whilst acknowledging the drawback this size has imposed upon limiting sample demographics and the impact this has had upon restricting meaning as indicated in consideration of impact on the data set. This means that another study of six participants with a different set of demographics and researcher background will likely yield a reasonably different interpretative phenomenological analysis, though with perhaps some comparable qualities in essence. Thus future studies of a similar nature could enrich, deepen and widen understanding of this phenomenon in a similar whilst different context in a meaningful way, in that another sample may include different type or focus of attachment relationships with varying impacts, prior to and during dementia care, or with varying roles within that caring relationship and with different impacts upon how dementia caring relationship may be experienced and understood.

Studies exploring the usefulness of applying any of the methodological research recommendations in response to methodological limits, possibly in line with exploring the impact of implementing tentative clinical guidelines suggested earlier in this thesis, could provide deeply meaningful psychological knowledge of either those caring as well as practitioner experiences of implementing Counselling Psychology interventions in similar contexts to those described here.

5.7 Conclusion

A broad research question opened up understanding of some nuanced and complex meanings of caring for a relative with dementia amongst a small sample of Punjabi Sikhs. Themes have been identified and discussed in a credible manner appropriate to the paradigmatic stance outlined to encourage meaningful debate amongst various professional practitioners for appropriate support services to be developed. Bringing forth participant voices into this wider debate of dementia care for people of BME backgrounds highlights the need for broad professional consideration of how Punjabi Sikhs' caring experience incorporates integrative models of health which hold significant meaning. The research indicates this population can benefit from Counselling Psychology's therapeutic relational approach in addressing aspects of dis-ease in caring with striking synergy to support transpersonal coping.

The thesis indicates usefulness of considering that conceptualisations of dementia are not necessarily culturally appropriate when applied in a purist fashion or implicated as being universal in essence, since they can seriously marginalise perceptions, negatively impacting experiences of caring. This highlights that a psychological stance to healthcare which demotes non-dominant phenomenological perceptions of dementia as ignorance or emphasises a purely cognitive-behavioural approach to managing difficulties in caring with BME populations such as Punjabi Sikhs may be reflective of wider underlying socio-economic-political trends potentially shifting traditionally integrative perceptions towards modern purist medicalisation, neuro-cogntivisation or neuro-psychologisation of health perception. Thus pure medical-service enmeshed conceptualisations of psychological care may be limiting service doors from opening Counselling Psychology support via medical avenues of referral unless acknowledged as being unhelpful; especially for Punjabi Sikhs who cannot transcend difficulties in caring as the participants in this study describe (through managing tensions between secular/medicalised and spiritual meanings or transpersonal strengthening processes). This thesis demonstrates how participant voices have influenced my personal capacity to hold inherent tensions in exploring the meaning of the experience of caring for a PWD for Punjabi Sikhs. This capacity is espoused in Counselling Psychology professional practice in which the therapeutic relationship embraces a validating approach to cultural sensitivity according to a continuum of meaning, in which the physical understanding forms only one meaning part of an inherently integrative perception of what a healthy experience of caring for a PWD may entail for Punjabi Sikhs.

The main findings of this thesis highlight that Punjabi Sikhs may indicate both surface and deep level awareness of dementia as an illness, though not necessarily or primarily with meaning being accorded to the medical model of disease but rather strikingly described in clarity as having spiritual purpose with emotional neediness (which represents underlying relational pain meanings from earlier life experiences in which loss or anger were unattended to) being at the root of dementia. This holds importance to participants for how dementia is addressed within the caring relationship, and impacts upon participants themselves and thus indicates potential signs that helping carers to source relevant pathways may include signposting psychological provision for their relatives and selves. The findings indicated, that services are described to be lacking responsiveness, however, to Punjabi Sikhs concerns in caring for their relatives through seeking proactive preventative measures from services, including the NHS, prior to receiving a diagnosis of dementia. This suggests that for some Punjabi Sikhs, awareness of dementia may be sufficient to seek and receive professional care that does not necessitate a medical pathologisation, medical diagnosis and medical treatment of dementia when viewed as dis-ease, stress, distress, or illness on a relational/social or spiritual level. This is particularly important considering there is no medical cure as this may act to distract from recognising, offering and implementing spiritually and socially/culturally informed psychological models of care. This becomes even more pertinent when findings of participant distress encircle the concept of psychological pain progressing into deeper identity or bodily levels of dis-ease and difficulties in caring are managed by transpersonal encounters in *simran* and spiritual principles of care as *seva*, to support perseverance in caring for their relatives with dementia, including transcending service barriers and limits which are deemed 'not right'.

