THE NEEDS OF SOUTH ASIAN PEOPLE WITH DEMENTIA IN RESIDENTIAL SETTINGS IN ENGLAND

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Declaration

This thesis is my own work, and I declare that the work has not been submitted for any other degree at the university.

Signed:

Dated: 30 October 2025

Word Count: 79400

My Surname has been officially changed from Kudiyirippil Babu to Vijay across all my identification documents.

The university has changed its name from Staffordshire University to the University of Staffordshire and has updated its logo accordingly.

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Abstract

Background: South Asian people with dementia (SAPWD) constitute a growing demographic in the United Kingdom, yet research exploring their experiences in residential care settings remains limited. Cultural values, language differences, religious practices, and social expectations profoundly influence care preferences and perceptions, underscoring the need for culturally sensitive approaches to promote well-being and quality of life. This study addresses a critical gap by examining the opportunities and barriers in delivering culturally appropriate care for SAPWD within residential care contexts.

Design: Employing a qualitative methodology guided by constructivist grounded theory, the research focused on co-constructing knowledge through in-depth semi-structured interviews with 21 individuals in three participant groups: SAPWD, their family members and staff, across four care homes in the East and West Midlands of England.

Findings: A core category emerged, identified as the theory of "Active Negotiation," representing the dynamic, ongoing processes through which residents, families, and care staff collaboratively negotiate care expectations, roles, and culturally informed practices. Four major categories, Entering Residential Care, Adjustment to Care, Being Supported by Family, Staff, and Management, and Continuing to Live in Residential Settings, highlight the multifaceted dimensions of care experiences, including uncertainty, loneliness, communication barriers, cultural dissonance, emotional strain on families, workload or training challenges for staff and resource restrictions for care home providers. The findings reveal that positive care outcomes are achieved when all stakeholders actively engage in negotiation, cooperation, and adaptation to individual cultural preferences, emphasising the importance of culturally competent care strategies, inclusive communication, and collaborative support mechanisms.

Conclusions and Recommendations: The study contributes both theoretically and practically by offering a grounded framework that captures the social processes underpinning culturally competent care, providing actionable insights for care home policies, staff training, and family engagement strategies. Ultimately, the research emphasises that culturally sensitive dementia care is socially constructed and requires ongoing negotiation, collaboration, and adaptation. To strengthen cultural inclusivity and accountability, the study recommends that UK care quality frameworks be reformed to include explicit cultural competency standards as a formal part of inspection and evaluation processes. Further research would be needed to build a more comprehensive, equitable, and contextually rich evidence base for culturally responsive dementia care.

Abbreviations

BPSD	Behavioural and psychological symptoms of dementia
ADL	Activities of daily living
IADL	Instrumental activities of daily living
CQC	Care Quality Commission
SAPWD	South Asian People with Dementia
NMC	Nursing and Midwifery Council
PCC	Participants, Concept, and Context
PRISMA-ScR	Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews
JBI	Joanna Briggs Institute
MeSH	Medical Subject Headings
CGT	Constructivist grounded theory
NICE	National Institute for Health and Care Excellence
DOLs	Deprivation of Liberty Safeguards
BSP	Basic social process
HCA	Healthcare assistants
VR	Virtual reality
WHO	World Health Organisation

CHAPTER 1: INTRODUCTION

1.1 Introduction

Dementia constitutes a significant public health concern, both on a global scale and within the United Kingdom, affecting millions of individuals and imposing significant social, emotional, and economic burdens on families, communities, and healthcare systems. In the UK alone, the ageing population has contributed to a rising prevalence of dementia, necessitating specialised approaches to care that extend beyond medical management to include social support, cognitive stimulation, and psychosocial interventions (Cipriani et al., 2020). One of the largest ethnic minority groups in the UK are the South Asian Communities, accounting for approximately 8.6% of the population, or 5.7 million people (Office for National Statistics, 2023). Approximately 944,000 people in the UK currently live with dementia, and this number is projected to rise to over 1.6 million by 2040 (Alzheimer's Society). Researchers estimate that around 25,000 individuals from ethnic minority groups in the UK are living with dementia (Kenning et. al, 2017). The number is predicted to double by 2026 and increase rapidly in South Asian communities as the ageing population ages. (Alzheimer's Society, 2022; and Soderman et al., 2016. This population includes individuals whose ancestral heritage originates from Bhutan, Afghanistan, Bangladesh, India, Nepal, Sri Lanka and the Maldives. Each country has a distinct culture, tradition, language, religion, and social characteristics that influence healthcare needs and access to services (Blakemore et al., 2018; Hossain et.al., 2019; Mukadam et al., 2019; Bhopal, 2007).

Residential and care services provide structured and supportive environments and play a pivotal role in enabling individuals with dementia to receive continuous support with activities of daily living, medical supervision, and opportunities for social engagement, while also offering relief and support to family caregivers (Jia et al., 2020). Despite the availability of these services, evidence indicates that specific ethnic minority populations, particularly South Asian communities, remain underrepresented in-service utilisation. This underrepresentation is influenced by cultural norms emphasising family-based care, language barriers, limited awareness of available services, and experiences of systemic exclusion. Focusing on South Asian communities in the East and West Midlands is particularly important due to the significant population density of these communities in these regions, coupled with indications of both high dementia prevalence and low engagement with formal care services (Livingston et al., 2020). Understanding the unique needs, preferences, and experiences of South Asian people with dementia in residential and respite care settings is essential for developing culturally responsive services

Most studies focused on South Asian communities, and few or no studies were conducted from the perspectives of SAPWD in care homes in the UK. Research on ethnicity, race, ageing and services for BAME is regarded as the neglected dimension of the ongoing investment in research in dementia care practice improvements, and the neglect is more evident in the care home sector (Botsford et.al, 2015 and Dening, 2015). This is the first study to investigate the needs of South Asian people with dementia living in care homes from the perspectives of SAPWD residents, family and staff. Residential care will continue to significantly contribute to the care of people with dementia in the future, so research that explores the dimensions of quality of life from the perspective of residents can make an important contribution to improving quality of life and developing effective care practices (Begum, 2006). This paradox of high need coupled with low service engagement highlights fundamental disconnections between mainstream care systems and the specific requirements of culturally diverse populations. This study aims to explore the opportunities and barriers in meeting these needs, with the ultimate goal of informing practice, policy, and culturally sensitive interventions that enhance care quality, promote equity, and support the well-being of both residents and their families.

1.2 Background and Context

This section provides a foundational understanding of dementia, its implications, and the specific challenges faced by South Asian communities in the UK, particularly within residential and respite care settings. Dementia, a progressive cognitive disorder, encompasses a range of conditions, including Alzheimer’s disease, vascular dementia, Lewy body dementia, and frontotemporal dementia, each characterised by cognitive, behavioural, and functional impairments that significantly affect daily living and independence. Globally and in the UK, dementia presents a growing public health challenge, with considerable social, economic, and familial burdens, including high healthcare costs, caregiver strain, and societal impacts. Within South Asian communities, the prevalence and risk factors for dementia are shaped by genetic, lifestyle, and comorbid conditions, compounded by cultural beliefs, stigma, and limited awareness of dementia as a medical condition (Ravindranath & Sundarakumar, 2021). Familial caregiving norms often gendered and culturally prescribed, alongside language and communication barriers, influence help-seeking behaviours and acces to formal care. In contrast, the heterogeneity of South Asian populations, including differences in religion, language, socioeconomic status, and degree of acculturation, adds further complexity.

In the UK, residential and respite care services play a crucial role in dementia management, offering structured support for medical, functional, and psychosocial needs; however, mainstream services often face limitations in cultural competency, language support, and accommodation of religious practices, contributing to inequities in care access (Malik et al.2022**)**. This creates a paradox where the high need for dementia services among South Asians is not matched by service utilisation, due to cultural, practical, and systemic barriers, which can result in delayed engagement, crisis-driven care, and negative impacts on quality of life. Addressing these challenges requires person-centred, culturally responsive care that respects individual identities, cultural preferences, and family involvement, guided by evidence-based approaches and intersectional understanding of diversity (Lee et al.2023**)**. Furthermore, national guidelines, care standards, and social justice considerations underscore the necessity of equitable and inclusive dementia care, highlighting the policy and practice imperatives for reducing disparities and ensuring dignity, autonomy, and well-being for South Asian people with dementia.

1.2.1 Dementia: Definition and Overview

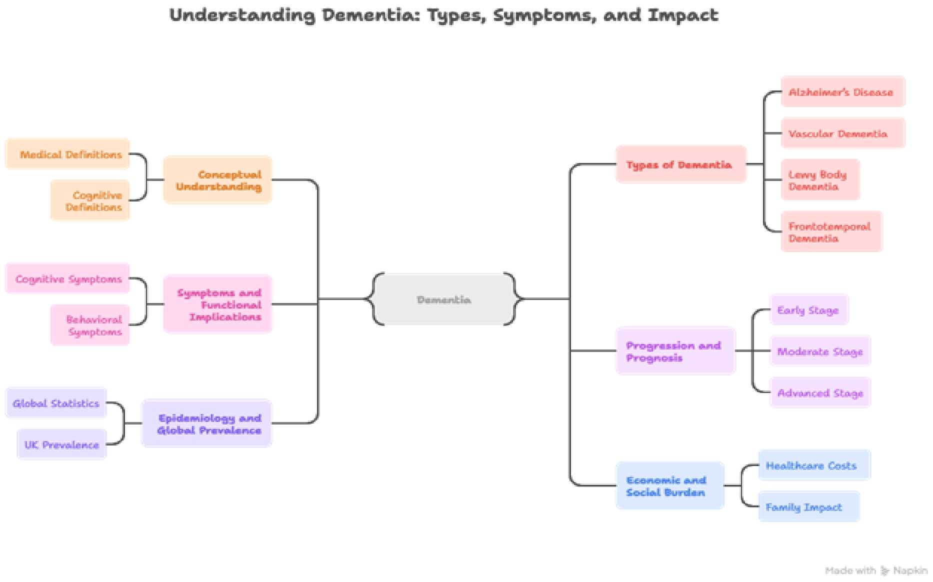


Figure 1.1: Understanding dementia

Dementia is a complex and progressive neurocognitive syndrome that profoundly impacts individuals, families, and societies, representing one of the most pressing health challenges of the 21st century, both globally and within the United Kingdom. Conceptually, dementia is defined from medical and cognitive perspectives, encompassing a spectrum of disorders characterised by a decline in multiple domains of cognitive functioning, including memory, attention, language, executive functioning, visuospatial abilities, and reasoning, which surpasses the normal variations observed in the ageing process and significantly interferes with the individual's capacity to perform everyday activities independently (Chin, 2023**)**. Medically, dementia is recognised as a syndrome resulting from neurodegenerative diseases, cerebrovascular conditions, or other neurological insults, which cause structural and functional alterations in the brain that manifest in progressive cognitive and behavioural impairments. Cognitively, dementia involves deficits that impair the acquisition, retention, and retrieval of information, alongside difficulties in problem-solving, judgment, and comprehension, which are essential for independent living (Cahill, 2020**)**. A crucial distinction must be made between normal aging and dementia, as age-related cognitive changes may involve occasional forgetfulness or mild declines in processing speed and attention but do not substantially interfere with daily functioning, whereas dementia is characterized by persistent, progressive, and multidimensional impairments that significantly compromise autonomy, social participation, and quality of life. Understanding this distinction is vital for accurate diagnosis, early intervention, and the development of appropriate care strategies, as misattributing dementia symptoms to normal aging can delay recognition, diagnosis, and access to supportive services (Livingston et al.2024**)**.

Dementia encompasses several major types, each with distinct etiologies, neuropathological features, clinical presentations, and trajectories, yet all share the core characteristic of cognitive decline that interferes with daily functioning. Alzheimer's disease is the most prevalent form of dementia, accounting for an estimated 60–70% of cases worldwide, and is characterized by progressive memory impairment, difficulties in language and communication, executive dysfunction, and eventual loss of independent functioning (Sommerlad et al. 2023**)**. Neuropathologically, Alzheimer's disease is associated with amyloid-beta plaques, tau protein neurofibrillary tangles, and widespread cortical atrophy, which collectively disrupt neuronal communication and lead to progressive cognitive and functional decline. Vascular dementia, the second most common form, arises from cerebrovascular pathology, such as ischemic or hemorrhagic strokes, small vessel disease, or chronic cerebral hypoperfusion, leading to multifocal brain damage.

Patients with vascular dementia often present with deficits in attention, processing speed, and executive functioning, and the onset may be sudden or stepwise, depending on the nature and location of vascular events (Griffiths, 2020**)**. Lewy body dementia, distinguished by the presence of alpha-synuclein protein aggregates within cortical and subcortical neurons, manifests clinically with fluctuating cognition, visual hallucinations, Parkinsonian motor symptoms, and REM sleep behaviour disorder. This type of dementia is particularly challenging due to the variability in symptom expression, which may lead to misdiagnosis or delayed recognition (McCleery, J., & Sharpley, 2020**)**. Frontotemporal dementia, less common but highly impactful, primarily affects the frontal and temporal lobes, leading to profound changes in personality, behaviour, and language, often with earlier onset than Alzheimer's disease. Patients may exhibit disinhibition, apathy, compulsive behaviours, or progressive aphasia, significantly affecting social relationships, occupational functioning, and family dynamics. Recognising the type of dementia is critical for care planning, prognostic counselling, and the selection of pharmacological and non-pharmacological interventions tailored to symptom profiles and patient needs.

The symptoms of dementia are multifaceted and encompass cognitive, behavioural, psychological, and functional domains, each contributing to the profound impact on daily living and independence. Cognitive symptoms typically include memory loss, particularly for recent events, impaired attention and concentration, difficulties with language expression and comprehension, and deficits in problem-solving, reasoning, and planning (Chowdhary et al.2022**)**. Behavioural and psychological symptoms are equally prominent and may include agitation, aggression, depression, anxiety, apathy, psychosis, and sleep disturbances, collectively termed behavioural and psychological symptoms of dementia (BPSD). These manifestations not only increase patient distress but also place significant emotional, physical, and financial burdens on caregivers. Functionally, dementia affects the ability to perform activities of daily living (ADLs), including personal hygiene, dressing, eating, managing finances, and medication adherence, as well as instrumental activities of daily living (IADLs), such as transportation, shopping, and household management (Canevelli et al.2020). The interplay of cognitive deficits, behavioural symptoms, and functional decline necessitates comprehensive care strategies that address medical, psychological, social, and environmental needs, emphasising person-centred and culturally sensitive approaches.

Dementia typically progresses through distinct stages, often categorised as early, moderate, and advanced, each with specific care implications. In the early stage, individuals may retain relative independence but experience mild memory loss, disorientation, and subtle behavioural changes, requiring support with complex tasks and early planning for future care needs (Van der Steen et al., 2025**)**. Moderate dementia is characterised by worsening cognitive deficits, pronounced functional limitations, increased reliance on caregivers, and the emergence of behavioural and psychological symptoms, necessitating structured interventions, caregiver education, and environmental adaptations to maintain safety and quality of life. Advanced dementia represents severe cognitive and functional deterioration, often with profound memory loss, communication difficulties, complete dependence for ADLs, and increased vulnerability to medical complications such as infections, malnutrition, and falls (Javeed et al., 2023). Understanding the disease trajectory is crucial for anticipatory care planning, resource allocation, and the development of support systems for both patients and their families. Prognosis varies according to the type of dementia, age of onset, comorbid conditions, and access to appropriate care, with life expectancy ranging from several years post-diagnosis in Alzheimer's disease to potentially shorter spans in rapidly progressive dementias or those complicated by comorbidities.

Epidemiologically, dementia is a global public health challenge, with prevalence rates rising in tandem with ageing populations, increasing life expectancy, and improved recognition and diagnosis. Worldwide, over 57 million individuals are estimated to be living with dementia, with projections suggesting a threefold increase to 152 million by 2050, predominantly in low- and middle-income countries, where healthcare infrastructure and caregiving resources may be limited (Lin et al., 2021). Epidemiological studies indicate variations in prevalence according to age, sex, socioeconomic status, and ethnicity, with older adults, women, and those from socially disadvantaged backgrounds disproportionately affected. Regional variations in the UK highlight the importance of localised planning for healthcare provision, workforce training, and community support services tailored to the demographic and cultural characteristics of specific populations (Calil et al., 2020). The economic and social burden of dementia is substantial and multifaceted, encompassing direct healthcare costs, indirect costs associated with informal caregiving, and broader societal impacts. Direct costs include medical care, hospital admissions, medications, and long-term residential or nursing care, which represent a significant proportion of national healthcare expenditures. Indirect costs arise from caregiver burden, lost productivity, reduced workforce participation, and psychological distress, with families often providing substantial unpaid care that would otherwise require formal services (Newby et al., 2023). Social challenges include the strain on family dynamics, reduced social participation for patients and caregivers, and the need for community and institutional support to maintain quality of life. The cumulative impact of these factors underscores the necessity for comprehensive dementia strategies that integrate prevention, early diagnosis, medical management, caregiver support, culturally responsive interventions, and public health policies aimed at mitigating the personal, familial, and societal consequences of this complex condition (Guo et al.2024**)**. Understanding dementia from conceptual, clinical, epidemiological, and socio-economic perspectives is therefore essential to inform effective healthcare planning, policy development, and the provision of person-centred and culturally sensitive care that addresses the diverse needs of affected populations while preparing for the increasing demands posed by an ageing society.

1.2.2 Dementia in South Asian Communities

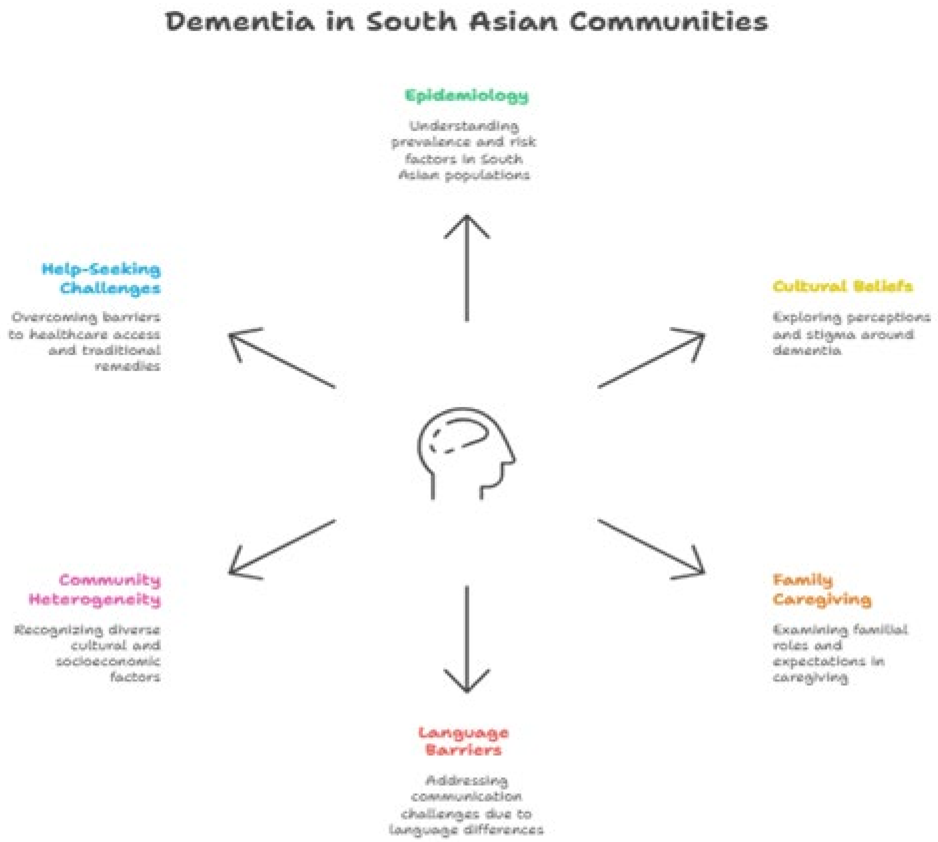


Figure 1.2: Dementia in South Asian Communities

Dementia in South Asian communities presents a complex interplay of epidemiological, cultural, familial, linguistic, and social factors that uniquely shape the experiences of individuals living with cognitive decline and their families, influencing patterns of recognition, help-seeking, and engagement with formal care services (Hossain et al., 2020**)**. Epidemiologically, research indicates that South Asian populations, both in their countries of origin and within diaspora communities such as those in the United Kingdom, experience comparable or even elevated prevalence rates of dementia relative to the general population, with variations linked to genetic predispositions, lifestyle factors, and comorbidities including hypertension, diabetes, cardiovascular disease, and metabolic syndromes, which are often more prevalent in South Asian populations due to genetic susceptibility, dietary practices, and sociocultural determinants of health (James et al., 2024**)**. While Alzheimer’s remains the predominant subtype, vascular dementia is also disproportionately represented given the higher rates of cerebrovascular risk factors, and the co-occurrence of multiple comorbid conditions may accelerate cognitive decline and complicate clinical presentation, resulting in increased functional impairment and greater care needs.

The intersection of these biological and lifestyle-related risk factors underscores the importance of culturally and demographically informed health assessment and intervention strategies, particularly as dementia often manifests in later stages among South Asians due to delayed recognition and diagnosis. Cultural beliefs and understanding of dementia further shape the lived experience of cognitive decline within South Asian communities, influencing explanatory models, illness perceptions, and attitudes toward care (Jayakody & Arambepola., 2022). Dementia is frequently conceptualised not as a biomedical condition but through culturally embedded lenses, including spiritual, moral, or religious frameworks, which may attribute memory loss, confusion, or behavioural changes to the natural ageing process, divine will, karma, or even social and familial transgressions (Jenkins & Kamal, 2024). These explanatory models often lead to secrecy around the condition, reluctance to discuss cognitive symptoms openly, and stigma associated with both the individual and their family, contributing to social isolation, emotional distress, and delayed engagement with healthcare services. Within many South Asian families, there exists a strong imperative to maintain family honour and uphold communal expectations, which can reinforce the concealment of dementia symptoms and reliance on informal home-based care rather than seeking professional or institutional support (Hossain, 2020**)**. Such cultural perspectives not only affect individual and family decision-making but also shape interactions with healthcare providers, as culturally specific beliefs may diverge from biomedical explanations and influence adherence to recommended interventions.

Family caregiving norms within South Asian communities are central to understanding the context of dementia care, as they are rooted in cultural expectations of filial duty, intergenerational responsibility, and collectivist values that prioritize the welfare of the family unit over individual needs. Adult children, particularly daughters and daughters-in-law, are often expected to provide extensive hands-on care for aging parents, including assistance with personal hygiene, medication management, emotional support, and supervision of daily routines. These caregiving responsibilities are highly gendered, reflecting societal norms and religious or cultural traditions that delineate caregiving roles along patriarchal lines. While this strong sense of familial obligation fosters intergenerational support and cohesion, it simultaneously places significant physical, emotional, and financial burdens on caregivers, particularly women, who may experience stress and burnout which leads to social isolation (Webster et al.2023**)**. The expectation of home-based care also has important implications for formal service utilization, as families may perceive residential or respite care as a failure to fulfill cultural duties, a source of shame, or a threat to family honor, thereby contributing to delayed or crisis-driven engagement with professional care services. Language and communication barriers further compound the challenges faced by South Asian individuals and families in navigating dementia care. Limited proficiency in English or the dominant language of the healthcare system can impede access to information, hinder effective communication with healthcare providers, and reduce understanding of diagnosis, treatment options, and available services. Information about dementia, available care pathways, and support mechanisms is often not provided in culturally and linguistically appropriate formats, creating additional obstacles to timely and informed decision-making. Language barriers may also affect the delivery of person-centered care, as residents may struggle to express needs, preferences, or discomfort, while staff may lack the linguistic or cultural competence to interpret symptoms accurately or provide meaningful engagement (Mukadam et al.2023**)**. These communication challenges can exacerbate feelings of isolation, reduce satisfaction with care, and contribute to disparities in health outcomes.

Heterogeneity within South Asian communities further complicates dementia care, as these populations are far from monolithic and encompass diverse religious, linguistic, regional, and cultural identities. Variations in religion, such as Hinduism, Islam, Sikhism, and Christianity, shape beliefs about ageing, illness, caregiving, and end-of-life care, influencing the acceptability of interventions, dietary preferences, religious observances, and social interactions. Differences in language, including Punjabi, Urdu, Hindi, Bengali, Gujarati, and Tamil, affect communication with care providers and the accessibility of culturally appropriate services. Socioeconomic status, education, and occupational background also intersect with health literacy, awareness of dementia, and the capacity to access or advocate for services. Generational differences and degrees of acculturation among diaspora populations create additional layers of complexity, as younger family members may be more familiar with Western healthcare systems and expectations, while older relatives may retain traditional beliefs and practices, potentially leading to intergenerational tensions in caregiving approaches and decision-making. Recognising and accommodating this heterogeneity is essential for developing effective, individualised, and culturally responsive care strategies that respect the diverse values, preferences, and needs within South Asian populations (Miah et al., 2021**)**.

Finally, challenges in recognition and help-seeking are pervasive among South Asian communities and significantly influence dementia outcomes. Cognitive symptoms are frequently identified late, with families often delaying presentation to healthcare services until functional decline becomes severe or behavioural disturbances reach crisis levels. The preference for home care and reliance on traditional remedies, coupled with stigma and fear of social censure, contribute to underdiagnosis and limited engagement with formal care pathways. Healthcare providers may encounter families only at advanced stages of dementia, when care needs are complex, behavioural symptoms are pronounced, and psychosocial support requirements are high. This pattern of late presentation not only complicates clinical management but also restricts opportunities for early interventions, cognitive rehabilitation, and engagement with support networks that could improve the well-being of both affected individuals and their caregivers (Armstrong et al., 2022**)**. Furthermore, the combined influence of cultural beliefs, familial expectations, language barriers, and heterogeneity underscores the need for culturally competent, linguistically accessible, and family-inclusive approaches to dementia care that address the unique barriers faced by South Asian communities. Interventions must consider culturally embedded explanatory models, respect familial caregiving traditions, facilitate communication in preferred languages, and acknowledge the diversity of practices, values, and expectations across religious, linguistic, and generational lines. By integrating an understanding of epidemiological risk factors, cultural perceptions, caregiving norms, communication challenges, heterogeneity, and barriers to help-seeking, healthcare providers, policymakers, and service developers can design more inclusive, responsive, and equitable dementia care services that meet the needs of South Asian populations, promote timely access to interventions, enhance quality of life, and support family caregivers in sustaining culturally congruent care practices while navigating the complexities of dementia management within formal care settings (Paria et al.2023).

1.2.3 Dementia Care Services in the UK

Figure 1.3: Dementia Care Services in the UK

Dementia care services in the United Kingdom constitute a multifaceted system designed to address the diverse and complex needs of individuals experiencing cognitive decline, with residential and respite care serving as central components in the formal care landscape. Residential care, also referred to as care homes, encompasses facilities that provide long-term accommodation alongside personal and nursing care for individuals who require continuous assistance with activities of daily living, medical monitoring, and psychosocial support (Giebel et al., 2021). These facilities vary in structure and specialisation, ranging from nursing homes that employ registered nurses to provide complex clinical care to residential homes offering personal care and support without on-site nursing provision. Dementia-specific care homes are increasingly prevalent, designed to offer structured environments tailored to the cognitive and functional needs of residents with memory impairment. The role of residential care in dementia management extends beyond mere supervision or custodial care; it involves the implementation of person-centred approaches that focus on maintaining independence, dignity, and quality of life, alongside addressing behavioural, psychological, and medical needs (Wittenberg et al., 2020**)**. Staff in residential care settings is expected to provide a combination of routine care, therapeutic interventions, social engagement, and support for activities of daily living, all of which are essential to managing the progressive nature of dementia and mitigating the impact of cognitive decline on residents and their families.

Complementing residential care, respite care provides temporary relief for family carers, enabling them to rest, attend to personal or professional responsibilities, or manage caregiver burden without compromising the safety and care of their relative with dementia. Respite care services may be offered in care homes, community centers, or through home-based support, and their objectives include reducing caregiver stress, preventing burnout, and facilitating continuity of care by ensuring that temporary arrangements align with the ongoing needs and preferences of the person with dementia. For families adhering to cultural expectations of caregiving, such as those in South Asian communities, respite care can present a culturally sensitive bridge between home-based care and formal service engagement, offering opportunities for professional support while respecting familial roles and responsibilities (Hossain & Khan.2020). The benefits of respite care extend beyond caregiver relief; they provide structured social interaction, engagement in meaningful activities, and monitoring of health and cognitive status for the individual with dementia, contributing to improved overall well-being and early identification of emerging care needs. Within the East and West Midlands, the provision of care homes reflects both regional variation and the broader structure of dementia services in the UK. These regions encompass a diverse population, including significant ethnic minority communities, necessitating consideration of demographic factors in service planning and delivery. Care home provision in these areas ranges from large, corporate-managed facilities to smaller, family-operated homes, varying in size, staffing levels, and specialisation in dementia care. Capacity and staffing profiles are critical determinants of quality and accessibility, with factors such as staff-to-resident ratios, availability of trained dementia care professionals, and continuity of care influencing outcomes for residents (Stamou et al.2021**)**. Demographic profiles of care home residents reflect a broad spectrum of socioeconomic, cultural, and health-related characteristics, and regional differences in funding, local authority support, and commissioning arrangements can impact the availability, quality, and cultural responsiveness of services.

Understanding the distribution, capacity, and characteristics of care homes in the East and West Midlands is therefore essential for identifying gaps in service provision, evaluating accessibility for ethnic minority populations, and planning interventions to enhance equity and quality in dementia care. Integration of formal care within dementia management is increasingly recognized as critical to addressing the multidimensional needs of people living with dementia. Multidisciplinary approaches, involving collaboration among nurses, care assistants, physicians, occupational therapists, social workers, and other professionals, facilitate comprehensive care planning that encompasses medical, functional, and psychosocial needs (Smith et al.,2021**)**. Residential and respite care services often operate within these multidisciplinary frameworks, offering coordinated interventions that support activities of daily living, monitor medical conditions, provide therapeutic engagement, and address behavioral or psychological symptoms. Structured care planning includes regular assessment of cognitive status, risk management, mobility support, nutrition, medication adherence, and psychosocial interventions, all tailored to the individual's preferences, abilities, and cultural background. The integration of formal care also involves liaising with family members, community resources, and primary healthcare services, ensuring continuity of care across settings and promoting shared decision-making that respects the role of families in ongoing care. The emphasis on coordinated, individualized care aims to reduce hospital admissions, manage behavioral challenges, enhance quality of life, and provide a supportive environment in which individuals with dementia can maintain as much autonomy and engagement as possible, even as their cognitive abilities decline (Surr et al.,2020**)**. Despite these advances, significant limitations persist in meeting the needs of ethnic minority populations, including South Asian communities, within UK dementia care services. A pervasive challenge is the lack of cultural knowledge and competence among care staff, which can lead to misunderstandings, misinterpretation of behaviors, and failure to accommodate culturally specific practices related to food, religious observances, daily routines, and social interaction patterns. This deficit in cultural responsiveness may result in the marginalization of residents from ethnic minority backgrounds, reduced satisfaction with care, and heightened distress for both individuals with dementia and their families. Limited language support further exacerbates these challenges, as communication barriers can hinder the accurate expression of needs, preferences, and discomfort, impede engagement in activities, and restrict access to information about care options, rights, and support services.

Inadequate provision for religious or cultural accommodations, such as prayer facilities, dietary options aligned with religious practices, or celebration of cultural festivals, may also undermine the person-centered care ethos and contribute to social isolation and emotional distress. Accessibility challenges, including geographic location of services, availability of culturally appropriate placements, and financial constraints, interact with systemic gaps in information provision to limit the timely and equitable utilization of care services by South Asian families (Herat-Gunaratne et al.,2020**)**. Moreover, care pathways are often designed around mainstream expectations and may not account for the complex interplay of cultural values, family dynamics, and generational differences, resulting in services that are poorly aligned with the lived experiences and preferences of minority populations. Addressing these limitations requires a multifaceted approach that combines workforce development, service adaptation, and community engagement. Training programs for care staff must include cultural competency, language skills, and awareness of ethnic minority caregiving norms, ensuring that staff can respond effectively to the diverse needs of residents. Organizational changes, including flexible care routines, inclusion of family and community networks in care planning, and incorporation of culturally specific interventions, are necessary to create an environment in which residents from South Asian and other minority backgrounds feel respected, understood, and supported (Lion et al.,2020). Information provision must be tailored to linguistic and cultural preferences, using accessible formats and trusted communication channels to facilitate informed decision-making by families.

Policymakers and commissioners must recognise the unique challenges faced by ethnic minority populations and allocate resources to expand culturally responsive care options, address geographic disparities, and monitor quality and equity outcomes. Research evidence indicates that when these strategies are implemented, care outcomes improve, including greater satisfaction with services, reduced behavioral disturbances, enhanced engagement in meaningful activities, and better overall quality of life for residents. In summary, dementia care services in the UK encompass a range of residential and respite provisions that play a critical role in supporting individuals with cognitive decline and their families. Residential care provides long-term accommodation and comprehensive support for daily living, while respite care offers temporary relief for family caregivers and contributes to continuity of care (Vinay, R., & Biller-Andorno, 2023). The East and West Midlands exemplify regional variations in care provision, highlighting the importance of capacity, staffing, and demographic considerations in service planning. Integration of formal care through multidisciplinary approaches ensures holistic support for medical, functional, and psychosocial needs. Yet, limitations in cultural knowledge, language support, religious accommodations, and accessibility continue to impede optimal engagement for ethnic minority populations. Addressing these gaps necessitates culturally competent workforce development, organisational adaptation, inclusive care planning, and targeted policy interventions to ensure equity, responsiveness, and quality in dementia care (Giebel et al., 2021). By focusing on these challenges and opportunities, the UK care system can better meet the needs of South Asian communities and other diverse populations, promoting dignity, autonomy, and well-being for individuals living with dementia while supporting families in navigating the complexities of caregiving within culturally sensitive frameworks. Recognising the interaction between regional service provision, multidisciplinary care integration, and the cultural, linguistic, and social needs of ethnic minority populations is essential for designing effective interventions and informing practice, policy, and research that advance equitable, person-centred dementia care across the United Kingdom (Baghirathan et al., 2020**)**.

1.2.4 The Paradox of Need and Access

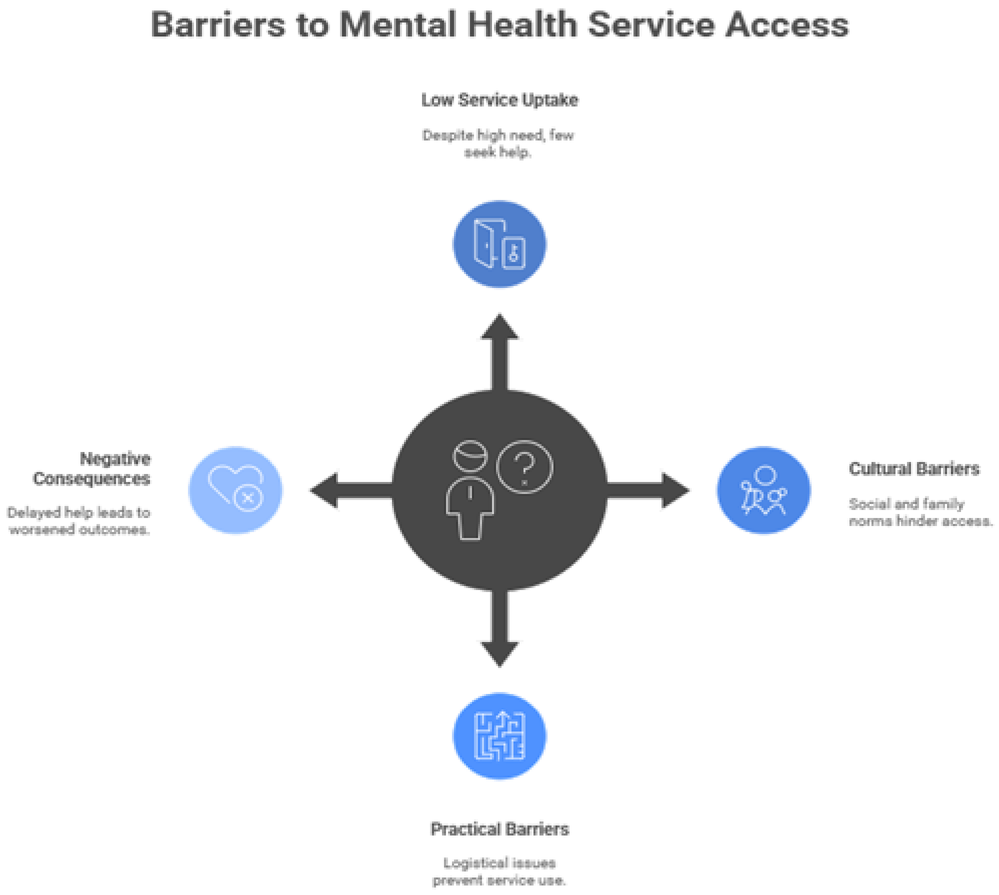


Figure 1.4: Barriers to mental health service access

The paradox of need and access in dementia care for South Asian communities reflects a complex and multifaceted challenge in which the prevalence of dementia is comparatively high, yet the utilisation of formal care services remains disproportionately low, resulting in unmet needs and suboptimal health outcomes. Epidemiological evidence indicates that South Asian populations experience dementia at rates similar to, or exceeding, those observed in the general UK population, driven by a combination of genetic predispositions, lifestyle factors, and comorbidities such as diabetes, cardiovascular disease, and hypertension (Giebel et al., 2021**)**. Despite this heightened vulnerability, engagement with residential and respite care services remains markedly limited, a discrepancy consistently documented in both UK and international studies. Data highlight that while the demand for dementia care is significant, service uptake is delayed or avoided, contributing to later-stage presentations, crisis-driven admissions, and increased caregiver burden. This discrepancy underscores the urgent need to understand the underlying factors that inhibit access and to develop interventions that are culturally and socially responsive to the lived realities of South Asian families navigating dementia care. Cultural barriers constitute a primary factor contributing to the paradox of need and access.

Within many South Asian communities, deeply ingrained values emphasise the responsibility of family members, particularly adult children and daughters-in-law, to provide care for elderly relatives, framing institutional care as a last resort that may signal familial neglect or failure to uphold cultural obligations (Groenvynck et al., 2022**)**. The placement of a relative with dementia into residential care can evoke feelings of shame, dishonour, and social stigma, often associated with societal judgment and internalised guilt. This cultural expectation creates substantial psychological and social barriers to accessing formal care services, leading families to delay help-seeking until a crisis emerges, such as severe behavioural disturbances or rapid cognitive decline. Illness perceptions within these communities further compound these challenges, as dementia may be understood through non-medical explanatory models, including spiritual or moral interpretations, reinforcing secrecy, denial, and reluctance to engage with professional services. Additionally, the preference for home-based care, grounded in cultural and religious norms, often outweighs perceived benefits of institutional care, even when such services could provide essential support and improve outcomes for both the individual with dementia and their caregivers (Ramakrishnan & Malhotra, 2025).

Practical and systemic barriers intersect with cultural factors to further limit access to care. Language proficiency poses a significant challenge for many South Asian families, as limited English fluency can hinder communication with healthcare providers, impede comprehension of available services, and restrict the ability to navigate complex care pathways. The scarcity of culturally and linguistically appropriate information exacerbates these difficulties, leaving families unaware of service options, eligibility criteria, and potential support mechanisms. Moreover, the limited cultural competency of many mainstream care providers contributes to experiences of exclusion and dissatisfaction, as staff may lack knowledge or skills to accommodate cultural practices, dietary requirements, religious observances, or communication preferences. Systemic barriers, including rigid institutional structures, insufficient staff training in cultural diversity, and inadequate organisational flexibility, further reinforce inequities, making it challenging for South Asian residents and their families to access care that aligns with their values, expectations, and needs (Stapley et al., 2025). In combination, these cultural, practical, and systemic barriers create a situation in which families may defer formal care engagement, relying instead on home care or informal networks, which can strain family resources and limit timely intervention. The consequences of these barriers are profound, both for individuals with dementia and their caregivers. Delayed help-seeking often results in engagement with services at more advanced stages of cognitive decline, when the complexity of care needs has increased, behavioural and psychological symptoms are more pronounced, and family stress is heightened.

Crisis-driven admissions can disrupt continuity of care, challenge the maintenance of personhood and dignity, and exacerbate feelings of guilt, shame, and social judgment among family members. For individuals with dementia, late access to formal care can lead to unmanaged symptoms, reduced participation in social and therapeutic activities, and a decline in overall quality of life (Zhang et al., 2024). Family caregivers experience increased stress, emotional burden, and potential health consequences due to prolonged periods of intensive home-based care without adequate support. The interplay between cultural reluctance, language barriers, and insufficient service responsiveness thus perpetuates a cycle of underutilization, unmet needs, and inequitable outcomes. Research underscores that without targeted interventions to address these barriers, South Asian communities may continue to experience disproportionate challenges in dementia care access, highlighting the need for culturally informed, linguistically accessible, and socially sensitive strategies to bridge the gap between need and utilisation.

Addressing the paradox of need and access requires a multifaceted approach that recognises the interdependence of cultural, practical, and systemic factors. Strategies must encompass culturally tailored education and outreach to increase awareness of dementia, normalise help-seeking, and reduce stigma, as well as the provision of interpreters, translated materials, and bilingual staff to facilitate effective communication (Rajkumar, 2021). Care homes and respite services must adopt culturally competent practices, incorporating flexible routines, culturally appropriate food, opportunities for religious observance, and family involvement in care planning and decision-making. Policy initiatives should prioritise equity and inclusion, ensuring that commissioning frameworks, quality standards, and funding allocations support the development of culturally responsive services that meet the needs of diverse populations. Community engagement, including collaboration with faith leaders, community organisations, and ethnic minority networks, is essential to build trust, disseminate information, and foster supportive environments that encourage early and sustained engagement with formal care.

By addressing the structural and cultural barriers simultaneously, it is possible to reduce delays in access, alleviate caregiver stress, improve quality of life for individuals with dementia, and promote equitable outcomes across populations (Simon et al., 2021**)**. Ultimately, the paradox of need and access in South Asian dementia care highlights the complex interrelationship between epidemiological realities, cultural norms, practical challenges, and systemic inadequacies. It emphasises that high prevalence alone does not translate into adequate utilisation of services and that effective dementia care requires an integrated, culturally sensitive approach that bridges the gap between need and provision (Duran-Kirac et al., 2020**)**. Understanding this paradox is foundational to the development of inclusive, responsive, and equitable dementia care services that honour cultural values while ensuring timely access, optimal support, and improved outcomes for individuals with dementia and their families. Research into these dynamics provides critical insights for healthcare practitioners, policymakers, and service providers, informing interventions that not only expand access but also foster culturally congruent, person-centred care that respects identity, promotes dignity, and strengthens family and community support networks (Ney et al., 2021).

1.2.5 Person-Centred and Culturally Responsive Care

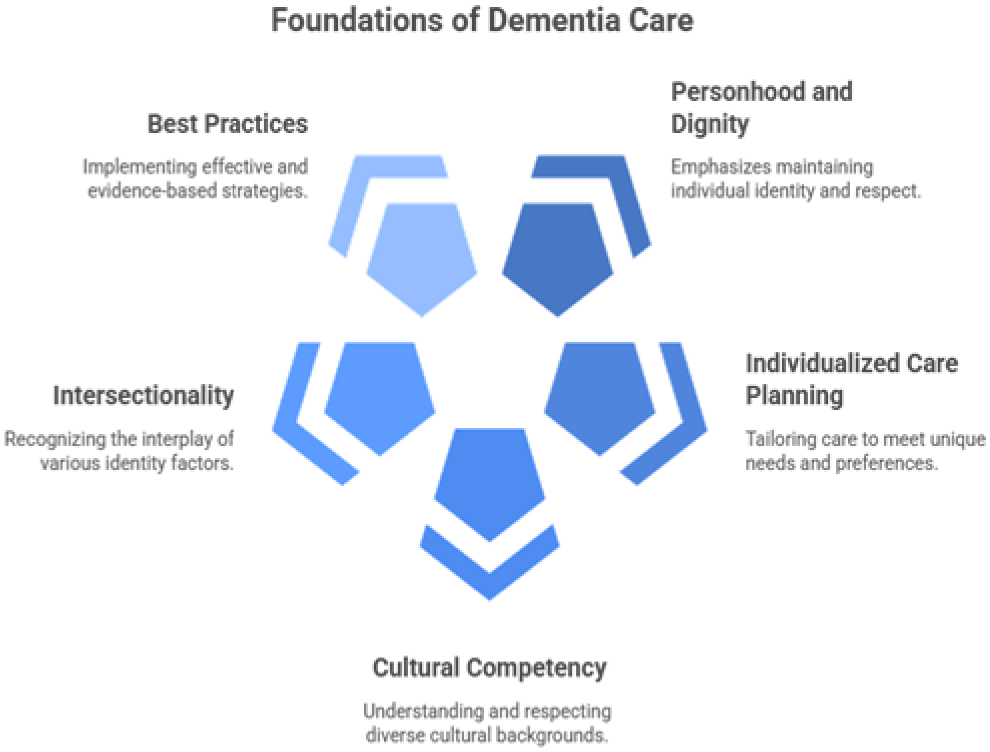


Figure 1.5: Foundations of dementia care

Person-centred and culturally responsive care represents a cornerstone of high-quality dementia management, emphasising the recognition of each individual as a unique person with inherent dignity, values, and preferences, while also acknowledging the cultural, social, and linguistic contexts that shape their experiences. At its core, person-centred dementia care prioritises the maintenance of personhood, ensuring that individuals with cognitive decline are treated with respect, empathy, and sensitivity to their psychological, emotional, and physical needs. This approach challenges care models that focus solely on symptom management, instead fostering environments that honour individuality, support autonomy, and enable engagement in meaningful activities that reflect personal history, interests, and social roles. Individualised care planning forms the practical foundation of this philosophy, requiring care providers to assess and document the unique abilities, preferences, and needs of each resident, integrating these insights into daily routines, therapeutic interventions, and decision-making processes (Son et al., 2025). Such planning not only supports the preservation of identity and dignity but also enhances cognitive stimulation, emotional well-being, and overall quality of life, particularly when tailored to accommodate the progressive nature of dementia and the evolving requirements of the individual. Cultural competency is an essential component of effective person-centred care, particularly for ethnically diverse populations such as South Asian communities, where cultural norms, religious beliefs, dietary practices, and family dynamics significantly influence perceptions of health, illness, and care expectations. Cultural competency encompasses a combination of awareness, knowledge, and practical skills that enable care providers to recognise, respect, and respond appropriately to cultural differences while avoiding assumptions or stereotypes (Smith et al., 2022). Awareness involves understanding one’s own cultural biases and acknowledging how these may affect care delivery, while knowledge entails familiarity with the beliefs, values, and practices of different cultural groups.

Practical skills include the ability to communicate effectively across language barriers, accommodate religious observances, adapt routines to cultural preferences, and engage in culturally sensitive problem-solving. Linguistic accommodations, such as provision of interpreters, bilingual staff, and translated informational materials, are critical to ensuring that individuals and families can participate fully in care planning, understand treatment options, and make informed decisions. Similarly, attention to religious accommodations such as opportunities for prayer, dietary restrictions, and observance of religious holidays reinforces a sense of respect and inclusion, promoting emotional well-being and reducing feelings of alienation within institutional care environments (Markey et al., 2023). The application of intersectionality theory further deepens the understanding of how person-centred and culturally responsive care should be operationalised in dementia care settings. Individuals with dementia occupy multiple, intersecting social identities, including ethnicity, gender, age, social class, immigration status, and health condition, each of which interacts to shape experiences of privilege and disadvantage. For South Asian individuals, the intersection of cultural minority status, advanced age, cognitive impairment, and language barriers creates layers of vulnerability that require nuanced and flexible care strategies. Care provision that considers these intersecting identities can more accurately anticipate potential barriers, accommodate diverse needs, and support equity in access and outcomes. Tailoring care to complex identities may involve not only recognition of individual preferences but also engagement with family members, community networks, and social structures that influence decision-making, caregiving responsibilities, and the resident's broader social context (O'Brien et al., 2021). For instance, the involvement of family in care decisions is often culturally mandated in South Asian communities, reflecting deeply held values regarding filial duty and intergenerational support.

A person-centred, intersectional approach ensures that these cultural imperatives are respected while simultaneously safeguarding the rights, dignity, and autonomy of the individual with dementia. Best practices and evidence-based approaches serve as guiding frameworks to operationalise person-centred and culturally responsive care, translating theoretical principles into actionable strategies that improve engagement, satisfaction, and health outcomes. Strategies to enhance engagement may include personalised activity planning that aligns with the resident's cultural background, interests, and abilities, the use of reminiscence therapy incorporating culturally relevant memories, and flexible routines that accommodate preferred mealtimes, social interactions, and religious observances. Evidence demonstrates that integrating cultural and familial considerations into care delivery reduces behavioural symptoms, improves mood, and enhances participation in therapeutic activities (Acha et al., 2021). The inclusion of family and community networks is another critical dimension, recognising that care is not solely the responsibility of professional staff but occurs within a broader social ecosystem. Involving family members in care planning, decision-making, and daily routines reinforces continuity of care, strengthens relational ties, and ensures that culturally specific preferences are maintained, even within institutional settings. Engagement with community organisations, faith leaders, and cultural associations further extends support networks, facilitates access to information and resources, and fosters a sense of belonging for residents and families alike.

Moreover, the adoption of evidence-based frameworks for dementia care underscores the importance of ongoing evaluation, reflective practice, and quality improvement initiatives that are sensitive to cultural diversity. Care providers are encouraged to engage in continuous professional development focused on cultural competency, communication skills, and person-centred interventions, ensuring that care delivery evolves in response to emerging evidence and the changing needs of diverse populations. Organisational policies must support these initiatives, embedding cultural responsiveness and individualised care planning into staffing models, resource allocation, and performance evaluation criteria. Evaluative measures may include assessments of resident satisfaction, family engagement, adherence to cultural and religious preferences, and outcomes related to behavioural symptoms, cognitive functioning, and overall quality of life (Sivertsen et al., 2022). By systematically integrating evidence-based practice with cultural and person-centred principles, care providers can mitigate the risk of marginalisation, enhance inclusivity, and deliver care that aligns with the holistic needs of South Asian residents and their families.

In summary, person-centred and culturally responsive care represents an integrated philosophy that combines respect for individual identity, maintenance of dignity, and responsiveness to cultural, linguistic, and social diversity. It requires the application of theoretical principles, practical skills, and evidence-based strategies to ensure that care environments are inclusive, flexible, and supportive, promoting well-being for individuals with dementia while acknowledging the central role of family and community networks. For South Asian populations, the effective implementation of these approaches is particularly significant given the cultural norms surrounding family caregiving, religious observances, and social expectations. By embracing person-centred, culturally competent, and intersectionally informed practices, care providers can bridge gaps in access, enhance engagement and satisfaction, and create dementia care environments that are not only clinically effective but socially and culturally affirming, ultimately contributing to improved quality of life, reduced caregiver stress, and equitable health outcomes for this growing and diverse population (Agbana et al., 2022).

1.2.6 Policy, Practice, and Social Justice Considerations

Figure 1.6: Enhancing dementia care through policy and practice

Policy, practice, and social justice considerations play a central role in shaping the delivery of dementia care, particularly for ethnically diverse populations such as South Asian communities, where systemic inequities, cultural expectations, and structural barriers intersect to influence access, quality, and outcomes. At the policy level, national guidelines and care standards in the United Kingdom establish a framework for ensuring that dementia care is safe, effective, and equitable across diverse populations, emphasising the principles of equality, inclusivity, and person-centred service provision (Mavrogordato & White, 2020). Key UK policies, including the National Dementia Strategy, the Health and Social Care Act, and the Equality Act, underscore the legal and ethical imperatives to address health disparities, promote cultural competence, and safeguard the rights of individuals with dementia, irrespective of their ethnic or cultural background. These frameworks mandate that care providers adopt culturally sensitive practices, respect linguistic needs, and accommodate religious and social customs, thereby ensuring that the design and delivery of dementia services align with the diverse identities of service users (Keddie, 2020). Regulatory frameworks governing care homes, such as those administered by the Care Quality Commission (CQC), establish minimum standards for safety, staffing, training, and care provision while emphasising the importance of personalised and culturally competent care. Compliance with these frameworks is essential to maintain high-quality service delivery, protect vulnerable residents, and mitigate the risk of discrimination or exclusion. National guidelines further provide structured recommendations for workforce development, resource allocation, and care coordination, highlighting the critical role of policy in bridging the gap between theoretical principles of equity and practical implementation within institutional care settings. In translating policy into practice, significant implications emerge for training and professional development, organisational culture, and service delivery models (Borras & Franco, 2020). Care staff require comprehensive training that extends beyond clinical competencies to encompass cultural awareness, communication skills, and the capacity to deliver person-centred care that respects diverse values, beliefs, and practices. Such training equips staff to recognise and respond to culturally specific needs, engage effectively with families, and tailor interventions that honour individual identity and social context. Professional development initiatives may include modules on culturally appropriate dietary practices, religious observances, linguistic accommodations, and approaches to engaging family caregivers in care planning, thereby enhancing the confidence and capability of staff to deliver inclusive and empathetic care. Beyond individual training, organisational changes are essential to embed inclusivity and equity into institutional culture.

Care homes must adopt policies and procedures that reflect a commitment to diversity, establish mechanisms for monitoring and evaluating cultural responsiveness, and foster leadership that prioritises social justice and person-centred practice. Organisational adaptations may include recruitment of multilingual staff, provision of culturally relevant recreational and therapeutic activities, flexible scheduling to accommodate religious or family obligations, and allocation of resources for staff to participate in ongoing professional development. These measures collectively create care environments that are supportive, culturally affirming, and responsive to the complex needs of residents from South Asian and other ethnic minority backgrounds. Social justice considerations are integral to understanding disparities in dementia care and to promoting equitable access and outcomes (Norman-Major, 2023). Ethnic minority populations, including South Asians in the UK, often face systemic barriers that limit access to formal care services, such as language difficulties, cultural incongruence with mainstream services, socioeconomic disadvantage, and limited representation within healthcare systems. Addressing these disparities requires a deliberate focus on equity, ensuring that care provision does not merely meet minimum standards but actively promotes fairness, dignity, and inclusion for all residents. Social justice in dementia care encompasses the elimination of structural inequities, the reduction of health disparities, and the recognition of cultural, linguistic, and social differences as legitimate factors that influence care needs and outcomes. Promoting dignity and autonomy is particularly important, as residents with dementia are vulnerable to disempowerment, marginalisation, and loss of agency, especially within institutional settings. Policies and practices must therefore safeguard residents' rights to participate in decision-making, express preferences, and maintain control over aspects of daily life, including routines, social engagement, and care choices (Bennett et al., 2021). Culturally safe care further ensures that resident's feel respected, valued, and understood, mitigating the risk of alienation, distress, and social isolation.

The implementation of social justice-oriented dementia care also necessitates engagement with families, communities, and broader social networks, recognising that health and well-being are influenced by relational, cultural, and social contexts. For South Asian populations, the family plays a central role in care provision, decision-making, and support, reflecting deeply held cultural norms regarding filial duty and intergenerational responsibility. Care homes and respite services must therefore adopt collaborative approaches that involve families as partners in care, facilitating communication, negotiation, and shared decision-making. Community engagement, including partnerships with cultural organisations, faith groups, and advocacy networks, further extends the reach and impact of dementia services, providing culturally relevant education, support, and resources that enhance both the quality and accessibility of care. Such integration of families and communities into care provision not only supports the resident's cultural identity and well-being but also contributes to broader social inclusion and cohesion, reinforcing the ethical and practical imperatives of social justice (Wilbur et al., 2020). In addition to practical strategies, policy and social justice considerations intersect with monitoring, evaluation, and accountability mechanisms to ensure that culturally responsive and equitable care is consistently delivered. Regular assessment of service outcomes, resident satisfaction, family engagement, and staff competencies provides critical feedback for continuous improvement and identifies areas where disparities persist. Data collection disaggregated by ethnicity, language, and cultural background allows for targeted interventions and evidence-based adjustments to practice, ensuring that care standards evolve in response to diverse population needs. Regulatory bodies, accreditation frameworks, and professional codes of conduct reinforce accountability, compelling organisations to uphold principles of equity, inclusivity, and culturally sensitive care while mitigating the risk of neglect, discrimination, or systemic bias. In conclusion, policy, practice, and social justice considerations form a triad that underpins effective, inclusive, and equitable dementia care for South Asian populations and other ethnic minority groups in the UK. National guidelines and care standards provide the legislative and ethical foundation, while practical implications for staff training, organisational development, and service delivery operationalise these principles within care settings (Kavanagh & Danielson, 2020). Social justice perspectives ensure that attention is focused not only on clinical effectiveness but also on the broader imperatives of equity, dignity, autonomy, and culturally safe care. Together, these considerations create a framework that supports the development of dementia services capable of meeting the complex, diverse, and evolving needs of residents, families, and communities, ultimately promoting well-being, reducing disparities, and advancing fairness in care provision. By integrating policy directives, practice innovations, and social justice principles, the dementia care sector can move towards a model that is not only clinically competent but also ethically and culturally responsive, fostering environments where all residents are respected, supported, and empowered to live with dignity throughout the dementia journey (Kikabhai,2022).

1.3 Problem Statement

The problem statement for this research highlights a critical gap in understanding the experiences and needs of South Asian people with dementia within residential settings. While existing literature has explored barriers to dementia care access among South Asian communities, much of this research has focused on family caregivers in community contexts, leaving the perspectives of residents themselves largely underexplored. This gap is significant because it limits the ability of care providers and policymakers to design interventions and services that are genuinely responsive to the cultural, linguistic, and social needs of South Asian residents

(Strommen et al., 2020). Moreover, the current care frameworks often fail to incorporate culturally sensitive practices, leading to reduced quality of life, dissatisfaction with care, and delayed engagement with formal services. Without in-depth knowledge of residents lived experiences, including how cultural beliefs, family expectations, and systemic barriers interact to shape care experiences, it is challenging to develop effective, person-centred, and culturally competent dementia care models (Ploeg et al., 2020). Therefore, there is a pressing need for research that captures the voices of South Asian residents, examines the perspectives of staff and family, and identifies barriers and opportunities for culturally responsive care frameworks that can enhance well-being, dignity, and satisfaction in residential settings. This research aims to fill these gaps by providing empirical evidence that informs both practice and policy, contributing to more inclusive, equitable and culturally attuned dementia care services.

1.4 Research Rationale

The research rationale for this study is grounded in the need to address critical gaps in understanding the experiences of South Asian people with dementia in residential care settings. Despite the growing recognition of dementia as a significant public health concern, there remains limited UK-based evidence capturing the perspectives of residents, their families, and care staff, particularly within ethnically diverse populations. This study is therefore essential for generating first-hand empirical data that can inform theory, policy, practice, and social justice initiatives. By examining cultural, linguistic, and familial influences on care experiences, the research contributes to the development of culturally competent and person-centred care models, while also expanding theoretical frameworks such as intersectionality in health research. Additionally, the findings hold practical relevance for care home staff training, care protocols, and the enhancement of resident well-being, and offer policy insights to support inclusive dementia care legislation and commissioning frameworks. Ultimately, this research aims to promote equity, dignity, and social justice in dementia care for ethnic minority communities, ensuring that services are responsive to their unique needs and experiences.

1.4.1 Empirical Significance

The empirical significance of this study lies in its focus on generating first-hand, qualitative data from three key stakeholder groups: South Asian residents with dementia, their families, and care home staff. While existing research has primarily examined dementia care in general populations or focused on carers in community settings, there is a notable lack of evidence capturing the lived experiences of South Asian individuals within formal residential care environments in the UK. By collecting direct insights from residents about their daily experiences, perceptions of care, and cultural needs, alongside the perspectives of families and staff, the study provides a comprehensive understanding of care dynamics in these settings. This empirical contribution not only fills a critical gap in UK-based dementia care literature but also offers practical and context-specific evidence that can inform service improvements, policy development, and culturally responsive care practices tailored to ethnic minority populations.

1.4.2 Theoretical Significance

The theoretical significance of this research lies in its potential to advance and expand existing frameworks for dementia care by integrating cultural competency, person-centred care, and intersectionality. By examining the experiences of South Asian individuals in residential and respite care, the study provides insights into how cultural beliefs, family dynamics, religious practices, and linguistic needs intersect with dementia care, thereby extending the applicability of cultural competency and person-centred care models to ethnically diverse populations. Furthermore, the research contributes to the broader theoretical discourse on intersectionality in health research by highlighting how multiple social identities, such as ethnicity, age, gender, and migration background, interact to shape unique experiences of disadvantage or vulnerability. This approach enables a more nuanced understanding of dementia care, emphasising the need for care models that are not only individualised but also culturally and socially informed, ultimately enriching theory development in gerontology, nursing, and health services research.

1.4.3 Policy Significance

The policy significance of this research lies in its potential to inform and shape dementia care policies that are inclusive, equitable, and responsive to the needs of

South Asian communities in the UK. By providing empirical evidence on the barriers and opportunities faced by South Asian individuals in residential care, the study can guide policymakers in refining equality legislation, ensuring that care standards explicitly address cultural, linguistic, and religious needs. Furthermore, the findings can support the development of inclusive care commissioning frameworks, enabling local authorities and health services to allocate resources effectively and design services that reduce disparities in access and quality of care. Ultimately, this research contributes to policy initiatives aimed at promoting culturally sensitive, person-centred care, ensuring that all individuals, regardless of ethnic background, can receive high-quality dementia care that respects their identity, dignity, and social context.

1.4.4 Practice Significance

The practice significance of this research centres on its potential to directly improve the delivery of dementia care within residential settings. By identifying specific barriers and opportunities in meeting the needs of South Asian residents, the study provides actionable insights for care home staff, including nurses, care assistants, and support workers, to enhance their training and develop culturally competent care protocols. This includes practical guidance on communication strategies, accommodating religious and dietary preferences, and involving families in care decisions. Implementing these evidence-informed practices can improve the overall quality of care, promote the dignity and well-being of residents, and increase family satisfaction and confidence in formal care services. In essence, the findings bridge the gap between theory and practice, supporting care providers in creating inclusive, person-centred environments that respond to the unique cultural and social needs of South Asian individuals with dementia.

1.4.5 Social Justice Significance

The social justice significance of this research focuses on addressing the systemic inequalities and disparities that South Asian people with dementia face within residential settings in the UK. Ethnic minority groups often experience reduced access to culturally appropriate care, leading to poorer health outcomes, marginalisation, and compromised quality of life. By identifying barriers and opportunities in service provision, this study aims to promote equitable care practices that respect and uphold the dignity, identity, and cultural values of South Asian residents. Furthermore, it highlights the importance of inclusive policies, staff training, and organisational practices that recognise diversity and ensure all individuals receive fair, respectful, and culturally responsive care. Ultimately, this research contributes to advancing social justice by reducing health inequalities, empowering marginalised communities, and fostering an environment of respect, inclusion, and equity in dementia care.

1.5 Key Concepts and Definitions

Cultural Responsiveness

The key concepts and definitions underpinning this research provide clarity and focus for examining dementia care among South Asian communities in the UK. Cultural responsiveness refers to the capacity of care services to recognise, respect, and appropriately respond to the cultural, linguistic, and religious needs of diverse populations, ensuring that care is both inclusive and person-centred. Barriers are factors that hinder access to, engagement with, or satisfaction in care services and can include structural obstacles, cultural expectations, language difficulties, financial limitations, and procedural challenges within healthcare systems (Abacioglu et al., 2020). Conversely, opportunities denote conditions or interventions that can enhance care quality, accessibility, and effectiveness, such as service improvements, policy reforms, targeted training, and innovative care practices. Residential care is defined as the provision of long-term accommodation coupled with nursing or personal care for individuals requiring support with daily living activities (Cruz et al., 2020). Finally, the term South Asian People with Dementia (SAPWD) encompasses individuals of South Asian descent, encompassing diverse nationalities, languages, religions, and socioeconomic backgrounds who are living with dementia and navigating formal care settings. Together, these concepts establish a framework for exploring both the challenges and potential strategies for delivering culturally sensitive, equitable dementia care.

1.6 Scope of the Study

The scope of this study is defined to ensure a focused and manageable investigation into dementia care experiences among South Asian communities in the UK. Geographically, the research is concentrated on the East and West Midlands, regions selected for their significant South Asian populations and the presence of diverse residential care facilities. The population scope targets South Asian residents living with dementia, capturing the perspectives of the individuals themselves, their families and staff, thereby addressing a critical gap in understanding the lived experiences of this community within formal care settings. The study setting includes both residential care homes, nursing homes and residential homes. While the study aims to provide comprehensive insights, it acknowledges certain limitations and delimitations, including the focus on only two regions, potential variability in cultural practices across different South Asian subgroups, and constraints related to access and consent within care homes. By clearly defining these parameters, the research maintains a balance between depth and feasibility while ensuring that findings are relevant and meaningful for policy, practice, and further academic inquiry.

1.7 Research Aims, Objectives, and Questions

1.7.1 Research Aim

The aim of this study is to explore the opportunities and barriers in meeting the care needs of SAPWD within residential care settings, focusing on enhancing culturally responsive and person-centred practices.

1.7.2 Objectives

- Identify barriers that hinder South Asian people with dementia from accessing and utilising residential care services.
- Explore opportunities to enhance culturally responsive and person-centred care within care homes.
- Examine the perceptions and experiences of residents, their families, and care staff regarding dementia care practices.

1.7.3 Research Questions

- What are the barriers faced by South Asian people with dementia in accessing and utilising residential care services?
- What opportunities exist to develop and enhance culturally responsive dementia care services?
- How do residents, their families, and care staff perceive the quality and effectiveness of care provided in residential settings?

1.8 Dementia Care and Nursing Practice

Dementia care in UK residential settings places nurses at the forefront of providing holistic support to individuals living with cognitive impairment. Nurses play a pivotal role in ensuring that care is person-centred and culturally sensitive, tailoring interventions to meet the unique needs, preferences, and cultural backgrounds of residents. This approach emphasises maintaining dignity, autonomy, and identity while supporting daily living and psychosocial well-being. However, nurses face several challenges, including resource constraints, high workloads, stigma surrounding dementia, and gaps in specialised training, which can limit the effectiveness of care delivery. Despite these challenges, opportunities exist to enhance dementia care through the integration of technology, advocacy for residents' needs, and active engagement with families and community networks. Aligning practice with the Nursing and Midwifery Council (NMC) standards ensures that nurses uphold professional competencies, ethical responsibilities, and engage in ongoing development, thereby promoting high-quality, safe, and culturally responsive care for residents with dementia.

1.9 Significance of the Study

The significance of this study lies in its multifaceted contribution to knowledge, theory, policy, practice, and social justice within the field of dementia care. By focusing on South Asian people with dementia in residential and respite care settings, the study addresses critical gaps in understanding how cultural, linguistic, and familial factors influence access to and quality of care. The findings are expected to enhance theoretical frameworks, particularly in cultural competency, person-centered care, and intersectionality, by applying them to real-world care experiences. From a policy perspective, the research provides evidence to inform equality legislation, commissioning frameworks, and inclusive care initiatives, ensuring that services meet the diverse needs of ethnic minority populations. In practice, insights from the study can guide training, care protocols, and organisational strategies to improve resident satisfaction, family engagement, and overall quality of care. Significantly, the study also advances social justice objectives by highlighting and addressing health inequities, promoting dignity, autonomy, and culturally safe care, and laying the groundwork for more equitable and responsive dementia care services in the UK.

1.10 Summary

The summary chapter serves to consolidate the key elements presented in the introduction, providing a clear overview of the study's rationale, the identified problem, its significance, and the theoretical frameworks guiding the research. It reiterates the critical gaps in understanding the experiences of South Asian people with dementia within residential and respite care settings, emphasising the limited evidence on culturally responsive care and the underrepresentation of ethnic minority perspectives in existing literature. The chapter highlights the study's importance in addressing these gaps through empirical investigation, theoretical contribution, and practical and policy implications. By synthesising these points, the summary reinforces the relevance of the research and sets a coherent foundation for the subsequent chapter, seamlessly transitioning into Chapter 2, which will provide a comprehensive literature review to contextualise and support the study's objectives and research questions.

1.11 Structure of the thesis

The thesis is structured into ten chapters, each building a comprehensive understanding of the opportunities and barriers to meeting the needs of SAPWD in UK residential care.

Chapter One sets the stage by providing the research background, significance, and rationale, while also contextualising dementia prevalence in South Asian communities.

Chapter Two presents a systematic scoping literature review to map existing knowledge and identify gaps.

Chapter Three outlines the methodological foundation, explaining the choice of constructivist grounded theory and detailing the processes of data collection and analysis that shaped the emerging theoretical model of the involvement of three groups in care.

Chapters Four presents the study's findings, including a detailed description of the various elements and the needs and experiences of SAPWD. These groups point towards a broad theory of Residential Care for SAPWD as a site of active negotiation in which staff, residents and family members are all involved in trying to work out what residential care for SAPWD should be like. South Asian communities and Residential Care managers are navigating a new relationship, and its parameters are taking time to be established.

Chapter Five to Eight present the empirical findings, discussing the four categories: Entering residential care, Adjustment to care, Being supported by family, staff, and management, and Continuing to live in residential settings, along with subcategories that underpin the core categories, while addressing both convergent and divergent cases.

Chapter Nine engages in a critical discussion of the proposed theory, reflecting on the research questions, quality criteria, and implications of the model.

Chapter Ten offers final reflections, practical recommendations, and conclusions, underscoring the need for collaborative involvement of all parties in shaping culturally responsive dementia care in residential settings.

CHAPTER 2: LITERATURE REVIEW

2. Introduction

In this chapter, a scoping review conducted to understand the needs of SAPWD in residential settings. Rationale for the scoping review, aim of the review, methods and design followed the six-step framework proposed by Levac et al. (2010), eligibility criteria using Participants, Concept, and Context (PCC) framework, information of search strategy, selection of sources, data charting, critical appraisal, synthesis of results, selection of source of evidence, characteristics of sources, summary of included articles, source of evidence, thematic findings and integrated thematic summary identified explained. Understanding both the barriers and opportunities within residential settings is therefore essential to ensure equitable, culturally sensitive, and person-centred dementia care for South Asian populations.

2.1 Rationale for the Scoping Review

A scoping review approach was considered appropriate for this study due to several reasons commonly identified in methodological guidance:

1. **To examine the extent, range, and nature of the existing literature** – Evidence on dementia care for South Asian people in residential settings is fragmented, with studies dispersed across qualitative, quantitative, and mixed-method designs, and often limited in scope or sample size.
2. **To identify gaps in knowledge** – Despite increasing recognition of cultural barriers to dementia care, limited research has focused specifically on the experiences of South Asian communities in residential and long-term care environments.
3. **To clarify key concepts and definitions** – Terms such as “culturally competent care,” “faith-sensitive support,” and “family obligation” vary across studies and require clearer conceptualisation within the context of residential care.
4. **To synthesise evidence to inform practice and policy** – Mapping existing findings helps identify culturally relevant strategies that can enhance service design, staff training, and policy frameworks.

5. **To guide future research and stakeholder engagement** – The review provides an evidence base that can support consultation with key stakeholders, including care providers, South Asian families, and cultural associations, ensuring that subsequent interventions are co-produced and contextually relevant.

2.2 Aims of the Review

This review aims to systematically map and synthesise the available evidence on dementia care for South Asian people in residential settings in the UK, with a focus on the East and West Midlands. Specifically, it seeks to address the following research questions:

1. What opportunities and barriers exist in providing culturally sensitive dementia care for South Asian residents in residential care settings?
2. How do cultural, religious, and gendered roles shape the experiences of South Asian people with dementia, their families, and care staff in these settings?
3. To what extent do current interventions, policies, and practices address the specific needs of South Asian residents with dementia in institutional care environments?
4. What knowledge gaps remain in literature, and how can these inform future research, policy, and culturally adapted models of dementia care?

2.3 Methods

2.3.1 Design: A scoping review was selected as the methodology due to the broad and exploratory nature of the topic. This review followed the six-step framework proposed by Levac et al. (2010), including identifying the research questions, searching for relevant studies, selecting studies, charting the data, collating and summarising results, and stakeholder consultation. In this review, consultation will be conducted as part of a subsequent research project involving nursing home managers, registered nurses, residents from South Asian backgrounds, their family carers, and cultural associations. The consultation aims to validate the findings and inform the development of culturally appropriate dementia care models in residential settings. The review is reported in accordance with the Preferred Reporting Items for

Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines to ensure transparency, methodological rigour, and consistency with best practices.

2.3.2 Eligibility Criteria (using PCC framework)

Eligibility criteria for this scoping review were guided by the Joanna Briggs Institute (JBI) Scoping Review Methodology (Peters et al., 2022) and structured around the Participants, Concept, and Context (PCC) framework. The participants included South Asian people living with dementia, their family carers, and care staff involved in their support. The concept focused on experiences, attitudes, and approaches to dementia care within residential settings, while the context encompassed nursing homes, long-term care facilities, and respite care services reflecting the provision of long-term residential support. Inclusion criteria were peer-reviewed empirical studies published between 2017 and 2025 that explored dementia care for South Asian individuals in residential care settings. Studies were excluded if they focused exclusively on community, acute, or hospice care settings; examined only staff experiences; primarily addressed racial disparities; centred on instrument or tool development; or were published in languages other than English. Reference lists of relevant reviews were also screened, and study authors were contacted where the care setting was unclear, to ensure eligibility criteria were met.

2.3.3 Information Sources

The information sources for this review comprise a comprehensive collection of recent empirical studies, qualitative investigations, mixed-methods research, and cohort analyses that focus on dementia care experiences among culturally and linguistically diverse populations, particularly South Asian communities in the UK. The included studies examine a range of topics, including dementia knowledge and public attitudes (Hossain et al., 2020), family caregiving experiences at home and in residential care settings (Herat-Gunaratne et al., 2020; Hossain et al., 2022), equity and access to care services (James et al., 2024; Carter et al., 2024), culturally tailored interventions for family carers (Webster et al., 2023; Rapaport et al., 2025), post-diagnostic support needs (Jutlla & Arblaster, 2023), and healthcare inequalities and service utilization patterns (Williamson et al., 2023; Watson et al., 2023). Several studies also explore the impact of ethnicity, religion, and social determinants on dementia care and outcomes (Kevern et al., 2022; Victor et al., 2024; Mukadam et al., 2023a; Mukadam et al., 2023b). These sources were identified through systematic searches in databases including Medline, CINAHL, Embase, PsycINFO, OpenAthens and Scopus, supplemented by reference list screening and hand searching to ensure comprehensive coverage. Collectively, the selected sources provide a robust evidence base to understand culturally and contextually specific experiences of dementia care, informing the scoping review's analysis of care provision in residential and long-term care settings.

2.3.4 Search Strategy

The search strategy for this review was carefully developed to ensure comprehensive identification of relevant studies published between 2017 and 2025. A combination of key terms such as Dementia AND South Asian AND Residential OR Nursing home AND Attitudes OR Experiences was employed to capture studies addressing dementia care within South Asian populations in residential settings. To enhance the precision and sensitivity of the search, controlled vocabulary terms including MeSH (Medical Subject Headings) for PubMed Medline, Mendeley, CINAHL, British Nursing Index, EThOS, PsycINFO, and AgeInfo were incorporated alongside free-text keywords. Limiting the search to the defined timeframe ensured that the review focused on contemporary evidence, reflecting recent developments. This systematic and structured approach maximised the likelihood of identifying all relevant studies while maintaining transparency and reproducibility of the review process.

2.3.5 Selection of Sources

The process of selecting studies for this review followed a systematic and rigorous approach to ensure the inclusion of relevant and high-quality evidence. Initially, duplicate records were removed to avoid redundancy. Titles and abstracts of all retrieved articles were screened to evaluate their relevance to the review objectives, ensuring that only studies aligned with the focus on dementia care experiences, service access, and caregiving practices among culturally and linguistically diverse populations were considered. Full-text articles of potentially eligible studies were then assessed against predefined inclusion and exclusion criteria to confirm their suitability.

This structured methodology ensured that the selected studies comprehensively represented the evidence needed to address the aims of the scoping review, supporting the reliability and validity of the findings.

2.3.6 Data Charting

Data from the included studies were systematically extracted using a predefined data charting template to ensure consistency and transparency in capturing relevant information. The extraction fields included author, year, country, study design, population, setting, aims, findings, themes, and implications, enabling both descriptive and thematic analysis. This structured approach facilitated comparison across studies, identification of recurring patterns, and synthesis of evidence concerning dementia care in South Asian residential settings. By employing this methodical charting process, the review ensures that all key study characteristics and outcomes are systematically documented, supporting a rigorous and comprehensive synthesis of the literature.

2.3.7 Critical Appraisal

Although critical appraisal is optional in scoping reviews, it was included in this study to assess the methodological quality and rigour of the included evidence. The review employed Joanna Briggs Institute (JBI) appraisal tools, which provide structured checklists tailored for qualitative, quantitative, and mixed-methods studies. These tools facilitated systematic evaluation of study design, data collection, analysis, and reporting, allowing identification of potential biases and limitations within individual studies. Incorporating critical appraisal enhances the interpretability of the findings by contextualising the strength and reliability of the evidence, and it informs recommendations for practice, policy, and future research.

2.3.8 Synthesis of Results

Given the inclusion of qualitative, mixed-methods, and quantitative observational studies, a convergent integrated synthesis approach was adopted to ensure that the analytical strategy reflected the methodological diversity of the evidence base. Thematic analysis, informed by Braun and Clarke, was applied specifically to the qualitative components of included studies to identify recurring cultural, structural, and experiential patterns relating to dementia care within South Asian communities. Quantitative and cohort studies were synthesised using descriptive numerical summarisation and narrative mapping to report epidemiological trends, risk factors, healthcare utilisation patterns, and identified disparities. Due to heterogeneity in study design, populations, and outcome measures, statistical aggregation was neither appropriate nor consistent with the objectives of a scoping review. Instead, qualitative themes and quantitative findings were integrated narratively to map the breadth, nature, and intersections of available evidence. This analytical strategy aligns with scoping review guidance from the Joanna Briggs Institute, which supports the use of thematic and descriptive synthesis methods when reviewing heterogeneous evidence, thereby ensuring that the review did not focus exclusively on qualitative data but incorporated multiple forms of evidence in a systematic and transparent manner.

2.4 Results

2.4.1 Selection of sources of evidence

The search strategy yielded a total of 1,150 articles, including five additional studies identified through hand searching of reference lists. After removing duplicates, 850 articles were screened based on titles and abstracts to assess their relevance to the review objectives. Of these, 75 articles were selected for full-text review. Following a thorough evaluation against the inclusion and exclusion criteria, 50 articles were excluded as they did not meet the review requirements. Ultimately, 25 studies were included in the scoping review. This selection process, guided by a structured screening framework, ensured that the included studies were directly relevant, comprehensive, and contributed meaningfully to understanding dementia care experiences, service access, and caregiving practices among culturally and linguistically diverse populations, particularly South Asian communities in the UK. The study selection process is visually summarized in the PRISMA-ScR flow diagram Figure:2.6.

2.4.2 Characteristics of Sources

The review included 25 studies published between 2020 and 2025, reflecting a contemporary focus on dementia care among South Asian populations in the UK. The majority of studies were qualitative (n = 17), using semi-structured interviews, focus groups, and ethnographic observations, while a smaller number were mixed-methods (n = 3) or observational cohort studies (n = 5) leveraging electronic health records to examine incidence, risk factors, and healthcare utilization. Study participants included people living with dementia, family carers, and healthcare staff, with sample sizes ranging from 7 to 62 for qualitative studies and up to hundreds of thousands in population-based observational research. The primary objectives were to understand caregiving experiences, cultural influences on care, barriers to accessing formal services, adaptation of interventions for cultural relevance, and health outcomes among South Asian groups. Findings consistently highlighted language barriers, stigma, culturally inappropriate services, multigenerational caregiving pressures, and inequitable access to care, while emphasizing the role of family, faith, and community support. Limitations commonly reported included small, localized samples, potential selection bias, reliance on self-reported data, and limited use of validated assessment tools in qualitative research. Overall, these studies provide rich, context-specific evidence on culturally sensitive dementia care, informing interventions and policies aimed at improving equity and quality of care for South Asian populations in the UK. Summary of included articles is shown in table 2.1.

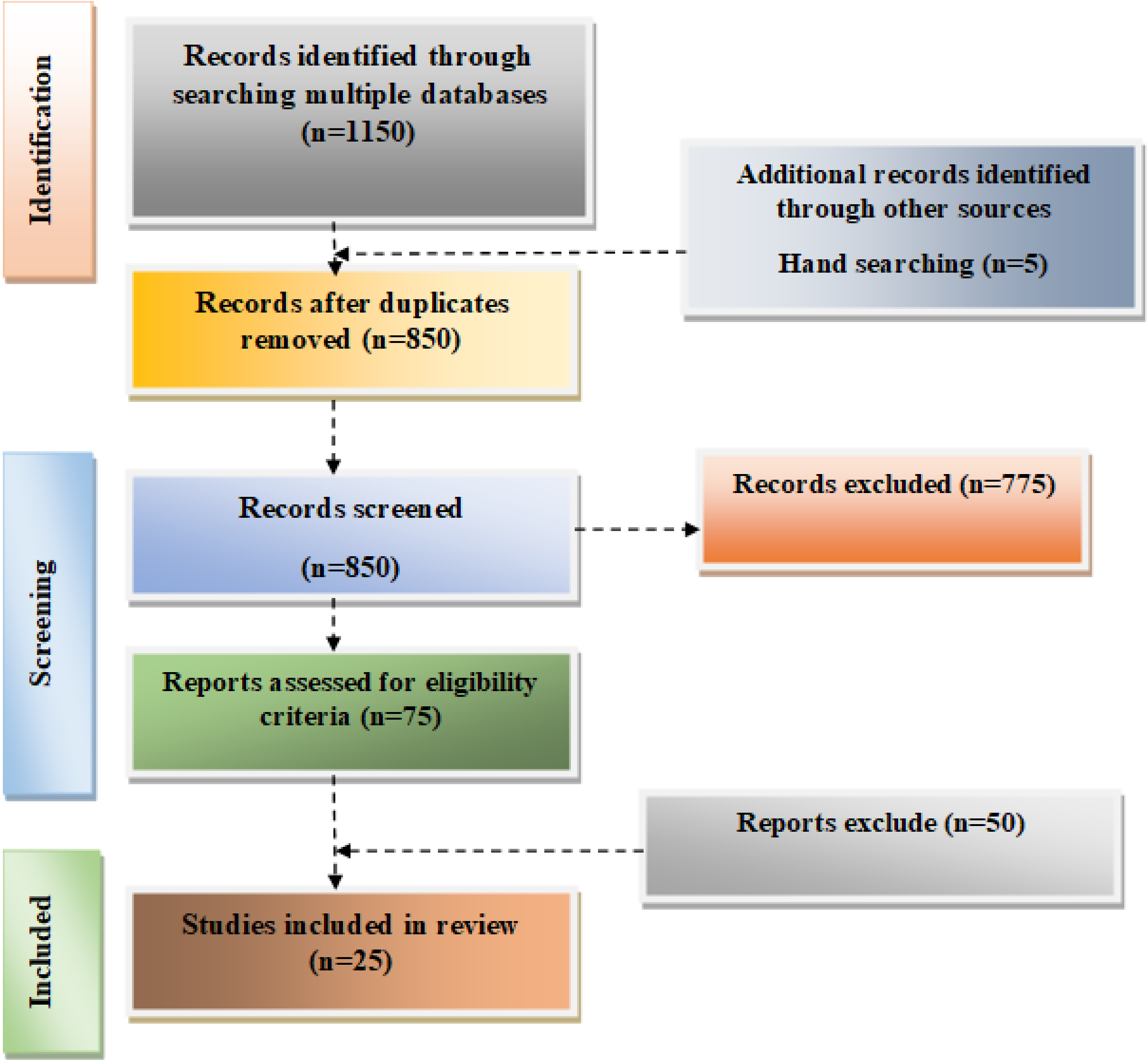


Figure 2.6: Preferred reporting items for systematic review and meta-analyses flowchart of literature search and inclusion.

Table 2.1: Summary of included articles

No	Citation	Country	Study type / design	Sample	Aim / purpose	Key findings	Limitations
1	Hossain et al., 2020	UK	Qualitative	South Asian women carers	Explore impact of migration on caregiving and gender roles	Women's caregiving roles evolving due to socioeconomic changes; traditional expectations persist	Small, potentially non-representative sample; lack of quantitative data
2	Herat-Gunaratne et al., 2020	UK	Qualitative	10 Bangladeshi and Indian family carers	Examine cultural and migration influences on caregiving and access to services	Strong sense of duty; culturally insensitive care; intergenerational tensions; informal networks important	Small sample; limited geographic locations
3	Rapaport et al., 2025	UK	Qualitative	11 family carers	Explore sleep disturbances and cultural adaptation of DREAMS-START intervention	Sleep disturbances influenced by multigenerational living; cultural adaptations needed for intervention	Small sample; limited geographic representation

4	James et al., 2024	UK	Qualitative	62 participants (13 PLWD, 24 carers, 25 clinicians)	Examine care experiences and equitable access across ethnicities	South Asian participants needed culturally aligned care; “double disadvantage” with fewer resources and options	Limited geographic regions; memory clinic focus limits generalisability
5	Victor et al., 2024	UK	Cross-sectional case-control	20 PLWD (minority ethnic), 60 White; 15 minority carers, 45 White carers	Compare quality of life, wellbeing, and carer stress between ethnic groups	Minority PLWD had poorer quality of life and higher loneliness; carers had higher stress	Small sample; exploratory analysis limits confirmation
6	Kevern et al., 2022	UK	Qualitative	7 Pakistani Muslim carers	Explore influence of religion on caregiving	Faith was a central support; limited engagement with wider faith community impacted access	Small sample; single ethnic/religious group
7	Hossain et al., 2021	UK	Qualitative	Bangladeshi carers	Explore caregiving burden	High physical, psychological, and socioeconomic burden; Bangladeshi carers	Small, non-representative sample; single ethnic focus

						assume more responsibilities	
8	Mukadam et al., 2023	England	Longitudinal observational	Adults ≥65 from White, South Asian, Black groups	Examine dementia incidence, age at diagnosis, survival across ethnicities	Higher incidence in Black participants; younger age of death in South Asian & Black groups	Possible misclassification; lack of socioeconomic/care access details
9	Livingston et al., 2023	England	Retrospective cohort	865,674 adults ≥65	Assess ethnic differences in dementia risk factors	Hypertension, obesity, diabetes higher in minority groups; greater risk impact in South Asian and Black groups	Potential data inaccuracies; residual confounding; subgroup granularity lacking
10	Nazir & Kevern, 2023	UK	Qualitative scenario-based interviews	11 Pakistani-origin participants	Explore dementia awareness and barriers	Low awareness; cultural/language barriers; reluctance to seek support	Small sample; scenario-based may not reflect real behavior
11	Carter et al., 2024	UK	Qualitative	61 participants (10 PLWD, 30 family, 16 professionals, 3	Explore factors affecting timing of dementia diagnosis in	Cultural practices shape help-seeking; stigma;	Purposive sampling; limited generalisability; self-reported data

				paid carers, 2 interpreters)	minoritised ethnic groups	multigenerational and gendered roles	
12	Gibson et al., 2024	UK	Protocol: ethnographic + interviews/focus groups	Up to 50 South Asian PLWD or memory concerns	Examine intersectional influences on dementia care at home	Anticipated insights on lived experiences and culturally sensitive service improvement	Small sample; selection bias; generalisability challenges
13	Victor et al., 2024	UK	Qualitative	18 minority ethnic carers	Explore caregiving motivations and cultural influences	Care motivated by time, reciprocity, cultural norms; faith not always primary driver	Small sample; Join Dementia Research recruitment may bias; limited generalisability
14	Hossain et al., 2022	UK	Qualitative	16 South Asian carers	Explore caregiving journey from diagnosis to end-of-life	Themes: lack of awareness, living with dementia, end-of-life prep, burial preferences; need for culturally sensitive support	Small sample; self-selection bias; limited generalisability
15	Jutlla & Arblaster, 2023	England, UK	Qualitative case-study	12 South Asian carers + 1 PLWD	Explore post-diagnostic support needs	“Double disadvantage”: limited access, culturally inappropriate	Small sample; online interviews; predominance of carers over PLWD

						services; recommend co-production	
16	Brown et al., 2025	UK	Qualitative	14 African Caribbean participants	Explore barriers to accessing dementia services	Cultural/historical factors, stigma, family expectations, mistrust limit service use; recommend awareness and community-led initiatives	Small sample; self-reported; limited generalisability
17	Williamson et al., 2023	UK	Retrospective population-based cohort	74,486 decedents with dementia	Identify determinants of ED visits in last year of life	South Asian ethnicity, chronic respiratory disease, urban residence → more ED visits; higher SES, nursing home beds → fewer visits	Administrative data may omit factors; potential misclassification; limited info on informal care
18	Muzambi et al., 2021	UK	Historical cohort	989,800 adults ≥65 without prior dementia	Examine infections and dementia risk	Infections increase dementia risk; sepsis and pneumonia strongest; diabetes raises risk	Possible misclassification; confounding factors; lack of infection severity data

19	Jenkins & Kamal, 2023	UK	Qualitative phenomenological	15 nurses from diverse backgrounds	Explore nurses' experiences supporting South Asian PLWD	Themes: communication challenges, bi-directional cultural impact, informal learning; unmet training needs	Small, single NHS Trust; limits generalisability
20	Webster et al., 2021	UK	Mixed-methods	Phase 1: 26 carers (15 South Asian, 11 Black); Phase 2: 21 carers (13 South Asian, 8 Black)	Culturally adapt and evaluate START intervention	Peripheral adaptations improved cultural fit; post-intervention improvements in mental health	Small sample; attrition; no long-term follow-up
21	Nair et al., 2022	UK	Qualitative	17 carers and PLWD from ethnic minority backgrounds	Explore eating and drinking experiences at home	Food culturally meaningful; familiar meals helped stimulate eating; carers needed culturally tailored advice	Small sample; recruitment bias; limited generalisability
22	van den Heuvel et al., 2020	UK	Qualitative	22 participants (community leaders,	Explore barriers to dementia service	Barriers: stigma, normalizing memory loss, lack of tailored	Small, non-representative sample; reliance on self-report

				older adults, carers)	access and quality of life	services; facilitators: family/community support, cultural recognition	
23	Baghirathan et al., 2020	UK	Grounded theory qualitative	27 interviews, 8 focus groups (76 participants), 16 staff/volunteers	Explore caregiving experiences in South Asian, African Caribbean, and Chinese communities	“Fear of diminishment”: carers hesitant to use formal services; relied on BAME-led VCSOs	Geographically limited; may not represent full community diversity
24	Sanatinia et al., 2020	UK	Mixed-methods	10,106 patient records, 4688 carers, 56 staff + 7 carers interviews	Identify hospital care features linked to quality and shorter stay	Early discharge planning, trained staff, carer involvement, senior support improved outcomes	Audit data variable; relied on carers’ perspectives
25	Watson et al., 2023	England	Population-based observational	142,302 PLWD	Explore social/spatial variations in healthcare use	Men, White ethnicity, deprived/rural areas → higher A&E and admissions; systemic interventions needed	EHR data may omit info; observational design prevents causal inference

2.4.3 Source of evidence

The sources of evidence included in this review predominantly consist of qualitative studies conducted in the UK, with a few large-scale observational and cohort studies. Qualitative research, such as focus groups, interviews, and ethnographic approaches, provided in-depth insights into the lived experiences of South Asian and other minoritised ethnic carers, highlighting cultural, religious, and migration-related influences on caregiving, barriers to accessing dementia services, and the need for culturally sensitive interventions. These studies consistently reported small, often non-representative samples and localised settings, which limit the generalizability of findings. Despite this, they offered a valuable thematic understanding of caregiver experiences, cultural norms, and service barriers. Observational and retrospective cohort studies, on the other hand, offered broader population-level evidence on dementia incidence, risk factors, healthcare utilisation, and outcomes across ethnic groups, providing quantitative rigour and comparative insights. However, these studies faced limitations such as potential data misclassification, residual bias, and incomplete consideration of socioeconomic or care-access variables. Mixed-methods studies added further depth by combining quantitative measures with qualitative perspectives, though they were often constrained by sample size and attrition. Overall, the evidence base is rich in cultural and experiential detail but is limited by small sample sizes, potential selection biases, and geographic concentration, indicating a need for more large-scale, representative studies to support generalizable conclusions.

2.5 Thematic Findings

The synthesis of the 25 studies reveals several recurring and interconnected themes that capture the experiences of South Asian and minority ethnic families providing dementia care in the UK. These themes highlight cultural, gendered, socioeconomic, and systemic factors shaping caregiving practices, access to services, and overall wellbeing.

2.5.1 Gendered Roles and Caregiving Responsibilities

Across the body of literature examining dementia caregiving among South Asian families in the United Kingdom, gendered expectations consistently emerge as a pivotal factor shaping caregiving responsibilities, with women predominantly assuming the primary caregiving role. This gendered division of care is deeply rooted in cultural norms and traditions, which historically assign the role of caring for older family members to daughters, daughters-in-law, and female relatives, reflecting the broader societal expectations regarding women’s duties within the household. Hossain et al. (2020, 2021) underscore this enduring pattern, illustrating that, within South Asian communities, women typically carry the majority of caregiving tasks, ranging from managing daily personal care and household responsibilities to emotional support and health management for relatives living with dementia. However, these studies also emphasise that such roles are not static; they are evolving in response to complex contextual changes brought about by migration, exposure to British societal norms, increased participation of women in the formal workforce, and socioeconomic transformations that influence family dynamics.

The research indicates that, while women continue to be primary caregivers, the intensity and expectations of caregiving are being renegotiated, particularly among younger generations who may balance employment, education, and personal aspirations alongside familial responsibilities. Herat-Gunaratne et al. (2020) further elaborate that caregiving duties are frequently structured around intergenerational expectations, where older family members and broader kin networks implicitly or explicitly anticipate women to assume care, creating a dual burden of fulfilling traditional cultural obligations while managing practical and personal challenges. Women often experience considerable emotional strain, including stress, guilt, and anxiety, as they negotiate the competing demands of caregiving, work commitments, and personal well-being. Employment challenges are particularly significant, as women may face interruptions in their careers, reduced work hours, or limited advancement opportunities due to caregiving responsibilities, thereby exacerbating socioeconomic vulnerability and reinforcing dependency on family support systems. Victor et al. (2024) and Nazir & Kevern (2023) corroborate these findings, emphasizing that, although caregiving roles are gendered, the allocation of responsibilities is not uniform and can be fluid, depending on family composition, health status of the care recipient, generational perspectives, and available support networks. For example, in multigenerational households, daughters-in-law may bear primary responsibility, while siblings, spouses, or male family members may provide supplementary assistance in varying degrees, reflecting negotiation and adaptation within family systems.

The literature also highlights the psychological and social implications of gendered caregiving. Women often report heightened role captivity, experiencing a sense of entrapment and reduced autonomy due to the relentless and prolonged nature of caregiving duties. This emotional burden can contribute to burnout, mental health challenges, and diminished quality of life, underscoring the profound impact of gendered caregiving on women's overall well-being. Moreover, the cultural expectation that women should provide care can simultaneously act as a source of personal identity, fulfillment, and social recognition, demonstrating the nuanced and ambivalent nature of caregiving roles, where duty, devotion, and personal sacrifice intersect. Collectively, these studies suggest that addressing gendered caregiving responsibilities requires multifaceted interventions that acknowledge both cultural imperatives and evolving societal roles. Policies and support programs must be designed to relieve the practical and emotional burden on women while respecting cultural values, for instance, through provision of culturally sensitive respite care, flexible work arrangements, community-based support networks, and psychoeducational programs that empower women to manage stress and maintain personal health. Recognizing the dual pressures of cultural duty and societal expectations is crucial for the development of interventions that are not only effective in alleviating caregiving burden but are also socially and culturally acceptable, thereby promoting equity, sustainability, and well-being for female caregivers within South Asian families in the UK.

2.5.2 Cultural Values, Identity, and Family Obligation

Cultural values, identity, and familial obligation emerge as pivotal determinants shaping caregiving practices among South Asian families caring for relatives with dementia in the United Kingdom, influencing not only motivations but also decision-making processes and engagement with formal care services. Across the literature, there is a consistent recognition that caregiving is deeply embedded within cultural norms, where a strong sense of duty towards family, respect for elders, and adherence to traditional roles guide the approach to care. Herat-Gunaratne et al. (2020) and Jutlla & Arblaster (2023) emphasise that South Asian carers frequently experience a compelling sense of familial responsibility, which often translates into reluctance to seek or accept formal care services, especially when such services are perceived as culturally insensitive or misaligned with their values. This reluctance is compounded by intergenerational expectations, where caregiving responsibilities are predominantly assigned to women, particularly daughters-in-law, reflecting deeply entrenched gendered norms. These expectations are further reinforced by cultural and religious practices that shape daily routines and caregiving approaches, as highlighted by Kevern et al. (2022) and Brown et al. (2025). Religious faith, rituals, and culturally meaningful practices not only provide emotional support to carers but also help maintain dignity, identity, and social cohesion for both carers and care recipients. For example, prayer routines, dietary observances, and traditional ceremonies are incorporated into caregiving, serving both practical and symbolic functions in the maintenance of cultural continuity.

The concept of “fear of diminishment,” described by Baghirathan et al. (2020), underscores how carers often prefer community-led or culturally aligned services over mainstream options, perceiving the latter as potentially undermining their cultural identity, familial respect, or the dignity of the person with dementia. This preference reflects a broader tension between the desire to access external support and the need to maintain cultural authenticity in caregiving practices. Furthermore, Rapaport et al. (2025) highlight that culturally adapting interventions, such as the DREAMS-START program, requires nuanced attention to language, religious observances, and culturally familiar routines to enhance engagement, acceptability, and effectiveness. Such adaptations include providing translated materials, incorporating culturally relevant examples and activities, scheduling interventions around religious obligations, and ensuring facilitators possess cultural competence and awareness of community norms. Collectively, these findings illustrate that cultural identity and family obligations function both as facilitators and constraints in dementia caregiving: they motivate carers, provide emotional and social support, and reinforce caregiving continuity, but they can also limit engagement with formal services and create challenges when existing care systems fail to accommodate cultural needs. The implications for practice are significant, suggesting that interventions and support programs must be co-designed with communities to align with cultural values, language preferences, and religious practices. By integrating culturally grounded approaches into service delivery, healthcare providers can enhance carers’ willingness to engage, reduce the burden of caregiving, and ensure care strategies are respectful, effective, and sustainable within the cultural framework of South Asian families, thereby bridging the gap between traditional family caregiving and formal care systems.

2.5.3 Barriers to Accessing Formal Care

Accessing formal dementia care services presents significant challenges for South Asian families in the United Kingdom due to a combination of structural, cultural, and systemic barriers that impede timely and appropriate support. One of the most frequently cited obstacles is language, which profoundly affects the ability of carers and people living with dementia to communicate effectively with healthcare providers, understand the nature of dementia, and navigate complex care systems. James et al. (2024) and Nazir & Kevern (2023) emphasise that limited English proficiency among some carers and older adults creates miscommunication, misunderstandings about the progression and management of dementia, and difficulties in completing necessary forms or accessing information about available services. Beyond language, the cultural appropriateness of services is a critical determinant of engagement. Hossain et al. (2020) and Herat-Gunaratne et al. (2020) report that families often encounter services that fail to respect cultural norms, dietary preferences, religious practices, or caregiving expectations, which discourages utilisation of formal support and reinforces reliance on family-based care. This lack of culturally sensitive care not only reduces engagement but can also exacerbate stress and feelings of isolation among carers, as the services provided are perceived as misaligned with family values and beliefs. Compounding these barriers is the pervasive stigma associated with dementia, which is influenced by cultural conceptualisations of cognitive decline. Carter et al. (2024) highlight that in many South Asian communities, dementia is often interpreted as a normal aspect of ageing, a moral failing, or a condition that should be managed privately within the family. This stigma discourages early help-seeking, delays diagnosis, and contributes to reluctance to involve external care providers, thereby limiting access to interventions that could improve quality of life and reduce caregiver burden. In addition to cultural and linguistic challenges, systemic and structural factors significantly shape access.

Williamson et al. (2023) and Watson et al. (2023) illustrate that disparities in service availability, socioeconomic resources, and geographic location influence whether families can obtain timely and appropriate care. Families with higher financial means or proximity to urban centres with specialised dementia services are more likely to access culturally aligned interventions. In contrast, those living in rural areas or with limited resources experience greater difficulty in obtaining care. These findings collectively highlight the multifaceted nature of barriers to formal dementia support, encompassing interpersonal, cultural, and structural dimensions. The implications for policy and practice are substantial: service models must be redesigned to address these intersecting barriers by incorporating language support, culturally competent staff training, flexible service delivery that respects religious and cultural practices, and equitable allocation of resources to underserved areas. Interventions should also include community engagement and education to reduce stigma, promote awareness of dementia, and encourage help-seeking behaviour among minority ethnic populations. By adopting a holistic approach that integrates cultural, linguistic, and structural considerations, healthcare systems can enhance accessibility, improve care experiences for both carers and people living with dementia, and ensure that services are responsive to the needs of ethnically diverse communities, thereby mitigating inequalities in dementia care provision and fostering more inclusive, person-centred support systems.

2.5.4 Caregiver Burden and Well-being

Caregiving within South Asian families caring for people living with dementia in the United Kingdom is consistently associated with substantial physical, emotional, and social burdens, reflecting a complex interplay of cultural expectations, family dynamics, and practical constraints. The literature indicates that minority ethnic carers often experience disproportionately high levels of stress, role captivity, and emotional strain compared to their White counterparts. Hossain et al. (2021) highlight that Bangladeshi carers, in particular, are more likely to assume primary caregiving responsibilities, enduring long hours of care while managing the progressive cognitive and behavioural changes associated with dementia. Victor et al. (2024) further support this, reporting that minority ethnic carers experience heightened emotional pressures, including anxiety, feelings of inadequacy, and a pervasive sense of obligation, often exacerbated by limited access to culturally appropriate support services. Multigenerational living arrangements, common in South Asian households, while offering opportunities for shared responsibility, can paradoxically intensify caregiving demands and create intergenerational tensions. Rapaport et al. (2025) emphasize that within such households, caregiving responsibilities are frequently concentrated on one or two individuals typically women leading to disrupted sleep patterns, fatigue, and increased emotional strain. These arrangements may also give rise to conflicts between younger and older family members regarding the interpretation of cultural norms, expectations for care, and the appropriate use of formal support services. Emotional challenges for carers extend beyond stress and fatigue; guilt, anxiety, and feelings of being socially isolated are pervasive. Herat-Gunaratne et al. (2020) document carers' struggles with balancing the desire to provide culturally and emotionally appropriate care against the practical realities of employment obligations, household management, and personal wellbeing.

Similarly, James et al. (2024) highlight that carers frequently experience strained personal relationships, as the intensity and duration of caregiving responsibilities leave little time for social engagement or self-care, thereby compounding the psychological burden. The cumulative effect of these emotional, practical, and social challenges underscores the necessity for interventions that address both the practical and psychological dimensions of caregiving. Effective support must go beyond generic respite care, encompassing culturally tailored strategies for stress management, psychoeducation, and social support networks that acknowledge familial duty and respect cultural values. Programs that facilitate peer support within ethnic communities, provide education on dementia management, and promote coping mechanisms sensitive to religious or cultural beliefs can help mitigate the negative impacts of caregiving. Moreover, flexible workplace policies, home-based interventions, and accessible respite services are crucial in alleviating the practical strains associated with balancing employment and caregiving responsibilities. Overall, the synthesis of evidence underscores that caregiver burden among South Asian families is multifaceted, interwoven with cultural identity, family obligations, and systemic limitations in care provision. To enhance wellbeing, interventions must adopt a holistic, culturally informed approach, recognising the emotional, social, and practical complexities of caregiving while empowering carers with resources, support, and strategies that are acceptable, feasible, and sustainable within their cultural and familial contexts. This approach not only benefits carers' health and quality of life but also indirectly enhances the care recipients’ wellbeing, promoting a more balanced, sustainable caregiving experience within minority ethnic communities.

2.5.5 Health Disparities and Epidemiological Insights

Health disparities in dementia outcomes among South Asian and other minority ethnic communities in the United Kingdom reflect a complex interplay of biological, cultural, and socioeconomic factors. Epidemiological evidence consistently indicates that minority ethnic populations face higher exposure to modifiable risk factors for dementia, such as hypertension, diabetes, obesity, dyslipidaemia, and sleep disorders, which contribute to both increased incidence and accelerated progression of cognitive decline. Mukadam et al. (2023) and Livingston et al. (2023) reported that South Asian individuals exhibit a higher prevalence of these comorbid conditions, which, coupled with lifestyle and environmental influences, results in a comparatively younger age at death following a dementia diagnosis compared to White individuals. These studies underscore the importance of understanding not only the clinical dimensions of dementia but also the social determinants that exacerbate vulnerability, including limited access to preventive healthcare, language barriers, and lower health literacy. Victor et al. (2024) further illuminate the lived experiences of people with dementia from minority ethnic backgrounds, demonstrating that their quality of life is often significantly poorer, with heightened loneliness, social isolation, and reduced engagement in meaningful activities. These disparities are compounded by caregiving pressures, family expectations, and cultural stigma surrounding dementia, which may delay diagnosis, restrict engagement with formal services, and limit participation in health-promoting behaviors. Collectively, these findings indicate that dementia outcomes cannot be understood solely through a biomedical lens; they are deeply embedded within broader cultural and socioeconomic contexts. Minority ethnic communities may face structural inequalities such as reduced availability of culturally appropriate healthcare services, limited representation of ethnic minorities among healthcare professionals, and systemic barriers to accessing preventive care, which further perpetuate disparities. Moreover, cultural beliefs about dementia and family-centered caregiving influence both the timing of help-seeking and adherence to medical advice, highlighting the need for culturally competent health interventions.

Public health strategies must therefore adopt a dual approach, addressing both modifiable biological risk factors and the socio-cultural determinants that influence disease trajectory and quality of life. Interventions aimed at reducing hypertension, diabetes, obesity, and other preventable conditions should be complemented by culturally tailored education, community engagement programs, and initiatives that promote early detection and routine monitoring. Simultaneously, care models must be sensitive to linguistic, religious, and cultural needs to enhance acceptability and utilization among minority ethnic populations. By integrating epidemiological insights with culturally informed strategies, policymakers and healthcare providers can target both prevention and management of dementia more effectively. This comprehensive approach has the potential to reduce health disparities, improve well-being for individuals living with dementia, and support family carers by alleviating associated burdens. Ultimately, addressing the intersection of biological, cultural, and socioeconomic factors is essential for equitable dementia care, ensuring that minority ethnic populations receive timely, appropriate, and effective interventions that enhance health outcomes and quality of life across the disease trajectory.

2.5.6 Importance of Informal and Community Support Networks

Informal support networks and community-based organisations emerge as critical components in the care of South Asian and other minority ethnic individuals living with dementia, complementing formal health and social care services. Across multiple studies, it is evident that these networks provide culturally resonant, practical, and emotional support that often cannot be fully met by mainstream services. Baghirathan et al. (2020) highlighted that caregivers frequently prefer voluntary sector and BAME-led organisations due to their trustworthiness, cultural sensitivity, and understanding of family-centred caregiving norms. These organisations offer advocacy, guidance, and resources tailored to the unique needs of ethnic minority communities, allowing carers to navigate care provision without compromising cultural values or family dignity. Similarly, van den Heuvel et al. (2020) emphasised that community-led initiatives play an essential role in facilitating access to services, reducing isolation, and fostering social cohesion, particularly in contexts where language barriers, cultural differences, or fear of stigma may prevent families from engaging with formal healthcare systems. Beyond logistical support, these networks reinforce cultural practices and traditions that enhance the well-being of people living with dementia.

Nair et al. (2022) described how culturally meaningful practices, such as shared meals, religious rituals, and festive celebrations, serve not only to maintain cultural identity but also to stimulate engagement, provide comfort, and support cognitive and emotional functioning. In multigenerational households, such practices can mediate intergenerational tensions and create shared spaces for social interaction and memory recall. Moreover, informal networks often bridge gaps left by formal services, particularly when culturally tailored care is limited or unavailable. They provide flexible, context-specific solutions, including peer support, respite care, educational workshops, and guidance on culturally appropriate coping strategies, which are crucial for sustaining long-term caregiving. The reliance on these networks underscores the necessity for health and social care planning to actively recognize, integrate, and collaborate with community organizations. Partnerships between formal services and community-led initiatives can enhance reach, effectiveness, and acceptability of care, ensuring that interventions align with cultural values and practices while addressing practical caregiving needs. By leveraging the strengths of informal networks, care systems can provide more holistic, culturally sensitive support, promoting wellbeing for both people living with dementia and their family carers. Such integration ultimately fosters resilience, mitigates caregiver burden, and strengthens social capital within minority ethnic communities, highlighting the indispensable role of informal and community-based support in dementia care.

2.5.7 Intervention Adaptation and Effectiveness

The importance of culturally adapting interventions for minority ethnic carers of people living with dementia has been consistently highlighted across recent research, demonstrating that culturally tailored approaches significantly enhance both engagement and effectiveness. Studies such as Webster et al. (2021) and Rapaport et al. (2025) emphasized that standard interventions, if implemented without cultural modification, may fail to address the specific needs, values, and lived experiences of carers from South Asian and other minority ethnic backgrounds. Cultural adaptation involves multiple layers, beginning with language translation to ensure comprehension and accessibility. Beyond mere translation, interventions must include culturally relevant examples, scenarios, and case studies that resonate with carers' daily lives, familial structures, and caregiving practices. This contextualization allows participants to relate the content directly to their personal experiences, fostering higher engagement and motivation to apply learned strategies in practical caregiving contexts. Religious considerations also form a crucial element of adaptation. Many minority ethnic carers, particularly within South Asian communities, integrate faith and religious practices into their caregiving routines, finding emotional support and a sense of purpose through these activities. Interventions that acknowledge and respect these practices, such as prayer schedules, dietary customs, and culturally meaningful rituals, enhance acceptability and reduce potential conflicts between formal care guidance and personal or family values. Facilitator cultural competence is another key component, as carers respond more positively when program facilitators demonstrate understanding of cultural norms, intergenerational dynamics, and language nuances.

Cultural competence includes sensitivity to gendered expectations, family hierarchies, and potential stigma surrounding dementia, which can influence willingness to participate and openly discuss challenges. Evidence from the implementation of adapted interventions, such as START and DREAMS-START, indicates that culturally sensitive modifications not only improve participation rates but also have measurable impacts on caregiver mental health, wellbeing, and coping skills. Carers reported reduced anxiety, stress, and depressive symptoms, while also demonstrating increased confidence and skill in managing caregiving demands. Adapted interventions additionally support sustained engagement over time, as participants perceive the program as relevant, respectful, and tailored to their lived realities. The findings underscore the broader principle that culturally adapted interventions are not merely peripheral adjustments but essential components for ensuring effectiveness in ethnically diverse populations. Importantly, these adaptations also enhance overall care outcomes for people living with dementia, as better-supported carers are more capable of providing consistent, high-quality care. From a policy and practice perspective, the research indicates that systematic integration of cultural adaptation processes into intervention design, delivery, and evaluation is critical. Co-production approaches, involving carers and community stakeholders in shaping program content, further enhance relevance and acceptability, ensuring that interventions align with the cultural, social, and religious contexts of minority ethnic families. By prioritizing culturally informed design and delivery, interventions can achieve greater reach, improved engagement, and meaningful benefits for both carers and care recipients, demonstrating the indispensable role of cultural adaptation in dementia care strategies.