Findings also highlighted that perceptions of caring as duty or burdensome do not detract from the spiritual significance of dementia and caring, which can provide strengthening and empowering processes which embody hope to help facilitate varying shifts in the caring relationship from the attitude of I-It to that of I-Thou. Contextualising Punjabi Sikh meanings with social-psychological theories of dementia care such as proposed by Kitwood and Breden (1992) may better 'meet' and bring into 'reality' experience of an I-thou experience of professional caring by sensitive facilitation for those caring for their relatives with dementia, to care as well as they hope within their spiritual and relational frameworks of being, and to provide emotionally remedial care in a timely manner that is more preventative and responsive than critically reactionary in nature. These qualitative findings leave one wondering, whether the literature suggesting that SA's tend not to seek dementia services, until crisis point, may be more reflective of a medical imperialism that is unwilling to dislodge from a monologic (I-It) vantage point, or anxiety about change.

The thesis has discussed the implications of the shifting nature of the I-It and I-Thou caring relationship for the well-being of the caring participant, for the PWD and for informing service developments (e.g. integrating spirituality into practice through drawing upon transpersonal principles of I-It and the I-thou caring relationship). The thesis interprets how the meaning of shifts in participant accounts may be reflected in terms of caring as dis-ease and caring as perseverance in the context of transpersonal theory by drawing on ideas of the caring relationship of I-It and I-thou. This represents how burdensome carer based experiences in the context of the PWD or service relationships (I-It) can be managed by caring descriptions depicted within their personal encounters (of I-Thou) with God in prayer can empower personal strength within the caring relationship (e.g. through a sense of 'sacredness' or consecration of the caring). Similarly, past relationship hurts from the PWD (I-It) can be transcended through forgiveness beyond their limited individual, physical and visible realities, relating to the physical remnants of the PWD by engaging with on a deeper level of meeting in meaningful experiences of aiming to provide corrective experiences for the PWD (e.g. by lifting the spirit by 'showing the way with love'). The shifting nature of the negative carer relationship experienced within service settings where concerns are ignored to a point of feeling condescended or helpless (I-It) can be managed through turning to God (I-Thou) for support. Although religious and spiritual coping models have been well developed in academia as appropriate to psychotherapy, a transpersonal approach may offer a route into providing cultural sensitivity in way that is specific to the practice of Counselling Psychology.

Providing tentative recommendations for working with Punjabi Sikhs in this area, considering the paucity of guidance for Counselling Psychologists, offers a significant highlight in this thesis given the tensions identified between cultural and spiritual perceptions of caring for a PWD as having spiritual purpose whilst being experienced as cultural entrapment. These findings may be utilised within Counselling Psychology Practice to help Punjabi Sikhs in similar contexts, to define caring according to a broader meaning of the caring relationship that is inclusive of transpersonal elements beyond the interpersonal attachment relationship, which may be all the more important in the context of dementia, when parts of the relationship with the PWD disappear. Normalising personalisation of care according to specific relational pains of the PWD may assist Punjabi Sikhs in their caring relationships by adopting an I-Thou position that is empowering without sole dependence on medication. Transcending experiences of caring as dis-ease may be facilitated through acknowledging psychosomatic understandings of health and strengthening personal caring identities through *simran* as meditation or reflection to help differentiate this from rumination, for example, on dementia or caring as karmic punishment but opening opportunity to consider contextualising caring as *seva* and thus karma as offering spiritual neutrality or opportunity. Modes of cultural sensitivity may also include exploration of other spiritual values, sensitivity to wider health environments such as the *Gurudwara* to assist coping, re-branding the concept of Memory Café as *Chah Bhath* (Tea and a Chat) as well as normalisation of difficulty in accepting a medical diagnosis and shifting nature of the caring relationship without imposing fixed caring or medical ideologies without spiritual support.