2.5.8 Awareness and Knowledge Gaps

A significant and recurring theme across the reviewed literature is the pervasive lack of awareness and understanding of dementia within South Asian communities, which has critical implications for early recognition, timely diagnosis, and effective engagement with healthcare services. Studies such as Nazir and Kevern (2023) and Carter et al. (2024) consistently highlighted that limited dementia literacy, misconceptions about the condition, and cultural interpretations of memory loss impede families from seeking formal support at early stages. Many community members often perceive memory decline and behavioral changes as a normal part of aging rather than potential indicators of dementia, leading to delayed help-seeking and underutilization of available services. This gap in knowledge is further compounded by cultural stigmas associated with mental health and cognitive decline, where dementia may be viewed as a shameful or embarrassing condition. Such stigma not only discourages open discussion within families but also restricts communication with healthcare providers, thereby delaying diagnosis, intervention, and access to support networks. The reviewed studies also indicate that awareness gaps are intertwined with language barriers, literacy levels, and generational differences. For instance, older adults and first-generation migrants may have limited proficiency in English, making it difficult to access information or navigate formal care services, while younger family members may possess more knowledge but face challenges in mediating culturally sensitive explanations to elders. This highlights the need for educational interventions that are not only linguistically appropriate but also culturally aligned with community norms, values, and practices. Importantly, culturally tailored education campaigns should incorporate relatable examples, use community leaders as advocates, and respect religious and familial structures to maximize engagement and acceptance. Outreach strategies, including community workshops, faith-based initiatives, local media, and targeted social campaigns, have been recommended as effective approaches to improve understanding of dementia, reduce misconceptions, and encourage proactive help-seeking. By increasing awareness, families are better positioned to recognize early signs, seek timely diagnosis, and engage with both formal and informal care systems, thereby improving care outcomes for people living with dementia. Additionally, raising dementia literacy can empower communities to challenge stigma, normalize discussion of cognitive decline, and foster supportive environments where caregiving responsibilities are shared and acknowledged. Beyond individual and family benefits, enhancing awareness at the community level can guide public health policies to allocate resources effectively, promote culturally competent service provision, and facilitate collaboration between healthcare systems and minority ethnic communities. In summary, addressing awareness and knowledge gaps is foundational for early intervention, stigma reduction, and improved dementia care. Targeted, culturally sensitive education that considers language, literacy, and cultural values is crucial for equipping South Asian communities with the information, confidence, and resources needed to recognize, respond to, and manage dementia effectively, ultimately promoting better outcomes for both caregivers and care recipients.

2.5.9 Integrated Thematic Summary

The synthesis of 25 studies highlights several key themes in dementia care among South Asian communities, as summarized in Table 2.2. Gendered Roles indicate that women are the primary caregivers, though migration and socioeconomic changes are shifting these responsibilities, necessitating interventions that address evolving gendered burdens. Cultural Identity and Values show that caregiving is shaped by duty, family obligations, and faith, emphasizing the need for care models that respect cultural and religious norms. Barriers to Formal Care such as language difficulties, stigma, and systemic disparities demonstrate the importance of culturally competent and accessible services. Caregiver Burden reflects high physical, emotional, and social demands, highlighting the need for respite and tailored support. Health Disparities reveal that minority ethnic groups face higher risks and poorer outcomes, calling for targeted public health strategies. Informal and Community Support illustrates reliance on family and voluntary organizations, suggesting integration of community support into formal care pathways. Intervention Adaptation shows that culturally tailored programs enhance engagement and outcomes, while Awareness and Knowledge indicate that low dementia awareness limits early diagnosis and help-seeking, making culturally and linguistically tailored education campaigns essential. These findings collectively underscore the necessity for culturally sensitive, community-integrated, and gender-aware approaches to dementia care.

Table 2.2: Integrated Thematic Summary

Theme	Core Findings	Implications
Gendered Roles	Women are primary caregivers; evolving roles due to migration and socioeconomic changes.	Interventions must address gendered burdens and evolving expectations.
Cultural Identity & Values	Care is shaped by duty, family obligation, and faith	Care models must respect cultural and religious norms
Barriers to Formal Care	Language, stigma, service inappropriateness, systemic disparities	Services must be culturally competent, accessible, and tailored
Caregiver Burden	High physical, emotional, and social demands	Provide respite, emotional support, and tailored resources
Health Disparities	Minority ethnic groups at higher risk and poorer outcomes	Public health strategies and prevention programs needed
Informal & Community Support	Reliance on family, community, and voluntary organisations	Integrate community support into formal care pathways
Intervention Adaptation	Culturally tailored interventions improve engagement and outcomes	Co-produced, adapted programs increase acceptability
Awareness & Knowledge	Low dementia awareness limits early diagnosis and help-seeking	Education campaigns must be culturally and linguistically tailored

2.5.10 Conclusion of Thematic Findings

The thematic synthesis highlights that dementia caregiving among South Asian and minority ethnic communities in the UK is complex, culturally embedded, and gendered**.** Caregiving experiences are shaped by interrelated factors: cultural identity, family obligation, migration context, socioeconomic resources, health disparities, and systemic barriers. Effective support requires culturally sensitive interventions, community engagement, and policies that address structural inequities, caregiver wellbeing, and tailored healthcare access.

2.6 Discussion

This scoping review synthesises evidence on dementia care experiences, service access, and health inequalities affecting South Asian and other minoritised ethnic communities in the UK. The findings reveal that caregiving is deeply embedded within cultural, religious, and gendered norms, with women predominantly assuming responsibility for care (Hossain et al., 2020; Herat-Gunaratne et al., 2020). Cultural identity, family obligation, and faith function both as sources of strength and as constraints, shaping help-seeking behaviours and engagement with formal services (Kevern et al., 2022; Baghirathan et al., 2020).

While the literature provides substantial insight into caregiver experiences, intervention adaptation, and structural barriers, a critical pattern emerges: the majority of studies prioritise carers, service providers, or epidemiological trends rather than the lived experiences of people living with dementia themselves. Even where culturally tailored interventions demonstrate promise (Rapaport et al., 2025; Webster et al., 2021), the experiential perspectives of South Asian people with dementia remain marginal within the evidence base.

Furthermore, most studies are situated within community contexts. Residential and respite care settings are rarely examined in relation to South Asian populations, despite increasing transitions into institutional care as dementia progresses (Williamson et al., 2023; Watson et al., 2023). This absence limits understanding of how cultural identity, belonging, language, and dignity are negotiated within formal care environments.

Importantly, the gap identified through this review is not merely methodological in terms of sample size or follow-up duration. Rather, it is conceptual and experiential. There is limited in-depth exploration of how South Asian people with dementia interpret their care environments, experience inclusion or exclusion, and maintain cultural identity within residential settings. Addressing this gap requires qualitative approaches capable of capturing narrative, relational, and contextual dimensions of care that are not accessible through population-level analyses.

2.7 Literature Gaps

Although research on dementia within South Asian communities in the UK has expanded, several significant gaps remain.

First, the perspectives of people living with dementia themselves are underrepresented. Most studies focus on carers' experiences, service delivery models, or health outcomes (Jutlla & Arblaster, 2023; Nair et al., 2022). The voices of South Asian individuals with dementia, particularly regarding how they perceive and experience care, are rarely centred.

Second, there is limited research examining residential or respite care environments. The existing literature predominantly explores community-based caregiving, leaving institutional contexts comparatively unexplored. This restricts understanding of how cultural practices, language, and identity are supported or potentially marginalised within care homes.

Third, while studies identify structural barriers such as language difficulties, stigma, and culturally inappropriate services (Nazir & Kevern, 2023; van den Heuvel et al., 2020), fewer investigations examine how these barriers are experienced subjectively by individuals living within care systems. The relational and emotional dimensions of care such as dignity, belonging, autonomy, and identity preservation remain insufficiently explored.

Finally, although culturally adapted interventions show promise (Rapaport et al., 2025), there is limited qualitative exploration of how such adaptations are experienced by care recipients themselves. Understanding whether culturally tailored services translate into meaningful improvements in lived experience requires in-depth interpretive inquiry.

Collectively, these gaps indicate the need for research that prioritises experiential understanding rather than broader generalisation. There is a clear need for qualitative studies that centre the voices of South Asian people with dementia, particularly within residential care settings.

2.8 Limitations

This review is limited by the scope and nature of the existing evidence base. Much of the literature focuses on carers, healthcare professionals, or population-level data, resulting in comparatively limited representation of people living with dementia themselves. Additionally, most studies are situated within community contexts, with residential care settings underexamined.

While several studies employ qualitative methodologies and provide rich cultural insight, their primary emphasis remains on caregiving burden, service access, or intervention outcomes. Consequently, there is limited exploration of how South Asian individuals with dementia experience institutional care environments from their own perspectives.

These limitations do not merely indicate the need for larger datasets; rather, they highlight the necessity for in-depth qualitative inquiry that foregrounds lived experience, cultural identity, and relational dimensions of care within residential settings.

2.9 Summary and Link to the Present Study

This scoping review demonstrates that dementia care within South Asian communities in the UK is shaped by cultural values, gendered expectations, systemic barriers, and health inequalities. While the literature provides substantial insight into caregiving dynamics and service disparities, it reveals a critical absence: the experiential perspectives of South Asian people living with dementia in residential care settings remain largely unexplored.

To date, no research has specifically centred the voices of South Asian people with dementia residing in care homes or respite facilities. As dementia progresses and transitions to residential care become more common, understanding how cultural identity, belonging, dignity, and care relationships are experienced within these settings becomes increasingly important.

The present qualitative study seeks to address this gap by foregrounding the lived experiences of South Asian people with dementia in residential care. By adopting an interpretive, qualitative methodology, this study aims to generate contextually grounded insights into how care is experienced, negotiated, and understood within institutional environments. Rather than seeking generalisability, the study contributes depth, nuance, and cultural understanding to inform more responsive and inclusive dementia care practices.

CHAPTER 3: METHODOLOGY

3.1 Introduction

This section introduces the research methodology and provides a clear roadmap for the study’s approach. It begins by restating the research purpose, which is to explore the opportunities and barriers in meeting the needs of SAPWD in residential care settings. Given the limited research available in care home contexts, most studies focus primarily on community-based support. This study seeks to address a significant gap in understanding how culturally sensitive care can be provided. Constructivist Grounded Theory (Charmaz, 2014) is adopted as the methodological framework due to its suitability for exploring complex social phenomena and generating theory grounded in participants lived experiences. The section also outlines the rationale for methodological choices, the procedures for data collection and analysis, ethical considerations, and the strategies employed to ensure rigour and trustworthiness throughout the study.

3.2 Research design

The research adopts a qualitative design grounded in the constructivist grounded theory (CGT) approach, as it is most appropriate for exploring the lived experiences of SAPWD in residential care settings, an area with limited prior research. This design emphasises understanding participants’ thoughts, emotions, and social interactions within their cultural context rather than quantifying variables or seeking causal relationships. Guided by an interpretive paradigm, the study employs in-depth interviews with SAPWD, their family members, and care home staff to capture diverse perspectives and uncover underlying social and cultural processes shaping care experiences. The use of CGT enables the theory to emerge inductively from the data through iterative methods such as constant comparison, memo writing, and theoretical sampling, ensuring that findings remain deeply rooted in participants’ realities. Moreover, conducting a preliminary literature review provides contextual grounding without constraining the emergent theory, allowing for a balanced integration of existing knowledge and new insights. Overall, this qualitative design facilitates a rich, holistic, and culturally sensitive understanding of the opportunities and barriers in dementia care, contributing to both theoretical advancement and practical improvements in service provision for minority communities.

3.3 Methodological rationale

The study adopts a constructivist grounded theory methodology as the most suitable approach to explore the opportunities and barriers in meeting the needs of SAPWD in residential care. This approach allows the researcher to engage actively with participants, co-constructing knowledge from their lived experiences rather than assuming an objective, detached perspective. It emphasises understanding the complex social processes, feelings, and perceptions of SAPWD, their families, and staff, capturing nuanced insights that conventional methods may overlook. Constructivist grounded theory is interpretive and naturalistic, recognising that reality and knowledge are socially constructed through interactions between the researcher and participants. It aligns with the values of nursing and education, enabling the researcher to make their role visible, reflects on their pre-understandings, and incorporates their own voice in the research process. By fostering empathetic understanding and rich, contextually grounded insights, this methodology supports the development of a theory that is relevant, practical, and sensitive to the subjective experiences of those involved in dementia care.

In adopting a qualitative and constructivist approach, this study recognises the importance of how social constructs, processes, and interactions relate to one another in data. Lincoln & Guba (1990) identified that ontologically, the constructivist paradigm is ‘relativist’ (in that aspects of human experience and culture are dependent in some way on their relationship with other aspects or elements), epistemologically ‘interactive and subjective’ (in terms of the nature of knowledge), and methodologically ‘hermeneutic and dialectic’ (focusing on social interactive processes).

Researchers construct data from theories grounded in past and present involvements and interactions with people, perspectives, and research practices. (Charmaz 2014) has taken grounded theory one step further from Corbin and Strauss's version by acknowledging the researcher's epistemological stance in the research process and its influence on producing what terms a `constructivist grounded theory. A process of constant comparative analysis can be employed to compare categories identified across individual transcripts and the relationships between data from people with dementia, their families (next of kin), and the staff. Data analysis in grounded theory is ‘iterative and interactive’ (Holloway & Todres, 2010). It is iterative in that the researcher moves back and forth between earlier data, codes and categories and subsequently collected data, utilising a process of constant comparison. Differences and similarities in the data are identified, and emergent patterns across and between the data are recognised to enable theory development.

The alternative approach considered was thematic analysis, and it has been discarded. Thematic analysis is a qualitative research method that can be widely used across various epistemologies and research questions (Ritchie et al., 2014). It is a method for identifying, analysing, organising, describing, and reporting themes within a data set (Braun & Clarke, 2006). A rigorous thematic analysis can produce trustworthy and insightful findings (Braun & Clarke, 2006); however, there is no explicit agreement about how researchers can rigorously apply the method. Thematic analysis is also helpful for summarising the vital features of a large data set, as it forces the researcher to adopt a well-structured approach to data handling, helping produce a clear and organised final report (King, 2004). My study's sample size is a small group of 21 participants. It was challenging to find SAPWD staying in nursing homes who can give consent, as they are from a minority ethnic group. In grounded theory, a minimum of 10 participants is enough, and there are no criteria for sample size (Charms 2014). In CGT, the sample size is determined by when information saturation is achieved.

Furthermore, thematic analysis accepts that it is impossible to understand the experiences of families affected by dementia and staff experiences through a static or thematic lens but requires a more dynamic approach. CGT uses qualitative data analysis. Qualitative data analysis, on the other hand, uses thematic analysis and content analysis to describe the data in detail. However, a criticism is that it often stops at the level of description, leaving unexplained links between the themes undeveloped. In grounded theory, these links are made explicit (Glaser, 2002). The disadvantages of thematic analysis become more apparent when considered alongside other qualitative research methods. The lack of substantial literature on thematic analysis compared to grounded theory, ethnography, and phenomenology, for example, may leave researchers unsure how to conduct a rigorous thematic analysis (Nowell et al., 2017). A simple thematic analysis is disadvantaged compared to other methods, as it does not allow researchers to make claims about language use (Braun & Clarke, 2006). While thematic analysis is flexible, this flexibility can lead to inconsistency and a lack of coherence when developing themes derived from the research data (Holloway & Todres, 2003).

After considering each method for planning the research study, grounded theory was selected for several reasons. CGT was selected for the following principal reasons. Firstly, Grounded Theory adopts an explicitly temporal approach to the study of experience and emphasises the role of social and psychological processes that shape and help explain people's experiences (Glaser & Strauss, 1967). This clearly emerged as important from the present literature (Baghirathan et.al.,2020; Botsford et al., 2015; Gibson et.al., 2024). My own experience with elderly people with dementia revealed that the understanding of their needs and unmet needs is dynamic. CGT allows for exploring these characteristics as an explicit goal of the method (Charmaz, 2012). Secondly, whilst it acknowledges the influence of prior work in the form of sensitising concepts (Rodwell, 1998), grounded theory also provides a 'clean sheet' in recognising the scarcity of previous research with SAPWD in residential care and an opportunity to be open to participant's accounts, in driving what should be explored over the course of the study.

Thirdly, and importantly, as the researcher, I was attracted to the opportunity of constructivist grounded theory in particular, as providing a transparent process for me to apply and consider how my own professional experience of caring and working with PWD and those close to them and the role of staff and family to improve the quality of life would interact with the data from participants and for the active role it allowed participants to play in the research process. Finally, GT and CGT provide the researcher with the tools to undertake comprehensive and systematic analysis to develop substantive theory. I found these approaches to fieldwork and analysis intuitive and reflective of my epistemology. Furthermore, as a researcher, I found the processes outlined by CGT researchers, such as Charmaz (2006), helpful in guiding my practice.

The overall goal of the research is to explore the opportunities and barriers to meeting the needs of South Asian people with dementia in residential care. A constructivist, grounded theory approach will be used to study the experience and needs of South Asian service users from their perspective (Charmaz, 2014) and to gather and analyse care staff and family/relatives' perceptions of willingness to meet the needs of South Asian residents, with the goal of an interpretive understanding of their actions and experiences within a complex social context. Both the sensitising concept of the needs of South Asian people with dementia (SAPWD) and the disciplinary perspective I have gained from many years of work experience in hospitals and nursing homes will provide a starting point for the study.

Constructivist grounded theory resists mechanical applications and favours flexibility (Charmaz, 2014). So, the rationale is to allow three groups of participants to shape their understanding of dementia care for SAPWD in a residential care setting, and to negotiate with each other to improve the care. Hence, the defining elements, which include the interaction between the researcher and participants in interpreting the meanings of the phenomenon, are suited to answer the questions modelled in this investigation and, therefore, to defend my selection of an appropriate version of grounded theory (Denzin & Lincoln, 2007). Furthermore, viewing the research as constructed removes the neutrality and value-free concepts of the researcher, promoting reflection.

3.4 Role of the Literature Review

The literature review plays a crucial role in this study by enhancing theoretical sensitivity and informing the research design, particularly within the CGT approach. While some grounded theory traditions caution against preconceptions from existing literature, the review in this study provides essential background knowledge about SAPWD, their carers, and culturally competent care, without constraining the emergence of new theoretical concepts from the data. It highlights key barriers such as cultural norms, communication challenges, stigma, and attitudes, which shape the experiences of SAPWD in both community and residential care. The review also underscores the marginalisation of SAPWD in residential settings, emphasising the need to explore their lived experiences and the perspectives of families and care staff. Furthermore, as a novice in grounded theory, the literature review guides the development of the research questions. It sensitises the researcher to important contextual and cultural factors, ensuring that data collection and analysis are informed yet open to new insights. In this way, the literature review supports the construction of a grounded, participant-centred understanding of care experiences for SAPWD.

3.5 Participants: Selection, Sampling and Recruitment

3.5.1 Inclusion Criteria: The inclusion criteria for this study define the participants who are eligible to contribute to the research, ensuring relevance and richness of the data collected. Participants include individuals of South Asian origin who have a formal diagnosis of dementia, can communicate in English and are residing in residential care or care homes, either for long-term care or respite care. The study also includes the participants' next of kin or relatives, encompassing both family and non-family caregivers, to gain insights into their perspectives on care provision. Additionally, Managers, registered nurses and support workers who provide direct care to SAPWD are included, as their professional experiences and observations are essential for understanding the opportunities, challenges, and dynamics involved in meeting the needs of this population. Collectively, these criteria ensure that the study captures a comprehensive and multi-perspective understanding of dementia care within the South Asian residential care context.

3.5.2 Exclusion criteria: The exclusion criteria for this study specify which participants are not eligible to take part, primarily to ensure ethical compliance and protect vulnerable individuals. There are no restrictions regarding the type of dementia, allowing participants with any form of dementia to be considered. However, frail individuals with dementia who may be physically or medically unable to participate are excluded. Importantly, individuals who are unable to provide informed consent, including those under the Deprivation of Liberty Safeguards (DOLs), are not included in the study, in line with the Mental Capacity Act, 2005 (Department for Constitutional Affairs, 2007), which safeguards vulnerable groups. These exclusion criteria ensure that all participants can provide informed consent voluntarily and actively engage in the research process, thereby maintaining ethical standards and the integrity of the collected data.

3.5.3 Participants groups and Recruitment: The participants in this study are categorised into three groups: SAPWD, family members, and staff. This categorisation allows for triangulation of evidence, capturing experiences and perspectives from multiple viewpoints to provide a comprehensive understanding of care in residential settings. Participants are recruited with the assistance of registered managers of the nursing homes, who act as key gatekeepers by identifying potential participants. The managers also facilitate the distribution of study materials, including the covering letter, information sheet, and consent form, to ensure that all three groups are fully informed and able to provide voluntary consent. This approach ensures ethical recruitment while enabling the collection of rich, multi-perspective data. The flow chart of participants given below

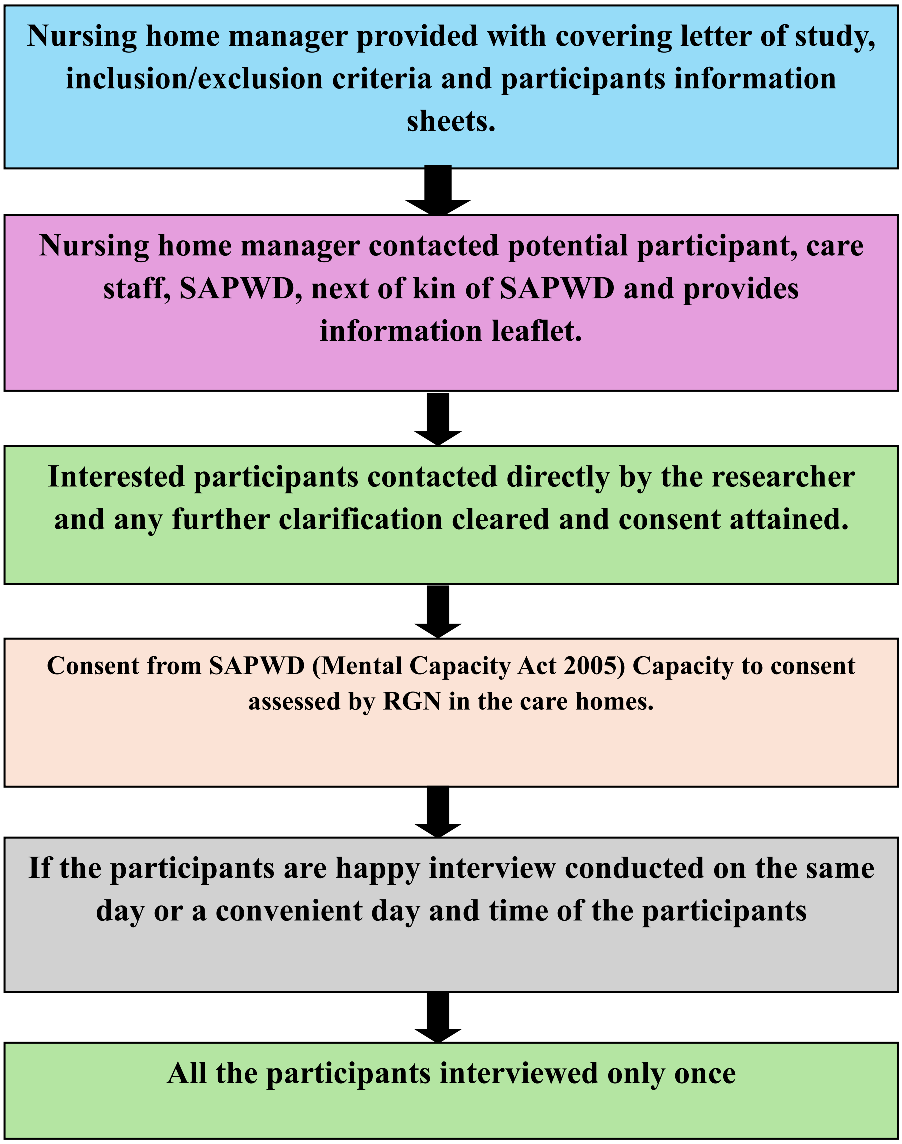


Figure 3.1: Participant Recruitment and Grouping Process

Integration of the Three Participant Groups

Although participants were categorised into three groups SAPWD, family members, and staff these were not treated as separate comparative cohorts. Instead, consistent with constructivist grounded theory, all participants were analysed as one integrated sample contributing three interrelated dimensions of the same phenomenon. The aim was not to compare groups in order to identify differences, but to develop a unified conceptual understanding of how culturally appropriate dementia care is negotiated within residential settings. Cross-perspective comparisons were used analytically to deepen theoretical development rather than to establish group contrasts. This integrative approach ensured that the emerging theory reflected the dynamic and relational nature of care across interconnected roles rather than discrete group-based experiences.

3.5.4 Consent from SAPWD

Consent from SAPWD is obtained using Dewing's (2007) method, which emphasises understanding that a person's capacity to consent may vary over time. Participants are provided with clear, appropriate information to help them understand the study and their involvement. Informed consent is treated as an ongoing process, with the researcher continuously checking and confirming understanding rather than relying on a single assessment. Participants have the full right to withdraw from the study at any time or to stop the interview whenever they wish, ensuring their autonomy and comfort are fully respected throughout the research process.

3.5.5 Recruitment

The recruitment process involved conducting 21 interviews, evenly distributed among the three participant groups: seven SAPWD, seven family members, and seven staff. To reduce stress for SAPWD, follow-up interviews were not conducted with them; instead, additional information was obtained from their family members or staff. This approach ensured participants' well-being while maintaining data richness. The sample size of 21 is considered sufficient for Grounded Theory studies, allowing for in-depth exploration and theory development, as supported by Thomas (2011).

3.5.6 Study settings

The study was conducted in the East and West Midlands of England, with data collected from two nursing homes and two residential homes, referred to as Units 1-4. Participants included South Asian people with dementia (R1–R7), their family or relatives (F1–F7), and staff (S1–S7). Each participant was interviewed once, with interviews lasting approximately 30 to 60 minutes.

3.5.7 Theoretical Sampling

In this study, theoretical sampling was used to recruit participants from nursing and residential homes, focusing on SAPWD, their families, and care staff. Participants' demographic characteristics, such as age, gender, and religion, were not predetermined. Sampling was guided by relevance to the research question, aiming to explore variations in experiences across different cultural backgrounds. Data collection, coding, and analysis occurred simultaneously, allowing interview questions to be refined iteratively. During the interview in Unit 1 with the first group of three participants, different cohorts related to residential care for SAPWD were sampled. Most participants come from different cultural backgrounds. This information became helpful in exploring how the core concerns may vary within the substantive field (Glaser & Strauss, 1998; Gibson & Hartman, 2014) and among participants from families and staff. Glaser and Strauss (1967, p.48) emphasise that the basis of theoretical sampling is for "purpose and relevance", not to verify facts but to generate theory (Glaser & Strauss,1967). Therefore, theoretical sampling was ongoing, providing a systematic and relevant rationale for collecting more data and for developing the properties of categories to construct theory. The process continued until theoretical saturation was reached, ensuring no new properties emerged (Charmaz, 2014). This approach supported the development of a substantive theory, later identified as the theory of Active Negotiation, integrating perspectives from all three participant groups.

Levels and variations of theoretical sampling

In this study, theoretical sampling allowed for variations in participant selection, which aligned with the constructivist approach. The sampling primarily followed Type 1 and Type 2 strategies, while occasionally incorporating Type 3 and Type 4. This flexible approach ensured the sampling remained valid and supported the development of theory from diverse perspectives.

Variations on theoretical sampling (from Corbin & Strauss 2008)

Type 1: A researcher may look for persons, sites or events where he or she purposefully can gather data related to categories, their properties, and dimensions.

Type 2: A researcher may gather data systematically (going from one person or place to another on a list) or by sampling based on convenience (whoever walks through a door or agrees to participate).

Type 3: A researcher may find that differences often emerge by chance rather than intention.

Type 4: A researcher may return to the data, reorganising them according to theoretically relevant concepts.

These four types of variations on theoretical sampling by Corbin and Strauss allow some flexibility. This prevents notions and doubts that theoretical sampling is not carried out solely as in type 1, and this flexibility is considered necessary in this investigation. As I was interviewed only once, type 1, type 2, and type 3 were used for theoretical sampling.

Theoretical Sampling Process

In this study, theoretical sampling guided the recruitment of SAPWD, family, and staff to develop emerging categories such as “Entering care home” and “Adjustment to care.” Participants were selected based on their ability to provide insights on cultural barriers, care adjustment, and support, with attention to variations in ethnicity, language, religion, and preferences. Challenges arose when some participants could not provide sufficient information, prompting further recruitment and refinement of interview questions. This iterative process ensured flexibility, allowed exploration of diverse perspectives, and supported the development of categories and theory grounded in the experiences of all three groups.

3.5.8 Data collection:

The data collection involved in-depth semi-structured interviews conducted in participants’ nursing homes, which were digitally recorded. Field notes and reflective memos were maintained throughout the study to capture insights, ideas, and emerging hypotheses (Charmaz, 2014). Interviews began with general questions about participants’ backgrounds, followed by the main topic: their experiences with residential care. Prompts were used to clarify or expand responses. Each interview concluded with questions to reorient participants and offered time for informal discussion to ensure participants' comfort. Initial impressions from interviews informed the ongoing development of the interview guide, allowing iterative cycles of data collection and analysis. A total of 21 interviews were conducted over one year and three months, with intervals of 3–6 months between sessions, depending on participants' convenience and the progress of analysis. All interviews were transcribed verbatim and anonymised for confidentiality. Tables 3.1, 3.2, and 3.3 present detailed demographic profiles of the participants, showing diversity in ethnicity, religion, education, and language backgrounds among SAPWD, their relatives, and care staff, thereby enriching the study with multiple cultural and professional perspectives essential for understanding the complexities of dementia care in multicultural residential settings. Appendix P, page number 334, shows the medical care needs of residents and the significance of twenty-four-hour care.

Table 3.1: Demographics of SAPWD

Location	Participants	Diagnosis	Age	Gender	Ethnicity	Religion	Marital status	Education	First Language	Languages Known
Unit 1	R1	Vascular dementia	82	M	Indian	Hindu	Married	School	Hindi	English
Unit 1	R2	Alzheimer's	73	F	Pakistani	Muslim	Married	Degree	Urdu	English
Unit 2	R3	Vascular	86	F	Indian	Christian	Widow	School	Hindi	English
Unit 2	R4	Frontotemporal	64	F	Sri Lankan	Hindu	Married	Degree	Sinhala	Tamil, English
Unit 3	R5	Alzheimer's	71	M	Bangladeshi	Muslim	Married	School	Bengali	English
Unit 4	R6	Vascular	69	M	British Indian	Hindu (Sikh)	Married	Degree	Punjabi	Hindi English
Unit 4	R7	Alzheimer's	76	F	Indian	Hindu (Gujarati)	Married	School	Gujarati	Hindi English

Table 3.2: Demographics of Family/Relative

Location	Participants	Age	Gender	Ethnicity	Religion	Marital status	Education	First Language	Languages Known	Relationship with SAPWD
Unit 1	F1	39	F	British Indian	Hindu	Married	Post graduate	Hindi	English	Daughter
Unit 1	F2	54	F	Pakistan	Muslim	Married	Degree	Urdu	English	Daughter in law
Unit 2	F3	51	M	Indian	Christian	Married	School	Hindi	English	Son
Unit 2	F4	27	F	Sri Lankan	Hindu	Married	Degree	English	Tamil, English	Daughter
Unit 3	F5	46	F	Bangladeshi	Muslim	Married	Degree	Bengali	English	Daughter
Unit 4	F6	31	M	British Indian	Hindu (Sikh)	Married	Degree	Punjabi	English	Son
Unit 4	F7	35	F	Indian	Hindu (Gujarati)	Married	PG	Gujarati	Hindi English	Daughter in law

Table 3.3: Demographics of Staff

Location	Participants	Age	Gender	Ethnicity	Religion	Marital status	Job Title	First Language	Languages Known
Unit 1	S1	37	F	British	No religion	Married	Senior Carer	English	French
Unit 1	S2	28	F	Indian	Christian	Single	Nurse	Malayalam	Hindi, English
Unit 2	S3	24	F	British Indian	Hindu	Single	Support worker	Hindi	English
Unit 2	S4	32	F	British	Christian	Single	Nurse	English	English
Unit 3	S5	39	F	Nigerian	Christian	Married	Senior carer	Ibo	English
Unit 4	S6	42	F	British Indian	Hindu	Single	Manager	Gujarati	Hindi English
Unit 4	S7	23	M	Indian	Hindu	Single	Health care assistant	Hindi	Gujarati,English

3.6 Ethical Considerations

Given that this study involves South Asian people with dementia residing in residential care settings, ethical considerations were central to the research design and implementation. As an empirical study involving a potentially vulnerable population, ethical rigour was prioritised throughout recruitment, data collection, analysis, and dissemination. Ethical approval was obtained from the University Research Ethics Committee of the University of Staffordshire prior to commencement of the study (Appendix A, page number: 304), and all procedures adhered to institutional guidelines and national research governance standards.

Mental Capacity and Informed Consent

Particular attention was given to issues of mental capacity in accordance with the Mental Capacity Act 2005. Capacity was assessed on a decision-specific basis, recognising that individuals with dementia may retain the ability to consent to participate in research when appropriate support is provided. In line with the principles of the Act, capacity was presumed unless there was evidence to suggest otherwise.

Participants were provided with accessible information sheets, and sufficient time was allowed for discussion and clarification. Where necessary, information was explained verbally and supported by family members or staff to enhance understanding. Capacity was recognised as potentially fluctuating; therefore, consent was treated as an ongoing process rather than a single event.

Individuals who were unable to provide informed consent, including those subject to Deprivation of Liberty Safeguards (DOLs), were excluded from participation in accordance with legal and ethical requirements.

Process Consent and Ongoing Monitoring

The study adopted Dewing’s (2007) model of process consent, which emphasises continuous assessment of participants’ willingness and comfort during research encounters. Verbal and non-verbal cues were monitored throughout interviews to identify signs of distress, confusion, or fatigue. Participants were reminded of their right to pause or withdraw at any stage without consequence. This approach ensured respect for autonomy and safeguarded participant well-being.

Safeguarding and Managing Vulnerability

Recognising dementia as a condition that may increase vulnerability, interviews were conducted sensitively and at a pace determined by participants. If distress occurred, the interview would be paused or discontinued. Clear safeguarding procedures were in place should any concerns regarding participant welfare arise during data collection.

Confidentiality and Data Protection

Confidentiality was ensured through the use of pseudonyms and removal of identifying information from transcripts. All digital recordings and transcripts were stored securely on password-protected devices in compliance with data protection regulations. Access to the data was restricted to the researcher and supervisory team. Data will be retained and destroyed in accordance with university policy.

Researcher Reflexivity and Power Dynamics

As this study adopts a constructivist grounded theory approach, reflexivity formed an integral component of ethical practice. The researcher remained attentive to potential power imbalances, cultural sensitivities, and the influence of professional background on data interpretation. Reflective memo writing supported ongoing critical awareness of positionality and its impact on the co-construction of meaning.

3.7 Data Analysis

3.7.1 Overview of Analytical Approach

The data analysis in this study followed Charmaz’s (2014) Constructivist Grounded Theory approach, which emphasises the co-construction of meaning between the researcher and participants through an iterative and reflective process. All interviews, reflective memos, and field notes were transcribed verbatim and systematically analysed using NVivo 12 software to ensure organised data management and traceability of emerging concepts. The analysis was conducted through a continuous cycle of comparison, where data were examined line-by-line and compared within and across interviews to identify patterns, similarities, and differences. Memo writing played a central role in capturing analytical insights and reflections, enabling the researcher to move from descriptive coding to more abstract conceptualisation. This iterative and comparative process facilitated the gradual development of categories and subcategories that were refined and validated through ongoing engagement with the data. Ultimately, theoretical sufficiency was achieved when the categories were well-developed and could account for new data without significant modification (Dey,1999), leading to the construction of a grounded theory that authentically reflected participants' experiences and interpretations.

3.7.2 Coding Process

The coding process in this study was conducted in three key stages following Charmaz's (2014) Constructivist Grounded Theory approach. The first stage, initial or line-by-line (open) coding, involved examining the data closely and generating low-level codes using gerunds to capture actions, interactions, and processes expressed by participants. This allowed the researcher to stay close to the data and remain open to new insights without imposing preconceived categories. In the second stage, focused coding, the most significant and recurring initial codes were grouped into meaningful subcategories, helping to identify relationships and patterns across interviews. These focused codes represented broader conceptual understandings of participants' experiences. The final stage, theoretical coding, integrated the major categories developed in the focused stage to identify the core category that encapsulated the central process of the study. Initially, Excel was used to code six transcripts for familiarisation with participants' narratives, after which the process was transferred to NVivo 12 for more systematic organisation, comparison, and refinement of codes. Throughout all stages, the analysis was guided by Charmaz's fundamental question, “What is happening here?”, ensuring that the coding remained grounded in the participants' lived experiences and the social processes underpinning their accounts.

3.7.3 Use of NVivo 12 for Data Management and Analysis

NVivo 12 was employed as a key tool to facilitate systematic data organisation, management, and analysis throughout the study. The software enabled the creation of structured folders categorised by participant groups, including SAPWD, family members, and care home staff, which ensured organised data storage and easy retrieval of transcripts. Casebooks were developed for each participant, containing key demographic and contextual attributes such as age, gender, and nursing home affiliation, allowing for detailed comparative analysis across groups. NVivo's powerful tools, such as memos, node trees, coding matrices, and diagram functions, were used to visualise emerging patterns, track relationships among categories, and capture evolving analytical insights. Memos were particularly useful for documenting reflections during coding, while node trees and matrices helped in mapping the progression from initial codes to higher-order categories. The visual mapping and linking features of NVivo further supported theory development by enabling the researcher to explore conceptual connections dynamically. Overall, NVivo 12 ensured a transparent, rigorous, and systematic approach to qualitative data analysis, enhancing the depth and credibility of the grounded theory that emerged from the study. An example of data analysis in NVivo 12 is illustrated in a screenshot in Appendix Q page number 339.

3.7.4 Coding Stages in Detail

(a) Open/Initial Coding

Open coding

According to Bowling (2005: 387), ‘coding means relating sections of the data to the categories which the researcher has either previously developed or is developing on an ongoing basis as the data are being collected'. Open coding is also referred to as `initial coding'. It requires the researcher to remain ‘open’ to exploring whatever theoretical possibilities they can determine in the data, thus having few or no preconceived categories (Charmaz, 2014). Open codes represent words and/or phrases usually noted in the margins of the transcript to represent a specific part of the text (Atkinson, 2002). As Charmaz (2014) notes, they are the initial step towards developing conceptual ideas about the data. There are a number of methods for applying open codes to the data. Charmaz (2014), for instance, suggests the use of line-by-line coding or sentence-by-sentence coding. When transcribing an interview, it was often difficult to identify the start and end of a sentence. I, therefore, used (...) as a symbol to indicate a short pause and reported any pauses that were three seconds or more. The following is an excerpt from one of the transcripts and is the format I have used when illustrating quotes from participants in the subsequent findings' chapters:

"So it's that sort of thing and... I think also... with my dad, there's a lot of bitterness from the fact that he ... now I use this term `dumped' in a nursing home. We are all busy, no time to visit… [3s pause] its our responsibility to look after our father, but what to do, we can't manage, he has wound dressings that need to be changed…not safe at home" (U1 F2).

In the open or initial coding stage, a detailed line-by-line examination of the interview transcripts was conducted to identify key ideas and actions emerging directly from the participants' narratives without imposing any preconceived assumptions. This process allowed the researcher to remain open to all possible interpretations and to capture the participants' experiences as authentically as possible. NVivo 12 was used to create free nodes for these preliminary codes, which represented discrete concepts or experiences. As the analysis progressed, these free nodes were gradually organized into tree nodes, enabling a more structured and hierarchical representation of the data. Constant comparison across transcripts was carried out to identify similarities, differences, and recurring patterns, helping to refine early insights and clarify the conceptual boundaries between codes. At this stage, significant initial codes such as uncertainty, prejudice, language barrier, and loneliness began to emerge, reflecting the participants' diverse experiences and challenges. This phase established the foundation for deeper conceptual analysis in the subsequent stages of focused and theoretical coding.

(b) Focused Coding and Comparisons

During the focused coding stage, related open codes generated in the initial phase were grouped into broader, more meaningful categories that captured significant patterns across the data. This stage involved moving from descriptive coding toward conceptual understanding by identifying key processes and relationships that explained participants' shared experiences. NVivo 12 facilitated this process through the organisation of nodes and the creation of diagrams that visually represented connections between emerging categories. Memo writing was also integral at this stage, as it allowed the researcher to reflect on analytical decisions, explore potential relationships, and document evolving interpretations. For instance, the focused category "Entering care home" emerged from subcodes such as stigma around institutional care, prejudice and language barrier, illustrating how individual experiences merged into a broader conceptual theme. Throughout this process, the constant comparative method was applied rigorously, comparing data within and between transcripts to highlight similarities, differences, and variations in experiences across participant groups. This iterative analysis helped refine the categories, ensuring that they remained grounded in the data while progressing toward theoretical development.

(c) Theoretical Coding

The theoretical coding stage represented the final and most integrative phase of the analysis, where the major categories developed during focused coding were systematically linked to identify overarching relationships and construct the emerging grounded theory. This process involved examining how different categories interacted, influenced one another, and collectively explained the central phenomenon under study. Theoretical codes served as conceptual connectors, providing a coherent framework that integrated all categories into a unified theoretical model. Through this analytical synthesis, the core category "Active Negotiation" emerged as the central social process that encapsulated participants' experiences and linked all other categories together. This core category reflected the dynamic strategies participants used to balance cultural expectations, personal needs, and care environments. By conceptualising these interconnections, theoretical coding moved the analysis from descriptive themes to a more abstract and explanatory level, establishing the foundation of the grounded theory that explained how meaning and adaptation were co-constructed within the research context. Coding Stages in Constructivist Grounded Theory Analysis (Open, Focused, and Theoretical Coding) is shown in figure 3.2.

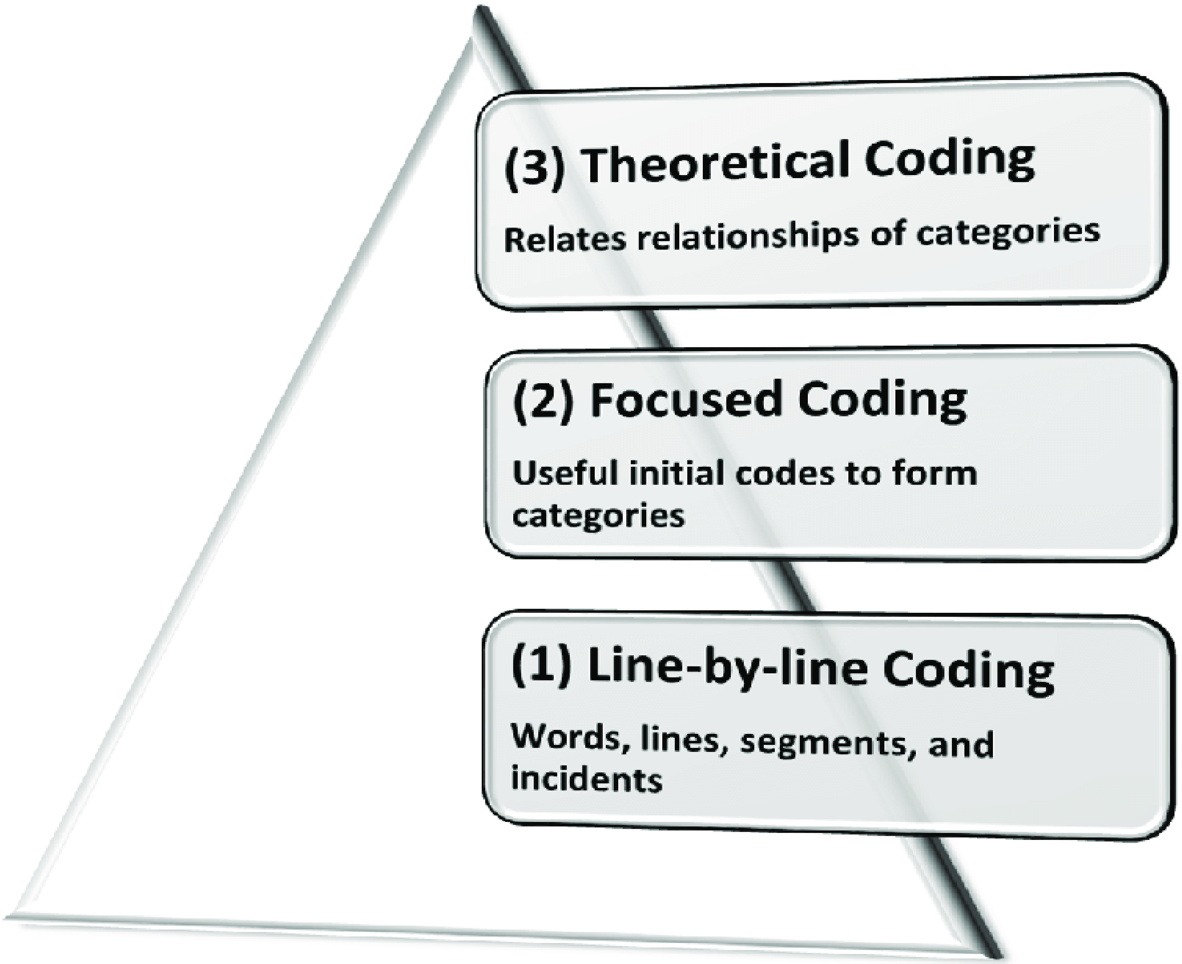


Figure 3.2: Coding Stages in Constructivist Grounded Theory Analysis (Open, Focused, and Theoretical Coding)

3.7.5 Comparative Analysis across Participant Groups

The comparative analysis was conducted iteratively across the three participant groups: SAPWD, family members, and care home staff, to capture a comprehensive understanding of the phenomenon from multiple perspectives. Data were systematically compared both within each group and across groups, enabling the identification of converging and diverging experiences related to dementia care and cultural adaptation. Guided by Boeije's (2002) comparative questioning framework, what is similar or different? Why are participants saying this? What new insights emerge from comparing perspectives? the analysis facilitated deeper exploration of underlying meanings and contextual influences shaping participants' views. This process highlighted nuanced differences in expectations, communication patterns, and perceptions of care between families and staff, while also revealing shared concerns such as emotional strain and cultural dissonance. The cross-group comparison not only enriched category development by integrating diverse viewpoints but also strengthened the credibility and validity of the findings through the triangulation of perspectives, ensuring that the emerging grounded theory reflected the complexity and multiplicity of lived experiences within the research context. Comparative Analysis across Participant Groups (SAPWD, Family Members, and Care Staff) is shown in Figure 3.3.

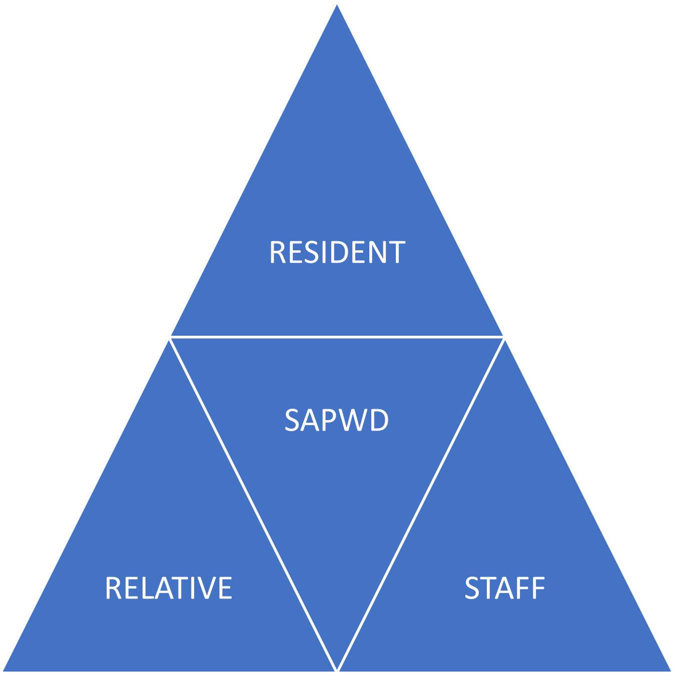


Figure 3.3: Comparative Analysis across Participant Groups (SAPWD, Family Members, and Care Staff)

3.7.6 Memo Writing

Memos are essentially notes made by the researcher that act as important reminders regarding the data (Bryman, 2004). Memo-writing is a crucial method in constructivist grounded theory because it prompts the researcher to think about their data and codes early in the research process, for ‘writing successive memos throughout the research process keeps you involved in the analysis and helps you increase the level of abstraction of your ideas' (Charmaz 2014: 72). Memo writing played a crucial role in bridging data collection and theory development by serving as an ongoing analytical tool throughout the research process. Memos were used to document emerging insights, conceptual reflections, and evolving interpretations as data analysis progressed. Within NVivo 12, short analytic memos were directly linked to specific transcripts and codes, allowing the researcher to capture immediate thoughts in context. In addition, more detailed conceptual memos were maintained in Word documents to elaborate on developing categories, explore their properties, and trace relationships among them. These memos provided a reflective space to question assumptions, refine analytical decisions, and record theoretical ideas as they emerged. Through continuous engagement with memo writing, the researcher was able to define and refine categories, specify their dimensions and interconnections, and ultimately identify the core category that unified the findings. Following these guidelines, I concluded that the 'Entering care home' was largely the outcome of the lack of knowledge regarding residential care, stigma around institutional care and cultural barriers presented in the South Asian community. Thus, memo writing functioned not only as a record of the analytical journey but also as a dynamic process that deepened theoretical insight and ensured coherence in the development of the grounded theory.

3.7.7 Theoretical Sampling and Saturation

The study employed theoretical sampling over a period of 15 months to iteratively refine emerging categories and address conceptual gaps within the data. This process involved revisiting participants or re-examining transcripts to explore developing ideas, clarify ambiguities, and ensure that categories accurately captured the range of experiences and perspectives across the three participant groups: SAPWD, their families, and care staff. Rather than aiming for absolute saturation, the study followed Charmaz's (2014) principle of theoretical sufficiency, whereby data collection continued until new information no longer meaningfully altered or expanded the existing categories. This iterative approach allowed the researcher to systematically test and refine the emerging theory, ensuring that the final conceptual framework, including the identification of the core category, "Active Negotiation", was robust, well-grounded in the data, and reflective of the complex social processes involved in residential care for South Asian people with dementia.

3.7.8 Development of Codes, Subcategories, Categories, and Core Category

In this study, a hierarchical coding structure was employed to systematically organise and interpret the qualitative data, progressing from initial codes to subcategories, then broader categories, and ultimately the core category. Initial codes were generated through line-by-line analysis, capturing key actions, processes, and experiences, which were iteratively compared across transcripts to identify patterns and similarities. These codes were then grouped into meaningful subcategories, which were further organised into four explanatory categories reflecting key dimensions of the residential care experience: Entering Residential Care, Adjustment to Care, Being Supported by Family, Staff, and Management, and Continuing to Live in Residential Settings. Through theoretical coding, the core category “Active Negotiation” emerged as the central process integrating all categories, representing the dynamic interactions and ongoing negotiation of roles, responsibilities, and culturally appropriate care practices among residents, families, and staff. This core category reflects the basic social process (BSP) underpinning the study, illustrating how care is collaboratively negotiated and continuously adapted to meet the diverse needs of South Asian people with dementia in residential settings.

3.7.9 Presentation of Subcategories and Categories

The presentation of subcategories and categories illustrates how the hierarchical coding structure was operationalised to capture participants’ experiences in residential care. Initial subcategories, such as uncertainty, loneliness, community prejudice, language barriers, culturally oriented care, complaints, busy schedules, medication, and support from family and staff, were identified through iterative coding and comparison across transcripts. These subcategories were then organised into broader categories representing key dimensions of residential care: Entering Residential Care, Adjustment to Care, Being Supported by Family, Staff, and Management, and Continuing to Live in Residential Settings. The core category, “A Site of Active Negotiation,” emerged as the overarching process connecting all categories, reflecting how residents, families, and care staff continuously negotiate expectations, roles, and culturally appropriate practices. This structure demonstrates the dynamic and socially constructed nature of care, highlighting the interactions, adaptations, and collaborative problem-solving that underpin the lived experiences of South Asian people with dementia in residential settings.

Tables 3.4 and 3.5 summarise how participants' experiences in residential care were analysed and organised. Table 3.4 compares perspectives across SAPWD, their relatives, and care staff, highlighting shared challenges such as cultural differences, gender bias, prejudice, language barriers, and stigma, as well as group-specific concerns like uncertainty and loneliness for SAPWD, worries and lack of cooperation for relatives, and training or workload issues for staff. Table 3.5 organizes these experiences into broader categories Entering Residential Care, Adjustment to Care, Being Supported by Family, Staff, and Management, and Continuing to Live in Residential Settings under the core category, "A Site of Active Negotiation," reflecting the ongoing negotiation of expectations, roles, and culturally appropriate practices that shape the lived experiences of SAPWD in residential care.

Table 3.4: Comparative Presentation of Subcategories and Categories across Participant Groups (SAPWD, Family Members, and Care Staff)

SAPWD	RELATIVE	STAFF
Uncertainty of future	Uncertainty about care	Lack of training
Loneliness	not supportive	Assumption
Missing family	Worried about not being able to care for their parents	Short staff
Staff busy	Most of the relatives do not have enough time to visit	Busy schedule
Cultural differences	Cultural differences	Cultural differences
Gender bias	Gender bias	Gender bias
Prejudice	Prejudice	Prejudice
Language barrier	Language barrier	Language barrier
Stigma	Stigma	Stigma
Lifestyle	Not cooperative	Family not cooperative
Medication	Medication	Medication

Appreciate staff's hard work	Appreciate staff for caring	Satisfied about the care provided
Medication concerns	Medication concern	Medication
Support from staff and family	Support from management and relatives	Support from management and staff
Adjustment	cooperation	Negotiation

Table 3.5: Hierarchical Structure of Core Category, Categories, and Subcategories

Core Category	**Category**	**Subcategory**
A site of Active Negotiation (Contextual category) Expectation of care Practice of care	Entering residential settings	Uncertainty Loneliness Community Prejudice Language barrier and communication
	Adjustment to care	Culturally oriented care Complaints and concerns Busy Schedule Medication
	Being supported by family, staff and management	Attitudes of family in supporting SAPWD Attitudes of care staff in supporting SAPWD Role of care providers in supporting SAPWD
	Continuing to live in residential settings	Cooperating with staff and family Cultural life

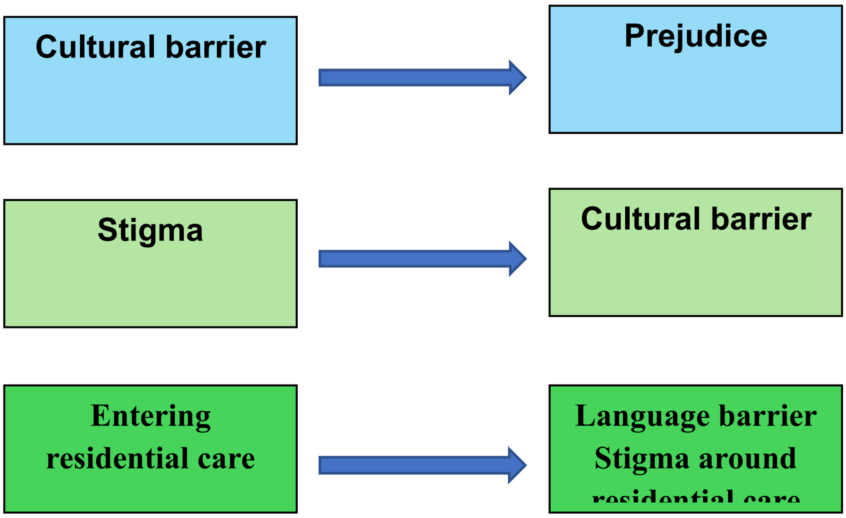


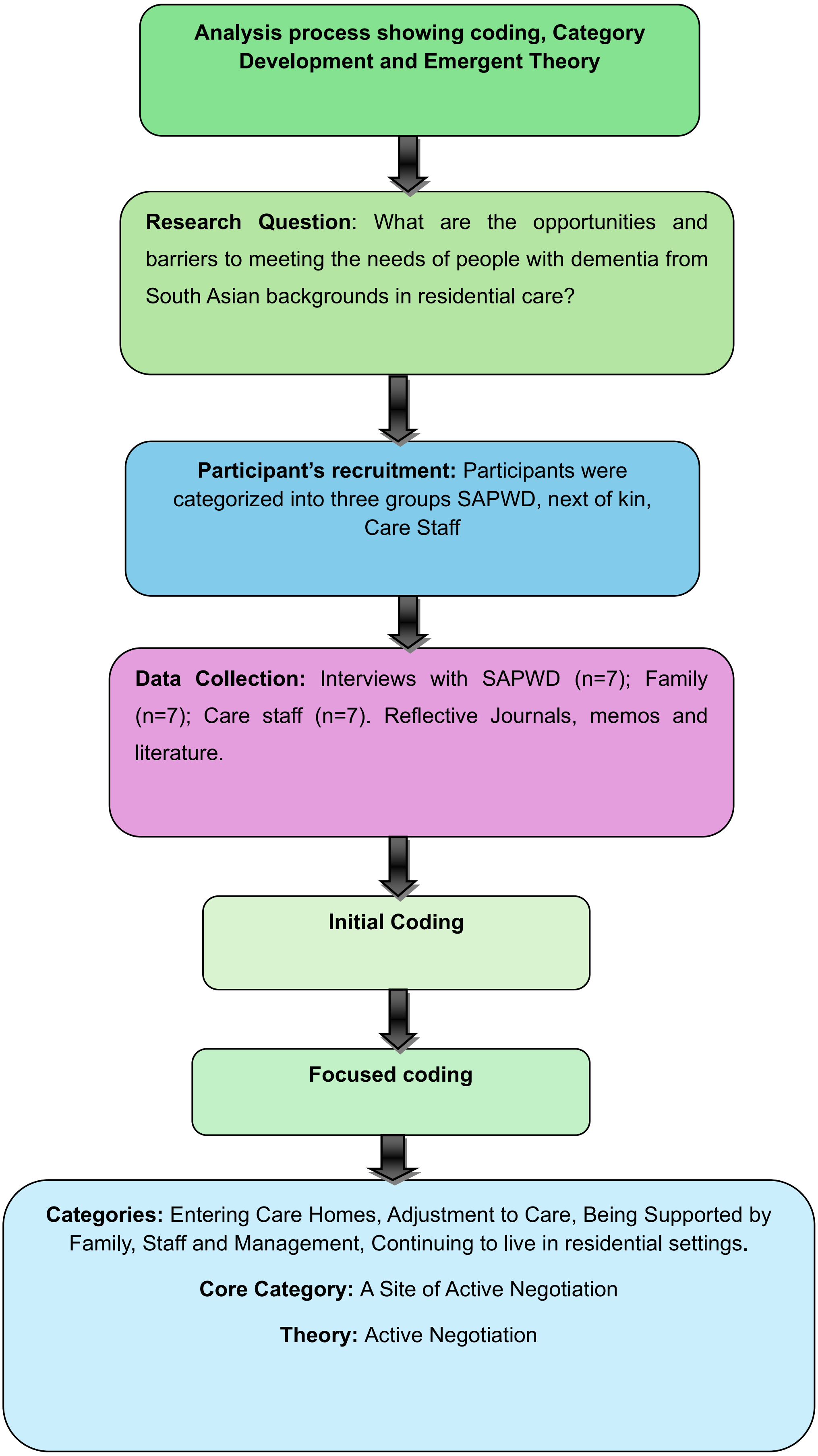
Figure 3.4: Interrelated Barriers in Accessing Residential Care for SAPWD

3.7.10 Development of the Core Category and Emerging Theory

The core category "Active Negotiation" synthesises the four main categories, serving as the central thread that connects all aspects of residential care for SAPWD. It reflects a dynamic, ongoing process in which residents, families, and care staff collaboratively navigate expectations, roles, and culturally appropriate practices. Through this continuous negotiation, the basic social process (BSP) demonstrates how culturally competent care evolves, highlighting the importance of interaction, compromise, and adaptation in addressing the unique needs of SAPWD. The emergent theory derived from this analysis emphasises that dementia care is socially constructed rather than fixed, shaped by the perspectives, actions, and relationships of all participants. It provides a conceptual framework for understanding how culturally sensitive care is developed and maintained within residential settings, capturing both the challenges and opportunities inherent in these interactions.

3.7.11 Diagrammatic Representation

A diagram was developed to visually represent the data analysis process, illustrating the progression from Initial Coding through Focused Coding, leading to Category Development, and culminating in the identification of the Core Category and the Emergent Theory. This visual representation, labeled as Figure 3.5: Analysis Process Showing Coding, Category Development, and Emergent Theory ("Active Negotiation"), provides a clear overview of the hierarchical and iterative nature of the analysis. It demonstrates how low-level codes were refined into subcategories, which were then grouped into broader categories, ultimately converging into the core category "Active Negotiation." The diagram helps convey the systematic, structured, and reflective approach used to develop a grounded theory, making the connections between codes, categories, and the emergent conceptual framework more accessible and understandable.



Analysis process showing coding, Category Development and Emergent Theory

Research Question: What are the opportunities and barriers to meeting the needs of people with dementia from South Asian backgrounds in residential care?

Participant's recruitment: Participants were categorized into three groups SAPWD, next of kin, Care Staff

Data Collection: Interviews with SAPWD (n=7); Family (n=7); Care staff (n=7). Reflective Journals, memos and literature.

Initial Coding

Focused coding

Categories: Entering Care Homes, Adjustment to Care, Being Supported by Family, Staff and Management, Continuing to live in residential settings.

Core Category: A Site of Active Negotiation

Theory: Active Negotiation

Figure 3.5: Progression from Codes to Emergent Theory

In summary, the data analysis for this study followed Charmaz's (2014) Constructivist Grounded Theory approach, with NVivo 12 and memo writing supporting systematic management and interpretation of the data. The analysis was iterative, comparative, and interpretive, involving continuous engagement with transcripts, reflective memos, and cross-participant comparisons to ensure rigor and depth. Through this process, four major categories Entering Residential Care, Adjustment to Care, Being Supported by Family, Staff, and Management, and Continuing to Live in Residential Settings emerged, all connected by the core category "Active Negotiation." This hierarchical structure and the identified basic social process provide the foundation for the study's theoretical framework. The findings chapter that follows will explore these categories in detail, examining their interrelationships and the ways in which they illustrate the social construction of culturally sensitive care for South Asian people with dementia.

3.8 Summary

This chapter explains why a qualitative methodology, specifically constructivist grounded theory, was chosen to explore the opportunities and barriers in meeting the needs of SAPWD in residential and respite care. It outlines the research processes, including data collection, analysis, and theory development, highlighting the iterative, non-linear approach used to generate a conceptual framework. The findings, presented in subsequent chapters, focus on the core category of 'Active Negotiation' and its four related categories, which emerged from initial subcategories. These categories collectively illustrate how SAPWD, their families, and care staff negotiate culturally appropriate care, addressing both opportunities and barriers. Contradictory or alternative cases are also considered to provide a comprehensive understanding of participants' experiences and the social processes shaping care practices within the South Asian community

CHAPTER: 4

Findings: Context and Conditions of Active Negotiation

4.1 Introduction

This chapter presents the development of the theory of *Active Negotiation*, explaining how the core category, “A Site of Active Negotiation,” emerged from the analysis of participants’ experiences. It describes how this central concept encompasses the dynamic, ongoing process through which residents, families, and staff negotiate expectations, roles, and culturally appropriate practices in residential care.

The chapter shows how this core category is supported by four interrelated categories:

1. Entering Care Homes
2. Adjustment to Care
3. Being Supported by Family, Staff, and Management
4. Continuing to Live in Residential Settings

These categories represent the conditions under which active negotiation occurs, and together explain how culturally appropriate, person-centred care is developed in practice. These, together, illustrate the key dimensions of care experiences and how negotiation shapes adaptation, support, and engagement in the daily lives of South Asian people with dementia in residential settings.

4.2 Identifying Theory and Integrating Existing Theory

The three participant groups in this study, residents, family members, and care staff, were interviewed. Their opinions, needs, and interactions in residential settings were highlighted, offering valuable insights into South Asian dementia care. The researcher was able to thoroughly engage with and understand the unique perspectives of each group by creating categories to record recurrent topics after each interview. The participants' shared view of effective care methods was reflected in the frequent references to cooperation, adjustment, support, help, and teamwork made during data analysis and memo writing. These recurrent themes served as the basis for defining the developing theory of Active Negotiation in residential care settings and demonstrated the value of cooperative relationships among residents, relatives, and staff in ensuring the well-being of those with dementia.

Participants emphasised the importance of adjustment to the situation.

> *"There should be less stigma about dementia…Dementia awareness programme by NHS allow us to gradually bring down our misconceptions regarding dementia and while also providing education to the SA community and understand better how to manage, approach and care dementia and stigma. But most of the family tries to* ***adjust to the situation****." (F3 U2)*
>
> *"I still have a lovely life, I am healthy, but sometimes I need help…my son always busy. Finally I have to come here this nursing home, now I am* ***adjusting and trying*** *to live here. Staffs are really helpful…" (R2 U1)*

This demonstrates the participants' negotiation and how they are adjusting to and cooperating with residential care.

The results of the data analysis showed that the theory of Active Negotiation was developed in part because of the experiences of the participants in residential care settings. This notion developed as a result of ongoing negotiations and collaborations between staff, residents, and families to develop care practices that are socially and culturally sensitive. This cooperative dynamic is depicted in Figure 4.1, which emphasises how these exchanges serve as the cornerstone of care delivery. As evidenced by its consistency and centrality, the core category, "A Site of Active Negotiation," first emerged in Unit 1 interviews and persisted throughout Units 2, 3, and 4. Reflective memos highlighted that participants consistently emphasised negotiation, cooperation, and adjustment, revealing that their experiences encompassed not only the management of dementia and physical health needs but also the wider social and relational aspects of care. Figure 4.1 shows the theory of active negotiation interrelated with categories and contextual categories. It is discussed in detail in Chapter 9.

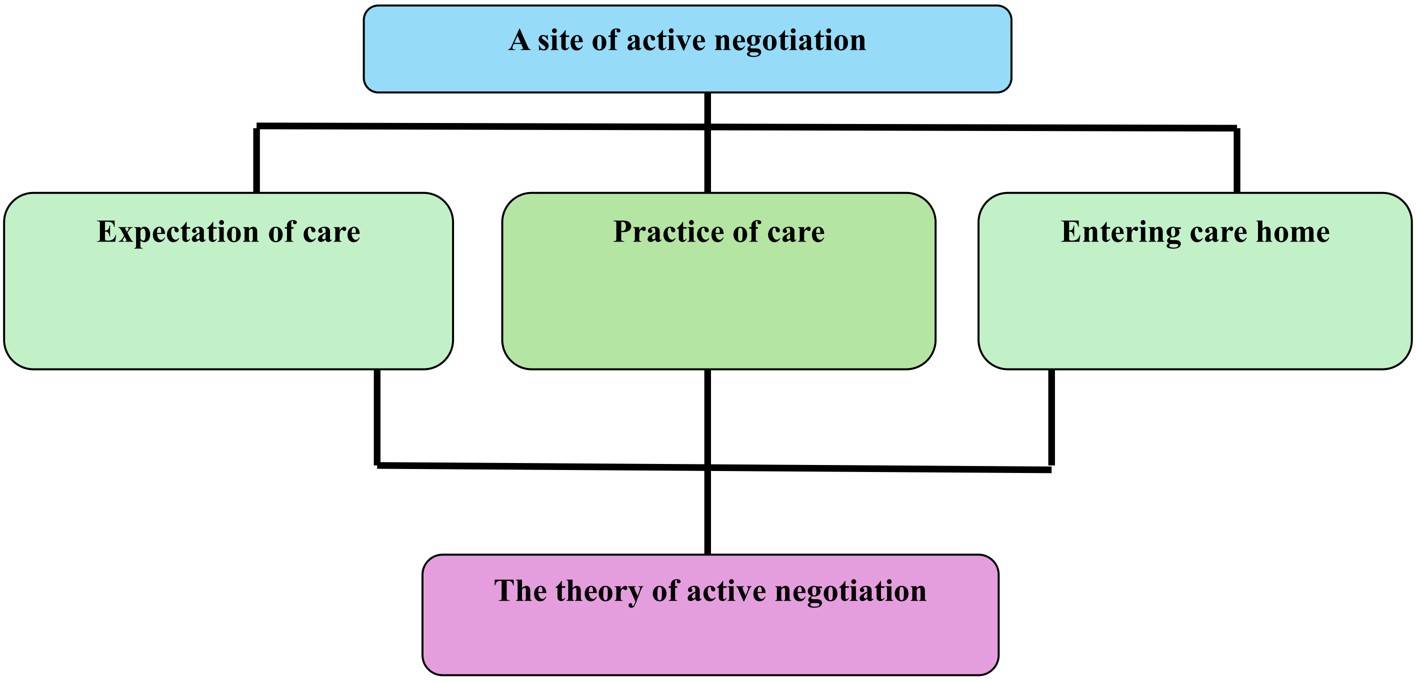


Figure 4.1: Conceptual Diagram of the Theory of Active Negotiation in Residential Care for South Asian People with Dementia

4.3 Emergence of the Core Category of A Site of Active Negotiation and its Related Categories in the Theory of Active Negotiation.

Through ongoing and critical analysis of the interview data (Strauss & Corbin, 1988). The core category **"A Site of Active Negotiation"** emerged, encapsulating participants' experiences of cooperation and negotiation within residential care for South Asian people with dementia. By staying open to the data, the researchers enabled the participants' perspectives to emerge as fully as possible (Glaser,2011). This category signifies shifts in participants' perceptions and understanding of dementia, emphasising the role of residential care in enhancing quality of life. Its emergence was validated by recurring patterns across the data and its strong connection to other categories. Positioning the core category alongside four related categories that collectively depict the dynamic process of active negotiation.

Participants across three groups, residents, family members, and care staff, shared their experiences of dementia care within South Asian residential settings. Data were analysed using constructivist grounded theory principles, where categories were developed iteratively through constant comparison.

Through this process, the core category “A Site of Active Negotiation” emerged as the central process explaining how care is experienced and delivered. The analysis showed that care is not fixed but is continuously shaped through cooperation, adjustment, and shared understanding among participants.

Participants’ accounts highlighted that:

- Care practices are negotiated between family expectations and institutional routines
- Cultural understanding develops over time
- Communication and cooperation are central to effective care

For example, participants emphasised the importance of cooperation:

> “Importance *of visitors/family and understanding their culture, past history and needs helps to complete the care plan....* **Cooperation** *from family and staff I think. My mindset and confidence have improved significantly with residents with dementia.” (S6 U4)*

Family members described learning and adapting:

> *“We don’t want to be a irresponsible family, I mean pretend to be ignorant…because it’s hard to understand what to do and I really don’t know and no other options rather than nursing home for better care, the further you learn and understand my mums routines it’s manageable to communicate…” (F2 U1)*

Staff reflected on changing perceptions through interaction:

> *“After interacting with dementia patients and their family, listening to their needs my impression on SAPWD improved and changed…” (S1 U1)*

These accounts illustrate that negotiation is an ongoing, relational process, forming the foundation of the emerging theory.

4.3.1 Core Category: A Site of Active Negotiation

By following the principles of a constructivist grounded theory approach, a core category, namely, 'A site of active negotiation by residents, family, and staff are all involved in better provision of residential care for SAPWD ' conceptualised as this appeared to capture the essence of the data arising from the interviews with all three groups. Within this core category, four categories- Entering Care Home, Adjustment to Care, being supported by Family, Staff and Management, and Continuing to live in Residential Care emerged and were discussed in the following chapters 5,6,7 and 8.

This core category was further strengthened through participants' self-reflection, which became evident as they developed a deeper understanding of dementia during their discussions. Through this process, many began to challenge their initial assumptions about living with dementia. The findings indicate that this reflection fostered greater self-awareness among participants, emphasising the significance of recognising the individual beyond the condition. Participants often described feeling inspired to look past the diagnosis and engage with the person's lived experience. Consequently, their perceptions of dementia evolved to become more individualised and person-centred.

The core category, "A Site of Active Negotiation," captures the dynamic and continuous process through which residents, families, and staff collaboratively shape care practices.

This core category reflects:

- Shifts in understanding dementia
- Movement towards person-centred care
- Ongoing adjustment to cultural and social needs

Participants described how understanding develops through experience:

> *"I feel that hearing about dementia in the media doesn't provide much real understanding… Learning through lectures or reading feels very different from actually experiencing it firsthand." (U1 S2)*
>
> *"To truly understand and gain deeper insight, you need real experience. I've learned so much more about dementia through listening and observing it has completely changed my perspective. Seeing the person as a whole has given me new ways of understanding dementia." But communicating with SAPWD was difficult to understand their needs. Family helps to know*

> *the likes and dislikes of the service user. Sometimes it’s hard when we are short-staffed.” (U2 S1)*

Recognising and understanding people with dementia as individuals living with a condition rather than as having a mental illness appeared to be the initial step in helping participants interpret dementia within a broader social context.

> *"It completely opened my eyes and changed how I think about dementia and residential care. With the support and care from the staff, my dad continues to live life to the fullest." (F7 U4)*
>
> *“Some SA people started to see dementia in a new way rather than mental illness.” (F3, U2)*

Through their experiences, staff participants began to look beyond the medical aspects of dementia traditionally seen as the primary focus of care and instead considered its wider impact on both the person and their family. This shift in perspective fostered a more person-centred approach, emphasising the importance of seeing residents as individuals rather than solely as residents with dementia.

Staff reflected on how firsthand experience helped them recognise the person behind the diagnosis, shifting focus from medical labels to social and emotional needs:

> *“On the first day of admission, you know very little about them you just see the person as a service user. But over time, you begin to recognise them as an individual, understanding dementia within a broader context that includes their culture and family.” (S2 U1)*

Participants across all groups emphasised the importance of seeing residents as individuals rather than solely as people with dementia:

> *“Not to label the person with dementia or mental illness. Nobody likes to be labelled. I don’t have dementia; I forget things…you know I am getting old.”* (R5 U3)
>
> *“It’s not enough to view dementia merely as a medical condition; you need to recognise and understand the person behind it.”* (S6 U4)

These reflections illustrate a transition from deficit-focused perspectives to a more holistic, person-centred approach, consistent with principles of social health: love, comfort, attachment, involvement, and identity.

The interdependence of residents, family, and staff was highlighted as critical to negotiating care effectively. Support from staff and family was central:

> *“There is one girl here, she is very nice…speaks my language (Hindi). Helps me a lot, then other staff, if they can’t understand what I am saying…ah…they show me pictures…sometimes it’s funny…they all try to help me.”* (R4 U2)
>
> *“Seeing my dad outside of our home in a nursing home, you see him as your dad, not a different person …we all are trying to manage the situation…hardest part is explaining to the relatives, they know only to blame.”* (F6 U4)
>
> *“In my mind, I thought dementia meant they couldn’t remember anything, but he is very different…he keeps his mind active, and you can see they can still have a good life despite dementia.”* (F5 U3)

These accounts demonstrate how cooperative negotiation between family and staff supports residents’ autonomy, cultural preferences, and social engagement.

Participants further described changing perceptions:

> *“Before admission to the nursing home, I had only heard the word dementia, but seeing and experiencing it firsthand is different…you observe it, you feel it…it’s more than just a word. It feels like we are on a journey alongside them, trying to understand and support them. It’s overwhelming at times, and we’re unsure what to do, but we are learning to* ***cope*** *with the situation…” (F4 U2)*
>
> “Interacting with people with dementia… has been life-changing… showing that a normal life is possible…” (S4 U4)
>
> *“seeing my dad outside of their own home in a nursing home, you see them as your dad, not a different person … we all are trying to manage the situation…hardest part is explaining to the relatives, they know only to blame.” (F6 U4)*
>
> *“In our culture its our responsibility to look after our parents, but we all are working full time and there is nobody to take care of my dad…All our family decided to get him a better care and my dad understands it. Its painful to watch him in here. Everything changing…for better care nursing home is always good.”(F4 U2)*

These findings show that care is co-constructed through interaction, where understanding, support, and adaptation evolve over time.

4.4 Conditions for A Site of Active Negotiation

The analysis identified four categories that represent the conditions under which active negotiation occurs. These categories were developed through constant comparison and are interconnected.

4.4.1 Entering residential Settings

This category reflects the initial transition into residential care, often characterised by uncertainty and emotional challenges.

Subcategories include:

- Uncertainty
- Loneliness
- Community Prejudice
- Language Barrier and Communication

Participants described the emotional impact of entering care:

> *"Finally, I have to come here this nursing home, now I am adjusting and trying to live here…" (R2 U1)*

This stage highlights how negotiation begins as individuals adjust to a new environment while managing expectations and cultural concerns.

4.4.2 Adjustment to Care

This category captures how residents and families adapt to care routines and institutional structures.

Subcategories include:

- Culturally Oriented Care
- Complaints and Concerns
- Busy Schedule
- Medication

Participants highlighted the role of awareness and adaptation:

> *"There should be less stigma about dementia… most of the family tries to adjust to the situation." (F3 U2)*

This demonstrates how negotiation involves balancing cultural expectations with care practices.

4.4.3 Being Supported by Family, Staff, and Management

This category reflects the importance of collaborative support systems.

Subcategories include:

- Attitudes of Family in Supporting SAPWD
- Attitudes of Care Staff in Supporting SAPWD
- Role of Care Providers

Participants emphasised shared responsibility:

> *"Seeing my dad… we all are trying to manage the situation…" (F6 U4)*
> *"They all try to help me." (R4 U2)*

Support is negotiated through relationships, communication, and mutual understanding.

4.4.4 Continuing to Live in Residential Settings

This category reflects long-term adaptation and ongoing engagement in care environments.

Subcategories include:

- Cooperating with Staff and Family
- Cultural Life

Participants described maintaining quality of life:

> *"They are just like anyone else, trying to live their lives…" (S5 U4)*

This stage shows how negotiation continues as residents seek meaning, identity, and cultural connection.

4.5 Summary

The findings of this study show that residential care for South Asian people with dementia is not a fixed or standardised process, but one that is continuously shaped through ongoing interactions between residents, family members, and care staff. The core category, *A Site of Active Negotiation*, explains this central process, while the four categories represent the conditions that influence how such negotiation unfolds in practice. Through these interactions, care becomes dynamic, with cultural understanding developing over time rather than being pre-defined. Participants collaboratively adapt expectations, roles, and practices, leading to more person-centred approaches that recognise the individual beyond their diagnosis. This ongoing process reflects the basic social process (BSP), where participants actively respond to challenges related to culturally appropriate care through adjustment, communication, and mutual support. Overall, the findings demonstrate that culturally sensitive dementia care is co-constructed through relationships and continuous negotiation within residential settings

Chapter Five

Findings: Entering Residential Settings

Subcategories related to Entering Care Home

- **-Uncertainty**
- **-Loneliness**
- **-Community Prejudice**
- **-Language barrier and communication**

5.1 Introduction:

This chapter presents the findings of the study, guided by a constructivist grounded theory approach, which informed the development of the overarching theory of Active Negotiation. The analysis explored the experiences of SAPWD in residential care settings, focusing on how cultural values, family dynamics, community influences, and institutional practices interact to shape their transition and adaptation.

The study identified four main categories: *Entering Residential Care*, *Adjustment to Care*, *Being Supported by Family, Staff, and Management*, and *Continuing to Live in Residential Settings*. Each category captures the emotional, social, and cultural challenges faced by residents, alongside strategies and support systems that facilitate adaptation and well-being.

The study identifies four categories, and each chapter will discuss one category and its subcategories. In the discussion of each subcategory, I have used subheadings to improve clarity and the dimensionality of headings.

The first category, *Entering Residential Care*, reflects the complex emotional and cultural challenges experienced by SAPWD during this transition. Access to residential care remains significantly lower among South Asian communities compared to other ethnic groups, largely due to socio-economic barriers, ethnocentric service provision, and limited culturally appropriate support. Deep-rooted cultural beliefs reinforce the expectation that caring for older family members is a moral duty; consequently, placing a parent in a care home is often viewed as shameful or a failure of responsibility. These perceptions, combined with misconceptions about dementia as a mental illness, contribute to delayed diagnosis and reduced service utilisation.

Language barriers further exacerbate residents’ uncertainty, as many fear that staff or peers will not understand their language or cultural needs. Additionally, some South Asian residents worry about financial implications, such as selling their homes to pay for care or losing social security benefits. Many SAPWD enter residential care during a crisis, often after hospitalisation, when families can no longer provide adequate support due to the progression of dementia or other health conditions. These transitions are not merely logistical or medical decisions but deeply emotional and culturally significant experiences, often accompanied by feelings of uncertainty, loneliness, and alienation.

Living with Dementia in Residential Care: The Role of Family Strength and Experience of Family Loss

The experience of SAPWD living in residential care is shaped by family bonds, cultural values, and community influences. For many participants, the family forms the core of identity, emotional support, and daily life. Within South Asian Communities Indian (Gujarati, Sikh), Pakistani (Shia or Sunni), and Bangladeshi extended families and community networks provide a sense of belonging, cultural continuity, and emotional reassurance.

Participants emphasised the role of family cohesion in sustaining emotional well-being:

Resident U1 R1 shared:

> *“I feel happy and positive when I see my family and friends. We talk about events and celebrations in our community; sometimes I forget, but they help me remember, and I feel part of my community even though I am here.”*

Family members highlighted collective responsibility as central to caregiving:

Family U1 F1 reflected:

> *“Together we are strong and positive with the family; with family, much settled and good, good.”*

Some families face difficult decisions about how to balance cultural obligations with practical needs when professional care is required.

Family U3 F5 described:

> *"I believe that as a family we have feelings for each other and nobody can look after my dad as we do…but unfortunately…due to my busy schedule we chose this residential home. Even I argued with my wife and brothers to bring back dad home, but everybody's opinion is he is not safe in our home and it's difficult to find a carer with experience in working in our culture. I know my dad is not really happy here, as the routines are different, he likes to spend time with his grandchildren. In a way, he lost his family and daily activities in the community."*

Families expect care institutions to understand residents' needs in a culturally sensitive way:

Family U2 F4 explained:

> *"We expect from this institution that the staff will observe, listen, and understand my mum's needs and care with empathy like a family member."*

Residents also recognised gaps in staff knowledge of personal histories or cultural preferences:

Family U1 F2 commented:

> *"The staff do not know the likes and dislikes of my mum and don't have my insider knowledge. My mum has a life story book, and not all the staff know about it. The staff work on their intuition when it's hard to communicate with mum as they are from different cultural backgrounds."*

Staff U1 S1 *noted:*

> *"For most of the SAPWD, family is everything."*

These reflections demonstrate that while families provide crucial emotional support, caregiving responsibilities can also generate tension when practical realities, such as work or health limitations, conflict with cultural expectations.

Social and community pressures often influence family decisions and residents' experiences:

Family U1 F2 reflected:

> *"Staying in a nursing home with mental illness…his kids are not looking after him, that's what my uncles commented about my father. We explained he needs special care, and it's not possible to look after him at home."*

Family U2 F3 described culturally framed judgements:

> *"Oh can you see what happened to him, he was not following any of our culture, no belief in God, now see what happened, God punished that's why he got mental illness. He didn't teach his children to follow our culture, look*

> *at his destiny… now he is in nursing home. They said this to my ma and she was upset and putting pressure on us to bring back dada to home. My ma is don't have enough strength to take care of him. The staff's were lovely and he get his medicines and food on time and the Quality of care is good. I am not bothered about my community and my preference is my dadas health."(U2F3)*

These accounts illustrate the tension between cultural norms and practical care needs, highlighting the negotiation families face between social expectations and the resident's well-being.

Religious beliefs often frame family obligations and perceptions of professional care:

Family U2 F5 stated:

> *"All family members believe there is order from the almighty for sons and daughters on how to behave with elderly people and how to take care at home."*

These beliefs can result in internal and external conflict, where family members recognise the necessity of professional care but feel guilt or fear community judgment. Despite these challenges, families often recognise the benefits of professional care. Residential homes provide structured routines, access to trained staff, medical supervision, and safety, particularly as dementia progresses and residents develop additional health needs. Participants highlighted that professional care offers relief for both the resident and the family, reducing stress and allowing family members to maintain other responsibilities.

Despite these beliefs, participants acknowledged the benefits of professional care:

Family U4 F7 reflected:

> "*The journey is so challenging, sometimes, I think residential homes or nursing homes can help professionally and care at home drains my health and I was stressed. There is a South Asian support group and we all meet together and share our feelings, which actually made me think that I had taken a good decision for my mum"*.

Awareness about dementia influenced family decisions. Participants noted that families in South Asian countries often lack familiarity with dementia care:

Family U2 F4 observed:

> *"Our family members don't know about dementia in Bangladesh and are not at all familiar with care homes."*

Family U3 F5 added:

> *"In India, we never sent our parents to old age homes; nowadays people are staying in retirement houses, somewhat like nursing homes…they don't have anybody to look after them; now you know the trend…all are in different countries."*

Families in the UK demonstrated better awareness, though cultural and social pressures remained significant:

Family U3 F2 noted:

> *"It's my dad; it's not significant for them as I do. If they understood what dementia is and what my dad needs, they wouldn't behave like this…My dad needs nursing care, and it's not possible at home."*

Healthcare professionals from South Asian backgrounds often serve as bridges, combining clinical expertise and cultural understanding to support families and residents.

This category highlights that entering and living in residential care for SAPWD is a complex negotiation between:

- Emotional support derived from family strength and cohesion
- Loss experienced through separation from daily family life and community
- Cultural and religious obligations
- Practical safety and care needs

Participants' experiences demonstrate the interdependent nature of care, with family, staff, and community shaping the resident's adjustment and well-being. This aligns with the overarching theme of Active Negotiation, showing how residents, families, and staff collaboratively navigate cultural, emotional, and practical aspects of dementia care.

5.2 Subcategory- Uncertainty

For SAPWD, moving into residential care often triggers profound uncertainty. This extends beyond medical concerns, encompassing loss of familiar surroundings, changes in routine, and perceived disruptions to identity and family roles. In this study, uncertainty emerged as a central theme, reflecting residents' ongoing negotiation of their new environment.

To improve coherence, this section is structured around three interconnected sources of uncertainty: (1) loss and confusion, (2) questioning purpose and life circumstances, (3) social isolation and family dynamics.

5.2.1 Loss and Confusion

Residents described immediate feelings of disorientation and emotional loss. One participant shared:

> *"I am confused and lost; I lost everything… er my family and friends." (R2 U3)*

Another highlighted the impact of diminished autonomy and changing abilities on their sense of self:

> *"I am not the same person anymore. I can't work or drive… they said it's not safe hmm… I feel I have lost my identity." (U3 R5)*

These narratives illustrate how uncertainty encompasses both practical limitations and a perceived erosion of personal identity.

5.2.2 Questioning Purpose and Life Circumstances

Uncertainty also involves existential questioning. Residents often struggled to understand their place in the care home and the trajectory of their illness. One participant expressed:

> *"I can't bear this pain, I don't have any control of my life… I lost my home, everything… my children… sometimes I think why I am here, I want to find out why I am here… I… I… it's all uncertain…" (U1 R1)*

Another described the unpredictability of daily life:

> *"It's an overwhelming feeling ah… you don't know what's going to happen." (U4 R7)*

These reflections highlight the emotional burden of uncertainty and the active effort required to negotiate daily experiences.

5.2.3 Social Isolation and Family Dynamics

Limited family interaction compounded feelings of uncertainty and isolation. A participant described:

> *“I am alone here, all time, staff comes and goes, they always ask me are you alright, I say ya, I am alright… Actually, I am not, I feel I am in an island, I feel I just stuck in this place, don't know what to do, I miss my family…” (U1 R3)*

Family members also faced uncertainty, balancing cultural expectations with the practicalities of care:

> *“So it's that sort of thing and… I think also… with my husband there's a lot of bitterness from the fact that he… now I use this word ‘dumped’ in nursing home. Our children are busy, no time to visit… it’s their responsibility to look after his forgetting illness, but what to do, they can't manage.” (U1 F2)*

Cultural perceptions of dementia further shaped these experiences. Some families viewed memory loss as a normal part of ageing, which often delayed intervention:

> *“Memory loss related to old age… when you are old, you will get dementia and illness.” (U1 R1)*

These examples show how uncertainty is embedded within both personal and cultural contexts, affecting residents’ emotional adjustment.

Healthcare professionals and family support helped residents navigate uncertainty. Strategies to negotiate uncertainty can include structured information about dementia and empathetic engagement, which enabled better coping. One family member reflected:

> *“Understanding different types of dementia and how it progresses has helped me support my father better and cope with the challenges of residential care.” (U4 F7)*

This demonstrates how active negotiation through education, support, and cultural sensitivity can reduce distress and foster acceptance.

Uncertainty for SAPWD in residential care is multifaceted, encompassing:

- Loss of autonomy and identity
- Social isolation and family dynamics
- Cultural interpretations of dementia
- Emotional responses such as confusion, fear, and stress

Residents and families actively negotiate these uncertainties by seeking understanding, support, and meaningful connections. Addressing uncertainty through empathetic, culturally informed care is essential for promoting well-being and facilitating adaptation to residential care.

5.3 Subcategory- Loneliness

Loneliness is a complex and deeply felt experience for SAPWD living in residential care. It encompasses both emotional isolations, arising from the absence of meaningful attachments, and social isolation, caused by limited social engagement. Admission to a care home often disrupts familiar social networks, reduces family contact, and limits psychological support, creating conditions where loneliness can become persistent and overwhelming.

In the interest of coherence, the section groups the discussion into five related dimensions of loneliness: (1) impact of care home admissions, (2) loss of skills, independence and social participation, (3) family and community relations, (4) emotional and psychological consequences, (5) strategies for mitigating loneliness.

Disrupted family interactions were a primary contributor to loneliness. One family member described the emotional impact of reduced visits:

> *"Its painful to watch my mum in this situation, I used to visit every week and now I could only visit once in a month. We used to talk a lot about our family, mums childhood in India, our tradition, when she migrated to Britain, struggles to cope up with the weather and financial problems…my mum…and dad worked hard to buy a house and now look she finally ended up here. She misses all her siblings and relatives in India and now she missing her friends…they used to visit and phone my mum…but as my mum health is declining and she is also not interested…everyone says my mum was energetic and its hard to see her very quietly sitting in one place…erm…(wiping tears) now a days she is not talking much and I feel guilty. My mum says she is alone here, nobody wants her." (U1 F2)*

Residents themselves expressed longing for their family and friends:

> *“I like more visitors coming to see me. I am lonely here… my son and daughter-in-law come only once in a month… I miss my grandchildren… they don’t like to come here.” (U4 R6)*
>
> *“I look forward for my daughter to come and spend some time with me… she rings me every day and checks on me. Without my family I am lonely… lonely…” (U1 F1)*

These narratives illustrate how loneliness is not simply the absence of people, but the absence of meaningful engagement with those who share cultural and familial connections.

Language differences and cultural unfamiliarity further intensified feelings of loneliness. One family member highlighted communication difficulties with staff:

> *“I know the staff helps a lot and encourage her to start a conversation and sometimes it works. She speaks English fluently, the slang is different.” (U2 F3)*

Similarly, residents reported challenges in understanding younger family members or staff:

> *“My mum says she can't understand a few staff’s English. She says the same thing with the grandchildren.” (U3 F4)*

These barriers limited opportunities for meaningful interaction, leaving residents feeling isolated even when others were present.

Positive interactions with staff helped alleviate loneliness, particularly when care was consistent and culturally sensitive. One resident reflected:

> *"I am happy to chat with staff and other residents…I like one of the care staff...she is lovely…all other staffs are always busy, she comes to my room and wish me and make sdsure that I am fine even though she is busy. I feel lonely if I couldn't see her every day. I know she can't work everday…but I am happy when I see and chat with this kind girl."(U2 R4)*

However, limited staff availability often constrained social engagement:

> *"We are always stuck in this room, staff comes and go, they ask me would you like to come to lounge or for any other activity…they are always busy and rushing…when I see the staffs are busy I just don't want to disturb them. I just stay alone in my room"(U2 R3)*

Staff themselves recognised the importance of culturally familiar interactions:

> *"When the residents see Asian healthcare professionals, they are happy and enquire about next visit. They like companionship and talking about their past in proud, where they are from, job, family, house, childrens job and they are interested in talking about anything…I think loneliness stretching out at times and its growing bigger and bigger when nobody to talk". (U4S7)*

Residents and families actively negotiate loneliness through maintaining contact, seeking culturally sensitive interactions, and participating in social activities when possible. Addressing loneliness requires not only ensuring opportunities for social interaction but also promoting culturally and emotionally meaningful engagement, which supports the overarching process of Active Negotiation in care home adaptation.

5.3.1 Impact of Care Home Admission

Admission to a residential care home represents a profound transition for SAPWD, often experienced as a loss of familiar surroundings, autonomy, and social connections. This transition can trigger trauma, helplessness, and heightened loneliness, affecting both residents and their families.

Residents' families frequently observed noticeable changes in behaviour and personality following admission. One family member described the emotional impact of these changes:

> *"The person appears altered… no longer seems the same person. My mum changed a lot, not eating and drinking, her mobility reduced, we don't know what to do… (crying). I want to take my mum back home, but… I am working, no time… and no support from my family." (U1 F3*)

Another family noted a decline in activity and engagement:

> *"My father was very active prior to the admission, he forgets things at times, but he was happy… Now look at him, lying in bed all the time and very quiet." (U2 F3)*

These accounts illustrate how relocation can compound the effects of dementia, leading to altered routines, reduced participation, and emotional distress.

Care home admission often follows hospitalisations or health crises, which can intensify feelings of uncertainty and loss. One family recounted the events leading to their relative's move:

> *"My father had a fall and was hospitalised. Then they sent him to this nursing home, diagnosed with dementia, we don't know what to do… We didn't tell any relatives or friends." (U2 F6)*

This narrative reflects not only the disruption caused by sudden health events but also the isolation families feel when navigating decisions about care placement.

Together, these experiences show that admission to a care home affects emotional well-being on multiple levels. Residents may feel disconnected from their previous social networks, while families experience guilt, helplessness, and stress. The compounded sense of isolation underscores the need for strategies that support both residents and families in actively negotiating this transition.

For SAPWD, care home admission is a pivotal moment that:

- Alters daily routines and social engagement
- Contributes to changes in behaviour and personality
- Amplifies feelings of loneliness and helplessness for both residents and families

Understanding these impacts allows caregivers and family members to implement supportive measures that facilitate adaptation, maintain meaningful connections, and promote well-being. Through education, empathetic engagement, and structured support, residents and families engage in Active Negotiation, seeking to manage the emotional and social challenges of residential care.

5.3.2 Loss of Skills, Independence, and Social Participation

Admission to a care home frequently results in a reduction of personal autonomy, life skills, and social participation for SAPWD. Residents described increased dependence on staff for everyday activities, which contributed to feelings of helplessness, loss of identity, and diminished agency.

Many residents reported that routine tasks, once independently managed, were now performed by care staff, highlighting a profound loss of autonomy. One participant explained:

> *“I can't do anything, I can't go out, I can't go to any family functions… no more family get-togethers… staff help me with everything, can you imagine, including washing and helping me to go toilet… life… But, I have to say one thing, staff are really awesome, good staff… thanks to God for that.” (U4 R1)*

Another participant emphasised how care decisions were made without their involvement:

> *“All the decisions were made by social worker, GP, nurse and family, including my food and medication.” (U1 R1)*

These accounts illustrate the tension between necessary support and the loss of personal control, showing how residents must actively negotiate their daily lives under structured care regimes.

Admission often led to a perceived loss of social status and financial autonomy, intensifying feelings of being a burden. One resident described:

> *“All my money is managed by my son and he is not even buying toiletries.” (U2 R1)*

Another highlighted reluctance to seek assistance, despite needing support:

> *“People, including family and staff, treat me as if everything is arranged for me. When I need help, I am reluctant to ask for help from staff.” (U3 R3)*

These narratives reflect how diminished independence impacts both practical and psychological dimensions of life, reinforcing social withdrawal and self-perception as a dependent.

Residents also described emotional consequences of reduced involvement in decisions, which contributed to loneliness and frustration. One participant explained:

> *“When I started to say something to my son or daughter-in-law, they just keep quiet and that hurts me a lot… (crying)… nobody is listening to me.” (U3 R2)*

This highlights the emotional burden of diminished agency and illustrates how social participation is intricately tied to well-being and identity in care home contexts.

Loss of skills, independence, and social participation in residential care leads SAPWD to:

- Depend on staff for daily activities
- Experience reduced involvement in decision-making
- Feel diminished social status and autonomy
- Face emotional distress and increased loneliness

Residents and families engage in Active Negotiation to manage these losses, seeking ways to maintain agency, communicate preferences, and participate meaningfully in care routines. Understanding these experiences supports strategies that balance safety with autonomy, fostering well-being and engagement in the care home environment.

5.3.3 Family and Community Relations

For SAPWD, family and community connections are central to emotional well-being. Changes in family dynamics, conflicts over care responsibilities, and limited engagement can intensify loneliness and impact the adjustment to residential care.

Tensions within families often prompted care home admission and shaped residents' experiences of loneliness. One participant described the conflict that led to their relocation:

> *"I had arguments with my son, daughter, and daughter-in-law. Nobody wanted to look after me and finally I decided to move to a nursing home." (U1 R3)*

Another resident highlighted how health concerns and family worries influenced placement decisions:

> *"My daughter worried about my walking at night to the toilet, which led to a hip fracture. After hospitalisation, I was sent directly to the nursing home." (U5 R1)*

These narratives illustrate how family tensions and practical considerations can precipitate residential care, creating emotional strain for both residents and families.

Regular contact with family mitigated feelings of loneliness and provided a sense of continuity and belonging. A resident reflected on the mixed experiences of family visits:

> *"I visit every week, usually mummy likes to chat with me and wife…but, some days she is quiet and I feel like I am not even existed in the room. It hurts me a lot…I know she is suffering with health issues and dementia, so I just sit down in the chair and watch TV. My kids doesn't like to visit, they say its boring nanna is not saying a word. They love their nanna a lot…its hard for kids to stay in one place for few minutes. If the kids are not with me then she will ask where is the kids. Hmm actually I am struggling in between my family and my mum. Few visits with kids were lovely and we all were happy".(U2 R3)*

These experiences highlight the nuanced ways family engagement can either reinforce connection or contribute to feelings of invisibility and isolation. For SAPWD, familial relationships are often prioritised over social interactions with staff or other residents.

One participant emphasised this preference:

> *"Family visits are most important. Talking to staff is not the same as seeing my children. When they can't visit, I feel invisible." (U2 R3)*

Even with active engagement from care staff, limited contact with family can leave residents feeling socially and emotionally disconnected, reinforcing the centrality of family in well-being.

Family and community relations shape SAPWD experiences of loneliness in residential care by influencing:

- Care decisions and admission to the care home
- Emotional security and sense of belonging
- Perceived social value and identity

Residents actively negotiate these dynamics, balancing their reliance on staff with the desire for familial contact and cultural continuity. Supporting consistent family engagement, addressing conflicts, and acknowledging cultural priorities are critical for mitigating loneliness and fostering well-being, reflecting the broader principle of Active Negotiation within care home adaptation.

5.3.4 Emotional and Psychological Consequences

SAPWD in residential care has profound emotional and psychological consequences. Participants described experiences of depression, helplessness, loss of belonging, and diminished self-worth. These emotional responses were closely tied to reduced autonomy, declining physical ability, and limited involvement in decision-making.

Some residents expressed deep emotional distress linked to feelings of invisibility and being a burden. One participant articulated this sense of alienation:

> *"It is hard to feel like I belong here. I feel like I am in the way. Sometimes I wish life would end sooner. It's lonely and painful." (U1 R1)*

This narrative illustrates how prolonged loneliness can evolve into hopelessness, where the absence of meaningful connection undermines a resident's sense of purpose and belonging.

Declining mobility and increased dependence on staff reinforced feelings of powerlessness. A participant reflected on the contrast between life before and after admission:

> *"Before admission, I was independent. Now, I rely entirely on staff, which makes me feel trapped and powerless." (U3 R5)*

This account highlights how physical dependency is not experienced solely as practical support but as a psychological loss of control, intensifying emotional vulnerability.

Perceived surveillance and reduced privacy further contributed to emotional distress. One resident described their discomfort with constant monitoring:

> *“I didn’t have any privacy here, they spy me up here, what I am doing… they check me every time.” (U2 R3)*

This perception of limited autonomy illustrates how safety measures within institutional care can be interpreted as restrictive, contributing to feelings of alienation and diminished dignity.

The emotional and psychological consequences of loneliness for SAPWD in residential care include:

- Feelings of hopelessness and diminished belonging
- Helplessness linked to dependency and declining mobility
- Distress arising from reduced privacy and autonomy

These experiences demonstrate that loneliness is not merely social isolation but a deeply embodied emotional state affecting identity, dignity, and self-worth. Within the broader framework of Active Negotiation, residents attempt to make sense of these emotional challenges while navigating institutional structures, family relationships, and personal loss. Recognising and addressing these psychological dimensions is essential for promoting culturally sensitive, person-centred care that supports emotional well-being alongside physical safety.

5.3.5 Strategies for Mitigating Loneliness

Addressing loneliness among SAPWD in residential care requires deliberate strategies that combine family engagement, cultural sensitivity, and meaningful social interaction. Residents and staff highlighted several approaches that help mitigate emotional and social isolation.

Regular visits from family or familiar community members were consistently identified as central to reducing loneliness. One staff participant emphasised the importance of family interaction in residents’ emotional well-being:

> *“Residents benefit greatly when family or familiar community members visit and engage in conversation. Staff involvement helps, but it cannot replace family interaction.” (U4 S7)*

This narrative illustrates that while staff support is important, familial presence remains indispensable for sustaining connection and identity.

Engaging residents in activities aligned with their cultural background and personal interests can foster participation and reduce isolation. Staff described how culturally sensitive engagement enhances social interaction:

> *"Engaging residents through conversation, activities, and family visits brings joy, reduces loneliness, and allows them to feel seen and valued." (U4 S7)*

Such interventions demonstrate that loneliness is not simply the absence of social contact but is shaped by meaningful interaction, recognition, and culturally appropriate communication.

Loneliness in SAPWD is multifaceted, influenced by emotional isolation, disrupted family connections, loss of independence, and restricted autonomy. Admission to care homes often accelerates these experiences through changes in identity, reduced social participation, and limited personal agency.

Mitigating loneliness requires active strategies that allow residents to participate in decisions affecting their lives, maintain family connections, and engage in culturally relevant activities. These efforts support residents' capacity to negotiate social, emotional, and cultural challenges, reflecting the principle of Active Negotiation.

Effective interventions for reducing loneliness in residential care include:

- Encouraging regular family and community visits
- Facilitating meaningful conversations with staff
- Tailoring activities to cultural backgrounds and personal interests
- Empowering residents to participate in decisions about their care and daily routines

By combining these strategies, care homes can enhance emotional, social, and psychological well-being, enabling residents to actively negotiate the challenges of residential life while maintaining a sense of dignity, connection, and belonging.

5.4 Subcategory- Community prejudice

Stigma is a pervasive issue affecting people with dementia, particularly in South Asian communities. It is generally conceptualised in three interrelated aspects: stereotype, prejudice, and discrimination. Stereotypes involve negative beliefs about a group, prejudice occurs when these stereotypes are internalised and elicit negative emotions or attitudes, and discrimination is the behavioural manifestation of prejudice. In the context of dementia care, these dimensions are interlinked, shaping the experiences of individuals, their families, and care staff.

For the sake of clarity and cohesion, this section adopts a five-part framework built around interrelated forms of community prejudice: stereotypes, prejudice, discrimination, cultural and community influences, and implications for care.

Participants reflected on community prejudice and stigma associated with entering care homes, which is identified under the subcategory *Community Prejudice* within the category *Entering Care Homes*.

One resident described the experience of being socially labelled after entering residential care:

> *"I don't know, you will end up in these elderly homes and you start getting labelled…some friends, several friends seemed to label me like that…I do get labelled, you know."* (R2 U2)

When asked to explain this perception, the participant further stated:

> *"Just the stigma, I suppose. People gossip that my sons and daughters don't love or respect me and that they don't have time."* (R2 U2)

These reflections illustrate the emotional and cultural barriers faced by SAPWD, emphasising that entering residential care is often perceived as a sign of family neglect. This cultural stigma contributes to the low rate of admissions to residential care. Such experiences highlight the need for equitable, culturally sensitive, and high-quality dementia care that addresses both practical and psychosocial needs within South Asian communities in the UK.

5.4.1 Stereotypes

SAPWD are often subject to social stigma and negative stereotypes, which shape perceptions of their abilities, health progression, and care outcomes. Common stereotypes include viewing dementia as an inevitable part of ageing, a punishment from God, insanity, or a condition leading to total cognitive and functional decline. Residents are frequently perceived as burdensome, incapable of contributing to society, and unable to communicate effectively.

Participants' narratives highlighted how internalised and societal stereotypes influenced their experiences:

One resident expressed feelings of helplessness linked to cultural notions of fate:

> *"I am tired… I feel like I can't do anything… its terrible. I think I will die soon without anybody near me… it's my fate …(U1 R1)*

Another resident reflected on the profound sense of invisibility and despair caused by the disease:

> *"Dementia attacked me… I am living dead in this place." (U3 R5)*

Family members similarly observed decline that they attributed to inevitable progression, reflecting stereotypical assumptions about dementia:

> *"My dad's health is worsening after coming here. I thought he would get better with the medications and good care." (U1 F1)*
>
> *"He was in good spirits at home; now I don't know… dementia is killing him slowly. It robbed my dad's health." (U3 R5)*
>
> *"Mum was in good health at home; she lost weight and is struggling to walk." (U2 F4)*

These accounts illustrate how stereotypes are internalised by residents and reinforced by family perceptions, shaping expectations about disease progression and recovery.

Some staff members also reflected stereotypical assumptions, interpreting dementia as synonymous with inevitable decline and multi-morbidity:

> *"If it's dementia, then there won't be any progress in the resident's health. Most of the residents' health decreases gradually and they are accompanied by other diseases." (U2 S4)*

These institutional perceptions may inadvertently influence care decisions, contributing to lowered expectations and limited opportunities for meaningful engagement or rehabilitation.

Cultural and Societal Influences

Cultural and societal misconceptions compound stereotypes. Within South Asian communities, admission to a care home is often stigmatised, associated with neglect or abandonment, and perceived as a stage of waiting for death. Limited awareness and education about dementia reinforce these beliefs, creating a broader social environment in which stereotypes persist and affect both families and care providers.

Stereotypes in dementia care affect residents, families, and staff, influencing:

- Expectations regarding disease progression and recovery
- Perceptions of autonomy, competence, and social value
- Institutional care practices and engagement opportunities

Residents and families actively negotiate these perceptions by challenging assumptions, seeking meaningful interaction, and advocating for care aligned with individual needs. Recognising and addressing stereotypes is crucial for promoting culturally sensitive, person-centred care, which aligns with the overarching principle of Active Negotiation.

5.4.2 Prejudice

Prejudice arises when stereotypes are internalised and influence attitudes, emotions, and behaviours toward individuals with dementia. Within South Asian communities, limited awareness of dementia often contributes to fear, anxiety, and avoidance, affecting family members, peers, healthcare providers, and the individuals themselves. This can result in shame, embarrassment, and social withdrawal.

Residents reported experiencing intense emotional distress due to prejudiced reactions from others, as well as their own internalised fears:

One participant described the embarrassment and confusion they felt as symptoms of dementia emerged:

> *“I didn’t understand what was happening to me. I was healthy, but suddenly became ill. I forgot things, and my son, wife, and grandchildren helped me. It was embarrassing, and I felt like a fool.” (U1 R2)*

Another resident reflected on how fear of dependence and being a burden intensified feeling of isolation:

> *“It was very difficult for me to even go to GP, because of my son and his worrying face…I went for appointment with son, then the specialist oh my God…I …I… couldn't believe or understand what was happening to me. Grandchildren they scared to come to my room. I couldn't eat or drink properly. Instead of toilet I passed urine in the corridor…I don't like depending on others, all are busy, I don't want to be a burden to my family. Everybody came to see me and I said I am perfectly alright. I am a proud person you know…I know they are struggling with me and decided to move to this nursing home. Everybody visited me, but sometimes I don't like to see anybody faces except my wife. Now only my son and wife visit and nobody wants me (U1 R1)*

These narratives demonstrate how prejudice can manifest both as external social pressure and as internalised self-criticism, contributing to shame, anxiety, and withdrawal from social engagement.

Prejudice, whether explicit or implicit, heightened concerns about being devalued or ignored within both the family and the wider community. These experiences underscore the psychosocial consequences of prejudice and how it reinforces isolation and emotional vulnerability.

Prejudice in South Asian dementia care impacts residents by:

- Amplifying feelings of shame, embarrassment, and social withdrawal
- Intensifying fear of dependence and being a burden
- Eroding self-esteem and perceived social value

Through Active Negotiation, residents navigate these challenges by balancing family expectations, personal dignity, and the need for support. Recognising and addressing prejudice through education, culturally sensitive care, and empathetic communication is essential for fostering well-being, sustaining identity, and promoting meaningful engagement in residential care.

5.4.3 Discrimination

Discrimination represents the behavioural expression of prejudice and is often observed in social exclusion, neglect, or unequal treatment within care settings. For SAPWD, discriminatory behaviors from peers, staff, and family members can intensify feelings of isolation, powerlessness, and vulnerability.

Some residents reported withdrawing from communal activities due to hostile behaviour from other residents. One participant described an incident in the lounge:

> *"I used to go to the lounge after breakfast, we did knitting with the activity lady…flower making and so on. One day a new resident came, looked at my face, and I said hello… she looked at me again with a furious face, shouted 'you go away from my country,' and pushed the tea trolley… few cups broke. I didn't understand what was happening, I was stuck…one of the staff members took me to my room and stayed with me, and the manager spoke to me. Whenever I see her, she stares at me, sometimes shouts and laughs at me… I was not comfortable, so I stopped going out of my room." (U2 R4)*

This narrative illustrates how peer discrimination can lead residents to withdraw from social engagement, reducing opportunities for interaction and participation.

Discrimination was also observed among staff, particularly when assumptions were made about residents' comprehension or abilities:

> *"Two staff came to my room and wished me good morning. They asked me something else; I was sleepy and didn't respond. I heard the other staff saying she doesn't know English… she has dementia, maybe confused; we can come later and ask her." (U2 R3*)
>
> *"Nurse was giving medicine to me and then the care staff brought food for me. Infront of me they both are talking and thought that I can't understand. (U1 R2)*

Such assumptions, based on dementia or language differences, reinforce social hierarchies, limit autonomy, and reduce dignity.

Family involvement is essential in care decisions; however, residents frequently experienced exclusion from decision-making processes:

> *"My son decides everything. They don't ask me…when I say something, he will say you don't know anything; I will inform the nurse." (U2 R4)*
>
> *"They say my voice is heard… no, it's already written, and the nurse will ask if I'm happy with the new care plan. If I suggest changes, I have to*

> *discuss with the manager and my son… they decide what I need to do.” (U2 R3)*
>
> *“I pressed the call bell for the toilet. The carer said I am always ringing the bell, don’t remember how many times they assisted me. Later, the nurse told me I had a urinary tract infection, that’s why I needed the toilet frequently. The HCA thought, because of dementia, I was asking unnecessarily. I told my daughter, and she informed the nurse.” (U1 R2)*

These experiences highlight how discriminatory behaviours can manifest through disregard for residents’ voices, assumptions about cognitive ability, and insufficient consultation in care planning.

Discrimination also affected social interactions with family and peers, contributing to isolation:

> *“My grandchildren visited me, and they were scared… didn’t come close to me…” (U3 R5)*
>
> *“My cousin was standing in the corner… he thought I would attack him.” (U2 R3)*

Fear, lack of awareness, and inadequate staff training underlie many of these discriminatory behaviours, while uniform approaches to care assuming all residents have the same limitations further exacerbate feelings of alienation and reduce quality of life.

Discrimination in residential care impacts SAPWD by:

- Limiting social participation and engagement
- Reducing autonomy and involvement in care decisions
- Reinforcing social isolation and emotional vulnerability

Through Active Negotiation, residents respond by withdrawing, adapting communication, or seeking advocacy from family or staff to protect dignity and well-being. Addressing discrimination requires cultural competence, tailored care approaches, and staff education to reduce bias and enhance inclusion, ensuring all residents experience equitable and respectful care.

5.4.4 Cultural and Community Influences

Cultural and community beliefs play a central role in shaping experiences of stigma for SAPWD. Limited understanding of dementia within these communities, coupled with fear of social judgment, often influences family and societal responses. Residents may experience isolation due to family anxiety about managing dementia, while social avoidance by the wider community reinforces feelings of rejection and shame.