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Appendix A: UEL Ethics Approval Letter

University of
East London

Dr Alison Macdonald

School of Psychology, Stratford

ETH/11/62,

22 November 2010

Dear Alison,

Application to the Research Ethics Committee: South Asian experiences' of caring for a relative with dementia at home: Exploring cultural influences and psychological coping processes. (D Gill).

I advise that Members of the Research Ethics Committee have now approved the above application on the terms previously advised to you. The Research Ethics Committee should be informed of any significant changes that take place after approval has been given. Examples of such changes include any change to the scope, methodology or composition of investigative team. These examples are not exclusive and the person responsible for the programme must exercise proper judgement in determining what should be brought to the attention of the Committee.

In accepting the terms previously advised to you I would be grateful if you could return the declaration form below, duly signed and dated, confirming that you will inform the committee of any changes to your approved programme.

Yours sincerely

Simiso Jubane
Admission and Ethics Officer
s.jubane@uel.ac.uk
02082232976

Research Ethics Committee: ETH/11/62

I hereby agree to inform the Research Ethics Committee of any changes to be made to the above approved programme and any adverse incidents that arise during the conduct of the programme.

Signed:.. Date: ....

Please Print Name:

Appendix B: UEL Ethics Confirmation of Title Change

Miss Dalbir Gill
26 Munsaugh House
48 Crispin Way
Uxbridge
Middlesex UB8 3WY

Date: 15 December 2011

Student number: 0733498

Dear Dalbir

Notification of a Change of Thesis Title:

I am pleased to inform you that the School Research Degree Sub-Committee has approved the change of thesis title. Both the old and new thesis titles are set out below:

Old thesis title: South Asian experiences of informal dementia care-giving: What is it like caring for someone with dementia at home?

New thesis title: An Interpretative Phenomenological Analysis of Punjabi Sikhs' lived experiences of caring for a relative with dementia.

Your registration period remains unchanged. Please contact me if you have any further queries with regards to this matter.

Yours sincerely,

James J Walsh.

Dr James J Walsh

School Research Degrees Leader

Direct line: 020 8223 4471

Email: j.j.walsh@uel.ac.uk

cc. Alison Macdonald

Appendix C: Advertisement inviting participation

ARE YOU PUNJABI SIKH?

Do you look after a relative with Dementia?

What is it like for YOU caring for your relative?

I would really like to hear about your experience in an interview which will be handled with sensitivity, care and without judgment. Your personal experience will be treated confidentially and used to help increase our understanding of this important topic. Whilst the interview is not therapy, it may include the opportunity to talk through difficult feelings, if these are relevant to your experience.

If you speak English, are 18-85 yrs old & would like to share your experiences in a confidential research interview I will send you more information about the study, to help you decide if you want to take part.

Please contact me
Miss Dalbir Gill on:
dalvir_1@yahoo.com
or 078 4646 8661

This research aims to broaden understanding of experiences such as yours. This information aims to help develop a deeper understanding of lived experiences and what may potentially count as culturally sensitive support, for Punjabi Sikh people who might be finding it difficult caring for someone with dementia in their own home.

This research is conducted as part of a Doctorate Degree in Counselling Psychology and has Ethical Approval from the University of East London.

Thank you.

Appendix D: Initial Interview Schedule

Interview Schedule

1. What made you choose to volunteer to participate in the study?

2. How did you know that your (relative – wife/mother etc) was developing dementia?

3. What does dementia mean to you? (as a Punjabi Sikh?)

4. What was it like for you to learn of your (relative) receiving this diagnosis?

5. Have you heard the term carer? If yes, what does that mean to you? If no- what comes to mind for you when you hear this?