Residents frequently described emotional distress linked to cultural expectations, memory loss, and social isolation. One participant reflected on the humiliation of being observed by others:

> *"I forget names and faces. It is humiliating when others notice. I feel ashamed and lonely." (U2 R5)*

Another resident highlighted the impact of perceived societal judgment:

> *"I worry that people think I am useless or a burden because I can't remember things. It hurts to be treated differently." (U1 R2)*

These accounts demonstrate how cultural norms and community perceptions can amplify feelings of inadequacy, guilt, and social withdrawal, shaping the psychosocial experience of dementia.

Within South Asian families, stigma may result in overprotection or isolation of the resident, often intended to shield them from judgment but inadvertently increasing loneliness. Residents may internalise these behaviours, attributing social avoidance to their cognitive decline rather than recognising broader cultural prejudice, which reinforces feelings of shame and self-blame.

Addressing cultural beliefs and community influences is critical to reducing stigma and fostering social inclusion. Awareness programs that target families, community members, and care staff can challenge misconceptions, promote understanding of dementia, and encourage supportive engagement. For residents, facilitating culturally sensitive communication and opportunities for meaningful participation helps counter isolation and reinforces a sense of dignity and belonging.

Cultural and community influences affect SAPWD by:

- Shaping family and societal responses to dementia
- Contributing to social withdrawal and emotional distress
- Reinforcing internalized shame, guilt, and perceived burden

Through Active Negotiation, residents navigate these dynamics by managing their interactions with family and community, balancing cultural expectations with personal needs, and seeking inclusion where possible. Care strategies that acknowledge and address cultural perceptions are essential to support emotional well-being, social integration, and dignity in residential care.

5.4.5 Implications for Care

Stigma in South Asian communities arises from an interplay of stereotypes, prejudice, and discrimination. Stereotypes of dementia as a terminal or debilitating condition influence prejudiced attitudes and discriminatory behaviours from family, staff, and peers. These experiences intensify loneliness, social isolation, and emotional distress among residents, often limiting engagement and autonomy.

Culturally sensitive care, family involvement, and staff awareness are essential to mitigating stigma. One staff member emphasised the importance of understanding the cultural background, involvement of the resident and family:

> *"Residents benefit greatly when staff understand their cultural background, involve them in decisions, and when family maintains regular, meaningful contact. This reduces loneliness and restores a sense of dignity." (U4 S7)*

Education and awareness programs are critical to dismantling misconceptions, fostering social inclusion, and improving the quality of life for residents with dementia.

5.5 Subcategory- Language barrier and communication

Language is a critical factor influencing person-centred and culturally appropriate care for South Asian people with dementia (SAPWD) in residential settings. Effective communication is essential for understanding residents' needs, implementing care plans, and promoting autonomy. However, misconceptions about residents' communication abilities often arise, particularly when they are non-native English speakers. Family members and staff may assume that residents with dementia cannot understand or respond effectively in English, even in early-stage dementia. These assumptions can reinforce stigma, insecurity, and social withdrawal.

This section uses three linked dimensions of language barrier and communication as an organising framework to help maintain coherence throughout: challenges with accents and linguistic diversity, miscommunication and psychological impact, and strategies to overcome language barriers.

5.5.1 Challenges with Accent and Linguistic Diversity

Families frequently prioritise care facilities with staff who speak the resident's first language. Even one familiar staff member can provide reassurance that care needs will be understood. Residents, although proficient in English, often experience anxiety about being misunderstood, particularly when interacting with staff from diverse linguistic backgrounds.

One family member explained the challenges related to the accent:

> *"My dad grew up in India, he was a doctor and then migrated to Britain and worked in NHS. He speaks English very well, but the accent is different, how can I say, yeah...he got Hindi accent, hmm… we call it 'desi accent'…I think he is insecure and told me, maybe the staff does not understand what I am saying, and he likes to talk to only familiar faces. He said when he was chatting with carer, the nurse was listening to him curiously and said his accent was different and its bit difficult to understand, since then he is reluctant to speak English and we always encourage him" (U4 F6)*

Similarly, another participant described the additional effort required to manage communication difficulties:

> *"Manger or nurse rings me when they can't understand what my mum is saying or when she is not replying to them. It usually happens when I visit and go, whenever mum is upset, she won't talk to anybody, no medicine water or food…and if my mum is angry she speaks in Gujarati…I have to travel back and spend some more time with her and when she fall asleep I go home" (U2 F3)*

Residents themselves acknowledged that emotional states can influence language use:

> *"Even though I know English, sometimes I prefer to speak Gujarati when upset. Staff who understand this can respond appropriately, making me feel respected and safe." (U2 F3)*

5.5.2 Miscommunication and Psychological Impact

Misunderstandings due to accent, pronunciation, or staff assumptions about cognitive decline can impede engagement and heighten feelings of insecurity. One resident reflected:

> *“Not really…sometimes I feel it’s hard to understand even though I speak English…when the carers are busy they talk to me fast and its hard to understand. Staffs are from different countries and they all speak different ways…I tell them to repeat if I can't understand and they also says excuse me please…then I know they didn't understand what I said and I repeat again."(U3 R5)*

Such communication barriers can lead to frustration, social withdrawal, and reduced participation in activities. Conversely, residents reported greater confidence and satisfaction when staff demonstrated linguistic awareness and cultural familiarity:

> *“When carers understand my language and speak slowly, I feel included. I can express what I want and feel confident that they understand me.” (U2 R3)*
>
> *“Good communication is not just about language; it’s about understanding, patience, and mutual respect. When staff make the effort to understand me, I feel safe, valued, and confident.” (U4 R6)*

5.5.3 Strategies to Overcome Language Barriers

Language barriers significantly influence the quality of care, social inclusion, and psychological well-being of SAPWD. Even residents with adequate English proficiency may experience anxiety, insecurity, and social withdrawal when their communication needs are not recognised or respected. Effective communication requires a combination of cultural sensitivity, staff training, family involvement, and structured support strategies. By addressing linguistic and cultural nuances, care homes can enhance person-centred care, reduce stigma, and foster an environment in which residents feel heard, respected, and included.

5.6 Summary

This chapter presented the findings of the study, highlighting the experiences of SAPWD in residential care and the development of the Active Negotiation theory. The analysis revealed that entering and adapting to residential care is a complex process influenced by cultural values, family dynamics, community perceptions, and institutional practices. Residents experienced uncertainty, loneliness, and loss of autonomy, compounded by social stigma, prejudice, and communication barriers. Family involvement, culturally sensitive care, and effective communication with staff were identified as crucial factors in supporting residents’ emotional well-being and facilitating adjustment. Overall, the findings underscore the multifaceted challenges

SAPWD face in residential settings and emphasise the importance of holistic, culturally informed strategies to enhance dignity, inclusion, and quality of life.

Chapter: 6

Findings: Adjustment to Care in a Residential Setting

Subcategories related to Adjustment to Care

- **-Culturally oriented care**
- **-Concerns and complaints**
- **-Busy Schedule**
- **-Medication**

6.1 Introduction

Adjustment to residential care for SAPWD involves navigating both practical and emotional challenges, with culturally sensitive support playing a central role in maintaining well-being. Key subcategories such as culturally oriented care, concerns and complaints from residents, families, and staff, busy schedules, and medication management highlight the complexity of daily life in care settings. Being involved in supportive relationships with staff and family members is particularly important for preserving a sense of identity, dignity, and emotional security. Residents valued reassurance through predictable routines, privacy, choice, and access to meaningful activities, as these factors contributed to their overall sense of well-being. However, many reported concerns about restrictions on daily activities, hobbies, and personal autonomy, emphasising the increasing dependence on staff for mobility and personal care. These experiences illustrate the delicate balance between receiving necessary support and maintaining independence, highlighting the importance of culturally responsive practices that promote engagement, respect, and continuity of identity.

6.2 Subcategory- Culturally oriented care

Culturally oriented care is essential for SAPWD in residential settings, as it addresses individual spiritual, dietary, linguistic, and social preferences, ensuring that care is respectful, person-centred, and meaningful. Recognising and accommodating cultural differences helps residents maintain dignity, autonomy, and a sense of belonging.

To strengthen coherence, this section is organised into four interconnected aspects of culturally oriented care: daily routines and spiritual practices; respectful social interactions; festivals; dietary preferences and religious restrictions; and diversity within South Asian communities.

6.2.1 Daily Routines and Spiritual Practices

Respecting residents' personal routines, including spiritual practices, emerged as a critical component of culturally sensitive care. One resident described the importance of morning rituals:

> *"I like to pray in bed when I wake up and then I start my day. But some of the nurses wake me up to give tablets, and I hate it. I told the manager I like to pray first, then toilet, breakfast, and medicine…that's how I start my day, but it's irritating if it's not in order." (U2 R3)*

Another resident described a detailed morning routine that incorporated spiritual and cultural practices:

> *"I go to toilet… that's the first thing in the morning…now a days I can't walk steadily, I need to wait for the staff to put me in wheelchair…then if I am ok and steady I will try to walk with frame and meet other residents in dinning room and have breakfast…I think around 10 O clock I am back to my bedroom and do my prayers…I recite our prayers…read Bhagavat Geetha and listen to divine songs and meditate for sometime*" (U4 R2)

Staff acknowledged the significance of these practices in supporting well-being:

> *"We try to follow residents' routines according to their preferences, and they are happy. At times, due to emergencies or staff shortages, it's not possible and we explain and apologise for the inconvenience." (U1 S1)*

6.2.2 Respectful Social Interactions

Cultural norms around respect and social interactions were also highlighted. In many South Asian cultures, addressing elders by their first name is considered disrespectful. One staff member reflected:

> *"One of the residents doesn't like to be called by her name. In her culture, it's disrespectful; they respect their elders and never say their name. Usually, we address a person by name, which is entirely different in their culture." (U2 S3)*

Family members reinforced the importance of cultural respect in communication:

> *“My mum liked to be called 'dadi ma' and she was shocked when staff called her name…she said, young girls calling my name… nowadays no respect…what a modern culture.” (U2 F3)*

Such differences highlight the need for staff to understand and accommodate cultural beliefs, ensuring residents feel respected and valued. Implementing these practices often involved recording preferences in care plans, yet lapses sometimes occurred with new or agency staff, affecting residents’ willingness to engage in care routines.

> *“Yeah, I talked to the manager and it was written in her care plan, she likes to be called 'dadi ma', but some new staff or agency staff calls name and my mum will be angry and she won't cooperate with the staff". (U2 F1)*

Language is another vital aspect of culturally oriented care. Communication in the resident’s first language fosters trust, reduces anxiety, and strengthens relationships with staff. Residents often felt comforted when staff could speak their native language or show willingness to learn simple phrases.

One resident expressed:

> *“I feel happy when I see a carer from my country, but they can’t speak fluently…know only a few words… it makes me happy…I teach them a few words and it’s fun.” (U1 R2)*

Staff observed similar benefits:

This approach helps residents maintain connections to their cultural identity, reduces isolation, and supports their emotional well-being.

6.2.3 Festivals, Dietary Preferences, and Religious Restrictions

Celebrating cultural and religious festivals was identified as a key strategy for promoting social engagement and joy. Residents appreciated recognition of traditions such as Eid and Diwali.

> *“Staff wished me Eid Mubarak and they arranged yummy biriyani, dates for me. It was a big surprise for me…my son brings food for me and chocolates*

> *for staff…this time he didn't come.. his leg was broken. I was upset and stayed in the room…the staff are so caring and lovely…" (U3 R5).*

Another resident described Diwali celebrations:

> *"On Diwali carer helps me to wear churidar and do my make up…there is no jasmine flower here so I just put a rose flower on my hair. We play music on our TV and dance…my leg hurts when I move, so I just move my head and hands… she brings some sweets and we share it with everyone" (U4 R7)*

Staff emphasised inclusivity by celebrating Christmas, Eid and Diwali.

> *"Most of our residents and staff are from India. We celebrate all the festivals and it makes them happy." (U4 S7)*

Respecting dietary and religious practices was another essential aspect of culturally oriented care. Misunderstandings about residents' dietary needs sometimes arose from assumptions or a lack of communication.

Misunderstandings sometimes occurred, requiring collaboration with families:

> *"When I came here, the carer offered mushroom pie and sandwiches… I like chicken and lamb, no beef or pork. My son brought chicken curry and rice. He talked to the nurse and now I am eating everything and the nurse ensured I could eat everything I liked" (U1 R1).*

Family members also highlighted culturally specific restrictions:

> *"When I came, dad's food was on the table, he didn't even touched it…I tried to encourage him to eat and he refused because he don't eat food with garlic and onion." (U1 F1)*
>
> *"My grandmother refused food with garlic and onion, as it was considered impure in our community." (U4 F7)*

These examples underscore the importance of understanding variations within South Asian cultures and avoiding assumptions based solely on ethnicity or religion.

6.2.4 Diversity within South Asian Communities

A recurring theme was the diversity within South Asian populations. Staff initially assumed uniform religious or dietary practices, but families clarified individual differences:

> *"We are Christians, but the staff assumed my mum was Hindu and kept talking about Goddesses…initially, they didn't believe us." (U2 F3)*

Acknowledging this diversity is critical for person-centred care and avoiding stereotypes. Staff training programs that focus on cultural awareness, including spirituality, food preferences, customs, and norms, are essential for improving care quality and resident satisfaction. Activities that connected residents to their cultural roots, such as reminiscence, storytelling, and discussions of traditions, were also beneficial. Many residents who migrated from South Asia expressed longing for their homeland, childhood, and family. Engaging in conversations about cultural practices or displaying familiar objects and photographs helped reduce feelings of isolation and reinforced residents' sense of identity. Staff observed that connecting residents to local cultural organisations or community events further supported their social inclusion and well-being. The study highlighted the importance of personalising care plans to accurately reflect each resident's cultural needs. Staff reported that recognising individual differences, rather than assuming uniformity within cultural groups, was crucial. This approach ensures that care remains respectful, dignified, and aligned with residents' values, fostering trust between residents, families, and care providers. In practice, culturally oriented care involved a combination of staff awareness, proactive engagement with families, flexible routines, inclusive activities, and continuous reflection on residents' evolving needs.

In summary, culturally oriented care for SAPWD requires a nuanced understanding of each individual's spiritual practices, dietary requirements, communication preferences, and personal routines. Staff must balance standard care procedures with flexibility to accommodate cultural needs, ensuring that residents feel respected, understood, and connected to their heritage. Incorporating culturally competent practices, such as acknowledging individual routines, supporting native-language communication, celebrating traditional festivals, respecting dietary and religious practices, and providing culturally aligned social interactions, enhances residents' quality of life and emotional well-being. Moreover, staff training and reflective practice are key to sustaining culturally sensitive care, promoting inclusion, and fostering positive relationships among residents, families, and caregivers. Ultimately, culturally oriented care acknowledges the “hyper diversity” of South Asian communities, moving beyond stereotypes to meet each resident’s unique needs while promoting dignity, respect, and holistic well-being.

This approach ensures residents feel respected, understood, and connected to their heritage, fostering emotional well-being, social inclusion, and dignity. Staff training, reflective practice, and collaboration with families are central to sustaining culturally sensitive care, supporting the broader principle of Active Negotiation in residential care.

6.3 Subcategory- Concerns and complaints

Concerns and complaints in residential care provide vital insights into the quality of care, communication, and organisational practices. For SAPWD, these mechanisms are particularly important, as they reflect not only care delivery but also cultural sensitivity, trust, and relationships between residents, families, and staff. Effectively addressing complaints demonstrates accountability and fosters collaboration, supporting the principle of Active Negotiation in care settings.

In the interest of coherence, the section groups the discussion into two related dimensions of concern and complaint: the relationship between care staff, residents, and family, and interpersonal relationships with the residents social isolation.

Residents often used formal or informal channels to voice concerns about their care experience. One resident expressed confidence in the responsiveness of management:

> *“I feel more confident knowing that when I raise a concern, it will be taken seriously, and action will be taken to improve the situation.” (U1 R2)*

This highlights the importance of validating residents’ voices and integrating their feedback into care planning. However, some residents were hesitant to complain, fearing repercussions or disruption of relationships with staff.

Families play a critical role in advocating for residents, but they sometimes balance advocacy with concern for staff relationships. One family member described this delicate negotiation:

> *"I don't want to make a big fuss, so I just said to the nurse that my dad is not happy with one of the staff. We had a meeting with the manager and the issue resolved, manager requested for a written complaint, but I don't want to put anybody in trouble." (U1 F1)*

This narrative demonstrates the careful negotiation families undertake to ensure their loved ones' needs are met while maintaining respectful interactions with care staff.

Staff members also face challenges when reporting complaints or abuse, including fear of confrontation, breaches of confidentiality, or professional repercussions. One care worker recounted:

> *"I complained to the manager and she was supportive to the senior carer. I reported to the council and the manager moved from here, and the management dismissed the senior carer for being rude with residents and staff…All the other staff were scared to report, and finally, they all appreciated me. The senior carer verbally abused the resident, I reported to the nurse in charge, and she supported me on how to complain formally." (U2 S4)*

This example illustrates the need for clear reporting procedures, supportive management, and a culture that encourages staff to raise concerns safely. Training and awareness programs are critical to building a transparent and accountable care environment.

Effective management of complaints also requires sensitivity to cultural and emotional contexts. Misunderstandings between families and staff can affect the care experience, especially when cultural expectations are not recognised. Encouraging open communication, active listening, and empathy helps to address concerns constructively. As one staff member noted:

> *"In our care home, we appreciate reporting any issues and consider them carefully." (U2 S3)*

This approach ensures that complaints are treated not as criticism but as opportunities for improvement, fostering trust and collaboration among residents, families, and staff.

The study highlighted the importance of a "listening culture" where residents, families, and staff feel empowered to raise issues without fear. Incorporating feedback into care routines enhances safety, well-being, and satisfaction. Proper staffing, training, and managerial support are essential for sustaining such a culture, particularly in ethnically diverse care homes serving SAPWD.

Concerns and complaints are integral to maintaining high-quality, culturally sensitive care. Key findings include:

- Residents value having their concerns acknowledged and addressed promptly, increasing confidence and participation.
- Families negotiate advocacy with relationship management, balancing cultural expectations and the desire for quality care.
- Staff require organisational support, clear reporting mechanisms, and protection from retaliation to raise complaints safely.
- Cultural and emotional awareness is essential for understanding and resolving issues effectively.
- Promoting a listening culture strengthens collaboration, trust, and accountability, aligning with the principle of Active Negotiation.

By recognising the perspectives of residents, families, and staff, care homes can create an environment that is responsive, inclusive, and culturally attuned, enhancing both care quality and relational dynamics.

6.3.1 Relationship between care staff, residents and family

The relationships among care staff, residents, and family members are central to the quality of residential care. Positive interactions promote trust, emotional security, and well-being, while misunderstandings or delays in care can affect satisfaction, autonomy, and safety. For SAPWD, these relationships are further shaped by cultural expectations, family involvement, and communication preferences, underscoring the principle of Active Negotiation in daily care.

Residents often develop close relationships with care staff, which can provide comfort but may occasionally create tension with family members. Families sometimes express guilt or concern, interpreting these attachments as indicative of insufficient familial care. One family member described their feelings:

> *“I sometimes worry that my dad is too attached to the carers…he smiles and laughs with them, and I feel like I’m being replaced. But I know they care for him, so I try to trust the staff and communicate with them regularly.” (U4 F6)*

This narrative highlights the need for open communication between families and staff to clarify intentions, maintain trust, and negotiate expectations, ensuring residents’ emotional needs are met while respecting familial roles.

A recurrent concern raised by both residents and families was delays in assistance, often due to staff being busy or understaffed. One resident described the impact of slow responses during personal care routines:

> *“It’s embarrassing to ask for help in toileting. At meal times, I have to wait ages to go to the toilet. If I wet myself, I shout to staff to come and help me quickly. It spoils my day…you know…I feel powerless.” (U2 R3)*

Family members also reported distress over the physical discomfort and potential health risks associated with delayed support:

> *“I was furious when my mum said she has to wait for long time in wheelchair after the meal. I reported to the nurse and she apologised to me they were short staffed, I said next time its not acceptable as my mum got back pain and swelling on legs, she need assistance in walking. Can you imagine if you are sitting in one place not comfortably for long time”(U2F3)*

Delays in assistance not only cause discomfort but may also increase the risk of falls or injuries, especially when residents attempt to move independently without adequate support. These examples underscore the importance of prompt responsiveness, managerial oversight, and proactive staffing strategies to ensure safety, comfort, and dignity for residents.

Food and mealtime experiences were another area influencing the resident-staff-family relationship. While care homes provided nutritionally appropriate meals, many South Asian residents expressed dissatisfaction with unfamiliar flavours and bland meals.One resident noted:

> *“I miss the spicy curries and familiar flavours from home. The meals here are nutritious but bland; sometimes I just don’t feel like eating.” (U3 R5)*

Families often acted as cultural mediators, communicating preferences and facilitating adaptations, such as home-cooked meals or modified menu options:

> *“I bring homemade dishes for my father and explain to staff how to prepare them safely. It makes him happy, and he eats properly.” (U1 F2)*

Respecting dietary needs, including spice levels, traditional flavours, and religious restrictions, reflects culturally sensitive care and reinforces residents' sense of identity, comfort, and well-being.

Residents' autonomy was closely tied to the quality of relationships with staff and family. Practices that pressure residents to finish meals or limit choices negatively impacted dignity and engagement. One participant explained:

> *"Sometimes I don't want to finish all the food on my plate. I like to decide how much I eat. Staff let me choose, and it makes me feel respected." (U2 R4)*

Ensuring flexibility and respecting preferences allows residents to participate actively in decision-making about their care, reinforcing the principle of Active Negotiation and enhancing collaborative relationships.

The study highlights that strong, respectful relationships between staff, residents, and families are foundational to person-centred care. Key findings include:

- Emotional bonds with staff provide comfort but require clear communication with families to manage expectations.
- Prompt responsiveness to residents' physical needs prevents discomfort, injury, and distress.
- Cultural and dietary preferences are central to residents' well-being and require family collaboration and staff awareness.
- Respecting autonomy, providing choice, and negotiating care routines enhance dignity and trust.
- Continuous dialogue and culturally sensitive practice strengthen relationships, supporting a safer and more inclusive care environment.

By recognising and negotiating these complex interactions, care homes can foster trust, enhance satisfaction, and promote holistic well-being for SAPWD while respecting family dynamics and cultural values.

6.3.2 Interpersonal relationships with the resident's social isolation

Social interactions and meaningful relationships are fundamental to residents' well-being in residential care. For SAPWD, the interplay of staffing limitations, family involvement, and cultural expectations shapes opportunities for engagement and influences social inclusion. In this study, all participating care homes reported staff shortages, which limited residents' participation in communal activities and their capacity to develop sustained relationships. This contributed to loneliness and social isolation, with emotional, cognitive, and physical consequences.

Residents reported that limited staff availability often reduced opportunities for social participation and peer engagement. One resident described her interactions with the activity coordinator:

> *"The activity lady comes to my room and asks me what would you like to do, its freezing outside…we can go tomorrow for a walk, then she asks me how about colouring? Ahh I am like, I am not a kid, I just say it in my mind, she looks at me turns the TV on and asks me do you want me to put your favourite channel and left me in this room…(mimicking the sound and smiling) (U2 R4)*

This narrative illustrates the tension between structured activity provision and residents' preferences, highlighting the need for negotiated engagement, where staff and residents collaboratively plan meaningful participation.

Staff acknowledged the emotional impact of isolation and emphasised efforts to provide support, even during busy periods:

> *"I understand that they are lonely and frightened and they need our support…they are alone in the bedrooms, could hear only our footsteps and when they hear our familiar sound, they are happy. We try to spend time talking, listening, and encouraging participation in activities, even if it's just a small interaction." (U4 S6)*

These interactions, though brief, were vital for alleviating feelings of loneliness and fostering a sense of connection.

Family members played a central role in mitigating social isolation and advocating for residents' needs. Participants described concerns regarding medication management and physical comfort:

> *"I found that whenever I visit my dad, he seems to be sleepy and tired, I asked the nurse and she said, Dad is quite restless today, wandering, the risk for falling is high and for his safety a sedative was given. Dad takes only a tablet if he can't sleep at night. I was angry and upset looking at Dad's condition and reported to the manager. She said it's for my dad's safety and for the other residents' safety. He was restless and wandering with the frame" (U1 F1)*

> *"I was furious when my mum said she has to wait for long time in wheelchair after the meal. I reported to the nurse and she apologised to me they were short staffed, I said next time its not acceptable as my mum got back pain and swelling on legs, she need assistance in walking. Can you imagine if you are sitting in one place not comfortably for long time"(U2 F3)*

These accounts demonstrate the importance of families' vigilance in ensuring residents' physical comfort and safety, while also reflecting cultural expectations of filial responsibility common in South Asian communities.

Delayed responses to call bells emerged as a frequent source of frustration, reflecting the challenges of balancing high workloads and diverse resident needs.

A resident described their experience:

> *"I press the call bell, staff comes and asks me are you alright and they just go…one of the staff cancel the call bell and says I will be back in a minute, but she never turns in" (U2 R3)*
>
> Staff recognised the difficulties of managing multiple demands:
>
> *Some of the residents just buzz the bell all the time, when they are bored or unknowingly. If its short-staffed activity lady respond. If the call bell goes more than 1 minute manager or deputy manager tries to attend…if they are busy its not possible. I don't know how to say it…we also like to spend more time with the residents rather than medication, personal care and feeding. When we have so much to do on the floor its hard to reach to each resident " (U2 S4)*

These accounts highlight the need for structured negotiation between staff priorities and residents' expectations to minimise frustration and isolation.

Dietary preferences were another key factor influencing social well-being. Residents valued familiar flavours and traditional dishes, while care homes aimed to meet medical and nutritional requirements. One resident explained:

> *"I miss the familiar flavours from home. The meals here are healthy but bland. It helps when staff try to incorporate traditional spices or when family brings home-cooked food." (U3 R5)*

Families often facilitated culturally appropriate adaptations, negotiating dietary changes with staff to ensure both nutritional adequacy and cultural satisfaction.

Staff also recognised that South Asian families' high expectations stemmed from close cultural bonds and a sense of obligation:

> *"People from South Asian backgrounds have a close relationship with their family. Their expectations are high. We provide high-quality care, rated*

> *outstanding by CQC, but families still raise concerns frequently due to worry or guilt.” (U2 S3)*

The study highlighted that open communication, empathetic listening, and involving families in care planning were effective strategies for addressing concerns, strengthening relationships, and reducing social isolation. Staff training on complaints and whistleblowing procedures ensured that concerns were raised safely and addressed promptly:

> *“We encourage families to share their concerns and explain the steps for formal complaints. When staff listen and respond, it demonstrates that residents’ needs are taken seriously, reducing conflict and building confidence in care.” (U4 S7)*
>
> *“I wanted to complain about a staff member who spoke rudely to residents. I wasn’t sure where to report, but the manager guided me, and the issue was resolved. It reassured me that the care home takes concerns seriously.” (U2 F4*)

These practices reinforced trust, promoted emotional security, and enhanced residents’ participation in communal life, mitigating the negative effects of social isolation.

Residents’ social well-being in residential care is shaped by the quality of interpersonal relationships, staff responsiveness, family involvement, and culturally sensitive practices. Key findings include:

- **Staff-resident interactions**: Even brief, empathetic engagement reduces loneliness and fosters a sense of belonging.
- **Family advocacy**: Families help monitor care, address concerns, and negotiate culturally appropriate practices.
- **Cultural and dietary negotiation**: Respecting traditional foods, routines, and cultural norms enhances emotional comfort and social engagement.
- **Active Negotiation**: Residents, families, and staff must collaboratively negotiate care routines, expectations, and participation to address social isolation effectively.

By integrating attentive care, culturally responsive practices, and open communication, residential settings can reduce social isolation, strengthen interpersonal relationships, and support holistic well-being for SAPWD.

6.4 Subcategory- Busy Schedule

In residential care homes, busyness is a persistent subcategory that significantly influences the quality of care and the well-being of both staff and residents. The shortage of nurses and care assistants creates a challenging working environment where staff struggle to meet residents' complex needs, especially those with dementia. Within residential settings, this sense of constant urgency often manifests as frustration, emotional exhaustion, and reduced opportunities for meaningful interaction with residents and their families.

To strengthen coherence, this section is organised into eight interrelated dimensions of cooperation: the nature of busyness in care settings, emotional and physical consequences, impact on quality of care, understanding between residents, families and staff, organisational and management perception, psychological implications for residents with dementia, emotional resilience and coping with dementia, and residents perception of busyness and empathy.

6.4.1 The Nature of Busyness in Care Settings

This subcategory examines how staff construct and experience "busyness" within the residential care environment. Rather than describing busyness simply as high workload, participants depicted it as a persistent state of unpredictability, interruption, and competing demands. Busyness was narrated as both structural and experiential, shaping how staff organise time, prioritise tasks, and interact with residents. Within the broader framework of *Active Negotiation*, busyness emerges as the context in which care is constantly balanced between institutional requirements and relational intentions.

Staff participants frequently framed busyness as working against time, particularly in the context of staff shortages. One staff member (U1 S2) described the experience succinctly:

> *"Busy schedules mean I'm always running against the clock. It's exhausting and frustrating."*

The phrase "running against the clock" conveys a sense of urgency and relentless time pressure. Busyness here is not episodic but continuous, producing emotional responses of exhaustion and frustration. Time becomes a governing force that shapes both workflow and emotional state.

Similarly, another staff participant (U2 S3) connected busyness directly to short staffing:

> *"Busy schedule means I couldn't finish the tasks in the available time…I feel frustrated at times, wondering how I am going to run the shift with short staff."*

This account highlights how busyness is experienced as insufficiency, insufficient time, insufficient staff, and insufficient capacity to complete tasks. The participant's questioning of how to "run the shift" reflects an ongoing negotiation between professional expectations and practical limitations.

Busyness was also constructed through the tension between direct care and administrative responsibilities. Staff described documentation requirements as essential but time-consuming, often competing with immediate resident needs.One participant (U1 S1) explained:

> *"I need to document all the records on the computer and it takes time…frequent updating is required. Sometimes I don't even have time to go for a break…whenever I sit in front of the system, everybody needs me…relatives want to talk, residents need medication, dressing, meetings and it's endless."*

This narrative illustrates the fragmentation of attention that characterises daily practice. The act of sitting at the computer becomes symbolic of divided priorities: while documentation ensures professional accountability and safety, it simultaneously distances staff from face-to-face engagement. The repetition of "everybody needs me" underscores the multiplicity of demands, reinforcing busyness as a state of constant interruption.

Importantly, participants expressed awareness that delaying documentation could compromise standards, yet prioritising it could reduce relational interaction. Busyness, therefore, is not merely about quantity of work, but about negotiating which responsibilities take precedence at any given moment.

6.4.2 Emotional and Physical Consequences

This theme explores the emotional and physical consequences of sustained busyness within the residential care setting. Participants described care work as demanding not only in terms of tasks, but in the emotional and bodily labour required to meet competing needs. These experiences reveal how staff wellbeing is closely intertwined with the everyday dynamics of care. Within the broader framework of *Active Negotiation*, staff accounts demonstrate how they continuously balance professional responsibility with personal limits.

Staff participants frequently described emotional exhaustion resulting from constant interruptions and competing demands. One staff member (U3 S4) reflected on the cumulative pressure of managing residents, families, and emergencies simultaneously:

> *“Some days I feel like I’m being pulled in every direction…residents, families, phone calls, emergencies. It’s overwhelming, and sometimes I just want to cry.”*

This narrative conveys more than temporary stress; it reflects a sustained emotional burden embedded in daily routines. The expression “pulled in every direction” illustrates fragmentation of attention and energy, while the admission of wanting to cry signals emotional vulnerability. Busyness, therefore, is experienced not merely as workload, but as emotional strain.

Another staff participant (U4 S5) described how this strain persisted even within team-based working arrangements:

> *“Even when we work as a team, it feels like you’re alone in the chaos. Everyone is just trying to survive the shift.”*

Although teamwork formally exists, this account highlights a subjective sense of isolation. The phrase “alone in the chaos” suggests that emotional labour remains individualised, even in collaborative environments. These findings align with prior research showing that excessive workload and understaffing contribute to psychological strain and burnout among care professionals. In the present study, emotional consequences are expressed as overwhelm, guilt, and a sense of merely “surviving” the shift rather than meaningfully engaging in care.

Alongside emotional stress, staff described physical exhaustion and the erosion of basic self-care practices. A nurse participant explained how continuous demands disrupted rest and recovery:

> *"I don't remember when I had a proper lunch break. The moment I sit, someone needs medication, a relative wants to talk, or an incident happens." (U2 S2)*

This account illustrates how the rhythm of institutional life overrides bodily needs. The inability to take a "proper lunch break" symbolises the broader disruption of work–life balance and physical recovery. Fatigue and skipped meals were described as normalised aspects of care work, further intensifying stress and reducing resilience.

Importantly, participants' narratives suggest that emotional and physical consequences are interdependent. Exhaustion diminishes emotional capacity, while emotional strain heightens physical fatigue, creating a cyclical pattern that shapes daily practice.

Across these accounts, the consequences of busyness are not isolated individual complaints but reflections of structural and relational pressures within residential care. Staff continually negotiate competing priorities, regulate their emotional responses, and push their physical limits to sustain care delivery.

Within the overarching theme of *Active Negotiation*, staff wellbeing becomes a central element of care quality. Emotional endurance and physical stamina are constantly balanced against professional expectations and residents' needs. The findings therefore suggest that sustaining quality care requires recognition of staff vulnerability, as their capacity to negotiate demands directly influences the atmosphere, relationships, and overall functioning of the residential setting.

6.4.3 Impact on Quality of Care

This theme explores how staff busyness shapes the quality of care experienced by residents and observed by families. Participants did not suggest that essential clinical tasks were neglected; rather, they described how relational and emotional aspects of care were often compressed under time pressure. Within the broader theme of *Active Negotiation*, quality of care emerges as something continuously balanced between task completion and meaningful engagement.

Staff participants reflected openly on the difficulty of sustaining person-centred interactions while meeting organisational demands. One staff member expressed feelings of guilt when time constraints limited conversations with residents:

> *"Some days I feel guilty that I couldn't even have 1 minute to have a conversation with our lovely residents…they know that I am busy, but it's my responsibility to have a good rapport with them." (U3 S5)*

This account illustrates the internal negotiation experienced by staff between professional responsibility and practical limitations. The participant recognises residents' awareness of busyness, yet continues to frame relational connection as a personal duty. Quality of care, therefore, is not defined solely by task completion but by the ability to sustain rapport, even when time is scarce.

Residents demonstrated awareness of staffing pressures and often moderated their expectations accordingly. One resident acknowledged staff shortages while reflecting on the value of personalised attention:

> *"They are always busy, can't you see? We can't expect any more. I think today they are short of two staff; they are sick. She usually brushes my hair beautifully and paints my nails, walks with me to the garden, talks to me when I am sad and brightens me up kind-hearted girl and gentle to everyone." (U2 R3)*

Here, the resident actively interprets busyness within the context of staffing shortages, showing empathy toward staff. At the same time, the description of hair brushing, nail painting, and companionship highlights what constitutes "quality" from the resident's perspective small relational acts that support dignity and emotional wellbeing. When these are disrupted, quality is perceived as diminished, even if essential tasks are completed.

For some residents, particularly those reliant on routine and reassurance, hurried interactions generated anxiety. One resident described how staff rushing affected their sense of security:

> *"When the staff hurry, I feel nervous. I know they're busy, but I wish they'd tell me if they'll be late. It makes me feel invisible when they rush past." (U1 R2)*

This account demonstrates how communication plays a crucial role in perceived care quality. The issue is not solely delay, but the absence of explanation. Feeling "invisible" reflects a disruption in relational recognition, suggesting that quality of care is closely tied to being acknowledged and informed.

Family members similarly identified delays as affecting basic care needs. One family participant expressed concern about waiting times:

> *"My dad waits too long for help. Sometimes I've been here for 20 minutes and no one came. He needs assistance for everything—this shouldn't happen." (U2 F1)*

Unlike residents who sometimes normalised busyness, this account highlights the limits of negotiation. When delays compromise fundamental assistance, concerns about safety and dignity become more pronounced. Quality of care, from the family perspective, includes timely responsiveness as well as compassion.

Across these accounts, the impact of busyness on quality of care is not presented as simple neglect, but as a continual balancing act. Staff negotiate between efficiency and empathy; residents negotiate expectations in light of visible constraints; families negotiate trust in the system while advocating for timely support.

Within the overarching theme of *Active Negotiation*, quality of care is revealed as relationally constructed. It is shaped not only by clinical competence, but by communication, recognition, timeliness, and emotional presence. When these relational elements are compressed by busyness, participants experience a subtle yet meaningful decline in perceived quality of care, even when essential tasks are completed.

6.4.4 Understanding Between Residents, Families, and Staff

This theme explores how mutual understanding between residents, families, and staff sustains care quality within a context of busyness and organisational constraint. Participants described understanding not as a given, but as something actively developed through relationships, communication, and everyday interactions. Within the broader framework of *Active Negotiation*, these relationships function as stabilising mechanisms that help balance expectations and limitations.

Staff participants emphasised that long-term relationship building with families fosters patience and shared understanding, particularly during periods of staffing pressure.

One staff member reflected on how familiarity and emotional connection shaped family responses:

> *"We've built strong bonds with some families. They know we're doing our best. We're like an extended family trying to manage with what we have." (U4 S6)*

This account positions understanding as relationally constructed over time. The metaphor of an "extended family" suggests emotional closeness and collective responsibility, reinforcing the idea that care is sustained through trust rather than solely through institutional efficiency. The phrase "trying to manage with what we have" reflects an ongoing negotiation of expectations, where families recognise systemic limitations and adjust their expectations accordingly.

Residents also described how small acts of compassion preserve dignity, even within brief encounters. One resident recounted an incident involving embarrassment and vulnerability after spilling tea:

> *"I spilled tea on the carpet and the housekeeping lady was not happy. She cleaned the carpet, and the way she looked at me was horrifying…I didn't do it purposely. I know she got plenty of work to do…One of the carers noticed this and told me it's okay, wiped my hands, helped me change my clothes, and made me comfortable in the armchair. Sometimes my hands are shaking…she got another cup of tea for me and helped me to drink." (U1 R2)*

This narrative highlights the emotional impact of staff responses. While the resident acknowledges the pressures faced by housekeeping staff ("I know she got plenty of work to do"), the distress caused by the reaction demonstrates how vulnerability can be intensified in institutional settings. In contrast, the carer's supportive actions, reassurance, physical assistance, and the simple gesture of replacing the tea restore comfort and dignity.

Here, understanding is enacted through attentiveness and empathy. The interaction illustrates how care is co-constructed in the moment: the resident recognises staff busyness, and the carer responds sensitively despite workload pressures. This mutual awareness reflects an ongoing negotiation between vulnerability, responsibility, and compassion.

6.4.5 Organisational and Management Perspectives

This theme explores how organisational structures and management processes shape everyday care practices within the residential setting. Participants described busyness not simply as an individual issue, but as an outcome of systemic constraints such as recruitment delays, funding limitations, and high staff turnover. Within the broader theme of *Active Negotiation*, care delivery emerges as something continually negotiated within these structural boundaries.

Staff participants consistently framed understaffing as an organisational challenge rather than a failure of frontline workers. One staff member described a meeting held with management to address staffing shortages:

> *"We staff had a meeting with the management and they are also helpless, management couldn't recruit qualified nurse and care assistants. Advertisement given for recruitment." (U2 S4)*

This account reflects a shared sense of constraint between staff and management. The participant's use of the word "helpless" suggests that recruitment difficulties are perceived as systemic rather than intentional. In this way, busyness is constructed as an organisational condition that both staff and management must negotiate collectively.

Similarly, another staff member described regular monthly meetings involving staff, residents, and family members:

> *"Once in a month we have meeting with staff, resident and family, we all know we need more carers needed to work on the floor. We are a family and we work together to improve. Unfortunately, recruitment is taking a long time." (U1 S2)*

This narrative highlights a discourse of collaboration and shared responsibility ("we are a family"), yet it also reveals the limits of such collaboration when structural improvements are delayed. Although concerns are acknowledged openly, meaningful change remains dependent on organisational capacity. The negotiation here operates at multiple levels relationally, through meetings and shared discussions, and structurally, through recruitment processes that lie beyond immediate control.

Participants also described how staffing shortages influence the nature of care delivered. When resources are limited, clinical and administrative tasks are prioritised, leaving less time for relational or emotional engagement. A resident reflected on this experience:

> *"They just come to our room, leave the food on the table, then they write on my file and go." (U2 R4)*

This account illustrates how organisational pressures translate into task-oriented interactions. The emphasis on documentation and efficiency appears to overshadow opportunities for social connection. From the resident's perspective, this shift affects the quality of everyday life, as care becomes procedural rather than relational.

Across these accounts, organisational and management perspectives reveal how care practices are continually shaped by structural realities. Staff, residents, and families recognise staffing shortages and participate in discussions aimed at improvement; however, their ability to effect change is constrained by recruitment delays and funding pressures.

Within the overarching theme of *Active Negotiation*, organisational structures form a critical context in which expectations, responsibilities, and care practices are constantly balanced. Care is not static but negotiated daily between ideals of relational support and the practical demands of institutional survival.

6.4.6 Psychological Implications for Residents with Dementia

This theme explores the psychological implications of staff busyness for residents living with dementia. Participants described how rushed interactions, disrupted routines, and reduced relational engagement could heighten anxiety, confusion, and withdrawal. Within the broader framework of *Active Negotiation*, residents with dementia appear particularly sensitive to fluctuations in staff availability, as their wellbeing relies heavily on consistency, reassurance, and predictability.

Residents with dementia expressed heightened emotional vulnerability when care was delivered hurriedly. One resident described how staff rushing affected their sense of security:

> *"When the carers rush me, I get nervous. I forget things and get scared they'll leave me alone." (U2 R3)*

This account demonstrates how pace directly influences psychological stability. The resident links rushing with nervousness, memory disruption, and fear of abandonment.

The experience of being hurried is not simply inconvenient; it becomes emotionally destabilising. Busyness, therefore, translates into feelings of insecurity, particularly for individuals already managing cognitive impairment.

Staff participants also recognised the tension between institutional scheduling and individualised dementia care. One staff member reflected on the difficulty of adhering to rigid timetables:

> *"We're told to follow the timetable, but every resident is different. It's hard to provide individual care when you're racing against time." (U4 S4)*

This narrative highlights the structural dimension of psychological impact. While timetables aim to ensure efficiency and coverage, dementia care often requires flexibility, repetition, and patience. The phrase "every resident is different" underscores the principles of person-centred care, which can conflict with time-driven routines. Staff, therefore, negotiate between compliance with institutional expectations and responsiveness to residents' emotional needs.

Family members further described how busyness affects residents' motivation and emotional wellbeing. One family participant observed changes in her father's behaviour:

> *"My dad depend on care staff to help him in daily activities, that's why he is here, but when the staffs are busy he is not bothered to call for help…he likes to go for a small walk everyday, because of short staff he can't go everyday." (U4 F6)*

This account suggests that repeated unavailability can lead to withdrawal. Rather than expressing frustration, the resident becomes reluctant to seek assistance. The inability to maintain simple routines, such as daily walks, disrupts not only physical activity but also emotional stability and autonomy. For residents with dementia, such disruptions may intensify feelings of dependence and invisibility.

Across these narratives, the psychological implications of busyness are evident in heightened anxiety, disrupted routines, and diminished engagement. Residents with dementia require reassurance, predictability, and relational presence; however, institutional pressures often constrain the time available for such interactions.

Within the overarching theme of *Active Negotiation*, dementia care involves continuous balancing between organisational efficiency and emotional responsiveness. Staff negotiate between timetables and individual rhythms, while residents and families adjust expectations in response to visible constraints. The findings demonstrate that psychological wellbeing in dementia care is not solely determined by clinical competence, but by the pace, tone, and relational quality of everyday interactions.

6.4.7 Emotional Resilience and Coping

This section explores how staff sustain emotional resilience within a context of sustained busyness and systemic constraint. While previous sections highlighted emotional strain and physical fatigue, participants also described coping mechanisms that enabled them to continue providing compassionate care. Within the broader framework of *Active Negotiation*, resilience emerges not as the absence of stress, but as an ongoing process of adapting emotionally to challenging circumstances.

Despite acknowledging stress and exhaustion, staff participants repeatedly emphasised their emotional commitment to residents. One staff member reflected on the meaning they derived from everyday interactions:

> *"It's stressful, but I still love my job. When I see a resident smile because of something small I did, it reminds me why I'm here." (U3 S3)*

This account illustrates how emotional connection acts as a sustaining force. The contrast between "stressful" and "I still love my job" suggests that resilience is rooted in relational reward rather than organisational ease. Small gestures and residents' responses provide affirmation, reinforcing professional identity and purpose.

Similarly, another staff participant described how expressions of appreciation strengthened their coping capacity:

> *"Even when it's chaotic, when residents say thank you or hold my hand, it makes all the struggle worthwhile." (U2 S5)*

Here, physical touch and verbal gratitude function as emotional anchors. In moments of chaos, these gestures reaffirm the value of care work. Resilience, therefore, is relationally constructed emerging through reciprocal recognition between staff and residents.

Resilience was not framed solely as an individual attribute. Participants also described the importance of teamwork and managerial awareness in sustaining morale. A management participant acknowledged both staff dedication and the need for structural support:

> *"Our staff are committed and hardworking. We're trying to reduce stress through flexible shifts and better support systems." (U4 S6)*

This statement highlights organisational recognition of emotional strain and the attempt to mitigate it through structural adjustments. Flexible shifts and support systems represent institutional strategies that complement individual coping mechanisms. Resilience, therefore, is co-produced through both personal commitment and organisational responsiveness.

Across these accounts, emotional resilience is constructed as a dynamic and relational process. Staff negotiate emotional exhaustion by drawing meaning from relationships with residents, peer support, and occasional organisational recognition. Rather than eliminating stress, these strategies enable staff to continue functioning compassionately within constrained conditions.

Within the overarching theme of *Active Negotiation*, resilience represents the adaptive dimension of care practice. Staff continuously recalibrate their emotional responses, sustain empathy under pressure, and seek affirmation in relational moments. The findings suggest that while busyness generates strain, the capacity to cope, supported by relational reward and organisational effort, plays a critical role in maintaining both staff well-being and care quality within the residential setting.

6.4.8 Residents' Perceptions of Busyness and Empathy

This area explores how residents interpret and emotionally respond to staff busyness. While residents widely acknowledged staffing pressures and competing demands, their accounts suggest that how busyness is communicated significantly shapes their sense of dignity, trust, and belonging. Within the broader framework of *Active Negotiation*, residents are not passive recipients of care; rather, they actively interpret staff behaviour and adjust their expectations accordingly.

Residents indicated that delays were often understandable when accompanied by an explanation. One resident described how communication altered their emotional response:

> *“If they tell me they’re busy and will come later, I understand. But when no one says anything, I feel forgotten.” (U1 R2)*

This account highlights that the issue is not busyness alone, but silence. The feeling of being “forgotten” reflects a perceived absence of recognition rather than mere delay. Communication functions as reassurance, preserving the resident’s sense of visibility and worth. In this way, empathy is enacted through acknowledgement, even when time is limited.

Residents also emphasised the importance of tone and attitude during hurried interactions. One resident explained how kindness mitigated the effects of rushing:

> *“When carers smile and talk kindly, even if they’re rushing, it makes me feel safe and cared for.” (U3 R5)*

Here, safety is associated not with speed or efficiency, but with emotional presence. Even within constrained timeframes, warmth and respectful communication sustain trust. The resident’s perception demonstrates how empathy can be conveyed through small relational cues, reinforcing dignity despite systemic pressure.

Conversely, negative reactions intensified vulnerability. A resident recounted an interaction that evoked shame:

> *“Once I saw a staff member get irritated because of my shaking hands. I felt ashamed. But another carer came, smiled, and helped me gently. That changed everything.” (U2 R3)*

This narrative illustrates the fragility of dignity in institutional contexts. Irritation heightened embarrassment, while gentleness restored comfort. The phrase “that changed everything” underscores how emotional tone can transform an experience of vulnerability into one of reassurance. Residents’ perceptions of care are therefore deeply influenced by relational responsiveness.

Across these accounts, residents demonstrate awareness of structural limitations while simultaneously asserting relational needs. They negotiate understanding by empathising with staff shortages, yet they also articulate expectations of communication, patience, and respect.

Within the overarching theme of *Active Negotiation*, residents’ perceptions reveal that empathy is not secondary to task completion but central to the quality of care. Busyness becomes psychologically manageable when accompanied by explanation and warmth; without these, it risks producing feelings of invisibility or shame. The findings suggest that care is co-constructed through everyday interactions, in which recognition and emotional tone play a crucial role in sustaining dignity in a busy residential environment.

6.5 Subcategory- Medication

Medication management emerged as a crucial subcategory in understanding the daily life and care experiences of SAPWD living in residential or nursing homes. Medication was viewed not only as a clinical necessity but also as a key aspect influencing residents' safety, autonomy, and well-being. For all participants, medicines formed an integral part of their daily routine and were a significant factor in their admission to residential settings.

For clarity and cohesion, this section adopts a seven-part framework built around interrelated forms of medication: importance of medication in care settings, challenges in medication adherence and resident engagement, pain management and perception of ineffective medication, understanding and expectations about dementia medication, the role of communication and person-centred practice, and balancing safety, compliance, and compassion.

6.5.1 Importance of Medication in Care Settings

This section explores the central role of medication management within residential and nursing care settings. In nursing homes, registered nurses administer prescribed medications, while in residential homes, trained senior care assistants perform this role. All the SAPWD participants in this study had additional health conditions, such as diabetes, hypertension, and arthritis, alongside dementia, requiring constant monitoring and 24-hour care. Their lives are entirely dependent on medicines, which are integral to their routine.

One of the main reasons for residing in a care home or residential home is that the participants are unable to take their own medicines, or their family members are also not confident in doing so. Taking multiple drugs and supplements increases the chances of medication mix-ups and leads to serious complications or death. (NICE 2014). Certain medications should be taken before or after food, not with certain foods or drinks, and may cause side effects such as drowsiness or an increased risk of falls. All risks were assessed and managed in care homes, and the care plan was reviewed and updated in line with the SAPWD's needs. Within this context, professional oversight became a source of reassurance.

Residents described relief at no longer having to remember complex medication schedules. One resident reflected on the difference between living at home and residing in the care setting:

> *"When I was in my home, I always forget to take medicines, now you see the nurse give me medicines on time and I feel better." (U1 R1)*

This account frames medication administration as a source of physical and emotional stability. Timely supervision alleviated anxiety about forgetting doses and reinforced a sense of security.

Similarly, another resident described previous medication errors at home and the relief associated with professional monitoring:

> *"I used to take the wrong tablet or skip it. My son worried a lot. Here, nurses remind me, and I don't have to stress about remembering." (U2 R4)*

Here, medication management is constructed not only as a safety measure but as a reduction in cognitive burden. The removal of responsibility lessened both personal stress and familial tension, highlighting how care settings redistribute responsibility in ways that protect wellbeing.

Family participants echoed this sense of reassurance. One family member explained:

> *"My father takes too many medicines, and we were scared he might forget or mix them up. Now we feel secure knowing professionals are monitoring him." (U1 F2)*

This narrative illustrates how medication management extends beyond the resident to the family system. Professional supervision reduces fear of harm and redistributes accountability from relatives to trained staff. Medication, therefore, becomes a shared point of negotiation between residents, families, and care providers.

Medication Management within Active Negotiation.

Across these accounts, medication emerges as a central organising feature of care. While residents relinquish autonomy in administering their own medicines, they gain safety, routine, and reassurance. Families, in turn, negotiate trust in professional systems to safeguard their loved ones.

Within the theory of *Active Negotiation*, medication management represents a structured form of negotiated dependency. Residents adapt to supervised routines, families adjust to shared responsibility, and staff assume clinical accountability within regulatory frameworks. The findings suggest that effective medication administration is not merely procedural but relational, shaping perceptions of safety, dignity, and trust within the residential care environment.

6.5.2 Challenges in Medication Adherence and Resident Engagement

While medication administration was structured and closely monitored, adherence was not always straightforward. This theme captures the relational and practical challenges involved in supporting SAPWD to take prescribed medicines. Cognitive decline, sensory aversions, repeated questioning, and resistance were recurrent features in participants' accounts. These moments reveal that medication rounds are not purely clinical tasks but negotiated interactions.

One resident described discomfort associated with the sensory experience of medication:

> *"I don't like the smell and taste of yellow tab, here no escape… staff make sure I had taken the tabs and asks me to open the mouth…" (smiling) (U4 R6)*

Although expressed lightly, this account reflects limited autonomy and the inevitability of compliance within institutional care. The phrase "no escape" suggests a recognition that medication adherence is enforced for safety reasons, even when personally unpleasant. Medication administration, therefore, becomes a site where bodily autonomy and clinical necessity intersect.

Staff participants emphasised that adherence often required sustained communication and patience. One nurse described the repetitive nature of these interactions:

> *"To be honest, we need lots of patience in giving medicines to some of the residents. They want to know drug's name, what it is for, contraindications and everything, that too whenever I give tablets, they ask the same questions (U2 S3)*

This account highlights how cognitive impairment reshapes the medication encounter. Repeated questioning is not framed as defiance but as part of the condition itself. Staff must therefore balance efficiency with explanation, reinforcing understanding even when information is quickly forgotten. Engagement becomes an ongoing relational process rather than a one-time instruction.

Another staff member described how refusal required flexibility rather than force:

> *"Sometimes residents refuse and we encourage them to take medicines and sit with them… or try again later… with few residents, it takes quite a while to administer the medicines." (U4 S7)*

Here, adherence is portrayed as negotiated rather than imposed. Delaying administration, sitting with residents, and attempting again later illustrate adaptive strategies that align with person-centred practice. Medication rounds are therefore extended beyond a technical task into a communicative act requiring emotional labour.

Not all residents experienced medication rounds as relationally supportive. One resident reflected:

> *"Nurses always busy, they just come, give the medicines and go." (U1 R1)*

This perception introduces tension between procedural efficiency and interpersonal engagement. While staff work within strict safety protocols and time-sensitive schedules, residents may interpret brief interactions as impersonal. Medication rounds thus become moments where institutional pressures and expectations of relational care collide.

6.5.3 Pain Management and Perceptions of Ineffective Medication

Pain management emerged as a significant area of concern among SAPWD and their families. While medication administration was structured and monitored, several participants questioned the effectiveness of pain relief and expressed dissatisfaction with the perceived reliance on standard analgesics, particularly paracetamol. These accounts reveal that medication was not only evaluated in terms of safety, but also in terms of visible improvement and perceived responsiveness to suffering.

One resident expressed frustration about the limited range of pain relief offered:

> *"For any pain headache or leg pain they only give paracetamol. It doesn't really help me." (U3 R5)*

This account suggests a perception of uniform treatment irrespective of the type or severity of pain. The statement reflects not only dissatisfaction with symptom relief but also an implicit expectation of more individualised care.

Similarly, another resident directly questioned the effectiveness of prescribed medication:

> *"My pain… paracetamol not good… it doesn't help me…" (U2 R3)*

Here, the repetition underscores ongoing discomfort and unmet need. Pain, in this context, becomes an embodied reminder of dependency, particularly when relief is perceived as insufficient.

Some residents also associated medication with worsening cognitive symptoms. One participant, shared:

> *"I think after taking the tablet I feel more confused and tired." (U3 R5)*

This narrative highlights the complex interplay between symptom management and side effects. For residents living with dementia, increased confusion or fatigue may be interpreted as deterioration caused by medication, thereby influencing trust in treatment.

Family members often evaluated medication effectiveness in relation to broader expectations of improvement. One family participant voiced dissatisfaction:

> *"We are paying a lot of money, but my mother's health is declining. Her medications don't seem to help, and her memory is worse now." (U2 F3)*

This account reflects a tension between financial investment and perceived outcomes. Medication is viewed as a marker of active treatment, and when decline continues, families may interpret this as ineffective care rather than as the natural progression of dementia.

Another family member described raising concerns with management regarding ongoing pain:

> *"Medications given to my dad doesn't help… I had talked to the manager and she said the GP is reviewing on his medicines." (U4 F6)*

This statement illustrates how dissatisfaction can lead to advocacy and negotiation. Families actively engage with management and medical professionals to seek reassessment and adjustment of treatment plans.