6. What does caring mean to you?

7. Can you please tell me about a typical day when you're looking after your (relative)?

8. What is it like for you when you're caring for your (relative)?

9. If they express difficulties – ask what was that like for you? Or how did that affect you, if at all? Was there anything that helped at those times?

10. If they don't express any difficulties – is there anything that made caring difficult or is there anything that didn't help?

11. If they don't mention any positive experiences – are there any benefits to caring?

12. Are there any (aspects of / or specific values relating to) being a Punjabi Sikh that may have influenced your experience of caring?

13. If they mention any service involvement – how did you experience the involvement of(service X)?

14. Have you or would you consider any professional counselling or psychological support for any of the difficulties that you have described?

15. Is there anything else that you would like to say, that I haven't asked you about?

Probes:
What was that like for you when....?
Can you tell me more about that?
Can you give me an example?
How did that affect you? / What did you make of that?
Can you explain a bit more about that?
If confused about something ask for clarification / what do you mean by....?
Follow their lead to unpack meaning, especially shared meanings

Appendix E: Final Interview Guide

Interview Guide

1. How did you know that your (relative – wife/mother etc) was developing dementia?

2. What is /was it like for you when you're caring for your (relative)?

3. Can you please tell me about a typical day when you're looking after your (relative)?

The following questions are more for prompting:

4. Are there any aspects of / or specific values relating to being a Punjabi Sikh that may have influenced your experience of caring?

5. If they express difficulties – ask what was that like for you? Or how did that affect you, if at all? Was there anything that helped at those times?

6. If they don't express any difficulties – is there anything that made caring difficult or is there anything that didn't help?

7. If they don't mention any positive experiences – are there any benefits/positive aspects to caring? What supported these aspects of caring?

8. If they don't mention any service or informal involvement – Has anyone else been involved in your caring experience in any way? How did you experience the involvement of (service X)?

9. Is there anything else that you would like to say, that I haven't asked you about?

Probes:

What was that like for you when....?
Can you tell me more about that?
Can you give me an example?
How did that affect you? / What did you make of that?
Can you explain a bit more about that?
If confused about something ask for clarification / what do you mean by....?
Follow their lead to unpack meaning, especially shared meanings

Appendix F: Participant Information Sheet

Participant Information Sheet

Project Title: An interpretative phenomenological analysis of Sikh carers' experiences of caring for a relative with dementia

Name of Researcher/Principal Investigator: Dalbir Gill

Deciding whether to participate

The purpose of this sheet is to provide you with the information that you need to consider when deciding whether to participate in this study. Please take time to read the information carefully, it tells you the purpose of the study, what will happen if you participate, the ethical conduct of the study including matters concerning confidentiality and what to do if you have any questions or concerns.

Study description and purpose

I am a student at the University of East London, conducting this research study as part of my doctorate training in a counselling psychology programme. The aim of the study is to explore the experiences of Sikhs to understand your experience of looking after a relative with dementia at home. As a Sikh who is currently living with and looking after your relative with a diagnosis of dementia at home, your views and experience will be essential in helping to understand more about what this is like. If you choose to participate in the study, interview questions will focus on exploring your understanding and experience of caring for your relative with dementia.

There is some evidence that culture can influence how people make sense of and experience caring for someone with dementia. Although some research about the experiences of caring for someone with dementia has been carried out in the South Asian community, little is known about what this is like, specifically for Sikhs in the UK and how they cope with caring. Although the research may not help you directly, the possible benefit of taking part in the study is that you are contributing to research that aims to help professionals in health services in the future, e.g. counsellors and psychologists to better understand and think about experiences such as yours. This might help to develop culturally sensitive support for Sikh people, who might be finding it difficult caring for a relative with dementia in their own home. The research interview should not be considered a therapy/treatment session.

What will happen to me if I take part?

It is up to you to decide voluntarily whether you want to take part in the study. If you decide to participate you will be given time to ask any questions or concerns about the study. If you feel your concerns have been satisfactorily answered and you understand what the research involves, and you still wish to participate, you will be asked to sign a consent form. Even once you have signed the consent form, you are free to withdraw from the study at anytime during or after the interview without having to give a reason for withdrawing and without disadvantage.

Before the interview starts you will be asked to fill out a short form to take down your demographics, (e.g. questions about your age and your country of origin) and G.P details. Taking part would mean attending an interview with the researcher, face to face, lasting approximately one hour, in a room provided by the organisation through which you received this information sheet, or at your home. If you are interviewed at home, your home address will be shared with the research supervisor or a local contact for safety reasons. Both the principal investigator, local contact and the supervisor will uphold their duty of confidentiality when holding this information. The interview will involve semi-structured questions, which means you will be invited to share your thoughts and experiences in response to some open-ended questions. The interview will be audio recorded using a digital recorder and later transcribed (typed out) for analysis. To protect confidentiality and anonymity, any names or places that you use that could identify you or others, will be given a different name (pseudonym or alias) when transcribed (typed out).

Because of the personal nature of the interviews, there is a small possibility that during the course of interview that you may find the interview distressing by recalling negative experiences relating to your caring for your relative. Your needs as a participant, take priority over the needs of the research and if you feel uncomfortable or distressed at any point, you can decline to answer any of the questions. If you wish, the interview can be stopped at any point and you can withdraw from the study without any disadvantage and being obliged to give any reason.

After the interview, the researcher will discuss what it was like for you to take part in the interview and to discuss any discomfort or distress you may have experienced during the interview. You will also receive a debrief form containing details of how to contact national and local support groups.

Confidentiality of the Data

The researcher will abide by the Ethical Principles for Conducting Research with Human Participants as set out by the British Psychological Society throughout the research process. If you disclose information during the interview that you are harming yourself or others or are highly distressed in the debrief after the interview, the researcher will write to your G.P. to briefly note your participation in the research interview and of this risk, and you will be advised to contact your G.P. at your earliest convenience.

The recording of the research interview and any associated data will be transported in a locked folder, transferred to and stored in a secure locked cabinet or a password protected laptop to which only the principal investigator will have access. At this time the original recording will be permanently deleted from the digital audio-recording device. During transcription, all identifiable information such as names of individuals and places will be changed to pseudonyms so as to protect the identities of those concerned.

Five years after the research programme has been completed, the recordings of the research interview and all data files containing transcribed interviews will be permanently deleted from the researcher's computer. Paper format of the transcriptions and any notes taken will also be destroyed using a paper shredder.

What else will happen to the information I provide?

The results will be presented in my doctoral thesis (including verbatim extracts from the interview transcript) which will be made available in the University of East London library. There is a possibility that the research study may be published in a journal. Again participants' personally identifiable information will be made anonymous using a different name (i.e. pseudonyms or aliases). Should research be published in a scientific journal, participants may provide contact details should they request to receive a copy of the article.

Will I be paid for participating in the research study?

There will be no payment for participation in order to maintain voluntary participation in the study.

If you would like to participate and contribute to this study, please contact Dalbir Gill to arrange an appointment.

The Principal Investigator

Dalbir Gill.

Telephone: 07846 468661.

E-Mail: dalvir_1@yahoo.com

What if I have any concerns or queries?

If you have any concerns or queries regarding the conduct of the programme in which you are being asked to participate please contact either, the principal researcher/interviewer, Dalbir Gill, or the Secretary of the University Research Ethics Committee.

University of East London Research Ethics Committee

Mr M. Harries.

Administrative Officer for Research, Graduate School, University of East London, Docklands Campus, London E16 2RD, Telephone: 0208 223 2976.

E-mail: m.harries@uel.ac.uk

Appendix G: Participant Consent Form

Consent Form to participate in the research study

Title of study: An interpretative phenomenological analysis of Sikh carers' experiences of caring for a relative with dementia

Prior to taking part in the study, the researcher asks you to sign this consent form depicting your compliance in taking part in this study. Once you have read the statement below, please write your name, sign and date below to indicate your consent and keep a copy for your own records. Any concerns you may have about the study can be raised with the University of East London, details of which are located at the bottom of the information sheet- also for you to keep.