In contrast, staff participants emphasised that medication use was clinically reviewed and monitored. One staff member explained:

> *"We review pain medications during MDT meetings with the GP. PRN medicines are available and given when needed, not just during rounds." (U3 S5)*

This account highlights the structured and multidisciplinary nature of medication review. From a professional perspective, treatment decisions are guided by clinical evaluation, risk management, and regulatory standards rather than expectations of cure.

Within the broader theme of *Active Negotiation*, pain management represents an ongoing dialogue between lived experience and professional authority. Concerns are raised, reviews are conducted, explanations are offered, and expectations are recalibrated. The findings demonstrate that perceptions of ineffective medication are not solely about pharmacology but about communication, trust, and shared understanding of what medication can realistically achieve in the context of progressive dementia.

6.5.4 Understanding and Expectations about Dementia Medication

This theme captures differing understandings about the purpose and limitations of anti-dementia medication. Family interviews revealed that expectations of cognitive improvement often shaped how medication effectiveness was evaluated. When observable improvement did not occur, dissatisfaction and doubt emerged.

One family participant linked financial investment in care with expectations of visible health improvement:

> *"We are paying lots of money and we are not getting the care we wanted, my mum health is declining day by day, most of the time she is lying on bed, medications not helping her, I think her memory also not improving, she was doing much better in our home." (U2 F3)*

This account reflects more than concern about pharmacological efficacy; it reveals an emotional and economic investment in hope. Medication is perceived as a tangible sign of treatment, and continued decline challenges the belief that professional care should produce improvement. The comparison with home care further intensifies the sense of disappointment.

Similarly, another family member expressed the expectation that medication would directly enhance cognitive function:

> *"I thought these tablets would improve my father's memory and confusion, but he is still the same. Maybe they should change the medicines." (U4 F5)*

Here, the assumption that medication should result in measurable cognitive gains underpins the call for change. The suggestion to alter prescriptions indicates an ongoing search for a more effective solution, reflecting difficulty in accepting the progressive nature of dementia.

In contrast, staff participants framed anti-dementia medication as symptom-managing rather than curative. One nurse described the challenge of addressing family expectations:

> *"We explain to families that medicines like memantine help with symptoms, not cure dementia. Many expect improvement, and it's difficult to manage those expectations." (U1 S2)*

This account illustrates the communicative labour required to bridge differing interpretations of treatment. For professionals, medication is positioned within clinical realism; for families, it often symbolises hope for stabilisation or recovery.

Across these narratives, dementia medication becomes a focal point for negotiating meaning. Families interpret treatment through hope, investment, and visible outcomes. Staff interpret treatment within biomedical limits and disease progression. When these perspectives diverge, tension arises not necessarily from negligence, but from differing understandings of what medication can achieve.

Within the broader framework of *Active Negotiation*, this theme demonstrates how expectations must be continually recalibrated through dialogue. Education, explanation, and repeated reassurance form part of the care process. The findings suggest that effective dementia care involves not only administering medication safely but also supporting families to reinterpret decline within the context of a progressive condition.

6.5.5 The Role of Communication and Person-Centred Practice

This theme explores how medication administration functions not only as a clinical task but also as a relational encounter. While medication rounds are structured around safety and timeliness, they also create opportunities for communication, reassurance, and person-centred engagement. Participants' accounts reveal a tension between institutional efficiency and relational care.

One staff participant described the constraints shaping medication rounds:

> *"If we are short-staffed, we have to finish the round quickly. We can't delay, because everyone's medicines are time-bound." (U2 S4)*

This account reflects the structural pressures within care settings. Medication administration is governed by strict schedules and safety protocols, leaving limited flexibility. The emphasis on "time-bound" medicines highlights clinical accountability and regulatory responsibility. However, it also illustrates how institutional demands may restrict opportunities for extended interaction. In this context, communication risks becoming secondary to task completion.

In contrast, residents interpreted medication encounters through a relational lens. One resident described the emotional impact of staff interaction during medication rounds:

> *"I feel good when the staff talks to me while giving tablets. It feels like she cares." (U4 R6)*

This narrative positions communication as integral to care rather than supplementary to it. The simple act of conversation transforms a routine procedure into a moment of recognition and dignity. For the resident, feeling "cared for" is linked not only to receiving medication safely but also to being acknowledged as a person.

The contrast between these accounts highlights differing priorities: staff emphasise timeliness and safety, whereas residents value relational presence. Medication rounds therefore become micro-level sites where professional obligation and emotional need intersect.

Within the theory of *Active Negotiation*, communication during medication administration represents an ongoing balancing act. Staff must negotiate between regulatory demands and relational engagement, while residents seek affirmation and understanding within structured routines.

The findings suggest that person-centred medication practice is not defined solely by adherence to protocols but by how those protocols are enacted. When communication is prioritized even briefly residents report greater reassurance and emotional comfort. Thus, medication rounds are revealed as more than procedural events; they are relational encounters where safety, dignity, and connection are continuously negotiated.

6.5.6 Balancing Safety, Compliance, and Compassion

This theme captures how medication management operates at the intersection of regulatory compliance, clinical responsibility, and relational care. All participating care homes adhered to statutory frameworks, including the Health and Social Care Act (2008) and NICE (2014) guidelines, which mandate accurate documentation of medication administration, refusals, omissions, and adverse effects. Within this regulatory environment, safety and accountability were prioritised.

One staff participant described the procedural obligations associated with medication management:

> *"We document every dose given, refused, or delayed. It's a legal requirement, but beyond work, we try to comfort residents who worry about medicines." (U4 S7)*

This account reflects the dual dimensions of practice. The first part of the statement foregrounds legal accountability and risk management, emphasising documentation as a safeguard against error and liability. However, the latter part introduces an ethical and emotional dimension "we try to comfort residents." This juxtaposition illustrates how staff navigate institutional compliance while attempting to preserve compassionate engagement.

The quote demonstrates that safety protocols do not necessarily exclude relational care; rather, staff operate within constraints that require constant prioritisation and adjustment.

Across the dataset, medication was interpreted differently depending on participants' roles. Staff framed medication in terms of responsibility, documentation, and risk prevention. Residents often associated medication with dependence but also with protection and reassurance. Families viewed medication as symbolic of treatment effectiveness and hope for stabilisation.

These differing interpretations reveal that medication is not merely a pharmacological intervention but a socially constructed practice shaped by expectation, emotion, and accountability. Safety standards ensure compliance, yet emotional responses shape how that compliance is experienced.

Within the broader framework of *Active Negotiation*, balancing safety, compliance, and compassion emerges as an ongoing process rather than a fixed achievement. Staff must negotiate between regulatory mandates and relational presence. Residents negotiate feelings of dependency alongside trust in professional care. Families negotiate hope for improvement within the realities of progressive illness.

Medication management, therefore, becomes a site where legal, clinical, and emotional dimensions intersect. The findings suggest that effective care is not defined solely by strict adherence to protocol but by how safety procedures are enacted with sensitivity and empathy. In this balancing act, compliance and compassion are not opposing forces but co-existing responsibilities that require continual negotiation.

6.5.7 Summary and Interpretive Reflection

The findings underscore that medication administration in residential settings for South Asian people with dementia is not simply a technical task but a complex, multifaceted process intertwined with emotion, culture, and expectation.

1. **Residents** valued structured medication routines for safety but desired more personal engagement and explanation.
2. **Families** expected medications to produce visible health and memory improvement, reflecting a limited understanding of dementia progression.
3. **Staff** focused on safety, adherence, and documentation but faced constraints of time and workload that hindered a fully person-centred practice.

This triadic tension among safety, expectations, and empathy defines the lived experience of medication management in residential care. Education for families on the purpose and limits of medication, regular communication between staff and families, and ongoing staff training in person-centred approaches can bridge these gaps. Ultimately, medication routines can be transformed from a purely clinical procedure into an opportunity for compassionate connection and reassurance, especially when cultural sensitivity and emotional understanding are integrated into care practices.

6.5 Summary:

The adjustment of SAPWD to residential care involves navigating a complex interplay of cultural, emotional, and practical factors. Culturally oriented care, including attention to spiritual practices, dietary preferences, language, and social norms, plays a vital role in supporting residents' identity, dignity, and sense of belonging. Strong relationships between residents, families, and staff help reduce loneliness, social isolation, and anxiety. In contrast, challenges such as staff busyness, delayed assistance, and medication management highlight the tension between clinical demands and person-centred care. Successful adjustment depends on culturally sensitive, empathetic, and collaborative approaches, where clear communication, family involvement, and attentive staff support collectively enhance residents' autonomy, emotional well-being, and overall quality of life.

Chapter: 7

Findings: Being Supported by Family, Staff and Management

Subcategories related to Being supported by family, staff and management

-Attitudes of the family in supporting SAPWD

-Attitudes of care staff in supporting SAPWD

-Role of care providers in supporting SAPWD

7.1 Introduction

The third category, “Being Supported by Family, Staff, and Management,” emphasises the interconnected roles that families, care staff, and care home management play in ensuring the holistic well-being of SAPWD. The attitudes of families toward supporting residents are shaped by strong cultural and religious values that emphasise filial responsibility, respect for elders, and collective caregiving. Family involvement not only provides emotional stability and cultural continuity but also reinforces residents’ sense of identity and belonging within the care environment. When families maintain regular contact, participate in care decisions, and communicate openly with staff, residents feel reassured and valued. The attitudes of staff are equally influential in shaping residents’ daily experiences. Compassionate, patient, and culturally competent staff foster trust, promote autonomy, and reduce the anxiety associated with being in a care home. Staff members who are sensitive to language differences, dietary needs, religious practices, and personal routines create an inclusive environment that respects individuality. Furthermore, the role of care providers and management extends beyond administrative oversight to ensuring that institutional policies and care practices are aligned with person-centred and culturally responsive principles. Effective management supports continuous staff training in cultural awareness, maintains appropriate staffing levels, and ensures regular assessments to meet residents’ evolving medical and psychosocial needs. When families, staff, and management work collaboratively, sharing information, coordinating care, and addressing challenges together, SAPWD residents experience a sense of safety, dignity, and empowerment. This collective approach not only protects residents from neglect or abuse but also enables them to live meaningfully and with self-determination within residential care settings.

7.2 Subcategory- Attitudes of the family in supporting SAPWD

Family attitudes significantly shaped how SAPWD adjusted to residential care. Placement in a care home did not signal the end of caregiving; rather, it marked a transition in how responsibility was enacted. The findings reveal that families continuously negotiated their roles, balancing cultural expectations, emotional attachment, and trust in professional care. Within South Asian communities, caregiving is strongly associated with moral duty and collective responsibility, making the move to residential care emotionally complex.

Across participants, attitudes ranged from pragmatic acceptance to ongoing guilt and emotional strain. These responses reflect not a contradiction but a negotiation between tradition and modern healthcare, between proximity and practical constraints.

For the sake of clarity and cohesion, this section adopts a four-part framework built around interrelated forms of attitudes of the family in supporting SAPWD: acceptance of residential care as responsible care; family groups and SAPWD; trust and mistrust.

7.2.1 Acceptance of Residential Care as Responsible Care

Some families framed residential placement as a necessary and protective decision. One family member explained:

> *"We understood he needed proper medical care and supervision. My wife and daughter work in the NHS, so they helped everyone see this is the best for him." (U2 F3)*

This account reflects informed acceptance grounded in healthcare knowledge. Rather than perceiving placement as abandonment, the participant reframes it as responsible action. Professional familiarity with dementia reduced stigma and supported collective family agreement. In this way, acceptance emerged through dialogue and reinterpretation of cultural duty.

Such attitudes positioned care homes as partners rather than replacements in caregiving.

Although residents relocated, families-maintained involvement through practical and symbolic acts of care. One participant described assisting with meals:

> *"My mum eats properly only when I feed her. When I visit and help her with meals, she seems happier and more settled." (U1 F2)*

Feeding here functions as emotional continuity. It reinforces relational identity and recreates familiar routines within institutional space. Care is expressed through embodied presence, not merely supervision.

Similarly, another participant described maintaining grooming responsibilities:

> *"Dad doesn't let staff shave him and I do it for him. It's my responsibility." (U4 F6)*

The emphasis on "my responsibility" reflects the enduring moral framework guiding involvement. These acts illustrate how families renegotiate caregiving roles within institutional boundaries, preserving dignity and relational trust.

Food emerged as a central expression of cultural continuity. One family member described bringing traditional meals:

> *"We bring rice and curry from home because he doesn't like the taste of food served by staff… we try to cook our favourite food and send it with someone else." (U1 F1*)

Food becomes more than nutrition; it represents belonging, familiarity, and identity. Even when daily provision was not feasible due to work commitments, the effort itself symbolised commitment. Through these gestures, families actively negotiated cultural adaptation within care settings.

Not all families were able to sustain regular involvement. Structural constraints such as employment, transport, and distance shaped participation. One resident expressed sadness:

> "*I feel sad when all other residents visited by their kids…friends…my kids have no time…they think I got everything and no responsibility…I worked hard all my life for good future…kids…(emotional, low in voice)" (U3 R5)*

This account highlights comparative loneliness and perceived neglect. Emotional strain was also evident among family members themselves. One participant described feeling conflicted:

> *“I would like to visit every week… I can’t drive… my son is busy… she complains we forget her…” (U1 F2)*

Here, guilt is intertwined with practical limitation. The narrative demonstrates that absence does not equate to indifference; rather, it reflects competing responsibilities within multigenerational family structures.

These tensions illustrate how family support is shaped by negotiation between intention and circumstance.

Families also positioned themselves as advocates within the care system. One participant explained:

> *“We make sure the staff know about dad’s habits what calms him, what foods he likes, and how to make him comfortable.” (U3 F5)*

This advocacy role reinforces family members as knowledge holders. They act as intermediaries between residents’ personal histories and institutional practice. Families function as essential communicators, bridging gaps between individual identity and formal care.

Such collaboration strengthened trust and facilitated culturally responsive care. Families who perceived care homes as collaborative partners reported smoother adjustment processes.

Across these accounts, family attitudes are neither wholly accepting nor wholly resistant. Instead, they reflect ongoing negotiation between:

- Cultural obligation and institutional care
- Emotional attachment and practical constraint
- Guilt and trust
- Traditional caregiving roles and professional systems

Strong cultural values of obligation can generate both emotional pressure and resilience within families. Family solidarity often remains a critical resource even when caregiving shifts to institutional settings. These cultural commitments should therefore be understood as strengths in developing collaborative care partnerships, rather than being framed as barriers to formal care acceptance. Family involvement emerged as a crucial factor influencing the adjustment and emotional well-being of SAPWD in residential settings. Families who maintained regular contact and participated in care activities helped reinforce the residents’ sense of identity and belonging. Their continued presence bridged cultural gaps, reduced stigma, and created a sense of continuity between home and care environments. Conversely, limited family interaction often led to emotional withdrawal among residents, highlighting the importance of sustained communication and engagement

The present findings support this perspective. South Asian families did not withdraw after placement; rather, they recalibrated their involvement. Residential care became integrated into, rather than substituted for, family responsibility.

7.2.2 Family groups and SAPWD

Family groups functioned as structured arenas of active negotiation, where families and staff collaboratively shaped the care experience of SAPWD. With the exception of U3, all units facilitated regular family meetings that enabled relatives to discuss care practices, raise concerns, and contribute to decision-making. These meetings were not merely administrative updates; rather, they served as relational spaces in which cultural expectations, care standards, and individual preferences were continuously interpreted and adjusted.

In U4, where most residents were of Indian origin, monthly meetings were conducted in residents’ native languages. This adaptation allowed families to articulate culturally specific expectations and supported residents in expressing their preferences. The use of familiar language created an inclusive environment where participation was meaningful rather than symbolic. Through these exchanges, care practices were actively aligned with cultural identity.

Staff narratives emphasised that family involvement was embedded within everyday care planning. One staff participant described their approach:

> *“We are always approachable and support residents and families emotionally and practically, with their consent, and include relatives in planning and providing care.” (U2 S4)*

This account highlights that inclusion was intentional and ethically grounded in consent. Decision-making was not imposed unilaterally by staff but developed through dialogue. The emphasis on approachability suggests that care planning was relational rather than hierarchical.

Similarly, another staff member explained:

> *“Visitors are allowed to visit at any time and encouraged to take part in our activities.” (U4 S7)*

This flexibility demonstrates how institutional boundaries were negotiated to accommodate family presence. By inviting participation in daily routines, staff repositioned families as collaborators rather than external observers. Such openness reinforced mutual trust and reduced the symbolic distance between home and residential care.

Family members described how ongoing communication and visible care practices fostered reassurance. One relative reflected:

> *“I am happy for my mum’s placement in this residential home; she is looked after by good people, and all her needs are met.” (U4 F7)*

This statement illustrates how trust developed through experience and observation. Confidence was not assumed at admission but built gradually through transparent interaction and inclusive meetings.

Another participant highlighted the importance of being informed about changes in care:

> *“It's a good feeling when staff inform us of the changes needed for better care, and I support my dad according to the needs.” (U4 F6)*

Here, communication enabled responsive adaptation. The family member’s willingness to “support… according to the needs” reflects shared responsibility, demonstrating how care was co-produced through ongoing negotiation.

Active negotiation extended beyond meetings into practical caregiving. One participant described coordinating walks with staff:

> *“If the staff are busy, they will inform us to take him for a walk… we all adjust and work together.” (U4 F6)*

The phrase “we all adjust and work together” encapsulates fluid caregiving roles. Responsibility shifted according to circumstance, illustrating a partnership model rather than a fixed division between professional and familial care.

Residents themselves experienced these interactions as emotionally sustaining. One resident described her daughter’s visits:

> *“My daughter sits with me, brushes my hair, folds my clothes neatly, and chats with me for a long time.” (U4 F4)*

This narrative demonstrates how family presence maintains intimacy and identity within institutional space. Grooming and conversation functioned not merely as tasks but as affirmations of belonging and relational continuity.

The findings further revealed that participation in family groups contributed to shifting community attitudes. Some families initially held reservations shaped by cultural stigma surrounding institutional care. However, direct involvement and open communication reframed these perceptions. One participant observed:

> *“If I see anyone struggling with caregiving at home, I recommend getting adequate support from health care services and considering residential care.” (U1 F2)*

This transition from hesitation to advocacy reflects experiential learning through engagement. Residential care came to be understood not as abandonment but as collaborative support integrated within family responsibility.

Across accounts, family groups functioned as sites of active negotiation where multiple tensions were navigated:

- Cultural expectations and institutional routines
- Emotional attachment and professional boundaries
- Traditional caregiving roles and shared responsibility
- Initial stigma and experiential trust

Rather than withdrawing after placement, families recalibrated their roles within a new care context. Structured meetings, open visiting practices, and shared daily caregiving enabled continuous negotiation of responsibility and identity.

Overall, family engagement emerged as integral rather than supplementary to effective residential care for SAPWD. Through dialogue, flexibility, and collaborative participation, families and staff co-constructed culturally responsive and emotionally supportive environments. The findings demonstrate that adjustment to care occurred through ongoing relational negotiation, reinforcing the overarching theme of Active Negotiation within residential settings.

7.2.3 Trust and Mistrust

Trust emerged as a dynamic, negotiated process that shaped how families and residents adjusted to residential care. Historical stigma surrounding care homes, often associated with neglect, staff shortages, or inadequate attention, framed many families' initial perceptions. As a result, placement did not automatically generate confidence. Instead, trust developed gradually through observation, communication, and relational consistency.

Several participants described entering the care setting with apprehension. One family member reflected on the emotional difficulty of transition:

> *"I was sceptical about how dad will be treated here… not sure how they will look after him, initially it was very hard for us to accept the fact that he is getting all the care." (U2 F1)*

This account reveals that mistrust was not rooted in hostility but in uncertainty. Acceptance required time and experiential reassurance. The participant's narrative demonstrates how trust is negotiated through lived interaction rather than assumed at admission.

Similarly, another family described concerns shaped by second-hand experiences:

> *"My aunty told me her grandmother was in care home and she passed away quickly because of neglect and bad care from care staff." (U2 F4)*

Here, mistrust was socially constructed through community narratives. Such accounts illustrate how stigma circulates within cultural networks, shaping expectations before direct engagement occurs.

Despite initial concerns, consistent staff interaction gradually transformed perceptions. A resident described this shift:

> *"When I first came here, I saw many Indian faces and felt happy…but I was not sure how they would look after me. Now, staff are so good… they are like my sons and daughters… we are like a family." (U4 R6)*

This transition from uncertainty to relational closeness highlights how trust developed through everyday care encounters. The metaphor of "family" reflects emotional security and belonging, signalling successful relational integration.

Families similarly identified observable staff behaviours—kindness, patience, and responsiveness—as central to building confidence. One participant noted:

> *“I trust the nurses and carers; they know when my dad’s mood changes and manage it well. Sometimes we need to explain things many times, but they remain patient.” (U4 F6)*

This statement demonstrates that trust was grounded in both professional competence and empathy. Recognising staff skill in managing behavioural changes reinforced reassurance and reduced anxiety.

Another family member acknowledged staff capability with humility:

> *“Carers doing better than me, they have lots of patience, they like him and now they know my dad better than me…its not easy to manage him…(smiling)” (U1 F1)*

This reflection indicates a renegotiation of caregiving identity. Rather than perceiving professional care as a threat to familial responsibility, the participant recognised staff expertise as complementary. Trust here enabled redistribution of responsibility without loss of dignity.

As trust strengthened, families became more actively engaged in care planning and daily routines. Trust reduced defensive monitoring and facilitated cooperative partnership. One participant summarised this sense of reassurance:

> *“I think care staff are awesome; this is the best place for my mum. She is happy, and I am satisfied.” (U4 F7)*

This account illustrates how resident well-being reinforced family trust. Observing happiness and stability became evidence of good care.

Trust also enabled practical collaboration. Families continued to assist with grooming, meals, shopping, and social activities, while maintaining communication through phone or video calls when physical visits were not possible. Even when distance or employment limited presence, emotional commitment remained intact. In this way, trust did not replace family involvement but strengthened coordinated care.

Across narratives, trust and mistrust were not fixed states but evolving positions shaped by:

- Community stigma and lived experience
- Observation of staff behaviour
- Communication and transparency

- Residents’ emotional responses
- Professional competence and empathy

Families entered residential care cautiously, often influenced by cultural narratives of neglect. However, through consistent interaction, respectful communication, and visible attentiveness, mistrust was gradually renegotiated into confidence.

Importantly, trust facilitated active negotiation. When families trusted staff, they were more willing to share personal knowledge, participate in care planning, and adapt to institutional procedures. Likewise, residents’ comfort strengthened family confidence, creating a reciprocal cycle of reassurance.

Overall, trust functioned as a cornerstone of effective residential care for SAPWD. It enabled cooperation, reduced anxiety, and supported culturally responsive, person-centred practices. Rather than emerging instantly, trust developed relationally through transparency, patience, and shared responsibility reinforcing the overarching theme of Active Negotiation within residential settings.

7.3 Subcategory- Attitudes of care staff in supporting SAPWD

Care staff attitudes significantly shaped the quality of life and adjustment experiences of SAPWD residents. Across the units, staff demonstrated empathy, patience, and professional commitment despite managing complex medical conditions, behavioural changes, and diverse cultural expectations. Staff who had received dementia and cultural competence training appeared particularly reflective and responsive in their approach. Staff emphasised that training strengthens person-centred and culturally sensitive care practices.

Rather than delivering standardised routines, staff described care as a dynamic process requiring continuous adjustment. Their attitudes reflected an understanding that effective support involved negotiation between clinical needs, personal preferences, and family expectations.

This section uses four linked dimensions of attitudes of care staff in supporting SAPWD as an organising framework to help maintain coherence throughout: individual and responsive care; interpersonal relationships and trust with SAPWD and their families.

7.3.1 Individualised and Responsive Care

staff consistently highlighted the importance of reviewing and adapting care plans as residents' conditions evolved. One staff member explained:

> *"We review the care plan and assessments if there are any changes in the health requirements and inform the next staff during handover." (U1 S1)*

This statement demonstrates structured responsiveness and continuity of care. The emphasis on handover communication reflects collective accountability, ensuring that care decisions are shared and consistently implemented. Such practices illustrate active negotiation between evolving health needs and institutional coordination.

Another staff participant described adapting care in response to behavioural change:

> *"Before, he liked to stay in the lounge; now he spends most of his time in the bedroom. We encourage staff not to force him but respect his need for a quiet environment." (U4 S6)*

The deliberate choice "not to force him" indicates sensitivity to autonomy. Rather than prioritising routine conformity, staff recalibrated expectations around the resident's changing preferences. This reflects negotiated care, where dignity and comfort are prioritised alongside safety.

Empathy emerged as central to staff attitudes. One staff member reflected on supporting a resident who resisted assistance:

> *"When they need help, some of the residents do it by themselves and struggle to even walk. I tried to give her a simmer frame and she pushed me away…to my luck, I didn't fall…we should understand the situation and act accordingly" (U2 S4)*

Here, resistance is interpreted not as defiance but as communication. The phrase "act accordingly" suggests reflexivity adjusting professional behaviour in response to residents' emotional states. This aligns with person-centred dementia care principles, where understanding behavioural expression is essential.

Residents recognised this attentiveness. One resident described staff accommodating his long-standing routine:

> *“I usually wake up 5:00 am in the morning, that’s my routine and I drink milky tea…strong tea…I know its hard for the night staff, but they always make me a cup of tea”. (U1R2)*

This example illustrates how staff respected personal history and habitual identity. Supporting such routines reflects negotiated flexibility between institutional scheduling and individual preference. Small acts of accommodation reinforced dignity and belonging.

Staff attitudes also shaped relationships with families. One staff participant described their approach:

> *“We are always approachable and support the residents and family emotionally and practically, including them in planning and providing care.” (U2 S4)*

This statement positions families as collaborative partners rather than peripheral observers. By integrating relatives into care planning, staff recognised their experiential knowledge and cultural insight. Collaborative engagement enhances holistic care outcomes.

Family members’ responses confirmed the impact of this approach. One participant reflected:

> *“Care staff are kind, patient, and always look after my dad. I am confident he is in good hands.” (U4 F6)*

Trust, in this instance, emerges directly from observable staff attitudes. Professional competence combined with relational warmth strengthened family confidence and reduced anxiety.

Staff acknowledged that cultural competence required attentiveness rather than assumption. Even when sharing similar ethnic backgrounds, they recognised that individual preferences varied. Through life story work, family consultation, and regular review meetings, staff aligned care practices with residents’ socio-cultural identities.

This approach reflects negotiated cultural understanding. Rather than imposing generalised cultural norms, staff engaged in dialogue to understand specific routines, dietary practices, language preferences, and family structures. Such reflexivity reduced misunderstandings and reinforced residents’ sense of belonging.

Across accounts, staff attitudes were characterised by negotiation between:

- Clinical responsibility and emotional sensitivity
- Institutional structure and personal autonomy
- Cultural awareness and individual differences
- Professional boundaries and relational closeness

Positive attitudes were not limited to kindness but were demonstrated through adaptive practice, collaborative engagement, and reflective decision-making. Staff frequently extended effort beyond minimum requirements, motivated by relational commitment and professional ethics.

Overall, the findings indicate that care staff attitudes were foundational to effective residential support for SAPWD. Through empathy, responsiveness, and culturally competent practice consistent with the literature, staff co-constructed environments where residents felt respected, secure, and valued.

In doing so, they reinforced the overarching theme of Active Negotiation, demonstrating that high-quality care is achieved not through rigid protocol but through continuous relational adjustment and shared understanding

7.3.2 Interpersonal relationships and trust with SAPWD and their families

Interpersonal relationships between care staff, SAPWD residents, and their families were central to building trust within residential settings. In culturally diverse environments, trust was not automatic; it developed through communication, responsiveness, and cultural sensitivity. Staff experiences revealed that confidence in relationship-building varied depending on prior exposure to cultural diversity and dementia care training.

Some staff from South Asian backgrounds reported greater ease in understanding residents' socio-cultural norms, language preferences, and family expectations. In contrast, staff from White British or European backgrounds initially expressed uncertainty about communication styles, appropriate greetings, and potential language barriers. These uncertainties sometimes created hesitation, which could affect the formation of early relationships.

Several staff acknowledged that assumptions about language differences initially shaped their interactions. Although most SAPWD residents spoke English fluently, occasional pronunciation differences led to misunderstandings. Such miscommunication risked reinforcing residents’ and families’ fears of cultural marginalisation.

One staff member described how relational engagement helped overcome these barriers:

> *“We try to make the place as homely as and the staff likes to listen to their stories… it creates a bond between the staff and resident.” (U4 S6)*

Listening to personal narratives functioned as a relational bridge. Rather than focusing solely on clinical tasks, staff invested in conversational engagement, which fostered familiarity and belonging. Trust, in this instance, emerged through shared storytelling and emotional presence.

Building trust also required careful negotiation between resident autonomy and family authority. One staff member reflected on an assessment process:

> *“During the assessment, it was her daughter answering all the questions, not letting the resident speak.” (U2 S4)*

This observation highlights tensions between protective family involvement and residents’ self-expression. Staff were required to balance respect for family roles with advocacy for residents’ autonomy.

Similarly, another staff participant explained:

> *“I encourage the SAPWD to take their own decision, because the family thinks it’s their right to make decision for their dad or mum.” (U1 S2)*

Encouraging resident participation in decision-making strengthened self-esteem and agency. It also reassured families that staff were attentive to dignity and independence. Trust was therefore built not by excluding families but by negotiating inclusive yet resident-centred dialogue.

Staff described adapting care practices to support cultural belonging. One participant shared:

> *“Assessment and review did by the manager, we report if there is any change in the needs of the resident and we all support…work with the flow…the manger got some magazines for the resident in their language…and u know the reaction and smile on the face of resident, a little thing brings lots of changes to resident, especially when they feel they don’t belong here”(U3 S5)*

This example illustrates how small culturally attuned gestures significantly enhanced emotional well-being. Providing reading material in a familiar language symbolised recognition and inclusion. Trust deepened when residents felt seen and understood beyond medical identity.

Even when staff felt uncertain about managing residents from unfamiliar backgrounds, collaboration mitigated anxiety. One staff member admitted:

> *“Not sure how we will manage if we have residents from different backgrounds, we will work together for better care.” (U1 S2)*

This statement reflects collective negotiation. Rather than allowing uncertainty to create distance, staff relied on teamwork and shared learning. Trust was built internally among staff and externally with families through openness and willingness to adapt.

Across accounts, trust was constructed through negotiation between:

- Cultural familiarity and cultural learning
- Professional authority and family involvement
- Resident autonomy and protective caregiving
- Communication uncertainty and relational effort

Interpersonal relationships developed gradually through listening, collaborative assessment, cultural accommodation, and reflexive practice. Staff who actively engaged residents in conversation, encouraged decision-making, and involved families in care planning strengthened relational bonds.

Rather than relying solely on formal policy, trust emerged through everyday interactions sharing stories, respecting language preferences, advocating for autonomy, and working collectively to address uncertainty. These practices reinforced emotional security and promoted a sense of belonging for SAPWD residents.

Overall, the findings demonstrate that interpersonal relationships were foundational to high-quality dementia care. Through relational flexibility and cultural attentiveness, staff and families co-constructed trust. This process reflects the overarching theme of Active Negotiation, where meaningful care relationships are formed through dialogue, adaptation, and shared understanding rather than assumption or rigid structure.

7.4 Subcategory- Role of care providers in supporting SAPWD residents

Care providers across nursing and residential homes play a central role in supporting SAPWD, not only through the delivery of physical and medical care, but also through cultural mediation, emotional reassurance, and collaborative engagement with families. In nursing homes, registered nurses provide clinical oversight, whereas residential homes focus primarily on personal and social care. Across both settings, safeguarding, dignity, mobility support, and the creation of a homely environment were prioritised.

This section demonstrates how care providers enact support through five interrelated practices: (1) professional development and dementia competence, (2) culturally responsive care, (3) environmental adaptation, (4) dietary accommodation, and (5) collaborative family engagement. Together, these practices illustrate an active and negotiated model of care.

7.4.1 Professional Development and Dementia Competence

Staff consistently identified mandatory and specialist training as foundational to quality care. Training was not described as procedural compliance alone but as transformative in shaping understanding of dementia and resident behaviour.

One participant explained:

> *"It's a requirement for us to attend the mandatory training and complete online training every year" (U2 S4).*

Another reflected on the value of dementia-specific training:

> *"All the staff should do training on dementia awareness, it helped me to understand different types of dementia" (U1 S1).*

These accounts indicate that ongoing training enhanced staff confidence, communication skills, and awareness of cognitive changes. Staff also received guidance on managing challenging interactions with families and were encouraged to seek supervision and psychological support when needed. Training extended to technology use and administrative systems, demonstrating how competence was framed as both relational and technical.

7.4.2 Culturally Responsive and Linguistically Inclusive Care

Cultural competence was embedded in recruitment, communication strategies, and admission processes. In line with research highlighting the importance of collective decision-making in South Asian families, staff recognised family involvement as a cultural strength rather than interference.

One staff member described workforce diversity as a deliberate strategy:

> *"In our nursing home, we have staff from India and Pakistan, and if residents are from other backgrounds, we seek help from interpreters. Management recruits diverse staff to support all residents" (U1 S2).*

Admission discussions were central to establishing culturally appropriate care:

> *"On admission day we discuss with family how to provide culturally appropriate care for their loved ones. Some of the family members and residents might be confused and worried about the care and we work together to know the preferences" (U4 S6).*

A family member reflected positively on this collaborative approach:

> *"It was good to discuss with the manager and staff about mum's wishes and do the changes according to her likes. She was happy when mum saw pooja area for worshipping…she was excited to introduce herself to other Gujarati residents." (U4 F7).*

These accounts illustrate how cultural practices such as religious observance and linguistic familiarity were incorporated into everyday care. In Unit 4, families were also offered dementia awareness training, strengthening shared understanding and reinforcing partnership.

7.4.3 Environmental Adaptation and Dementia-Friendly Design

Environmental support was framed as central to safety, independence, and emotional comfort. Staff described practical safeguarding measures:

> *"We make sure the floor is not slippery, residents walk with the Zimmer frame, adequate measures implemented by the management for the safety of residents…handrails and grab rails…" (U4 S6).*
>
> *"Regular inspections are carried out to find any hazards and safety measures implemented" (U3 S5).*

Residents valued the ability to personalise their rooms:

> *"Mum was very happy when the management allowed her to decorate her room with ornaments and furniture from home" (U1 F2).*

Personalisation fostered familiarity and continuity of identity. Quiet and sensory areas were also available:

> *"I don't like to sit in the lounge…its noisy…I always relax in the silent area" (U4 R6).*

However, not all environments were fully dementia-friendly. One unit was described as having narrow corridors and congested spaces, limiting mobility. Staff training tended to emphasise safety compliance rather than imaginative dementia design. This highlights a tension between regulatory safeguarding and the potential for more creative, culturally resonant spaces.

7.4.4 Dietary Accommodation and Resource Constraints

Food provision emerged as both a strength and a challenge. Unit 4 demonstrated culturally responsive catering, employing chefs from similar backgrounds to residents. A family member contrasted this positively with previous experience:

> *"Before she was in another care home and didn't like the food, she always had issues with food choices. I am grateful that she is happy with the menu here" (U4 F7).*

In other units, provision was more limited. One resident explained:

> *"I eat halal food from Asda or Sainsbury…my family brings food once a week" (U3 R5).*

These accounts reveal variability in dietary support, often shaped by staffing and budget constraints. While vegetarian and halal options were available, fully culturally specific menus were not consistently provided. This reflects broader structural limitations rather than unwillingness from staff.

7.4.5 Family Engagement and Multidisciplinary Collaboration

Family collaboration was central to the quality of care. Staff framed admission discussions as a partnership-building opportunity and encouraged ongoing participation in routines and cultural activities.

Care providers also coordinated with external professionals to ensure holistic support:

> "Physiotherapists, Chiropodists, hairdressers, appointments booked by administrative staff, and we work closely with other professionals to support residents" (U1 S2).

> *“Appointments to hospital booked in advance and transportation arranged” (U3S5).*

This multidisciplinary coordination extended beyond basic care to include rehabilitation, grooming, and medical management, reinforcing continuity and comprehensive support.

Across the units, care providers demonstrated adaptability in responding to the evolving needs of SAPWD residents. Their role extended beyond task-oriented care to include cultural mediation, environmental modification, dietary negotiation, and family partnership. Engagement with local South Asian communities and religious leaders further strengthened culturally responsive practice.

However, variability between units indicates that culturally competent care is influenced by leadership priorities, staffing diversity, and resource allocation. Where proactive recruitment, family training, and flexible catering were implemented, residents and families reported higher satisfaction. Where environmental design or dietary provision was constrained, support was more limited.

Overall, care providers functioned as active negotiators of care, balancing regulatory requirements, cultural expectations, family involvement, and individual resident preferences. This negotiated approach underpins residents’ well-being, sustains dignity, and builds family confidence in care home placement.

7.5 Summary

Providing culturally appropriate dementia care for South Asian people in UK care homes presents challenges. However, the positive attitudes and adaptive strategies demonstrated by families offer valuable insights for improving care. Collaborative partnerships, cultural sensitivity, and active family engagement not only enhance residents' well-being but also foster satisfaction among families and staff. These experiences show that cultural values can be leveraged as strengths rather than obstacles, enabling care homes to develop more inclusive, responsive, and effective care practices. By building on these foundations and learning from successful examples of family involvement, care providers, policymakers, and researchers can create approaches that respect cultural diversity while ensuring high-quality care for the growing population of South Asian older adults with dementia.

Chapter 8

Findings: Continuing to live in residential settings

Subcategories related to continuing to live in residential settings

-Cooperating with staff and family

-Cultural Life

8.1 Introduction:

Continuing to live in residential settings presents both challenges and opportunities for SAPWD, as they adjust to a structured environment away from home while maintaining their cultural identity and personal preferences. Person-centred care is essential in this context, as it prioritises the individual's needs, wishes, and past experiences, ensuring that residents are treated with dignity and respect. Understanding each resident's life history, cultural background, and personal expectations allows care staff to provide support that is meaningful and responsive, helping residents feel included, valued, and part of the community. Residential care should not merely focus on physical health but also address psychological, social, and cultural well-being, enabling SAPWD to continue living fulfilling lives while fostering autonomy, choice, and a sense of belonging within the care home environment.

8.2 Subcategories related to continuing to live in residential settings

Continuing to live in residential care for SAPWD involves multiple interconnected aspects, captured under key subcategories such as cooperation with staff and family, and engagement with cultural life. Cooperation with staff is essential for residents' daily routines, safety, and well-being, as many require assistance with personal care, mobility, medication, and participation in activities. Effective cooperation is fostered through trust, clear communication, and mutual understanding, enabling residents to adapt to the structured environment and maintain a sense of autonomy. Equally important is cooperation with family, which supports residents emotionally, reinforces cultural connections, and facilitates participation in care planning and social activities. Cultural life plays a critical role in maintaining identity, belonging, and psychological well-being, encompassing dietary preferences, language needs, religious practices, festivals, and culturally meaningful activities. Together, these subcategories highlight that a supportive, culturally sensitive, and collaborative environment is crucial for SAPWD to continue living meaningfully in residential care while preserving their individuality and quality of life.

8.3 Subcategory- Cooperation with staff and family members

Cooperation with staff and family is central to the well-being of South Asian people with dementia in residential care. Residents rely on staff for assistance with daily activities, medical needs, and participation in social and recreational programs, and effective cooperation is built through trust, clear communication, and mutual understanding. Similarly, family involvement provides emotional support, helps maintain cultural connections, and ensures that residents' preferences and care needs are respected. Together, collaboration with staff and engagement with family create a supportive environment that promotes residents' independence, dignity, and quality of life.

8.3.1 Cooperation with staff

Cooperation between SAPWD residents and care staff emerged as a negotiated and relational process rather than passive compliance. Within the overarching theme of *Active Negotiation*, residents were not simply recipients of care; instead, they adapted to routines, interpreted staff intentions, and chose how to engage. Cooperation was shaped by levels of dependency, trust, communication, and opportunities for participation.

To strengthen coherence, this section is organised into four interrelated dimensions of cooperation: (1) negotiated dependence in personal care, (2) cooperation through therapeutic encouragement, (3) adherence to shared routines and rules, and (4) participatory feedback and relational trust.

Negotiated Dependence in Personal Care

Most residents in this study required assistance with mobility, hygiene, and medical routines. However, dependence did not eliminate agency. Residents described consciously choosing to cooperate, particularly when they recognised staff efforts and intentions.

One resident reflected on her reliance on staff following a fall:

> *"Look at me I can't do anything by myself, I depend on staff, whats the point in angry with staff, it is not their fault, my daughter and son put me here. Initially I didn't like the staff, they are nice and help me, I cooperate with carers because they are helping me, I like them…u know these girls helps me to get up, shower me and sat me on wheelchair and take me to lounge, after the fall I can't walk properly" (U2 R3)*

This account illustrates emotional adjustment and reframing. Rather than resisting assistance, the resident interpreted care as support rather than control. Cooperation here was an adaptive response to vulnerability.

Similarly, cooperation was evident in medical routines. A resident receiving ongoing wound care stated:

> *"Nurse give me the medication and do the wound dressing, I had diabetic foot and it takes long time to dressing, I am thankful for what she is doing" (U1 R1).*

Gratitude functioned as a relational bridge, reinforcing trust and compliance with lengthy procedures. These examples demonstrate that cooperation in personal care was grounded in recognition of staff competence and goodwill.

Cooperation Through Therapeutic Encouragement

Staff encouragement to participate in exercises and activities formed another site of negotiation. Some residents complied because they trusted staff judgement.

One resident explained:

> *"I just listen to the staff when they request to do some exercise, I know they are prompting for my goodness" (U4 R6).*

This statement reflects cognitive trust—residents believed staff recommendations were beneficial. Cooperation therefore stemmed from perceived shared goals.

From the staff perspective, engagement was variable:

> *"Some of the residents enjoy doing strengthening exercises for legs, we encourage them to participate and help… few residents cooperate and others will say we are too old to do this" (U2 S3).*

This highlights that cooperation was not uniform. It required persuasion, encouragement, and sensitivity to individual attitudes.

Social activities further strengthened collaborative engagement. A resident described shared participation in leisure tasks:

> *"I play games with care staff, do some crafts work together" (U1 R2).*

Although another resident expressed ambivalence about the activities themselves, she valued the relational aspect:

> *"We play bingo, cards its all fun activities, sometimes I feel silly for playing games with staff. I don't like the games, but I enjoy spending time with staff and other residents" (U3 R5)*

Here, cooperation was motivated less by the activity and more by social connection. Engagement fostered belonging, reinforcing relational bonds central to negotiated care.

Adherence to Shared Routines and House Rules

Cooperation also involved navigating institutional policies. Residents were informed about routines and safety procedures upon admission. Rather than presenting rules as restrictive, participants described adapting to them pragmatically.

One resident acknowledged the complexity of policy documents but actively sought clarification:

> *"You know the policies and procedures paper, its too long, I ask staff to tell me the important things and cooperate with the rules. I like to smoke, not allowed to smoke in bedroom, so the staff take me out for smoking, I am always nice to staff" (U4R6).*

This quote demonstrates negotiation in practice. The resident complied with safety regulations while staff accommodated personal preference within permitted boundaries. Cooperation was therefore reciprocal and flexible.

A staff member described a collective culture of compliance:

> *"All the residents follow the policies and procedures, we cooperate and help each other, we are a family" (U3 S5).*

The language of "family" suggests that rule adherence was framed as communal responsibility rather than institutional enforcement.

Participatory Feedback and Relational Trust

Structured meetings provided formal opportunities for residents to express preferences and concerns. Feedback functioned as a mechanism of shared governance.

A staff participant explained:

> *"We have meeting with the residents every month, it helps to get the feedback from the residents and do the necessary changes" (U4 S6).*

From a resident perspective, voice was essential to cooperation:

> *"If I don't tell them what I like or dislike, how will they know? Staff listens and acts on our feedback." (U2R4).*

These accounts highlight that cooperation was dialogical. Residents articulated preferences; staff responded with adjustments. This exchange strengthened trust and reinforced mutual respect.

Trust was repeatedly identified as foundational. One staff member described relational closeness as enabling smoother care interactions:

> *"We have a good relationship with the residents, we are like friends and we share our thoughts. When the resident trust us, its easy to understand and leads to a good conversation" (U2S4).*

Trust reduced resistance, facilitated communication, and supported emotional well-being. Cooperation thus emerged not as obedience but as relational alignment.

Synthesis: Cooperation as Active Negotiation

The findings indicate that cooperation between SAPWD residents and staff is multidimensional and reciprocal. Residents negotiated dependence, evaluated staff intentions, complied with routines, and exercised voice through feedback mechanisms. Staff, in turn, adapted communication, encouraged participation, and demonstrated flexibility within regulatory boundaries.

Rather than portraying residents as passive recipients of care, these accounts illustrate agency within constraint. Cooperation functioned as a strategy for maintaining dignity, fostering belonging, and sustaining positive relationships. When trust, respect, and open communication were present, residents were more willing to engage in personal care, therapeutic activities, and communal life.

In alignment with the broader theme of *Active Negotiation*, cooperation was a shared accomplishment constructed through dialogue, empathy, and mutual adjustment. This relational dynamic contributed to enhanced well-being, smoother caregiving processes, and greater satisfaction with residential care.

8.3.2 Cooperation with family

Cooperation with family emerged as a central dimension of *Active Negotiation* in residential care. Rather than diminishing family roles, care home placement reshaped them. SAPWD residents continued to rely on family members for emotional reassurance, decision-making support, cultural continuity, and advocacy. Cooperation was not passive dependence; it involved dialogue, persuasion, shared decision-making, and ongoing relational adjustment.

To strengthen thematic coherence, this section is organised into four interconnected aspects of cooperation: (1) sustaining emotional connection, (2) negotiated decision-making in care planning, (3) shared participation in cultural and social life, and (4) advocacy and mediated communication.

Sustaining Emotional Connection

Regular contact through visits and phone calls-maintained continuity between residents and their family networks. These interactions reinforced belonging and reduced feelings of abandonment.

One resident described the significance of her daughter’s daily visits:

> *“My daughter visits everyday and brings me food, sometimes we don’t have much to talk about… She talks about kids and relatives, we gossip… we chat about TV dramas, I understand my daughters hardwork and how she struggles to manage work and home. Still she comes to see me everyday to make me happy” (U1 F2)*

This account reflects reciprocal awareness. The resident not only received emotional support but also recognised her daughter’s sacrifices. Cooperation here involved mutual understanding and shared emotional labour, reinforcing dignity and connection despite institutional living.

Negotiated Decision-Making in Care Planning

Care planning meetings functioned as formal spaces for negotiation between residents, families, and staff. Family members often played a persuasive or mediating role when residents were hesitant about aspects of care.

One resident initially resisted using a wheelchair due to feelings of shame. During a care plan review, staff explained the clinical necessity, and her daughter encouraged her to reconsider:

> *"When they ask me to use wheelchair I was ashamed and didn't want to use it, I stayed in my bedroom, I just told my daughter I don't like to sit on wheelchair…when they reviewed my careplan staff talked about the importance of using wheelchair because my legs don't have enough strength to walk, my daughter convinced me and finally I agreed" (U1 R2)*

This example illustrates cooperative negotiation rather than imposed compliance. The resident's acceptance emerged through dialogue, explanation, and familial reassurance. Family members thus acted as trusted intermediaries, facilitating adaptation to changing physical needs.

Shared Participation in Cultural and Social Life

Family involvement in cultural events and outings strengthened identity and belonging. Participation in festivals and shared meals enabled residents to maintain cultural continuity within the care setting.

A resident described outings with her daughter:

> *"We go out to an Indian restaurant to have meal, we enjoy food there, it's delicious sometimes she brings food from home, sometimes we go out for a walk… it depend on the weather" (U2 R3).*

Another resident reflected on the emotional impact of a family-inclusive celebration:

> *"I missed all the festivals after coming here, when the staff invited my family for the event and it was a surprise for me… grandchildren also came" (U2 R4).*

These accounts show how cooperation extended beyond practical support to shared joy and cultural affirmation. Celebrations created intergenerational spaces where residents felt valued and socially integrated. In this sense, cooperation preserved cultural identity while adapting to institutional life.

Advocacy and Mediated Communication

Family members frequently acted as advocates, particularly when residents required assistance in communicating needs or concerns to staff. This advocacy strengthened residents' sense of security.

One resident explained:

> *"If I need any help, I ask my son to inform the staff. He always makes sure they know what I need" (U4 R6).*

Here, cooperation operates through representation. The resident exercised agency by identifying needs, while the son facilitated communication with staff. This mediated process ensured responsiveness without undermining the resident's voice.

Family advocacy also reinforced trust in the care system. When residents felt confident that relatives would intervene if necessary, anxiety decreased and adaptation improved.

Synthesis: Family Cooperation as Relational Negotiation

The findings demonstrate that cooperation with family is multidimensional and dynamic. Emotional connection sustained belonging; care planning discussions enabled negotiated adaptation; shared cultural participation reinforced identity; and advocacy mechanisms ensured responsiveness.

Importantly, cooperation was reciprocal. Residents adjusted expectations, acknowledged family efforts, and participated in decision-making. Families balanced respect for autonomy with protective concern. Through ongoing dialogue, they collectively navigated the transition to residential care.

Within the broader framework of *Active Negotiation*, family cooperation functioned as a stabilising force. It mediated institutional routines, preserved cultural identity, and enhanced emotional well-being. Residents who maintained strong, communicative relationships with family members reported greater satisfaction, confidence, and sense of inclusion.

Thus, cooperation with family is not peripheral but foundational to person-centred dementia care. It sustains dignity, strengthens autonomy through shared decision-making, and ensures that SAPWD residents remain embedded within their familial and cultural worlds while living in residential settings.

8.4 Subcategory- Cultural Life

This subcategory explores how cultural life is actively negotiated within residential settings for SAPWD. Cultural life was not a fixed or uniform construct; rather, it was shaped by residents' migration histories, linguistic backgrounds, dietary practices, religious traditions, and family expectations. In keeping with the overarching theme of Active Negotiation, the findings demonstrate how staff, residents, and families continually negotiated cultural identity within the structural constraints of care provision.

To improve coherence, this section is structured around six interconnected sources of cultural life: cultural identity as individual, not collective; food as a site of cultural recognition; festivals, rituals and collective belonging; inclusion, exclusion and intra-cultural differences; generational shifts and changing cultural expectations.

8.4.1 Cultural Identity as Individual, Not Collective

Although residents were often grouped under the broad category of "South Asian," the data revealed significant diversity within this population. Even residents originating from the same country and speaking the same language demonstrated distinct lifestyles and preferences. For example, residents in Unit 1 and Unit 2 were both Hindi-speaking and born in India, yet dietary practices differed considerably, with one group identifying as vegetarian and the other consuming meat.

Most residents had migrated to the UK for employment, marriage, or family reunification. These migration trajectories shaped their adaptation processes and current expectations of care. The findings reinforce the argument that South Asian culture is dynamic and shaped by migration, integration, and generational change. Treating SAPWD as a homogeneous cultural group risks overlooking important individual differences. Cultural life therefore required negotiation at an individual level rather than being assumed on the basis of ethnicity or language.

8.4.2 Food as a Site of Cultural Negotiation

Food emerged as a central expression of cultural identity and belonging. Residents and families frequently evaluated care quality through the lens of dietary provision. In several units, culturally appropriate meals such as halal, vegetarian, or vegan options were provided. One resident reflected positively on receiving halal food, stating:

> *“Halal food was given to me and I was happy, but the taste was not very good” (U3 R5).*

This quote illustrates both satisfaction and limitation: while religious requirements were acknowledged, authenticity and quality remained areas of concern.

A staff member described how dietary choice was structured within organisational routines:

> *“Three choices are given in the menu, they can choose and some of the residents were curious about the ingredients, we make sure that meals are served according to the dietary requirements of the resident” (U1 S2).*

Here, negotiation is visible between institutional efficiency and personalised cultural provision. While care homes could not feasibly provide fully individualised meals daily, efforts were made to incorporate choice within operational constraints.

Family members were often more critical of food quality than residents themselves. Their expectations sometimes reflected cultural norms surrounding hospitality and care, particularly given the financial costs of residential placement. These findings align with Abbey et al. (2015) and Runci et al. (2014), who emphasise that culturally appropriate nutrition significantly influences well-being and family satisfaction in aged care contexts.

However, in nursing units where residents had complex health conditions or swallowing difficulties, dietary modifications such as puréed diets prioritised physical safety over cultural authenticity. This tension further illustrates how cultural life is negotiated within clinical realities.

8.4.3 Language, Communication and Cultural Recognition

Language functioned as both a bridge and a barrier. In culturally aligned units, residents and families valued staff who shared linguistic and cultural backgrounds. One family member explained:

> *"Here we have staff from India and Pakistan. It's good to see people from our culture, and I think they understand my father better" (U2 F3).*

This comment reflects the perceived link between shared culture and emotional safety. Staff members who shared residents' backgrounds were often viewed as better able to interpret subtle cultural cues and unspoken needs.

Conversely, in larger and more culturally mixed units, staff described confusion when caring for residents from multiple backgrounds:

> *"I got confused with the cultural background of the resident when there were residents from different countries. It's hard to understand and fulfil their wishes when we are short-staffed" (U1 S1).*

This illustrates how multiculturalism within care settings requires continuous negotiation. Cultural diversity enriched care environments but also created practical challenges, particularly under conditions of staffing shortages and task-oriented systems.

8.4.4 Festivals, Rituals and Collective Belonging

Participation in religious and cultural celebrations strengthened residents' sense of belonging. In units where festivals were organised, residents reported emotional reconnection with their heritage. One resident described the impact of being surprised with a family-inclusive event:

> *"I missed all the festivals after coming here. When staff invited my family for an event, it was a surprise for me. Grandchildren also came, and we enjoyed the day together" (U2 R4).*

This account highlights how culturally responsive practice can restore disrupted intergenerational connections. Celebrations functioned not merely as entertainment, but as symbolic reaffirmations of identity.

Similarly, a staff member observed how cultural outings stimulated memory and storytelling:

> *“Cultural events bring the old memory back to residents, they like to chat about it a lot and some of the residents are non-stop” (U3 S5).*

These experiences align with interpretivist understandings of dementia care, where meaning-making and reminiscence are central to well-being. Cultural activities acted as triggers for memory, reinforcing psychosocial engagement beyond physical care tasks.

8.4.5 Inclusion, Exclusion and Intra-Cultural Differences

While culturally aligned homes met many residents’ needs, homogeneity also produced unintended exclusion. In one setting where the majority of residents were Gujarati and Hindu, communal television programmes and prayers reflected this dominant culture. The resident, from a Sikh background, speaks Punjabi, and the participant felt he was alone on an island. The care staff speaks multiple languages, including Punjabi, Gujarati, Hindi and English. Participant R6 speaks Punjabi, Hindi, and English, despite feeling lonely because most residents were from Gujarati backgrounds. The activities were more concentrated on Gujarati culture.

A Sikh Punjabi-speaking resident reported feeling isolated despite receiving individualised care:

> *“I felt like I am alone on an island. I could speak many languages, but most of the activities here are in Gujarati” (U4 R6)*

This example demonstrates that even within the broader South Asian category, intra-cultural differences can create marginalisation. Cultural life, therefore, required negotiation not only between “South Asian” and “British” identities, but also among regional, linguistic, and religious subgroups.

8.4.6 Generational Shifts and Changing Cultural Expectations

Residents’ narratives also reflected generational transitions. One resident expressed frustration at limited engagement from younger family members:

> *“My grandson visits me every week, but he just sits on the chair, eyes on his mobile all the time. If I ask something, he doesn’t even look at me. I don’t know why kids are like this nowadays” (U2 R3).*

This highlights how cultural life is influenced not only by ethnicity and tradition, but also by technological and generational change. Migration and acculturation processes have reshaped family dynamics, requiring residents to negotiate evolving social norms.

Synthesis

Cultural life within residential settings was not static or uniformly delivered; it was continuously negotiated between residents, families, and staff within structural and organisational limits. Food, language, festivals, daily routines, and intergenerational interactions all functioned as arenas where identity and belonging were either reinforced or constrained.

Where care homes incorporated culturally sensitive practices, provided diverse staffing, and facilitated meaningful activities, residents reported greater satisfaction and emotional connection. Where staffing shortages, task-based systems, or dominant subcultural norms prevailed, psychosocial needs were sometimes secondary to physical care priorities.

Consistent with previous research, the findings demonstrate that culturally responsive dementia care enhances well-being and quality of life. However, this study extends the literature by illustrating how cultural care is achieved through Active Negotiation a dynamic process shaped by diversity within South Asian communities, institutional constraints, and ongoing collaboration between residents, families, and care staff.

In sum, supporting cultural life for SAPWD requires more than acknowledging ethnicity; it necessitates continuous interpretive engagement, individualised care planning, and reflexive negotiation to ensure that residents' identities are respected, preserved, and meaningfully expressed within residential care.

8.5 Summary

This research explored the opportunities and barriers in meeting the needs of SAPWD in residential care, using a constructivist grounded theory approach. The study identified a core category, active negotiation by residents, family, and staff, which captured the collaborative processes essential for providing effective and culturally sensitive care. Four main categories emerged: approach to residential care, reflecting residents' quest to understand their stay and the role of family and community perceptions; acceptance of residential care, highlighting the impact of dementia on daily life, experiences of loneliness, and family perspectives; being supported by family, staff, and management, which examined practical coping strategies and the importance of interpersonal relationships; and continuing to live in residential care, emphasizing quality of life and adaptation. Overall, the study provides descriptive and interpretative insights into the experiences of SAPWD, showing how culture, ethnicity, family involvement, staff support, and individualised care intersect to influence well-being in residential settings. The rich qualitative data, supported by participants' voices, underscore the need for collaborative, person-centred, and culturally aware approaches to dementia care.

Chapter 9: Discussion

9.1 Introduction

The concept of active negotiation highlights the continuous, evolving process through which the interactions among staff, residents, and family members shape residential care for SAPWD. It emphasises that care is not fixed but develops through ongoing dialogue, adjustment, cooperation and compromise between cultural expectations, family values, and institutional practices. This process reflects a balance between personal and cultural needs on one hand, and professional, organisational, and regulatory constraints on the other. As care practices unfold, they influence and reshape expectations, creating a cyclical process of learning and adaptation. Ultimately, residential care for SAPWD is portrayed as a co-constructed relationship built on mutual understanding, flexibility, and the blending of diverse cultural and professional perspectives.

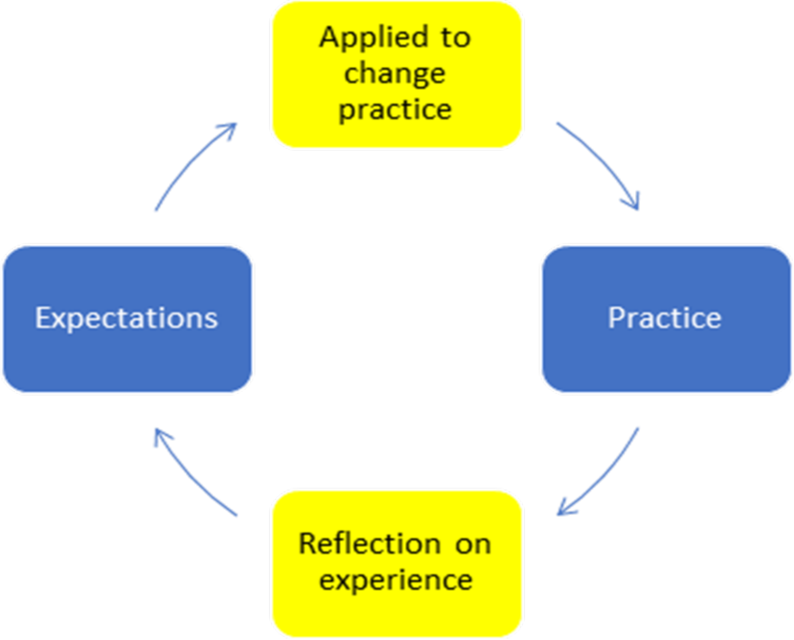


Figure 9.1 The Cycle of Active Negotiation in Culturally Responsive Dementia Care for SAPWD

This chapter explores the care expectations of South Asian people with dementia and their families alongside the actual practices observed within UK care homes. By integrating empirical findings, theoretical perspectives, and the policy contexts discussed throughout the thesis, the thesis highlights the intricate interaction between cultural values, institutional structures, and systemic challenges and opportunities in delivering dementia care to South Asian communities (Patel et al., 2007). The gap between what is expected and what is practised goes beyond issues of service provision; it raises deeper concerns about fairness, respect, and the ability of healthcare systems to meet the needs of increasingly diverse populations (Bhopal, 2007).

The findings of this study highlight a continuous process of negotiation between the expectations and needs of SAPWD residents and their families and the care ultimately provided in residential settings. This dynamic has important consequences for residents' well-being, family satisfaction, and the pursuit of health equity within dementia care (Mukadam et al., 2019). Gaining insight into the challenges and opportunities within this context is crucial for shaping more adaptive care models that close the gap between expectation and practice, fostering environments that are truly person-centred and culturally attuned (Brooker, 2007).

This chapter provides an interpretive discussion of the findings presented in Chapters 4-8. The discussion demonstrates how the theory of Active Negotiation is grounded in participants lived experiences while situating it within existing dementia care, person-centred care, and culturally responsive care literature.

Re-Examining the Core Theory: Active Negotiation

The findings identified *Active Negotiation* as the core process shaping residential care experiences for SAPWD. This negotiation occurred between residents, families, staff, and management, and was embedded within institutional, cultural, relational, and structural conditions.

The concept extends person-centred care theory, particularly Kitwood's (1997) emphasis on personhood, by illustrating how personhood is not simply preserved through staff attitudes but actively co-constructed through ongoing relational engagement. Rather than being passive recipients of care, residents demonstrated agency within dependence. Their cooperation with routines, medication, and personal care was conditional upon trust, empathy, and recognition of dignity.

Similarly, Surr et al. (2016) argue that person-centred dementia care depends on meaningful relationships and organisational support. The present findings deepen this understanding by showing that, in culturally diverse settings, relational work must also involve negotiation of language, food, religious practice, and family roles. Thus, Active Negotiation operates as both a relational and cultural process.

First Category- Entering Residential Care: Negotiating Identity, Stigma, and Belonging

The transition into residential care emerged as emotionally and culturally complex. Participants described uncertainty, loneliness, and loss of autonomy, reflecting wider literature that links relocation to emotional distress among people with dementia (Moyle et al., 2011).

However, for SAPWD, this transition was further shaped by community stigma and cultural expectations of filial responsibility. Research by Juttla (2015) and Parveen et al. (2018) highlights how dementia within South Asian communities may be associated with shame, secrecy, or moral judgement. The findings confirm that admission to residential care could be interpreted as family failure, intensifying emotional strain.

Importantly, the data show that families did not withdraw after placement. Instead, they redefined caregiving roles within institutional contexts. This aligns with Lawrence et al. (2011), who suggest that strong cultural obligations can generate both resilience and pressure. Katbamna et al. (2004) similarly emphasise that family solidarity persists even when care shifts to formal settings. The present study supports and extends these arguments by demonstrating how families actively mediate between cultural values and institutional systems.

Language barriers further complicated entry into care. Consistent with broader dementia communication research, language discordance increased vulnerability and withdrawal. However, culturally aligned staff and first-language communication strengthened belonging and trust. Thus, entry into care was not a single event but the beginning of ongoing negotiation around identity, dignity, and inclusion.

Second Category- Adjustment to Care: Cultural Responsiveness within Structural Constraints

Adjustment to residential life revealed tensions between cultural sensitivity and organisational limitations.

i) Culturally Oriented Care

Participants valued recognition of prayer routines, dietary practices, religious texts, and culturally appropriate forms of address. These findings resonate with literature on culturally competent dementia care, which emphasises the importance of tailoring services to cultural identity (Mukadam et al., 2011; Hailstone et al., 2017; Williamson, 2012).

However, this study advances the literature by illustrating intra-cultural diversity. Cultural identity was not homogeneous; differences in religion, language, migration history, and regional background required reflexive practice rather than standardised “ethnic matching.” Sandhu (2018) similarly warns against essentialising minority communities. The present findings demonstrate how staff must engage interpretively, rather than relying on assumed cultural knowledge.

Food emerged as a particularly powerful site of negotiation. Abbey et al. (2015) and Runci et al. (2014) note that culturally familiar food supports emotional well-being in dementia care. The current findings reinforce this, but also show that food functions symbolically as a connection, a memory, and an identity, while also becoming a source of dissatisfaction when institutional catering cannot accommodate preferences.

ii) Busyness and Organisational Pressures

Chronic time pressure and understaffing shaped daily practice. Although essential tasks were completed, relational care was often compressed. This reflects evidence linking staffing levels to care quality (Harrington et al., 2000; Aiken et al., 2012; Nagington et al., 2013).

What the present study adds is insight into how busyness is experienced relationally. Residents often empathised with staff but simultaneously felt invisible when interactions were rushed. For people with dementia, abrupt or hurried care heightened anxiety and confusion. Thus, structural constraints directly influenced emotional well-being.

Active Negotiation was evident even here: staff derived motivation from relational rewards, and managers attempted flexibility within systemic limitations. Nevertheless, sustainable culturally responsive care requires structural support, not solely individual goodwill.

iii) Medication: Safety, Expectations, and Communication

Medication management represented another domain of negotiation. Families often associated medication with improvement, while staff emphasised symptom management rather than cure. This divergence reflects broader public misunderstandings about anti-dementia drugs and aligns with clinical guidance indicating that such medications manage symptoms but do not reverse disease progression (NICE, 2014).

Residents' dissatisfaction with uniform pain relief highlights the need for individualised assessment. Moreover, medication rounds sometimes became task-focused under staffing pressure, potentially undermining dignity. The findings suggest that even technical practices such as medication administration are relational events requiring explanation, reassurance, and respect.

Third Category- Being Supported by family, staff and management: Relational Foundations of Trust

Family involvement remained central after placement, reinforcing the collectivist values identified in previous research (Adamson & Donovan, 2005; Bramble et al., 2009). Rather than relinquishing responsibility, families continued caregiving through feeding, grooming, advocacy, and cultural continuity.

Trust emerged gradually through consistent staff behaviour and communication. Kerr et al. (2005) and Wilkinson et al. (2005) emphasise that staff attitudes significantly influence residents' well-being. The present findings support this and further demonstrate that trust in culturally diverse settings requires visible respect for religious practice, dietary needs, and language preferences.

Management also played a crucial role. Diversity in recruitment, openness to feedback, and support for family meetings strengthened collaborative partnerships. Patel et al. (2007) argue that culturally competent services require organisational commitment. This study confirms that cultural responsiveness cannot be sustained without leadership engagement.

Fourth Category- Continuing to Live in Care: Agency within Dependence

Chapter 8 illustrated that long-term residence involves sustaining dignity and belonging through continuous negotiation. Cooperation with staff was not passive compliance but relationally constructed. When empathy and competence were perceived, residents willingly engaged in care routines.

Participation in cultural and religious events reinforced identity and belonging, consistent with literature linking culturally meaningful engagement to improved quality of life (Abbey et al., 2015; Runci et al., 2014). However, multicultural complexity sometimes generated intra-community tensions, reinforcing the importance of reflexive practice.

Generational shifts and technology altered family interaction patterns, introducing new forms of negotiation around communication and expectations. Thus, Active Negotiation is dynamic, evolving alongside social change.

9.2 Expectations of care

The findings indicate that South Asian families approach care home placements with strong cultural and religious expectations that are often not fulfilled in practice (Seabrooke & Milne, 2004). These expectations represent essential conditions for preserving dignity, cultural identity, and spiritual well-being, rather than optional preferences open to compromise (Lawrence et al., 2011). Care expectations in care homes often vary depending on the range of services offered and the policies and procedures in place. According to the findings, participants from all three groups noted that most SAPWD residents were admitted directly from the NHS or dementia assessment units for ongoing care needs. For some residents and their families, this unplanned admission process generated anxiety and concern, largely due to the stigma surrounding dementia care. In contrast, two residents who experienced planned admissions reported less stress and uncertainty, highlighting that structured admissions can ease the transition and help residents settle more comfortably. While a planned admission is not the sole determinant of a positive care home experience, it can significantly contribute to early adjustment and well-being. Ultimately, the quality of interpersonal relationships among SAPWD residents, their families, and staff depends heavily on effective management and teamwork. A supportive environment where all three groups are respected, valued, and actively involved in care planning is essential for promoting person-centred and collaborative dementia care.

> *“I feel when the staff listen to me, they understand me… I feel…I am heard and if any changes made, they will let me know” (U4 R7)*

Building and maintaining interpersonal relationships in care settings is often challenging; therefore, care providers should prioritise regular training and reflective supervision to help staff strengthen their relational and communication skills. Encouraging staff to form positive, trusting relationships with SAPWD residents and their families is essential for improving the overall quality of care. Senior care assistants and care assistants typically spend the most time with residents, assisting with personal care and daily routines, while nurses, deputy managers, and managers often have less direct interaction due to administrative and procedural responsibilities. Nurses, in particular, are heavily occupied with medication management, nursing procedures, and extensive documentation, which can limit opportunities for meaningful engagement with residents and families. Managers and deputy managers are often preoccupied with operational demands, external communications, and crisis management, leaving little time for personal connection. Consequently, care assistants often develop the deepest understanding of SAPWD residents, their needs, and their preferences across all units.

Managers also face challenges balancing the high expectations of families with the external pressures and persistent stigma surrounding dementia care. Negative societal attitudes toward care homes often shaped by misconceptions about neglect or abuse further complicate their role. However, across all four units, staff consistently strived to deliver quality, compassionate care despite occasional concerns and complaints. Care assistants and senior carers reported any issues promptly to the nurse in charge or manager, who then worked collaboratively to resolve them and communicate with families. The findings revealed that while family members frequently voiced complaints and held high expectations, all SAPWD residents expressed general satisfaction with the care received, though most felt their social needs were not fully met except in Unit 4, which demonstrated a more person-centred and culturally sensitive approach.

From the participants' perspectives, it was evident that SAPWD residents value strong connections with their families, friends, and the broader South Asian community. Such engagement fosters a sense of belonging, continuity, and purpose, reinforcing their cultural identity and emotional well-being. As a society, there is a shared responsibility among families, communities, and institutions to challenge the stigma surrounding dementia and residential care.

A key issue that requires ongoing attention is the public perception of care homes. Instead of distancing from these facilities, communities should adopt a constructive and supportive outlook. The number of care home beds in the UK now exceeds hospital beds, reflecting an increasing dependence on long-term residential care—a trend projected to continue, with the number of nursing homes expected to double within the next three decades. Currently, dementia stands as the leading cause of death in the UK; according to the Office for National Statistics, Alzheimer's disease and dementia were the primary causes of death in 2022 (Alzheimer's Research UK, 2023). Reducing stigma is therefore crucial for improving access to dementia care in residential settings, both now and for future generations. Providing adequate information and culturally appropriate support to the South Asian community can foster greater acceptance of care homes as positive, supportive environments. Encouragingly, residents in Unit 4 reported particularly positive experiences, with satisfaction spreading through word-of-mouth within their communities.

> *"My mum was happy, and she likes to participate in the activities…she chats with other residents and is friendly with the staff. They are like a family…I told my friend about the good care provided to my mum, and they recommended this place to their uncle…he is happily staying here". (U4 F7)*

Nursing and residential homes hold a fundamental responsibility to deliver high-quality care that meets the diverse and evolving needs of their residents. While it may not always be possible to fulfil every requirement SAPWD, the findings reveal that care staff, with the support of families, residents, and management, make genuine efforts to provide compassionate and responsive care. With sustained commitment, care homes can transform into positive, nurturing environments that are valued for the quality of care they provide to individuals as they age and experience cognitive decline.

To address the negative perceptions surrounding residential care, it is essential to examine what contributes to these attitudes understanding what aspects of care homes are appreciated, which areas are misunderstood, and how their role in the broader care system is recognised. Every individual’s needs are unique, and therefore, care cannot be generalised. Choosing an appropriate care home that aligns with the resident’s cultural, emotional, and personal preferences is crucial, as it can help reduce loneliness and promote a sense of connection with family and community. Creating supportive, engaging, and culturally familiar surroundings allows SAPWD residents to regain a sense of belonging and adjust more comfortably to life in a care home.

Equally important is valuing and supporting care staff, whose empathy, dedication, and emotional investment form the foundation of quality dementia care. Recognising their efforts and providing adequate appreciation and resources not only enhances morale but also strengthens the overall care environment. When residents receive compassionate and person-centred care from well-supported staff, the negative stigma surrounding care homes begins to fade. Conversely, neglecting the maintenance, morale, and development of residential settings today could lead to diminished care quality in the future. Therefore, investing in both people and environments is key to ensuring that care homes remain dignified, trusted, and healing spaces for those living with dementia.

In residential settings, working together between resident care staff and family is vital in establishing a positive atmosphere and helps psychosocial and physical health. Effective communication between SAPWD residents, their families, and care staff is vital for building trust and ensuring quality care. Families often act as advocates, voicing concerns and helping bridge communication gaps, especially when residents face language or confidence barriers. While some family members may express frequent dissatisfaction due to guilt or high expectations, residents themselves were generally content once they became comfortable expressing their preferences regarding diet, activities, and daily routines. Initially, residents were hesitant to communicate their needs, but family involvement in care plan reviews helped improve understanding. Care staff also play a key role by clearly explaining routines and safety procedures, promoting cooperation and mutual respect within the care environment.

9.2.1 Expected Cultural Provisions: South Asian families hold clear and deeply embedded expectations that care homes will provide holistic cultural and religious support as part of everyday care. Expected culturally sensitive support, staff from the same cultural background in supporting personal care and of the same gender. They expect facilities to respect and facilitate religious observances by offering designated prayer areas, integrating prayer times into daily routines, ensuring access to sacred texts and materials in relevant languages, and enabling visits from religious leaders. Additionally, recognition and celebration of major festivals and holy days are viewed as essential to preserving spiritual connection and cultural continuity (Adamson & Donovan, 2005). Dietary provisions are also expected to go far beyond merely offering halal or vegetarian meals; families anticipate the preparation of familiar dishes using traditional spices, authentic cooking methods, and culturally resonant presentation styles that evoke the warmth and comfort of home life (Katbamna et al., 2004). These provisions are not seen as luxuries but as integral to maintaining identity, belonging, and overall well-being within the care environment. However, some family participants expect five-star hotel service, as they are funding their loved ones' care.

9.2.2 Actual Care Practices: In practice, the study finds that most care homes offer only limited and often superficial forms of cultural accommodation. Although some facilities make basic dietary adjustments, such as offering halal or vegetarian options, these efforts seldom extend to preparing authentic South Asian meals that reflect residents’ traditional flavours, cooking styles, and culinary rituals (Bowes & Wilkinson, 2003). Similarly, religious needs are frequently acknowledged in principle but rarely supported in meaningful, structured ways. Spiritual practices are tolerated rather than actively encouraged or facilitated. Many care homes lack dedicated prayer spaces, and institutional routines are often too rigid to accommodate the flexibility required for observances that must occur at particular times of the day (Purandare et al., 2007). As a result, cultural and spiritual needs tend to be treated as secondary to operational convenience, leading to care experiences that feel impersonal and disconnected from residents’ cultural and religious identities.

9.2.3 Conflicts in Expected Care

This highlights the underlying conflict between uniform institutional care models built around efficiency and consistency, and the personalised, culturally grounded care approaches necessary for South Asian residents (Kitwood, 1997). Care homes often function within organisational frameworks that emphasise routine, regulation, and standardisation, which in turn create systemic obstacles to the adaptability required for authentic cultural responsiveness (Spector et al., 2020). Family members play an active role in residents' care by assisting with feeding, monitoring care quality, and raising concerns when necessary. Within the South Asian community, many relatives experience a sense of guilt, as cultural expectations often dictate that caring for elderly parents is the responsibility of sons or daughters rather than care institutions. At times, tensions may arise among family members due to differing opinions or competitive involvement in caregiving. At the same time, communication gaps can occur when important information about residents' needs or conditions is not promptly shared with care staff. The findings chapter reveals that all family participants were concerned about the care provided to SAPWD residents, even though the care homes sought to provide a high standard of care with limited resources. Family members have a fundamental duty to ensure the standard of care at a care facility. Even though 2 Units strives to offer top-notch services, concerns and complaints were made regarding personal hygiene, diet, physical and psychological health, deterioration in health, and medications.

Another problem with family members' competitive care is the possibility of financial and legal conflicts. Issues over power of attorney and inheritance, such as a house or financial assets, might cause disputes. Family members sometimes influence or manipulate the residents' financial decisions for their gain, leading to long-lasting family splits. Those family members who did not financially benefit will not visit the resident. Residents could feel stressed, confused, and worried about family disputes without regular visits from family members. The reasons behind family members visits to residents in residential settings may also influence these competitive dynamics. The intention of visiting could be to ensure the quality of care or to contradict expectations. Understanding these motivations is important for developing interpersonal relationships that foster better cooperation among family members and staff, thereby enhancing residents’ overall care experience (Y. Tsai et al., 2012).

Competitive care among family members can affect the care experience and relationships by causing role conflict, stress, and difficulties with collaboration. Addressing these dynamics is essential for improving family members' cooperation. Competitive care dynamics among family members impact the standard of care residents receive. Issues between family members and role conflict lead staff to negotiate care tasks. The staff's perception is that they experience difficulties when the family members assert their role in residents' care. Examples include adding sugar to a diabetic resident's tea, walking a resident without a rollator, or questioning the staff's responsibility, which can minimise collaboration. The identified relationship dynamics are that family members do not share information about residents, are not cooperative, and struggle to control care responsibilities, thereby impacting the quality of care.

Another challenge identified is the staff's lack of confidence in managing potential conflicts between family members regarding their roles. The lack of confidence can discourage staff from actively involving families in planning care interventions. Residential settings face multifaceted challenges in implementing shared family care models, including knowledge gaps, cultural considerations, organisational support, and staff confidence. Addressing these barriers is essential for enhancing family engagement in care processes.

The benefits of family participation in care home include improved quality of care and increased cooperation and negotiation among residents, staff, and family members. Studies by Garfat (2011) and Marion et al. (2024) have emphasised the advantages and disadvantages of shared family care in residential settings. Positive outcomes, such as increased family participation, increased interaction between all parties, and care satisfaction, have been associated with family-oriented interventions. These interventions involve staff training, which promotes collaborative decision-making and family satisfaction in providing care to residents (Eltaybani et al., 2022). Incorporating SA families into care plan reviews has also been shown to enhance care outcomes, despite this field being underexplored.

All the family participants in this study experienced guilt due to the embedded belief and custom that they must care for their parents at home. Because carers demonstrate a dedication to caring for their family members and see it as a natural and honourable task, this sense of duty can lead to an optimistic outlook on caregiving (Sathish, 2023). This guilt can be made worse by language and communication barriers, as well as culturally inappropriate services that do not fit with their values and practices (Baker et al., 2002). To address this guilt, families can recognise that medical and emotional support that may not always be available at home can be obtained through professional care. Continuing to be emotionally connected, visit, and participate in decision-making with their loved ones and promoting culturally sensitive policies, educating the public about the advantages of assisted living facilities and stressing that receiving high-quality care is not an indication of neglect but rather an outgrowth of love and accountability. By changing their viewpoints, families can ensure their elderly loved ones receive the best possible care by striking a balance between practical care solutions and cultural expectations. The findings chapter indicates that family participants feel guilty when they cannot serve traditional food. Traditional culinary practices may clash with nutrition guidance in care homes, making tolerant dietary recommendations necessary.

Addressing guilt among family participants, the issue of family engagement in nutrition, ensuring quality, and vigilance in residential settings interrelate with family expectations for culturally appropriate care for SAPWD residents. The literature in the context highlights the importance of family obligations and cultural expectations in dementia care. However, no literature directly addresses the guilt associated with care in the SA community. Families can continue to be involved in caring for their loved ones while overcoming the difficulties associated with placing SAPWD individuals in care homes by assisting in feeding, quality assurance, and vigilance. Residents feel valued and respected when the family members maintain the emotional connections and ensure culturally appropriate care is provided in the care home. Adapting to modern caring needs while retaining cultural values requires addressing shame, guilt and dispelling the stigma associated with care homes in the South Asian community. Families that engage actively in bridging traditional and modern dementia care options ensure SAPWD residents' esteem and well-being.

9.3 Expectations in Communication and the Realities

Findings from this study identify language as a major source of disconnect between expected and actual care, carrying substantial consequences for the quality of care and the overall well-being of residents (Turner et al., 2005). All participants have different cultural backgrounds, which hindered effective communication due to differences in accent styles among SAPWD residents and staff, even though all residents could speak English fluently.

9.3.1 Expected Communication Support

South Asian families hold strong expectations that care homes will offer comprehensive communication support to ensure residents can clearly express their needs, engage meaningfully with staff, and sustain their linguistic and cultural identities (Nielsen et al., 2011). They expect bilingual staff who can communicate fluently in residents’ preferred languages, fostering trust, comfort, and emotional security. Additionally, families value the use of professional interpreters for significant discussions related to health, care planning, or personal matters to prevent misunderstanding and exclusion. Beyond verbal communication, they also anticipate culturally sensitive environmental adaptations such as signage, notices, and informational materials presented in commonly spoken South Asian languages to create a sense of familiarity, belonging, and inclusivity within the care environment (La Fontaine et al., 2007).

9.3.2 Actual Communication Practices

The findings indicate that bilingual support within care homes is minimal, with only a small number of facilities employing staff who speak residents’ preferred languages, and even in these cases, such linguistic abilities are rarely acknowledged, utilised effectively, or rewarded (Giebel et al., 2018). Professional interpreter services are seldom accessed, with care homes often depending on family members or untrained staff to bridge communication gaps, leading to frequent misunderstandings and placing undue emotional and practical burdens on families (Mackenzie, 2006). Moreover, the study highlights a widespread lack of staff training in culturally sensitive or cross-cultural communication techniques, which further exacerbates challenges faced by residents who are unable to communicate due to distress or revert to their first language. Environmental support, such as multilingual signage, translated materials, or visual aids, are also notably absent in most care settings, leaving residents feeling isolated, misunderstood, and disconnected from both their caregiver and the broader care environment.

9.3.3 Consequences of lack of communication

The linguistic issues identified in this study have profound, far-reaching consequences for residents' safety, comfort, and overall quality of life. Miscommunication often leads to unrecognised expressions of pain or distress, inaccurate behavioural assessments, and even medication errors, undermining both clinical accuracy and compassionate care (Hailstone et al., 2017). Beyond the clinical impact, residents frequently experience social isolation and emotional withdrawal due to their inability to engage meaningfully with staff or participate in care planning discussions. As dementia advances and English proficiency declines, this communication divide deepens further, with residents increasingly reverting to their first languages. Consequently, expressions of frustration, confusion, or unmet needs are often misinterpreted as signs of disease progression rather than manifestations of linguistic and cultural disconnection (McCleary et al., 2013).

The findings also suggest that role ambiguity between staff and family members contributes to these challenges. Many South Asian families struggle to transition from primary caregivers at home to visitors in residential care. Feelings of guilt, stigma, or emotional distress may discourage them from maintaining open dialogue with staff. Similarly, staff may not always approach families proactively, leading to misunderstandings and mistrust. Fielding et al. (2021) noted that divergent perceptions of caregiving roles often create communication barriers, where family members either withhold or delay sharing relevant details due to uncertainty, conflict, or lack of confidence in staff. Research by Galessiere et al. (2022) indicates that positive relationships between staff and family members can significantly reduce negative affect and depressive symptoms among residents, underscoring the importance of open and continuous communication in enhancing residents' quality of life. Delays in passing information between family members and care staff not only disrupt care continuity but also hinder the delivery of culturally sensitive and person-centred support for SAPWD. Emotional barriers, role ambiguity, and logistical challenges must be addressed through proactive communication, technological tools, and structured collaboration. Establishing mutual trust and maintaining open communication channels between families and care providers are fundamental to ensuring that residents receive holistic, culturally attuned, and high-quality dementia care that preserves their dignity and enhances their overall well-being.

9.4 Family Involvement Expectations versus Care Home Practices

The study highlights a fundamental mismatch between South Asian families' expectations of active involvement in caregiving and the institutional norms that shape care practices within UK care homes (Parveen et al., 2018). The findings highlight that active family involvement plays a crucial role in promoting the well-being and happiness of SAPWD in care homes. Conversely, limited involvement can lead to loneliness and emotional decline among residents. Cooperative relationships and open communication among families, residents, and care staff foster a positive atmosphere and help ensure that residents' needs are effectively met. Families who maintained frequent contact with staff felt more connected and reassured about their loved ones' care, while sharing information about residents' preferences, routines, and cultural or dietary needs enabled staff to provide more individualised and holistic support. However, language barriers sometimes hindered effective communication, as both families and staff from diverse cultural backgrounds struggled with English pronunciation and comprehension. Despite these challenges, families who visited regularly developed stronger relationships with staff and contributed meaningfully to care planning.

The involvement of family members plays a crucial role in supporting SAPWD living in care homes. Families often hold high expectations regarding the quality of care, driven by strong cultural values of loyalty, filial duty, and respect for elders. In South Asian culture, caring for ageing parents is traditionally seen as a family responsibility, and placing them in residential care may lead to feelings of guilt or social stigma. As a result, families expect exceptional standards of care to compensate for their absence and to ensure their loved ones are well looked after. Some family members, however, have unrealistic expectations, such as hoping for a cure or significant physical improvement despite the progressive nature of dementia. Many also expressed dissatisfaction when they perceived their relatives' health deteriorating or when dependency on care staff increased. A few families even compared care homes to luxury services, expecting hotel-like standards due to the financial costs involved. These findings highlight a complex dynamic between cultural beliefs, emotional guilt, and practical expectations, illustrating the need for better communication and understanding between families and care providers to align expectations with the realities of dementia care.

Many expressed a desire to assist with daily care but faced constraints due to work commitments or distance. A welcoming environment, flexible visiting hours, and staff friendliness encouraged family participation, while factors such as noise and lack of privacy in communal areas discouraged some visits. Overall, family engagement not only supports residents' emotional well-being but also enhances the quality of care through collaboration, trust, and cultural understanding. Encouraging families to participate in activities, celebrations, and decision-making strengthens relationships between residents, staff, and relatives, creating a more inclusive, compassionate, and person-centred care environment for SAPWD residents.

9.4.1 Expected Family Roles

South Asian families anticipate being closely and continuously involved in all dimensions of their relatives' care, extending far beyond occasional visits or consultations. They expect to actively participate in daily caregiving tasks, play central roles in care planning and decision-making, and enjoy regular, unrestricted access to residents, fostering a genuine partnership with care staff (Katbamna et al., 2004). These expectations are deeply rooted in cultural values that prioritise collective family responsibility, strong filial duty, and the moral imperative to provide hands-on support to elders. Families also view themselves as indispensable contributors to care quality, believing that their intimate understanding of the resident's personal history, preferences, and routines is vital for ensuring comfort, dignity, and culturally congruent care (Adamson & Donovan, 2005). Cooperative relationships and open communication between families, residents, and care staff foster a positive atmosphere and help ensure that residents' needs are met effectively. Families who maintained frequent contact with staff felt more connected and reassured about their loved ones' care, while sharing information about residents' preferences, routines, and cultural or dietary needs enabled staff to provide more individualised and holistic support. However, language barriers sometimes hindered effective communication, as both families and staff from diverse cultural backgrounds struggled with pronunciation or understanding English. Despite these challenges, families who visited regularly developed stronger relationships with staff and were able to contribute meaningfully to care planning. Many expressed a desire to assist with daily care but faced constraints due to work commitments or distance. A welcoming environment, flexible visiting hours, and staff friendliness encouraged family participation, while factors such as noise and lack of privacy in communal areas discouraged some visits. Overall, family engagement not only supports residents' emotional well-being but also enhances the quality of care through collaboration, trust, and cultural understanding. Encouraging families to participate in activities, celebrations, and decision-making strengthens relationships between residents, staff, and relatives, creating a more inclusive, compassionate, and person-centred care environment for SAPWD

9.4.2 Actual Institutional Practices

The findings indicate that most care homes function within Western-centric models of care that prioritise resident autonomy and individual choice, frequently perceiving substantial family involvement as intrusive rather than collaborative (Greenwood et al., 2013). Rigid schedules often limit visiting arrangements, and opportunities for family participation in care planning tend to be symbolic rather than genuinely influential. In many cases, family contributions are acknowledged superficially but not integrated into everyday decision-making or care delivery. Furthermore, staff members often receive little to no training in culturally responsive, family-centred care approaches, leaving them ill-equipped to understand or accommodate the collective caregiving values that are central to South Asian cultures (Jolley et al., 2006). This disconnect reinforces a sense of exclusion among families and strains relationships between care providers and relatives.

9.4.3 Culture Conflicts

This misalignment reflects a deeper cultural clash between the individualistic ethos underpinning Western care models and the collectivist values that shape South Asian family structures (Bhopal, 2007). The study reveals that when care homes do not adjust their practices to support culturally appropriate levels of family involvement, it frequently leads to tension, misunderstandings, and emotional strain among families and staff. Such neglect of cultural expectations often results in family dissatisfaction, erosion of trust in the care system, and a perception that institutional care is unable to uphold the relational and moral responsibilities that families consider essential to dignified caregiving (Shah et al., 1998).

9.5 Expectation-Practice Knowledge Deficits

The study reveals substantial gaps in knowledge among care home staff and management concerning South Asian cultural practices, religious beliefs, and expectations surrounding care (Botsford et al., 2011).

9.5.1 Lack of Knowledge in Staffs The findings highlight that many care staff have only a superficial understanding of the cultural and religious diversity within South Asian communities, often viewing residents from Indian, Pakistani, Bangladeshi, Sri Lankan, and other South Asian backgrounds as a single, uniform group (Nazroo, 2006). This lack of cultural nuance leads to generalised care practices that overlook critical distinctions in language, traditions, and belief systems. Moreover, staff frequently demonstrate limited awareness of the core principles and observances of major South Asian religions such as Hinduism, Sikhism, Islam, and Buddhism, resulting in inadequate or inappropriate support for residents’ spiritual needs and rituals (Turner et al., 2005). Notably, the study exposes substantial gaps in understanding dietary customs, with many staff unaware of the deep religious and cultural meaning attached to food choices, preparation techniques, and the communal nature of mealtimes within South Asian culture (Seabrooke & Milne, 2004). This lack of cultural competence undermines residents’ comfort, dignity, and sense of belonging within the care home environment.

9.5.2 Lack of Knowledge in Care Home Providers

The findings reveal that many care home providers have limited awareness of the strategic and ethical importance of cultural competence, often perceiving culturally responsive care as an optional or burdensome addition rather than as an integral component of quality improvement and person-centred practice that enhances outcomes for all residents (Brooker, 2007). This narrow perception contributes to a lack of proactive investment in staff training, resource allocation, and culturally informed policy development. Furthermore, management teams frequently underestimate the depth and prevalence of unmet cultural needs while overestimating their organisation's existing level of cultural competence, leading to complacency and resistance to change. Such misjudgements hinder meaningful progress toward inclusive care standards and perpetuate systemic inequities within the care home sector (Care Quality Commission, 2023).

9.5.3 Inadequate Training

The study shows that existing cultural competency training within care homes is often limited in scope and depth, offering only surface-level cultural awareness rather than equipping staff with the practical skills and confidence required to deliver genuinely culturally responsive care (Sue & Sue, 2019). Such training tends to rely on generic overviews of cultural sensitivity without addressing the complex, context-specific needs of individuals with dementia from minority ethnic backgrounds. Moreover, opportunities for continuous learning, reinforcement, and evaluation of cultural competence are scarce, with training typically delivered as a one-time exercise rather than as part of an ongoing professional development framework. This lack of sustained, practice-oriented education contributes to persistent gaps in understanding and perpetuates inconsistent standards of culturally appropriate dementia care (Williamson, 2012).

9.6 Care Providers and Resource Constraints

The gap between expectations and actual practice is largely shaped by the organisational frameworks and resource constraints that characterise care home operations.

9.61 Expectations and Reality in Staffing Challenges

Managers' and nurses' expectations do not align with the practice of health care assistants, who make pragmatic compromises to manage care within the staffing and time constraints. Although healthcare assistants (HCAs) play an important role in the operation of healthcare systems, their day-to-day work frequently deviates from the standards set by nurses and managers. HCAs usually must make pragmatic compromises to provide care within the constraints of limited staff and time. Management and nurses expect HCAs to deliver patient-centred care that complies with institutional policies and procedures. This section highlights the need for practical modifications in healthcare settings by examining the concerns between management and nursing expectations and the lived realities of HCAs. They must also collaborate with colleagues to modify routines based on resident needs or to make decisions that deviate from accepted practices in the given circumstances. These modifications draw attention to the discrepancy between HCAS's real-life experiences on the care home environment and the theoretical care model. It can result in practical compromises in providing care when managers' and nurses' expectations about the HCA's role are not aligned.

According to research, there are differences in registered nurses' and nurse managers' perspectives on the roles of registered nurses in healthcare settings. These differences can lead to confusion and role conflict, which might extend to HCA who work within the same environment, potentially affecting their ability to manage care successfully within the limits of staffing and time (Mohale, 2005). Nurses' perspectives on workload, staffing, and collaboration show that unequal task allocations and low staffing levels are significant issues in modern healthcare. These factors can lead to increased medical errors and lower patient satisfaction, suggesting that HCAs may feel pressured to compromise their care delivery to meet the demands of their roles under such conditions (Ohler et al., 2017). The liaison of teamwork, staffing, and workload indicates that HCAs prioritise immediate patient needs over standard care practices when faced with these challenges, reflecting a pragmatic approach to managing care within existing limitations.

The research highlights several critical staffing-related barriers that hinder the delivery of culturally responsive care. High staff turnover disrupts continuity and prevents the development of sustained cultural competence and trusting relationships with residents. Chronic understaffing further limits the time available for individualised attention or meaningful cultural accommodation, forcing staff to prioritise routine efficiency over personalised care. The lack of workforce diversity compounds these challenges, as few employees possess the linguistic abilities or cultural understanding necessary to meet the needs of South Asian residents effectively. Moreover, care homes often struggle to attract and retain bilingual staff, largely because language skills are neither formally recognised nor adequately compensated, leading to underutilization of these valuable competencies (Greenwood et al., 2013). Collectively, these staffing constraints perpetuate the expectation–practice divide and undermine efforts toward inclusive, person-centred care.

The International Nursing Symposium addressed the importance of safe staffing, retention, and recruiting to enhance care delivery. Empowering nurse leaders and implementing staffing solutions can help all staff, including HCAs, improve the working environment (Sienko, 2024). The literature shows that when managers and nurses have different expectations, HCAs may have to make practical concessions to accommodate staffing and time restrictions when providing care. HCAS navigate through the expectations of managers and nurses in a clinical setting through a complex interplay of roles, responsibilities, and communication dynamics. A study by Crevacore et al. (2024) identified that HCAS frequently struggle to clarify their role in practice, which can cause uncertainty and burnout with hectic shifts. HCAs report to be part of the team, influencing their willingness to accept delegated tasks from registered nurses (RNs).

Good teamwork significantly impacts HCAs decisions to accept or refuse delegated responsibilities, emphasising the importance of supportive relationships in the workplace. The interpersonal relationship between RGNs and HCAs is categorised as ongoing negotiations in providing care to residents. As nurses have additional responsibilities, they give more tasks to HCAs , which can cause stress when not managed effectively. Effectively using the roles of HCAs as a resource for resident care are formed by the negotiations and expectations of resident, families, staff and management. HCAs face challenges in balancing the duties with the policy expectations of care home providers and managing the practical realities. The lack of training opportunities and inadequate support for staff in cross-cultural work may contribute to healthcare inequalities that SAPWD residents and their families experience in relation to residential care.

9.6.2 Financial and Environmental Restrictions

The findings show that care homes face substantial financial pressures that restrict their ability to invest in cultural competency development (Age UK, 2023). Existing funding models, which are largely designed around standardised approaches to care, fail to allocate sufficient resources for the additional time, specialised training, and environmental adjustments needed to deliver culturally responsive support. Moreover, current commissioning frameworks seldom prioritise or reward cultural competence, offering little financial or structural incentive for care providers to make sustained investments in this area (NHS England, 2019). As a result, the pursuit of culturally inclusive care often competes with budgetary constraints, reinforcing systemic inequities in service provision. The physical design of many care homes, which often fails to account for cultural diversity, poses significant obstacles to culturally responsive care (Lawrence et al., 2011). A lack of adaptable spaces for religious practices, kitchens unequipped to prepare culturally specific meals, and environments built around Western cultural norms all exacerbate the gap between expectations and actual care practices. Institutional and resource barriers are persistent challenges. Staff acknowledged that while they strive to meet residents' diverse dietary expectations, limited budgets, staffing shortages, and lack of skilled chefs restrict their ability to deliver authentic and varied meals. As D. Bellis et al. (2017) and Anderson et al. (2011) suggest, understanding cultural diversity and dietary preferences improves satisfaction with care services, but without adequate institutional support, even well-intentioned staff struggle to maintain high standards. The study findings align with Meeusen (2003) and S. Chanduloy (2009), who observed that although care staff appreciate the importance of culturally appropriate food, practical limitations often hinder consistent implementation.

9.7 Regulatory Gaps

The study shows that systemic shortcomings in policy, regulation, and quality assurance frameworks continue to reinforce and sustain the gap between expectations and actual care practices (Cooper et al., 2010). Existing care home regulations primarily focus on safety, clinical outcomes, and uniform care standards, offering little direction regarding cultural competence expectations (Care Quality Commission, 2023). Quality inspection frameworks rarely evaluate how effectively services address cultural diversity, and there are currently no mandatory cultural competency requirements tied to care home registration or staff accreditation (Department of Health and Social Care, 2021). The research highlights a clear gap between policy effectiveness on diversity and inclusion and the practical realities of implementation within the care home sector (NHS England, 2019).

Although national and organisational policy documents frequently emphasise the importance of culturally responsive and equitable care, they rarely translate these commitments into actionable strategies supported by adequate funding, guidance, or accountability structures. As a result, care providers are left without the resources or frameworks needed to embed cultural competence into everyday practice. Furthermore, while national dementia strategies are comprehensive in addressing diagnosis, treatment, and support, they often overlook the distinct cultural, linguistic, and religious needs of minority ethnic groups, particularly South Asian communities (Alzheimer's Society, 2024). This policy–practice disconnect affects systemic inequities, leaving cultural responsiveness as an aspirational ideal rather than a standardised component of dementia care. The findings underscore a significant lack of research focused specifically on the experiences of South Asian individuals in care home settings, leading to insufficient evidence to guide meaningful policy or practice development (Mukadam et al., 2019). The absence of culturally relevant outcome measures further hinders the evaluation of cultural competency initiatives and limits the ability to hold care homes accountable for delivering culturally responsive care.

9.8 Consequences of the Expectation-Practice Gap

9.8.1 Impact on Residents

The disparity between expectations and actual care practices carries serious implications for South Asian residents living with dementia (Lawrence et al., 2011). The study reveals that neglecting the cultural and religious needs of South Asian residents with dementia has deep psychological and emotional repercussions. When cultural identity and familiar practices are overlooked, residents often experience heightened anxiety, depression, and profound feelings of alienation within care environments that feel unfamiliar and disconnected from their way of life (Giebel et al., 2018). The inability to observe religious rituals or maintain spiritual routines further contributes to emotional and spiritual distress, which can intensify cognitive decline and exacerbate behavioural symptoms (Spector et al., 2020). Additionally, communication barriers, particularly the absence of opportunities to speak in one's preferred language, lead to social isolation, frustration, and a diminishing sense of autonomy and selfhood (Turner et al., 2005). Collectively, these experiences undermine residents' emotional well-being and erode the very foundations of person-centred care.

The findings indicate that the lack of culturally sensitive care has tangible and often serious consequences for the physical health of South Asian residents with dementia. Inadequate attention to dietary preferences and religious food practices frequently results in poor appetite, reduced food intake, and subsequent weight loss or nutritional deficiencies, compromising overall health and resilience (Purandare et al., 2007). Cultural misunderstandings in personal care, such as neglecting modesty norms or failing to consider gender-sensitive care preferences, can lead residents to resist assistance with hygiene or daily routines, increasing the risk of infection and poor health maintenance. Furthermore, communication barriers exacerbate clinical risks, as difficulties in expressing pain, discomfort, or symptoms can result in medication errors, misdiagnosis, and inappropriate treatment (Nielsen et al., 2011). Together, these factors illustrate how culturally unresponsive care directly undermines both the physical well-being and safety of residents.

The study reveals that when the cultural needs of South Asian residents with dementia are overlooked, the resulting distress often manifests through behavioural changes that are frequently misunderstood by care staff. Actions commonly labeled as aggression, agitation, or resistance are, in many cases, expressions of frustration, confusion, or protest against care practices that disregard residents' cultural or religious values (Mackenzie, 2006). Such behaviors may arise from disruptions to established routines, unfamiliar food, inappropriate personal care approaches, or environments that feel alien and culturally invalidating. Unfortunately, these responses are often misinterpreted as signs of disease progression or behavioral deterioration, rather than as meaningful indicators of unmet emotional and cultural needs (Hailstone et al., 2017). This misinterpretation not only leads to inappropriate interventions but also reinforces a cycle of misunderstanding and depersonalization within care settings.

9.8.2 Impact on Families

The gap between expectations and actual care practices places considerable emotional strain and practical burden on South Asian families (Parveen et al., 2018).The research highlights the profound emotional toll experienced by South Asian families when cultural expectations are not met within care settings. Feelings of guilt, shame, and anxiety are common, as families perceive these shortcomings as personal failures in fulfilling their cultural and religious duties toward elder care (Katbamna et al., 2004). This emotional strain is often compounded by internal family tensions, with disagreements emerging over the decision to place relatives in care homes and the appropriate response to instances of cultural insensitivity or neglect. Such conflicts reflect the deep moral and emotional dilemmas faced by families navigating the intersection between traditional caregiving values and institutional care structures (Adamson & Donovan, 2005).

The findings indicate that South Asian families frequently shoulder substantial practical burdens to compensate for the lack of culturally appropriate care within institutional settings. Family members often take on additional roles bringing home-cooked food to ensure dietary authenticity, organizing religious observances, providing translation or interpretation support, and persistently advocating for their relatives’ cultural and spiritual needs to be recognized (Greenwood et al., 2013). While these efforts reflect deep familial commitment and cultural responsibility, they impose considerable strain on families, disrupting employment, social life, and caregiving balance. Over time, this continuous advocacy and supplementation of care can become emotionally and physically exhausting, highlighting the unsustainable nature of relying on families to bridge systemic cultural gaps within care homes (McCleary et al., 2013).

The research reveals that the persistent failure to meet cultural expectations significantly undermines trust in care providers and the wider healthcare system. When South Asian families witness cultural neglect or insensitivity in residential settings, it fosters deep skepticism toward institutional care, leading to reluctance in seeking formal support in the future (Bowes & Wilkinson, 2003). This erosion of trust extends beyond individual experiences, as families often share their dissatisfaction within their social and religious networks, amplifying communal mistrust and reinforcing negative perceptions of care homes. Such narratives perpetuate stigma surrounding institutional care, discouraging future engagement and exacerbating health inequalities among South Asian communities (Shah et al., 1998).

9.8.3 Impact on Staff and Care Providers

The expectation–practice gap also poses significant challenges for care home organisations, undermining both service quality and institutional reputation. Evidence indicates that care homes demonstrating inadequate cultural responsiveness often develop unfavourable reputations within South Asian communities, leading to mistrust, reluctance to engage, and underutilization of their services (Jolley et al., 2006). Damaged family relationships, stemming from unmet cultural expectations, further intensify complaints, conflicts, and in some cases, legal disputes, undermining the organisation’s credibility and community partnerships.

The research highlights that care staff operating within culturally unresponsive environments often experience significant moral distress, frustration, and emotional exhaustion when they recognise but cannot meet residents’ cultural needs due to organisational limitations (Botsford et al., 2011). This disconnect between professional values and workplace practices undermines job satisfaction and a sense of purpose, contributing to burnout, high turnover rates, and challenges in recruiting or retaining staff who are genuinely committed to person-centred, culturally sensitive care.

The study demonstrates that inadequate cultural responsiveness has a direct and detrimental effect on resident well-being, leading to heightened behavioural and psychological symptoms, overreliance on medication to manage distress, and a greater incidence of physical health complications (Giebel et al., 2018). Residents who experience culturally inappropriate care often show diminished engagement, increased withdrawal, and reduced overall quality of life. These adverse outcomes not only compromise the dignity and comfort of residents but also negatively influence external quality assessments, inspection ratings, and the broader public reputation of the care home, highlighting the organisational cost of neglecting cultural competence in dementia care.

9.9 The changing expectations of SAPWD residents and their families in residential settings

As SAPWD residents come from different backgrounds, expectations significantly impact care home experiences. Culturally appropriate dementia care involves more than medical health needs; it includes social, emotional, and spiritual needs. Because of the strong cultural beliefs around family caring, many South Asian families find it challenging to send loved ones to care homes. However, as families and residents experience a positive attitude from staff, they adjust and negotiate their expectations. The SAPWD residents and their families were initially concerned about culturally appropriate care and then shifted to a more practical understanding of the benefits and challenges of residential care. This section discusses how the experience of receiving care reshapes the expectations of SAPWD residents and their families.

SAPWD residents and their families expect a high level of cultural sensitivity, which includes culturally appropriate dietary requirements and language support for individuals who speak Hindi, Bengali, Punjabi, Urdu, or South Asian languages. Accommodations for religion and spirituality include places for prayer, dietary restrictions (such as vegetarian or halal food), and access to religious authorities. Adherence to gender and societal standards, such as female staff for female residents or certain customs around modesty and personal hygiene. These early assumptions fluctuate due to worries about whether care facilities can provide high-quality dementia care that values and fosters cultural identity. Adjustment and understanding of dementia care. Families start re-evaluating their expectations immediately after the SAPWD resident joins a care home because of the positive experience.

Family members and residents understand that professional care offers emotional and medical assistance they would find difficult to deliver at home. Twenty-four-hour access to staff, regular routines, and specialised dementia care services can enhance the residents' well-being. Although most care homes try to meet the demands of their residents' cultures, families may not be happy at first if these changes are inconsistent or due to high expectations. They may eventually change their expectations after realising that, although certain aspects of culture can be preserved, it is challenging to recreate a home setting completely. When an individual with dementia is transferred to a care home, South Asian families frequently experience feelings of guilt and fear; however, their perspective changes when they witness their relative receiving quality care and adjusting emotionally. Families may initially be reluctant to entrust their loved one's care to non-South Asian staff. However, they gradually gain faith in the care home's capacity to offer suitable support through pleasant experiences like positive interactions and compassionate care.

An adjustment between cultural requirements and realistic Care happens when SAPWD residents and their families adapt to life in care settings, their expectations change to reflect a balance between traditional values and practical considerations. These include prioritising complex health care needs over cultural practices, celebrating cultural festivals like Vaisaki, Eid, Christmas, and Diwali, and engaging in meaningful activities. When the participants engage actively with staff, implement a culturally appropriate intervention plan, and understand that collaboration improves quality care. Recognising and accepting that residential care is more beneficial than family or home care.

According to Santos (2019), transitioning into a care home reshapes residents' expectations of care, as they anticipate higher-quality services and culturally appropriate environments. Among SAPWD, expectations often stem from financial contributions and a desire for care that respect's cultural identity, language, and traditions. Studies (Hasson et al., 2011; Vigdis et al., 2018) show that residents expect meaningful activities, social engagement, and personalised attention that promote dignity and self-worth. When care is person-centred addressing individual preferences and enabling autonomy residents report greater satisfaction and perceive the setting as homelike (Wang et al., 2016; Behrens et al., 2022). Conversely, institutional or impersonal care lowers satisfaction and expectations. The quality of care, social connections, and family involvement strongly influence how residents experience and evaluate care (Boldy et al., 2006; Cohen et al., 2014; Friedemann et al., 1999). Organisational culture and staff attitudes also shape expectations, as supportive, communicative, and culturally sensitive staff foster trust and engagement (Nakrem, 2015). Despite awareness of the value of culturally oriented care, many Units lacked such practices due to limited time, staff shortages, and funding constraints. Residents often found activities meaningless, while staff assumed lack of motivation or language barriers. These differing perspectives among residents, families, and staff highlight the need for collaboration and culturally responsive practices to enhance the quality of dementia care for SAPWD residents.

9.10 Discussion in Relation to Literature

The findings of this study reinforce and extend existing research on dementia care for SAPWD by highlighting how cultural, familial, and institutional dynamics interact within care home settings. Prior studies have shown that the quality and cultural responsiveness of care are key determinants of residents' well-being, satisfaction, and trust in services (Giebel et al., 2015; Juttla et al., 2016; Wilkinson et al., 2003). The present study aligns with these findings, showing that SAPWD residents' experiences of care are deeply influenced by cultural identity, communication patterns, and the degree to which care homes recognise and respect traditional values. This demonstrates that culturally appropriate care is not an additional feature but a central component of effective dementia care.

Consistent with Kitwood's (1997) theory of person-centred care, which emphasises understanding the individual beyond the diagnosis, this study found that SAPWD residents respond positively when their care reflects familiarity, empathy, and cultural awareness. Practices such as gender-sensitive assistance, traditional meals, and communication in native languages were identified as essential to comfort and dignity. These findings echo Mendes (2018) and Daker et al. (2018), who argue that care environments that support cultural continuity foster emotional well-being and reduce the sense of displacement common among minority ethnic residents. The evidence from this study adds nuance by demonstrating how culturally tailored interactions like speaking in a resident's first language or incorporating familiar religious and social activities help sustain identity and belonging, particularly as cognitive decline progresses.

The findings also build upon literature on racism and structural inequality in dementia care (Kind et al., 2023; Gundavapu et al., 2021), revealing that SAPWD residents and their families continue to experience subtle forms of discrimination and discourtesy. These experiences often stem from staff's lack of cultural competence or assumptions about linguistic ability, reinforcing the need for cultural sensitivity training and policy reforms. As seen in previous studies (Epstein et al., 2024), targeted education for healthcare workers can help mitigate these issues by fostering empathy and awareness. This study contributes to this discourse by identifying how institutional biases and communication barriers directly shape residents' emotional well-being and trust in care homes.

Another critical dimension emerging from the data relates to family involvement and competitive caregiving, an issue discussed in the broader caregiving literature (Tsai et al., 2012; Garfat, 2011). The study revealed that while families aim to support residents, role ambiguity and rivalry among family members can generate tension, delay communication, and hinder collaborative care. This aligns with the findings of Eltaybani et al. (2022), who note that unresolved family dynamics can negatively impact residents' psychological health. At the same time, consistent with Friedemann et al. (1999) and Marion et al. (2024), the study underscores that family engagement when structured and supported enhances care quality and satisfaction. It suggests that staff-led mediation, structured family meetings, and clear communication protocols could bridge the gap between professional care and familial expectations. The study also highlights communication barriers and delays in information sharing, echoing Fielding et al. (2021), who noted that unclear roles and emotional distress among family members often impede information exchange. The evidence here shows that such delays can lead to inappropriate interventions and misaligned care. This supports Galessiere et al. (2022), who emphasised that open communication and positive family–staff relationships reduce residents' distress and depressive symptoms. The findings reinforce the importance of digital and interpersonal communication strategies that facilitate timely updates and coordination, especially for culturally diverse families.

In terms of residents' expectations of care, this study mirrors the findings of Santos (2019), Hasson et al. (2011), and Vigdis et al. (2018), who collectively show that residents entering care homes expect more personalised and stimulating environments. The SAPWD participants in this study expressed similar desires for culturally meaningful activities and social engagement. Their expectations were shaped by both cultural background and perceived quality of interaction with staff, aligning with Beherens et al. (2022) and Boldy et al. (2006), who linked satisfaction with person-centred and respectful care. However, this study extends the literature by illustrating that unmet cultural needs can lead to lower expectations and emotional withdrawal, particularly when institutional routines override cultural individuality.

Finally, this study contributes to the growing body of research emphasising the integration of cultural competence within dementia care frameworks. While much of the literature recognises the need for inclusivity, this study shows that active negotiation among staff, residents, and families is key to achieving it. This negotiation process echoes the collaborative care model proposed by Cohen et al. (2014), where care practices evolve through shared understanding and adaptation. The findings also support Nakrem (2015), who suggested that residents’ perceptions of care quality are strongly influenced by how “homelike” and inclusive the institutional culture feels. In sum, this research extends the literature by demonstrating that culturally appropriate dementia care for SAPWD is an evolving, co-constructed process shaped by the ongoing negotiation between cultural identity, family involvement, and professional care structures. It bridges theoretical and practical insights, advocating for a more relational and adaptive approach to care one that values diversity, promotes equity, and upholds dignity within institutional settings.