I confirm that I have read, understood and agree to the information in the information sheet for the above study and have been able to convey this back to the researcher. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. I confirm that I am 18 years of age or older, am Punjabi Sikh, and live(d) and care(d) for my relative with a formal diagnosis of dementia. I consent to the audio recording of the research interview, storage methods, confidentiality and caveats, the anonymity of data, and the use of information I provide, as described in the information sheet. I acknowledge that my participation is voluntary and that I have the right to not answer any questions if I find these uncomfortable or distressing and can withdraw from the study at anytime without reason or prejudice. I will be debriefed at the end of the interview which includes being made aware of where and how to get support should I require, as described in the information sheet. I voluntarily agree to take part in the above study.

Participant's Signature:_______________________________________

Date:____

Print Name:____

Researcher's Signature:_______________________________________

Date:____

Print Name:____

Thank you for agreeing to take part in this study.

Appendix H: An Example of One Participant's transcript with Initial and exploratory comments (RHS column) made from the transcript (middle column) contributing to emergent themes (L column).

Global impact	1. hard every, everywhere	
Difficulty planning - lost future Stuck – no choice Constant/relentless/persistent hardness brushed off	2. P1: It's hard, that's affect 3. me, nothing else you know, it's 4. hard, I can't make 5. any plans you know, to. Last 6. year I had to go to India you 7. know and she give me hard 8. time all the way (laughs) even	Impact of caring upon other parts of his life – All consuming Devoid of otherness in life - difficulty of preparing for future arrangements Harassement Feeling victimised by PWD (Powerlessness) is laughed off
	9. R: Um, how did she give 10. you a hard time?	
Stuck in responding to difficulties in PWD's movements PWD's immobility Managing PWD's resistance with humour Stuck in PWD's stuckness (fear or near paralysis) Immersion or engulfment in PWD's feelings or way of being) Fluctuating perceptions of dementia contribute Restlessness?	11. P1: Hard time, she 12. doesn't go to the toilet even 13. and I have to take her (R: um) 14. she don't want to get up from 15. the seat, on the way from Delhi 16. to India, you know Punjab when 17. we go there, (R:um) we were 18. sitting on the coach, you know, 19. she don't want to get up, she 20. get in there, but she won't get 21. out (laugh) (R:um) She get 22. scared sometimes, you know 23. like that, three, four steps on 24. the coach,you know, the coach, 25. so (R: um,so how do you, oh 26. sorry) I had to pull her out, you 27. know, help, get somebody help 28. you know to (R: um) put her 29. down, you know, so I have to 30. keep an eye all the time, keep	Word 'even' and tone of voice again suggest Victimised - Cornered? Difficulty managing PWD need is experienced and perceived as resistance or rigidity rather than inability – PWD's action is choice based (see below – she'll get in but not want to get out – this suggests he perceives PWD may be responding to her own desires - stuck emotion- reflecting stuck physicality?) Dejected by dealing with PWD's Stubborn behaviour. Coping with challenging behaviour using humour (Perseverance, resilience or denial?) So does he respond to his sense of her emotion with his own emotion? Tone focusing on function. Phenomenologically drawn in or sucked up by the other's experience?) Conflicting feelings – own concerns of not moving reflected in restlessness (itching to move by seeking assistance to hurry her out – speaks fast – yet humourises) Conflict -PWD perceived as expressing fearful resistance to move. Compare this empathic view with above victimisation – fluctuating awareness of experiencing PWD whilst caring Need help managing PWD's fear of moving

Appendix I: An Example of numbered emergent themes from Sukhdeep clustered to form sub-ordinate themes before cross-analysis forming sub-themes perseverance & helplessness in Theme 3.

Superordiante theme	Emergent theme	Key word
Caring as Persistence and hope in diligence	77.Peseverance in face of inexorability	She says, I tell her
	79.Clinging to hope	Touchwood
	100-1.Acting early (mind occupation)	Make sure, stays
	80.Hope through proactive intervention	Trial- we started, anything – I try
	69b.Persevering	
		Try to give, try to keep
	41.Active intervention	Pay somebody to keep an eye on her
Persistence in help-seeking despite adversity (for self and PwD)	71-2.Determination & continued help-seeking	Kali mirch – I will try,
	17 & 19.Proactive	Doesn't make difference, went to India
	81-2, 87. Trust in support and hope for more	She might be do that Another days, for me less burden
		Pray for her, that's all
	95. Asking God (single minded)	Another days, bit more for me
	92. Craving support	
		Pay somebody to keep an eye on her
	41. Active Intervention	
Let down by services	15. Futility in help-seeking	I took her doctors – Nothing in the medical, didn't help it
	70a.Confused/ unhelpful medical advice	Kali mirch & patasah, its for the memory, doesn't make a difference. Used back home, digestive, natural remedy Any cure?
	70b.Helplessness of Natural Remedy	
	74. Helplessness of biomedical model	No cure. No treatment. Kali mirch, doesn't make difference
	21. Helplessness of biomedical model	
	71/2. Failure of traditional remedies	Doctors don't worry anything, so I ask her any new medicine, nothing new for a while.
	23. Futility in help-seeking (Lack concern)	
	25. Helplessness/Inappropriate support	They go on about, but money no good to me
	75. Disbelief in efficacy of medical help	
		No medicine help her
		Don't think its helping

Appendix J: An example of Cross-analysis sub-theme development from individual emergent /sub-ordinate themes

Sub-THEME : Engulfment	**Possible Sub-theme: Dementia as a blockage system or stuck communication (blocked channel of relationship – wiped off the register)**	**Description**	**Emergent Theme Sukhdeep**	**Emergent Theme for Dilraj**	**Emergent Theme for Parminder**	**Emergent Theme for Akashpreet**		**Emergent for Harshdeep**
			She's blocked (non-registration)	**Blocked communication – both are stuck**	**Registration is not just blocked but wiped off**	**Cant visualise the PWD's need (similar to Dilraj) blocks communicatio**		**Confused by PWD's communication – blocked reception**
	Analysis: **Not enough examples /emergent themes within individual transcripts to be represented as sub-ordinate themes for each participant. Also the links between emergent themes are weak and do not do justice to coherence within the theme**	This sub-theme is useful to convey how stuckness is perceived as coming from the PWD's condition in the same way sub-theme Mind occupation illustrates the movement of dis-ease engulfment from PWD to carer How do these two possible sub-themes link to showing carer becoming Stuck or blocked by Dementia care as lost communication? Dilraj illustrates this but some of these emergent themes/quotes are better used to represent other sub-themes, e.g. Dilraj – pained and can still be used to contribute to dis-ease in this way without representing as separate sub-theme.	Sees dementia as Not registering – information can't go in and can't come out – Describes dementia as plaques in the brain. Include Quote P1	P2.29.787-808. At least, at least if, if her voice there, at least we should know what problem she got. That's a very er, bad thing to us, she can't speak. If, if she can speak, then a bit more easy for us to look after her (R: um). But now she not speak, and it is very, very hard to look after her. (R: um). I mean I can explain if I am sick, I can say well, I've got a pain here, they can take to doctor, I can tell them I've got pain here. I can't eat, I've got a tummy pain, but she can't say anything. That's why I feel bad. And I, I can't imagine what, I can't imagine what she got. That's why I feel bad.	Personally forgotten She's not aware that this is not correct (wiped off the register) Include quote P3.	P4.2254-2262 It's not even curable, it's not even, you know, it's, there's no emo... there's, you know, I don't know. To look at any person like that it would be hard to see that he doesn't even, he can't even tell you whether he's hungry, whether he's in pain.	P5	P6.2.40 We thought you know this thing happened a long time ago and um why is she bringing this up? Wanting to understand a deeper explanation than medical diagnosis of dementia