9.11 Summary

In summary, the care experience of SAPWD in residential settings highlights the evolving nature of expectations among residents, families, and staff. Initially shaped by strong cultural and familial values, these expectations transform as families recognise the necessity of professional dementia care within institutional environments. Aligning these perspectives through culturally competent practices such as culturally appropriate meals, language and religious support, and trained, empathetic staff promotes mutual understanding and trust. When care homes integrate cultural sensitivity with specialised dementia care, they enhance both the well-being of residents and the satisfaction of families. Ultimately, fostering open communication, collaboration, and continuous adaptation ensures that SAPWD receive compassionate, person-centred care that respects their cultural identity while addressing their complex cognitive and emotional needs.

Chapter 10: Conclusions

10.1 Introduction

Drawing together the data presented in this study, the findings demonstrate that residential care for South Asian people with dementia is best understood as a dynamic site of Active Negotiation, where residents, families, staff, and management continuously shape care through relational, cultural, and organisational interactions. The transition into care was marked by uncertainty, loneliness, stigma, and language barriers, yet families remained actively involved, redefining caregiving roles rather than relinquishing responsibility. Adjustment to care required culturally responsive practices, including recognition of religious routines, dietary preferences, first-language communication, and respect for intra-community diversity, all within the constraints of staffing pressures and institutional routines. Ongoing support was sustained through trust-building, collaborative care planning, and small but meaningful acts that reinforced dignity and belonging. Ultimately, quality of life for residents was enhanced not simply through policy or procedure, but through sustained relational engagement that acknowledged cultural identity, preserved personhood, and balanced safety with compassion. The study therefore concludes that culturally responsive dementia care is not a fixed model but an evolving, negotiated process grounded in everyday interactions and shared commitment to dignity and inclusion.

This study provides a detailed understanding of the experiences of SAPWD within residential care settings, highlighting the complex interplay of cultural values, family involvement, and staff practices in shaping care outcomes. Through a constructivist grounded theory approach, the research identified that the provision of culturally sensitive care is a dynamic, collaborative process, encapsulated in the core category, a theory of “Active Negotiation,” where residents, families, and staff continuously negotiate expectations, roles, and practices to meet individual needs. The findings underscore that successful care depends not only on clinical competence but also on empathetic communication, cultural awareness, and flexibility in addressing language barriers, religious considerations, and lifestyle preferences. Barriers such as uncertainty, loneliness, stigma around dementia and institutionalised care, and staff workload were shown to affect residents’ adjustment and well-being. In contrast, facilitators such as family support, staff engagement, and culturally oriented care practices enhanced the quality of life for SAPWD. This study contributes both theoretically and practically by offering a grounded framework that captures the social processes underpinning culturally competent care, providing actionable insights for care home policies, staff training, and family engagement strategies. Ultimately, the research emphasises that culturally sensitive dementia care is socially constructed and requires ongoing negotiation, collaboration, and adaptation, highlighting the importance of addressing cultural, emotional, and organisational dimensions to improve care experiences and outcomes for SAPWD in residential settings.

This thesis has examined the multifaceted landscape of care provision for SAPWD in UK care homes, offering a comprehensive exploration of the social, cultural, and institutional factors shaping their care experiences. It identifies the persistent barriers that hinder effective and culturally responsive dementia care, while also highlighting emerging opportunities for reform and innovation (Patel et al., 2007; Bowes & Wilkinson, 2003). Through a systematic review of existing literature, empirical inquiry involving residents, family members, and staff, and critical engagement with current policy frameworks, this study advances new insights into one of the most urgent challenges facing contemporary dementia care systems (Mukadam et al., 2019). The findings emphasise that as the UK's South Asian population continues to age, the demand for dementia services that recognise cultural, linguistic, and religious diversity has become not only a research priority but a moral and professional necessity (Office for National Statistics, 2023).

The research reveals a striking paradox in dementia care provision: although South Asian communities experience similar or even higher rates of dementia prevalence compared with the general population, they remain significantly underrepresented in residential care and frequently report lower satisfaction when they do access such services (Cooper et al., 2010; Pham et al., 2018). This underrepresentation and dissatisfaction reflect broader structural inequalities embedded in healthcare systems and expose the limitations of “one-size-fits-all” care models that fail to meet the nuanced needs of multicultural populations (Bhopal, 2007). This concluding chapter, therefore, synthesises the key findings of the research, underscoring its theoretical and practical contributions to dementia care. It draws attention to the need for culturally competent practices, inclusive policy design, and collaborative family-staff partnerships to enhance quality of life for SAPWD. Furthermore, it outlines implications for future research and practice, offering evidence-based recommendations to guide the development of equitable, person-centred dementia care within an increasingly diverse UK society (Spector et al., 2020).

10.2 Summary of Key Findings

10.2.1 The Nature and Extent of Unmet Needs

This research has shown that SAPWD residing in UK care homes face a multifaceted range of unmet needs that go well beyond the conventional biomedical understanding of dementia care (La Fontaine et al., 2007; Lawrence et al., 2011). The study highlights that their experiences are shaped not only by medical or cognitive challenges but also by deeply rooted cultural, emotional, linguistic, and social factors that influence daily life and overall well-being. The findings identify five key domains of need that remain insufficiently met within existing care frameworks, underscoring the necessity for a more holistic, culturally responsive approach to dementia care that integrates medical treatment with social, psychological, and cultural dimensions of support.

10.2.1.1 Cultural and Religious Identity Preservation

The preservation of cultural and religious identity emerged as a central theme in this research, representing a fundamental and non-negotiable aspect of well-being for SAPWD living in UK care homes. As Seabrooke and Milne (2004) emphasise, cultural and religious identity forms the core of selfhood and continuity for individuals whose cognitive abilities are gradually deteriorating. The study revealed that when care environments fail to acknowledge or incorporate residents' cultural traditions, languages, and religious routines, the resulting sense of alienation can intensify confusion, anxiety, and behavioural challenges. This loss of cultural connection was observed to heighten cognitive decline and significantly diminish quality of life (Lawrence et al., 2011). Conversely, when residents are supported in observing daily prayer rituals, dietary restrictions, and cultural celebrations, they demonstrate improved emotional stability, engagement, and trust in staff (Adamson & Donovan, 2005). These practices, such as providing space for worship, facilitating familiar music or festivals like Eid and Diwali, and ensuring culturally appropriate meals, should not be viewed as optional amenities but as essential components of person-centred, dignified care (Kitwood, 1997). Integrating such practices affirms identity, nurtures belonging, and reinforces respect for cultural diversity within institutional dementia care settings.

10.2.1.2 Language and Communication Support

Language and communication support emerged as one of the most critical yet insufficiently addressed dimensions of dementia care for South Asian residents in UK care homes. SAPWD residents can speak English; the diversity of staff accents sometimes leads to communication difficulties. The findings revealed that linguistic barriers profoundly affect residents' ability to express their needs, emotions, and discomfort, leading to significant disparities in care outcomes (Turner et al., 2005). As dementia advances, many South Asian individuals revert to their native languages, such as Hindi, Urdu, Punjabi, or Bengali, resulting in communication breakdowns when staff lack proficiency in these languages (Mackenzie, 2006). This regression often isolates residents, diminishing their ability to participate in social interactions or daily decision-making, which can exacerbate feelings of loneliness and distress (Nielsen et al., 2011). The absence of adequate language support was found not only to hinder effective caregiving but also to lead to the misinterpretation of behavioural expressions as agitation or aggression, resulting in inappropriate medication or care interventions (Giebel et al., 2018). Verbal and non-verbal communication, talking clearly and slowly, incorporating bilingual staff, using interpreters, or employing culturally and linguistically adapted communication tools could significantly enhance person-centred care. Ensuring language accessibility is therefore not a supplementary service but a core element of ethical, inclusive, and effective dementia care that upholds dignity and promotes genuine understanding between residents and caregivers.

10.2.1.3 Family-Centred Care Approaches

Family-centred care emerged as a vital yet often neglected aspect of dementia care for South Asian people in UK care homes. The study found that significant misalignments exist between Western models of individualised, autonomy-focused care and the collectivist ethos that defines South Asian family structures (Katbamna et al., 2004). In South Asian cultures, caregiving is viewed as a shared familial duty grounded in respect, interdependence, and emotional obligation toward elders. Consequently, family members expect to remain closely involved in decision-making processes regarding care routines, medical treatments, and lifestyle choices (Parveen et al., 2018). However, current care home systems often lack frameworks that facilitate meaningful family engagement, treating relatives more as visitors than as active partners in care. This institutional disconnect not only leads to frustration and mistrust but can also result in delayed communication, inconsistent care coordination, and emotional distress for both residents and families (Ahmad & Walker, 2000). The findings highlight that fostering genuine collaboration through structured family meetings, joint care planning, and transparent communication channels can significantly improve the quality and cultural relevance of care. Integrating family-centred practices ensures that care aligns with both professional standards and cultural expectations, ultimately enhancing trust, satisfaction, and residents' overall well-being.

10.2.1.4 Dietary and Nutritional Requirements

Dietary and nutritional care emerged as one of the most emotionally and culturally significant aspects of daily life for South Asian people with dementia, extending far beyond the boundaries of medical nutrition or religious observance. The research revealed that food carries deep cultural meaning, serving as a powerful link to memory, identity, and belonging for residents experiencing cognitive decline (Purandare et al., 2007). Familiar tastes, aromas, and traditional cooking styles not only evoke positive emotions but also offer a sense of comfort and orientation amid the confusion of dementia (Hailstone et al., 2017). However, the study found that many care homes continue to overlook these vital cultural and sensory needs, providing standardised Western meals that fail to reflect residents’ ethnic preferences or religious dietary requirements. This lack of culturally sensitive nutrition often leads to poor appetite, reduced intake, weight loss, and distress for both residents and families, who view food as a fundamental expression of care and respect (Bowes & Wilkinson, 2003). Moreover, cross-contamination concerns, inadequate staff training, and limited access to South Asian ingredients further exacerbate the challenge. Addressing these issues through culturally inclusive meal planning, employing chefs familiar with diverse cuisines, and involving families in menu development can significantly enhance nutritional outcomes, emotional well-being, and residents' sense of dignity and cultural continuity within care homes.

10.2.1.5 Social Connection and Community Belonging

Social connection and community belonging emerged as central determinants of well-being for South Asian people with dementia, underscoring the profound role of cultural and communal identity in sustaining emotional and cognitive health. The findings revealed that many South Asian residents in UK care homes experience profound loneliness and cultural dislocation due to the absence of familiar social networks, linguistic compatibility, and culturally resonant activities (Greenwood et al., 2013). Within South Asian cultures, identity and self-worth are deeply intertwined with family, religion, and community participation values that contrast sharply with the individualistic orientation of most Western care environments (Nazroo, 2006). The lack of culturally familiar companionship, opportunities for communal worship, and interaction with peers who share the same traditions or language often leads to isolation, depression, and increased behavioural disturbances among residents (McCleary et al., 2013). Furthermore, limited staff understanding of cultural socialisation patterns contributes to environments that feel alien and impersonal. The research highlights that fostering social belonging requires more than occasional cultural celebrations; it demands ongoing, structured efforts to integrate community elements into daily care, such as group prayer sessions, traditional music, language-based social clubs, and intergenerational activities involving local South Asian communities. By embedding culturally meaningful social engagement into care routines, care homes can not only improve residents' emotional and psychological well-being but also create a more inclusive, dignified, and identity-affirming living environment.

10.2.2 Systematic Barriers to Effective Care Provision

The research identified that barriers to effective care provision for South Asian people with dementia operate across multiple levels of the healthcare system, encompassing individual, institutional, and structural dimensions (Mukadam et al., 2011).

10.2.2.1 Individual-Level Barriers

At the individual and family level, numerous barriers impede effective dementia care for South Asian residents, reflecting a complex interplay of linguistic, cultural, and socioeconomic factors. Limited English proficiency remains one of the most persistent obstacles, restricting both residents' ability to express their needs and families' capacity to communicate effectively with care providers (Shah et al., 1998). This communication gap often results in misinterpretation of symptoms, underreporting of distress, and inappropriate or delayed interventions. Additionally, many South Asian families possess limited familiarity with the structure and function of UK care systems, which can appear impersonal and bureaucratic compared to traditional family-based caregiving norms. Cultural stigma surrounding mental illness and dementia further exacerbates these challenges, as memory loss and behavioural changes are often perceived as a normal part of ageing or as a private matter that should be managed within the family (Boneham et al., 1997). This cultural reluctance to seek professional help often leads to late diagnosis, limited access to early interventions, and crisis-driven placements in care homes, which heighten emotional strain for both residents and their families. Stigma or shame associated with residential care can lead to underutilization of services and low trust in institutions. Financial barriers also play a significant role, as care services are often perceived as costly, inaccessible, or of uncertain quality. Consequently, many South Asian families attempt to balance cultural expectations of filial responsibility with practical constraints, resulting in guilt, stress, and fragmented care arrangements. Addressing these individual-level barriers requires culturally sensitive outreach, education, and support programs that normalise help-seeking, empower families to navigate care pathways, and promote understanding of dementia as a diagnosis and the importance of residential care, along with multiple health needs and a social condition rather than a source of shame.

10.2.2.2 Organisational-Level Barriers

At the organisational level, care home institutions encounter multiple structural and operational barriers that hinder the delivery of culturally responsive care for South Asian people with dementia. A key issue identified is the persistent lack of cultural competence among staff, many of whom have limited awareness or training in understanding the cultural, linguistic, and religious needs of diverse residents

(Botsford et al., 2011). This gap often results in generic, one-size-fits-all approaches that fail to acknowledge the importance of cultural familiarity in shaping residents' comfort, identity, and psychological well-being. The absence of bilingual or culturally matched staff further compounds communication challenges, leaving residents unable to express their needs effectively or connect meaningfully with caregivers. Moreover, many care home policies and operational frameworks remain rigid and bureaucratic, emphasising procedural uniformity and institutional efficiency rather than individualised and culturally sensitive care practices (Care Quality Commission, 2023). Staff training programs tend to focus primarily on clinical or safety protocols, with minimal emphasis on cultural awareness, religious accommodation, or inclusive communication techniques. Financial constraints and limited staffing resources also restrict opportunities for specialised cultural training or community engagement initiatives. Consequently, the organisational culture of many care homes reflects an institutional model that values routine over relationships, leaving little room for flexible, person-centred adaptations such as culturally appropriate dietary options, prayer facilities, or celebration of cultural festivals. This lack of organisational adaptability not only diminishes residents' quality of life but also leads to dissatisfaction among families who expect care that respects cultural identity and dignity. To overcome these barriers, care homes must embed cultural competence into staff recruitment, training, and management practices, and support leadership that prioritises inclusivity, collaboration, and cultural respect as essential components of quality care delivery.

10.2.2.3 Systemic-Level Barriers

At the systemic level, significant structural barriers persist within the wider health and social care framework, limiting the capacity of care homes to deliver culturally responsive and equitable services for South Asian people with dementia. National and local policy frameworks continue to emphasise standardised models of care that prioritise uniformity, measurable outcomes, and cost-efficiency over individualised, culturally nuanced support (Department of Health and Social Care, 2021). This institutional emphasis on standardisation often sidelines the importance of cultural identity, language needs, and religious practices, reducing care to a set of procedural tasks rather than a holistic, person-centred experience. Commissioning arrangements also play a critical role in perpetuating these inequalities, as funding models rarely incentivise the development of culturally specific services or the recruitment of bilingual and culturally trained staff. Consequently, care providers often lack both the motivation and the resources to adapt their practices to meet the diverse needs of minority ethnic communities. Moreover, regulatory systems such as the Care Quality Commission (CQC) focus heavily on safety and compliance indicators but fail to adequately evaluate or enforce standards of cultural competence within care provision. Workforce development strategies further reinforce these systemic gaps by neglecting comprehensive cultural diversity training and by failing to address the underrepresentation of ethnic minority professionals in leadership and frontline roles. This absence of diversity at decision-making levels limits institutional awareness of the lived realities faced by South Asian residents and their families. As a result, cultural inclusion remains peripheral rather than central to national dementia care strategies. Addressing these systemic-level barriers requires policy reform that embeds cultural competence as a core element of quality assurance, funding mechanisms that reward inclusive practices, and national workforce strategies that promote diversity, equity, and cross-cultural understanding within the care sector.

10.2.2.4 Structural-Level Barriers

The research revealed that structural-level barriers present some of the most deeply embedded challenges to achieving equitable dementia care for South Asian populations in the UK. These barriers stem from longstanding institutional and societal inequalities that shape how care is conceptualised, funded, and delivered. Institutional racism within healthcare systems remains a pervasive issue, manifesting not only in discriminatory attitudes or behaviours but also in the structural organisation of services that systematically disadvantage ethnic minority groups (Karlsen & Nazroo, 2013). The underrepresentation of South Asian professionals and other minority ethnic groups in leadership and decision-making positions exacerbates these disparities, as policies and practices often fail to reflect the cultural realities and priorities of diverse communities. Furthermore, the research and evidence base underpinning dementia care is overwhelmingly derived from studies focusing on White, English-speaking populations, resulting in a lack of culturally relevant data to inform inclusive care strategies and interventions. This exclusion reinforces a cycle where minority experiences are marginalised and their needs are rendered invisible within mainstream care models. Economic and policy frameworks also contribute to these inequities by undervaluing culturally responsive care approaches often perceiving them as optional or secondary rather than integral to quality care. Consequently, funding allocations rarely support initiatives such as culturally specific meal preparation, bilingual staffing, or faith-sensitive practices, which are essential for the well-being of South Asian residents with dementia. Collectively, these structural barriers perpetuate systemic inequities, leaving minority ethnic communities underserved and underrepresented. Overcoming these challenges requires a fundamental reorientation of healthcare structures toward inclusion, prioritising anti-racist policy development, equitable representation in leadership, investment in culturally diverse research, and economic models that recognise and reward culturally competent care as a central marker of service quality.

10.2.3 Emerging Opportunities for Improvement

Despite the considerable challenges identified, the research also revealed several promising opportunities to enhance the quality, inclusivity, and cultural responsiveness of dementia care for South Asian populations.

10.2.3.1 Policy Development Opportunities

Recent national policy frameworks, such as the NHS Long Term Plan (NHS England, 2019), strengthened equality and diversity legislation, and updated national dementia strategies offer valuable opportunities to advance culturally responsive dementia care. These initiatives signal a growing recognition at the policy level of the need to reduce persistent health inequalities and ensure that services better reflect the diversity of the UK’s ageing population. The NHS Long Term Plan, in particular, emphasises personalised, community-based, and integrated models of care, which align closely with the principles of culturally tailored dementia support. Similarly, equality legislation and dementia strategies mandate fair access to services and require healthcare organisations to demonstrate inclusive practices that address the distinct cultural, linguistic, and religious needs of minority communities. These frameworks create both the structural mandate and the moral imperative for care providers to implement reforms that promote equity, dignity, and cultural sensitivity. Furthermore, increased government attention to social care reform and the inclusion of minority voices in policy consultation processes represent important steps toward embedding cultural competence within mainstream care standards. Collectively, these policy developments establish a favourable environment for transforming dementia care into a more inclusive, person-centred, and culturally informed system that better serves South Asian people with dementia and their families.

10.2.3.2 Technological Solutions

Emerging technologies present transformative opportunities to enhance culturally responsive dementia care by bridging communication gaps, preserving cultural identity, and strengthening family connections. Innovations such as AI-powered translation tools, multilingual communication platforms, and digital cultural content systems can play a vital role in overcoming long-standing language barriers between South Asian residents and care staff (WHO, 2023). These technologies enable real-time translation, allowing residents to express their needs and emotions more effectively while supporting staff in delivering empathetic and accurate care. Beyond communication, technology can also foster cultural engagement. Digital platforms can stream religious services, traditional music, or cultural films in residents' preferred languages, helping maintain a sense of familiarity and belonging in institutional environments. Virtual reality and interactive media offer further potential for reminiscence therapy, enabling residents to revisit culturally meaningful places or experiences that stimulate memory and emotional well-being. Moreover, remote monitoring systems and telehealth applications enhance safety and continuity of care, allowing family members, particularly those living at a distance, to stay informed and involved in residents' daily lives. By integrating these digital innovations into dementia care frameworks, care homes can create more inclusive, responsive, and connected environments that honour both the cultural and personal identities of South Asian people with dementia.

10.2.3.3 Workforce Development Initiatives

The increasing recognition of the importance of diversity and inclusion within healthcare has created valuable opportunities to strengthen the dementia care workforce through enhanced training, cultural competence development, and inclusive recruitment strategies. A culturally diverse and well-trained workforce is central to improving the quality of care for South Asian people with dementia, as it ensures that care practices reflect residents' cultural, linguistic, and spiritual values (Sue & Sue, 2019). Care organisations are increasingly implementing structured cultural competency programs that go beyond basic awareness to foster deeper understanding, empathy, and respect for diverse traditions and communication styles. These initiatives are complemented by innovative models of cultural mentorship, in which staff receive guidance from experienced practitioners or community representatives familiar with South Asian customs, dietary practices, and religious observances (Williamson, 2012). Such mentorship promotes confidence among staff when delivering person-centred and culturally appropriate care. Moreover, targeted recruitment and retention of staff from minority ethnic backgrounds help bridge language barriers and enhance trust between residents, families, and care providers. Some care homes are also engaging directly with local community and faith groups to co-design training workshops, organise cultural events, and encourage community participation in care delivery. Collectively, these workforce development efforts not only improve staff competence and satisfaction but also foster a more inclusive, respectful, and culturally aligned care environment that better supports the well-being and dignity of South Asian residents with dementia.

10.2.3.4 Partnership and Collaboration Models

The research revealed that effective partnerships and collaborations are essential for improving culturally responsive dementia care for South Asian residents in UK care homes. Successful examples have shown that when care homes actively collaborate with South Asian community organisations, religious institutions, and cultural associations, they can significantly enhance the quality and inclusivity of their services (Ballard, 1994). These collaborations help care providers tap into valuable community knowledge, linguistic support, and cultural insights that inform more sensitive and appropriate care practices. By involving trusted community and faith leaders, care homes can bridge the gap between formal healthcare systems and South Asian families, many of whom may be hesitant to engage with institutional care due to cultural stigma or misconceptions about dementia and institutional care. Such partnerships foster mutual trust, encourage family participation, and promote a sense of belonging among residents, ultimately leading to more holistic and person-centred care (Simpson et al., 2008).

10.2.3.5 Innovation in Care Approaches

Alongside collaborative partnerships, the study also identified a growing trend toward innovative, person-centred care approaches that place cultural identity and family involvement at the forefront of dementia care. Some care homes have introduced models that respect collective family decision-making, integrate religious and spiritual practices into daily routines, and make environmental adaptations that reflect residents' cultural heritage, such as displaying familiar art, serving traditional foods, or organising cultural celebrations. These creative adaptations not only preserve residents' sense of identity but also foster emotional comfort and engagement. As noted by the Alzheimer's Society (2024), culturally responsive care benefits not only South Asian residents but enriches the care environment for all residents by promoting empathy, inclusion, and mutual respect. Collectively, these partnership-based and innovative approaches demonstrate that culturally competent care is both achievable and deeply impactful, enhancing quality of life, family trust, and community confidence in dementia care services.

10.3 Original Contributions to Knowledge

This thesis makes several significant and original contributions to the existing body of knowledge, offering new insights that advance the understanding and practice of culturally responsive dementia care.

10.3.1 Theoretical Contributions

Integration of Cultural Competency and Person-Centered Care Models

This research makes a key theoretical contribution by developing an integrated framework that merges cultural competency theory (Sue & Sue, 2019) with person-centred care principles (Kitwood, 1997), specifically tailored to the context of dementia care. While person-centred care emphasises the importance of dignity, empathy, and individual recognition, this study advances the model by embedding cultural identity as a central element of personhood rather than a peripheral consideration. The integrated framework highlights that for South Asian people with dementia, cultural beliefs, language, religion, and family values are inseparable from the individual's sense of self and must be preserved throughout the dementia journey (Spector et al., 2020). This synthesis of theories contributes to existing knowledge by demonstrating how cultural competency and person-centred care can function together to inform practical, compassionate, and contextually relevant dementia care within multicultural environments.

Application of Intersectionality Theory to Dementia Care

Another major contribution of this thesis lies in its systematic application of intersectionality theory (Crenshaw, 1989) to the study of dementia care, marking one of the first detailed explorations of how intersecting social identities influence the experiences of South Asian residents in institutional care settings. By examining how ethnicity, religion, gender, age, language, and class interact, the research uncovers the complex layers of privilege and disadvantage that shape care experiences and access to support (Vertovec, 2007). This approach moves beyond simplistic cultural categorisations to reveal the nuanced and overlapping factors that determine how individuals engage with care systems. The application of intersectionality provides a richer analytical lens for understanding diversity within the South Asian community itself, challenging homogeneous assumptions and encouraging more precise, equitable, and inclusive care strategies across policy and practice.

Development of a Cultural Responsiveness Framework

Building on these insights, the study has developed a comprehensive Cultural Responsiveness Framework for dementia care that advances the field beyond traditional notions of cultural awareness. Rather than focusing solely on surface-level gestures such as food preferences or holiday celebrations, this framework emphasises deep structural and systemic transformation necessary for truly equitable care delivery (Blakemore & Boneham, 1994). It integrates elements of policy reform, staff training, organisational culture, and family engagement into a cohesive model that guides care homes toward long-term, sustainable cultural inclusion. The framework offers a practical roadmap for policymakers, practitioners, and educators to evaluate and improve cultural responsiveness at multiple levels—individual, institutional, and systemic ensuring that dementia care for South Asian populations is not only respectful of difference but actively shaped by it.

10.3.2 Empirical Contributions

First Comprehensive Examination of Care Home Experiences

This study represents the first in-depth empirical investigation of the experiences of South Asian people with dementia residing in UK care homes, marking a significant advancement in dementia research and service understanding (Jolley et al., 2006). While earlier studies have largely focused on community-based dementia services or broader healthcare experiences among ethnic minorities, this research fills a critical gap by exploring the institutional care environment, where cultural, social, and organizational dynamics intersect most visibly. The findings reveal how cultural dissonance, communication barriers, and structural inequities shape the lived realities of South Asian residents, offering unprecedented insights into the ways in which cultural needs are negotiated, met, or overlooked within care settings. This empirical contribution provides an essential evidence base for future policy reform and service innovation in multicultural dementia care.

Multi-Stakeholder Perspective Integration

A distinctive strength of this research is its integration of multiple stakeholder perspectives, encompassing the voices of South Asian residents with dementia, their family members, and staff (Levac et al., 2010). By capturing this diversity of viewpoints, the study constructs a comprehensive and balanced understanding of the dementia care experience, highlighting both areas of consensus and sources of tension. The inclusion of residents' lived experiences, alongside the insights of those who provide and regulate care, allows for a multi-layered analysis that goes beyond individual experiences to expose systemic and organisational issues. This holistic approach not only enriches the empirical depth of the study but also strengthens its practical relevance, offering a more complete and inclusive picture of the challenges and opportunities in providing culturally responsive care.

Identification of Specific Intervention Points

Another important empirical contribution lies in the identification of targeted intervention points within the dementia care pathway where changes could significantly enhance outcomes for South Asian residents (Peters et al., 2020). The research pinpoints critical moments such as admission, assessment, care planning, communication, and family engagement where tailored strategies can address barriers to culturally competent care. These include introducing structured family involvement protocols, implementing language and communication support mechanisms, and developing culturally inclusive care training for staff. By clearly mapping where and how these interventions can be implemented, the study provides actionable guidance for policymakers, practitioners, and care home managers seeking to improve service delivery. This contribution ensures that the research moves beyond description toward practical transformation, aligning evidence with realistic strategies for advancing equity and quality in dementia care.

10.3.3 Methodological Contributions

This research makes important methodological contributions by pioneering innovative and culturally sensitive approaches to studying South Asian people with dementia, a population often underrepresented in academic and clinical research. It developed and validated culturally appropriate research methods, including adapted consent processes, bilingual data collection, and family-inclusive participation designs that align with South Asian cultural norms of collective decision-making and respect for family hierarchy (Khalil et al., 2016). These methodological adjustments ensured ethical integrity, participant comfort, and authenticity of responses, thereby improving the depth and validity of the findings. Additionally, the study demonstrates the effective integration of participatory research principles with traditional academic methodologies, ensuring that the voices of residents, families, and care staff informed both the design and interpretation of the research (Grant & Booth, 2009). This collaborative approach fostered mutual trust and enhanced the practical relevance of the results, showing how community involvement can coexist with scientific rigor. Furthermore, through the application of a systematic scoping review methodology, the research offers valuable insights into mapping diverse and heterogeneous literature across multiple disciplines bridging gaps between health, social care, and cultural studies (Arksey & O’Malley, 2005; Tricco et al., 2018). Collectively, these methodological innovations establish a robust framework for conducting ethically sound, inclusive, and interdisciplinary research in multicultural dementia care contexts.

10.3.4 Practice and Policy Contributions

This study makes significant contributions to both practice and policy by providing clear, evidence-based pathways for improving cultural responsiveness in dementia care within UK care homes. It offers evidence-based practice recommendations that translate research findings into actionable strategies, including practical assessment tools, culturally informed care planning templates, and service modifications designed to enhance inclusivity and person-centredness (Munn et al., 2018). These recommendations support care providers in embedding cultural sensitivity into daily operations, ensuring that South Asian residents receive care aligned with their linguistic, religious, and social needs. Furthermore, the research delivers a critical analysis of existing policy frameworks, identifying gaps in national dementia strategies and equality legislation that hinder equitable care provision (Colquhoun et al., 2014). It proposes targeted policy reforms that would incentivise cultural competence, improve data collection on ethnic minority care outcomes, and strengthen accountability for diversity in service delivery. In addition, the thesis contributes to workforce development through the creation of training and development resources aimed at enhancing staff cultural awareness, communication skills, and confidence in working with diverse populations (Tricco et al., 2016). These resources provide a foundation for continuous professional development and organisational learning across care settings. Collectively, these practices and policy contributions bridge the gap between research and real-world implementation, offering a scalable model for culturally responsive dementia care that promotes equity, dignity, and quality of life for South Asian residents.

10.4 Implications for Policy

10.4.1 Regulatory and Quality Frameworks

The findings of this thesis carry substantial implications for the regulation and evaluation of care quality within the UK's health and social care sector. Although existing frameworks, such as those established by the Care Quality Commission

(CQC, 2023), provide comprehensive mechanisms for assessing safety, clinical standards, and service efficiency, they fall short in recognising cultural competency and responsiveness as central dimensions of quality care. This research demonstrates that for South Asian people with dementia, cultural accommodation is not an optional enhancement but a core determinant of effective, person-centred, and equitable care (Department of Health and Social Care, 2021). Cultural factors such as language, faith, dietary needs, and family engagement are integral to maintaining residents' dignity, identity, and emotional well-being. Therefore, embedding cultural responsiveness into regulatory and quality assurance processes is essential for achieving genuine inclusivity in dementia care.

Recommendation for Regulatory Reform

To strengthen cultural inclusivity and accountability, the study recommends that UK care quality frameworks be reformed to include explicit cultural competency standards as a formal part of inspection and evaluation processes. These standards should be incorporated into CQC assessment criteria and quality ratings to ensure that cultural responsiveness is systematically measured and valued alongside safety, effectiveness, and compassion. Key indicators should include staff cultural awareness and training, language accessibility, provision of culturally appropriate meals and spiritual support, and active family engagement in care planning. By embedding these expectations within regulation, policymakers can drive consistent implementation of culturally competent care across all care homes and ensure that service providers are held accountable for meeting the diverse needs of residents.

Development of Cultural Quality Indicators

This research further advocates for the creation of specific cultural quality indicators to evaluate the degree of cultural responsiveness within care homes. These indicators should capture measurable aspects such as resident and family satisfaction with cultural accommodations, availability of culturally appropriate services and resources, and evidence of ongoing staff training in cultural competence and diversity awareness. Data gathered through these indicators can inform national benchmarking, encourage transparency, and highlight best practices across the sector. By institutionalising these cultural quality measures, care regulators and policymakers can ensure that dementia care moves beyond compliance-based models toward genuinely inclusive, person-centred standards of excellence that respect the cultural identities and lived experiences of all residents, particularly those from South Asian and other minority ethnic communities.

10.4.2 Commissioning and Funding Arrangements

The findings of this research highlight the critical shortcomings in the current commissioning and funding arrangements within the UK's dementia care system, which often prioritise cost control over care quality. Such an approach creates disincentives for care homes to invest in culturally responsive practices, including staff training, recruitment of bilingual workers, and provision of culturally appropriate food or religious support (NHS England, 2019). While these cost-saving strategies may appear efficient in the short term, the study reveals that they lead to long-term consequences such as poorer health outcomes, reduced family satisfaction, increased distress among residents, and higher demand for crisis interventions. To address these systemic inefficiencies, the research recommends introducing commissioning reforms that link financial incentives to cultural competence and quality outcomes. Specifically, care homes that demonstrate effective cultural responsiveness and achieve improved outcomes for minority ethnic residents should receive quality premiums as recognition of the additional investment required to deliver inclusive care. Furthermore, the study advocates for a shift toward outcome-based commissioning models, where funding decisions are guided not by standardised service delivery metrics but by measurable improvements in resident well-being, family satisfaction, and community engagement. Such a model encourages innovation, accountability, and a stronger alignment between economic structures and equitable, person-centred care for diverse populations, particularly South Asian people with dementia.

10.4.3 Workforce Development Policy

The findings of this research highlight major deficiencies in the workforce development policies that underpin dementia care delivery in the UK, particularly in relation to cultural competency and inclusivity. While existing training frameworks equip staff with essential clinical and safety skills, they largely overlook the interpersonal, cultural, and linguistic dimensions that are fundamental to providing effective, person-centred care for diverse populations (Sue & Sue, 2019). This omission is especially concerning in an era of growing demographic diversity and complex care needs, where a lack of cultural awareness and communication skills can lead to misunderstandings, inappropriate care practices, and diminished quality of life for residents (WHO, 2023). To address this, the research strongly advocates for the introduction of mandatory cultural competency training within care worker qualification standards. Such training should extend beyond theoretical awareness to encompass practical applications, including cross-cultural communication techniques, respectful collaboration with interpreters, and the ability to adapt care routines to accommodate religious observances, dietary customs, and cultural norms. Furthermore, the study emphasises the importance of diverse workforce recruitment and retention policies. Encouraging care homes to employ staff from minority ethnic backgrounds can enhance both linguistic accessibility and cultural understanding, creating an environment where residents feel recognised and respected. These workers can serve as cultural intermediaries, helping bridge communication gaps between residents, families, and care providers. Ultimately, by embedding cultural competency within workforce policy and practice, care homes can foster greater empathy, trust, and inclusivity, leading to improved care experiences and outcomes for South Asian people with dementia and other ethnically diverse residents.

10.4.4 Integration with Health and Social Care Systems

The research underscores the critical importance of integrating care homes within the broader health and social care systems to achieve continuity and consistency in culturally responsive dementia care. At present, there is a clear fragmentation between care homes, community health services, and social care agencies, resulting in the loss of cultural accommodations and personalised practices when residents transition between settings (Brooker, 2007). This lack of coordination often leads to distress, confusion, and a sense of cultural dislocation for SAPWD and their family members, undermining both the quality of care and trust in the system. To address this gap, the study recommends the establishment of integrated care pathways that explicitly document and communicate residents' cultural, linguistic, and religious needs across all stages of care from hospital discharge to residential placement and ongoing community support. Such pathways would ensure that culturally responsive practices, once implemented, are not disrupted by institutional transitions. Furthermore, the research advocates for stronger partnerships between care homes and community-based organisations, including South Asian cultural associations, faith groups, and local voluntary bodies (Ballard, 1994). These collaborations can provide valuable cultural resources, facilitate spiritual and social continuity, and help care providers better understand community expectations. Embedding such partnerships within formal policy frameworks would strengthen the links between institutional care and community life, creating a more holistic, culturally aligned care system. Ultimately, this integrated approach ensures that residents maintain a consistent sense of identity, belonging, and well-being, regardless of the care setting, while also enhancing collaboration and communication across health and social care providers.

10.5 Implications for Practice

The research highlights that achieving genuinely culturally responsive dementia care requires a profound transformation in organisational culture and leadership, rather than limited adjustments to existing policies or procedures (Bhopal, 2007). Many care homes currently approach cultural responsiveness as a compliance issue, meeting minimal diversity requirements rather than embedding it as a fundamental organisational value that informs everyday practice. To address this, the study emphasises the critical role of leadership development in shaping inclusive and culturally aware care environments. Leaders and managers must receive targeted training that helps them understand the ethical, social, and economic importance of cultural responsiveness, as well as the business case for diversity in improving care quality, resident satisfaction, and staff retention. Strong leadership can foster an organisational culture that values cultural diversity as an asset rather than a challenge. Moreover, the research underscores the importance of staff engagement and empowerment, noting that frontline workers often recognise residents’ cultural and religious needs but are constrained by limited time, training, or institutional support (Botsford et al., 2011). Encouraging open dialogue, providing ongoing education, and ensuring access to culturally appropriate resources are essential to enabling staff to advocate for residents’ cultural preferences confidently. Empowered and culturally competent staff not only enhance residents' quality of life but also contribute to a more cohesive, empathetic, and motivated workforce. Ultimately, embedding cultural responsiveness into organisational leadership and culture ensures that care homes move beyond tokenistic practices toward systemic, sustainable change that upholds dignity, equity, and respect for all residents.

10.5.1 Person-Centred Care Planning

The research emphasises that truly person-centred care planning must extend beyond clinical and functional assessments to encompass the cultural dimensions of personhood, which are central to identity and well-being for South Asian people with dementia (Kitwood, 1997). While many care homes claim to practice person-centred care, existing approaches often overlook critical factors such as cultural background, language, religion, family dynamics, and community belonging (Brooker, 2007). This study highlights the necessity for developing and integrating comprehensive cultural assessment tools that go beyond surface-level demographic data to capture residents lived cultural experiences, rituals, values, and preferences (Hailstone et al., 2017). Such assessments should be dynamic, regularly reviewed, and adapted as residents' needs change, and conducted collaboratively with families who hold valuable cultural knowledge and emotional insight. The inclusion of family in care planning is especially vital in the South Asian context, where caregiving and decision-making are collective responsibilities deeply rooted in cultural expectations (Katbamna et al., 2004). By engaging families as active partners rather than peripheral participants, care homes can ensure that residents' cultural and spiritual identities are preserved while still respecting individual autonomy. This collaborative, culturally sensitive model of care planning not only enhances residents' comfort and trust but also strengthens relationships between staff and families, leading to more coherent, compassionate care delivery. Ultimately, embedding cultural understanding within person-centred care planning bridges the gap between professional care frameworks and the lived realities of diverse residents, ensuring that care remains meaningful, respectful, and responsive throughout the dementia journey.

10.5.2 Environmental Design and Accommodation

The research underscores that environmental design and communication support are central to delivering culturally responsive dementia care, as both the physical and communicative environments profoundly shape residents' comfort, inclusion, and well-being. Traditional care home designs in the UK often reflect Western assumptions about privacy, personal space, and social engagement, which may conflict with South Asian cultural values emphasising community interaction, collective prayer, and family closeness (Lawrence et al., 2011). The study highlights the need for flexible spatial design that accommodates diverse cultural practices, including designated prayer rooms, communal spaces for family gatherings, and areas for celebrating cultural and religious festivals. Such physical adaptations reinforce a sense of belonging and continuity, helping residents maintain cultural and spiritual identity within institutional settings. The inclusion of culturally meaningful environmental cues—such as familiar artwork, traditional music, and culturally resonant décor—can stimulate memory, reduce anxiety, and promote a sense of home, provided these are authentic representations rather than tokenistic symbols (Seabrooke & Milne, 2004).

Equally crucial is the provision of effective communication and language support, which forms the foundation of person-centred care. Many South Asian residents experience language regression as dementia progresses, making English-only care environments isolating and disempowering (Turner et al., 2005). To address this, care homes must ensure access to professional interpreter services for important discussions, rather than depending on family members or bilingual staff without proper training (Nielsen et al., 2011). Moreover, recruiting multilingual staff who share residents' linguistic and cultural backgrounds can enhance trust, reduce miscommunication, and improve the quality of interactions. Integrating translation technologies and communication aids, while recognising their limitations for emotional or nuanced conversations, can further support day-to-day engagement (WHO, 2023). Collectively, culturally informed environmental design and robust communication support systems help create inclusive care spaces that honour residents' heritage, enhance understanding, and promote emotional security—fundamental pillars of culturally competent dementia care.

10.6 Implications for Future Research

10.6.1 Intervention Development and Evaluation

This thesis has identified numerous opportunities for improving care provision, but there remains a critical need for developing and rigorously evaluating specific interventions designed to enhance cultural responsiveness in dementia care (Munn et al., 2018).Complex Intervention Development: Future research should focus on developing complex interventions that address multiple barriers simultaneously rather than targeting isolated issues. These interventions should be theoretically grounded, evidence-based, and co-designed with South Asian communities to ensure appropriateness and acceptability (Peters et al., 2020).

Implementation Science Applications

Understanding how to implement culturally responsive care successfully across diverse care home contexts requires sophisticated implementation science research that examines barriers and facilitators to adoption, sustainability, and scale-up (Colquhoun et al., 2014).

Economic Evaluation

The business case for culturally responsive care requires a robust economic evaluation that captures both costs and benefits, including quality-of-life improvements, family satisfaction, reduced behavioural symptoms, and decreased staff turnover. The research highlights a pressing need for targeted intervention development and evaluation to advance culturally responsive dementia care, particularly for South Asian populations in UK care homes. While existing evidence underscores the importance of cultural sensitivity, there remains a significant gap in tested, evidence-based interventions that address the multifaceted barriers identified in this study (Munn et al., 2018). Future research should prioritise the development of complex interventions that integrate multiple dimensions of care, such as language support, family engagement, dietary accommodation, and staff cultural training, rather than focusing on isolated issues. These interventions must be co-designed with South Asian communities, ensuring that they are contextually appropriate, culturally acceptable, and grounded in both theoretical frameworks and lived experiences (Peters et al., 2020).

Furthermore, the adoption of implementation science methodologies is essential to understand how culturally responsive care models can be effectively integrated into diverse care settings. Such research should explore the barriers and facilitators influencing the adoption, long-term sustainability, and scalability of interventions, paying close attention to workforce capacity, leadership engagement, and institutional readiness (Colquhoun et al., 2014). Beyond implementation, the economic dimension must be rigorously examined through comprehensive cost-benefit analyses that go beyond immediate financial considerations. This includes evaluating the broader impacts of culturally responsive care, such as improved resident quality of life, reduced behavioural and psychological symptoms of dementia, higher family satisfaction, and lower staff turnover, each contributing to more efficient and compassionate care systems. Building a strong business case for cultural responsiveness through empirical economic evaluation will help influence policymakers and care providers to view such practices not as optional enhancements but as essential investments in equitable, effective dementia care.

10.6.2 Longitudinal and Outcome Studies

The current body of research on dementia care among South Asian populations in the UK offers valuable cross-sectional insights but remains limited by a lack of longitudinal and outcome-based evidence that captures the long-term effects of culturally responsive care (Greenwood et al., 2013). To advance understanding and inform sustainable improvements, longitudinal cohort studies are essential to track South Asian residents with dementia over extended periods. Such studies would help determine how consistent cultural accommodation through language support, religious practices, dietary relevance, and family engagement impacts key outcomes such as cognitive progression, emotional well-being, behavioural symptoms, and overall quality of life. These data could provide critical evidence on how culturally responsive practices influence the lived experience of dementia and residents’ adaptation within care environments.

In addition, comparative effectiveness research is needed to evaluate outcomes across care homes with varying degrees of cultural responsiveness. By systematically comparing resident well-being, family satisfaction, and staff retention in culturally inclusive versus standard care models, researchers can generate concrete evidence supporting the practical and ethical value of cultural adaptation (Cooper et al., 2010). Equally important are family impact studies, which explore how culturally aligned care practices affect caregivers’ emotional health, perceived burden, and long-term engagement with care institutions (Parveen et al., 2018). Understanding the ripple effects of culturally responsive care on family trust and satisfaction can guide the design of family-inclusive care models that foster continuity, cooperation, and emotional stability for both residents and their relatives. Collectively, such longitudinal and outcome-based studies are essential for building an evidence-based foundation that validates the importance of cultural accommodation in improving not only clinical outcomes but also the holistic well-being of South Asian residents and their families within the dementia care continuum.

10.6.3 Diversity Within South Asian Communities

The research underscores that while South Asian communities are often treated as a single homogeneous group in dementia care policy and practice, they are, in fact, highly diverse in terms of ethnicity, religion, language, socioeconomic background, and migration history (Nazroo, 2006). This internal diversity profoundly shapes how different subgroups experience dementia, interpret care, and engage with health services. Therefore, future research must employ detailed subgroup analysis to capture these distinctions, exploring, for instance, how cultural expectations and care preferences differ among Indian, Pakistani, Bangladeshi, and Sri Lankan residents, or between Hindus, Muslims, Sikhs, and Christians. Such research would reveal specific cultural and religious practices, communication styles, and familial structures that must be recognised to tailor care effectively (Vertovec, 2007).

Equally vital is the use of intersectional analysis, which examines how overlapping identities such as gender, class, disability, age, and religion interact to shape individuals' access to and experiences of care (Crenshaw, 1989). For example, older South Asian women may face unique vulnerabilities due to compounded effects of gender norms, language barriers, and financial dependency, leading to different care needs than their male counterparts. Furthermore, understanding generational differences is essential, as first-generation immigrants often retain strong cultural affiliations and language preferences, whereas their descendants may be more acculturated and have different expectations regarding autonomy, diet, or spirituality (Simpson et al., 2008). These generational shifts affect how families negotiate care responsibilities and perceive institutional care.

By addressing these nuanced differences through subgroup and intersectional research, future studies can develop more precisely targeted interventions and culturally adaptive care frameworks. This approach ensures that dementia care for South Asian populations moves beyond broad cultural generalisations to genuinely person-centred, context-sensitive models that reflect the full spectrum of diversity within these communities.

10.6.4 Technology and Innovation Applications

Emerging technologies present transformative opportunities to address many of the challenges identified in this research, particularly in enhancing communication, cultural connection, and person-centred support for South Asian people with dementia. However, systematic research is required to evaluate their effectiveness, accessibility, and cultural appropriateness (WHO, 2023). Digital health applications such as mobile communication platforms, video-calling tools, and culturally tailored multimedia resources can play a vital role in maintaining residents' connections with family, faith, and community. These technologies enable regular interaction in native languages and provide access to culturally relevant music, prayers, and festivals, helping to reduce loneliness and promote emotional well-being.

Similarly, assistive technologies, including smart home devices, reminder systems, and adaptive communication aids, can be customised to reflect cultural norms and preferences. For example, tools that use familiar language prompts or incorporate culturally meaningful design elements can enhance residents' comfort, autonomy, and daily functioning. However, to maximise their impact, such technologies must be developed in consultation with South Asian users and tested within culturally diverse care environments to ensure usability and relevance.

Moreover, virtual reality (VR) and immersive technologies offer exciting possibilities for cultural reminiscence and cognitive engagement. VR can recreate familiar cultural experiences such as visiting places of worship, attending traditional festivals, or viewing landscapes from residents' countries of origin, thereby helping individuals reconnect with their heritage and reduce psychological distress associated with displacement. These immersive experiences may also strengthen memory recall, reduce agitation, and improve overall mood.

Future research should focus on evaluating these technologies within dementia care frameworks, ensuring they are implemented ethically, with attention to privacy, accessibility, and inclusivity. By integrating technology with culturally responsive care principles, care homes can enhance residents' quality of life, bridge linguistic and cultural gaps, and promote a deeper sense of belonging and identity preservation for South Asian residents with dementia.

10.6.5 Workforce Development Research

The research underscores the urgent need for systematic workforce development research to address the persistent challenges in delivering culturally responsive dementia care (Sue & Sue, 2019). Despite growing recognition of the importance of cultural competence, there remains a lack of empirical evidence on the most effective ways to train, support, and retain a diverse and culturally skilled workforce. Future studies must focus on evaluating the effectiveness of different cultural competency training models, including experiential learning, simulation-based education, and community-led workshops, to determine which approaches most successfully improve staff understanding, empathy, and practical communication skills. Such evaluations should assess not only immediate knowledge gains but also long-term behavioural changes and impacts on resident outcomes.

Equally important is research on workforce diversity, examining how the composition of care teams influences care quality, communication, and resident satisfaction. Diverse care teams can provide linguistic and cultural familiarity that fosters trust and belonging among South Asian residents with dementia. However, diversity also introduces challenges such as managing intercultural communication and power dynamics. Research should therefore identify optimal staffing models and support mechanisms that enhance team cohesion while leveraging cultural strengths to improve care delivery (Williamson, 2012).

Furthermore, there is a critical need to explore career pathways for workers from minority ethnic backgrounds within the dementia care sector. Many culturally competent workers face barriers to career progression, including limited access to leadership roles, lack of mentorship, and systemic biases in promotion practices. Investigating these barriers and developing strategies for professional development and leadership training can help build a more inclusive workforce that reflects the populations it serves. Comprehensive workforce development research spanning training evaluation, diversity impact, and career advancement will provide an evidence base for sustainable policy reforms and organisational strategies. Such work is essential to ensure that dementia care staff possess not only clinical competence but also the cultural insight, confidence, and inclusivity required to meet the complex needs of South Asian and other minority ethnic residents in care homes.

10.7 Study Limitations and Reflections

10.7.1 Methodological Limitations

While this research offers valuable and comprehensive insights into dementia care for South Asian people in UK care homes, several methodological limitations must be acknowledged when interpreting its findings and implications (Levac et al., 2010). First, there are notable geographic limitations, as the study was conducted primarily within the East and West Midlands of England, which may restrict the generalizability of findings to other parts of the UK, such as Scotland, Wales, and Northern Ireland. These regions have distinct policy frameworks, healthcare systems, and community demographics that could shape different experiences and models of culturally responsive care. Broader geographical representation in future research would therefore help validate and expand upon these findings.

In terms of sample characteristics, although the study achieved meaningful diversity across participants, certain subgroups within South Asian communities were underrepresented. Recent immigrants, individuals with limited English proficiency, and those from smaller or more dispersed South Asian populations may experience unique barriers that were not fully captured. Their perspectives are crucial, as these groups often face compounded disadvantages due to linguistic isolation, limited-service awareness, and lower socioeconomic status (Office for National Statistics, 2023).

Additionally, the temporal design of the research presents inherent constraints. The cross-sectional nature of much of the data provides valuable snapshots of experience but limits the ability to explore how cultural needs, adaptation processes, and expectations evolve over time as dementia progresses or as residents and families adjust to care home environments (Alzheimer's Society, 2024). Longitudinal research would enable a deeper understanding of how care trajectories and satisfaction change over time.

Finally, researcher positionality is a key methodological consideration. The researcher's cultural background, professional experience, and interpretive lens inevitably influenced data collection, analysis, and interpretation (Khalil et al., 2016). While reflexivity and transparency were maintained throughout the research process to minimise bias, complete neutrality is unattainable in qualitative inquiry. Recognising this influence is critical for contextualising interpretations and ensuring credibility. In sum, while these methodological limitations do not undermine the validity of the findings, they highlight areas where future research could expand scope, enhance representativeness, and adopt longitudinal and reflexive approaches to strengthen the evidence base for culturally responsive dementia care.

10.7.2 Scope Limitations

The scope limitations of this research must be acknowledged to ensure appropriate interpretation of its findings and to guide future inquiry. The setting limitation arises from the study's focus on care homes, which, while well aligned with the research objectives, restricts the generalizability of results to other care environments such as day care centres, respite care, or community-based support services (Grant & Booth, 2009). Dementia care within community settings often involves distinct dynamics of family involvement, resource availability, and cultural negotiation compared to institutional care, suggesting that the challenges and opportunities identified in this research may manifest differently outside residential contexts. Expanding future studies to include multiple care settings could therefore provide a more comprehensive understanding of culturally responsive dementia care across the continuum of services.

The population limitation also warrants consideration. Although the study deliberately focused on "South Asian" communities, this term encompasses a wide array of subgroups differentiated by religion, language, migration history, and socioeconomic status (Bhopal, 2007). This broad categorisation, while useful for thematic analysis, may obscure nuanced differences among Indian, Pakistani, Bangladeshi, and Sri

Lankan populations, each of whom may have distinct expectations and experiences of dementia care. Consequently, while the findings offer valuable general insights, they may not be equally applicable to all subgroups within the South Asian diaspora.

In addition, stakeholder representation presents a further limitation. Although this study sought to integrate perspectives from residents, families, and staff, the voices of individuals with more advanced stages of dementia were necessarily underrepresented, as ethical and cognitive considerations constrained their participation in direct interviews and discussions. Their experiences were often relayed indirectly through family members or caregivers, which, while valuable, may not fully capture the lived reality of those most affected by institutional care. Including proxy accounts adds depth but also introduces interpretive bias.

Taken together, these scope limitations highlight the importance of adopting a more inclusive and diversified research design in future studies. Broader representation across care settings, greater differentiation among South Asian subgroups, and innovative methods for incorporating the perspectives of residents with advanced dementia would help to build a more comprehensive, equitable, and contextually rich evidence base for culturally responsive dementia care.

10.7.3 Contextual Limitations

The contextual limitations of this research are primarily shaped by the evolving policy and economic environments within which dementia care operates. The policy context limitation arises from the dynamic nature of health and social care policy in the United Kingdom. Since the implementation of the Care Act 2014 and subsequent frameworks such as the NHS Long Term Plan and national dementia strategies, there has been continuous reform in commissioning practices, regulatory frameworks, and equality standards (Department of Health and Social Care, 2021). As these policy shifts occur, the relevance and applicability of certain findings may change, particularly regarding how cultural competency and person-centred care are operationalised within institutional settings. The research captures a snapshot in time within a policy environment that is in flux; therefore, future developments such as enhanced funding for dementia services or revised cultural competence standards may reshape the challenges and opportunities identified in this study.

The economic context limitation further constrains the generalizability of the findings. The care sector in the UK continues to face severe financial pressures due to rising operational costs, workforce shortages, and limited public funding (Age UK, 2023). These economic challenges influence how care homes implement recommendations related to culturally responsive care, such as specialized staff training, recruitment of bilingual workers, and provision of culturally appropriate food and religious spaces. For some care providers, economic limitations may lead to prioritizing immediate operational survival over long-term investment in quality improvements. Similarly, families particularly those from lower socioeconomic backgrounds—may struggle to afford care homes that offer enhanced cultural accommodations, leading to inequities in access to high-quality, culturally sensitive dementia care.

Furthermore, the financial realities of both public and private care models create disparities in service delivery that can amplify cultural and social inequalities. Economic instability, compounded by workforce turnover and underfunding, may limit the scalability of interventions proposed in this thesis, even when they are evidence-based and ethically justified. As such, the study's recommendations should be interpreted with an awareness of these structural economic barriers that shape both policy implementation and the lived experience of care provision.

10.7.4 Reflexive Considerations

The reflexive considerations within this study underscore the intertwined dimensions of personal growth, emotional engagement, and professional development that have shaped the research process. I completed the Postgraduate Certificate in Higher and Professional Education, which enhanced my knowledge and skills in conducting and disseminating research, wider professional practice, teaching and learning in higher and professional education, and in research proposals.

The journey has been both intellectually and personally transformative, fostering a deeper awareness of cultural competence, ethical sensitivity, and the complexities inherent in healthcare delivery for SAPWD. Engaging directly with participants and families revealed the emotional weight of witnessing unmet care needs and systemic inequities, demanding constant reflexivity to manage empathy while preserving academic rigour and neutrality. This emotional proximity, though challenging, also strengthened the researcher’s resolve to ensure authenticity and cultural sensitivity in interpretation. Furthermore, navigating the tension between advocacy and objectivity emerged as a critical reflexive task balancing the moral imperative to highlight disparities with the scholarly duty to present unbiased, evidence-based analysis (Spector et al., 2020). As Arksey and O’Malley (2005) note, reflexivity is central to maintaining transparency and credibility in qualitative inquiry, allowing the researcher to critically examine how positionality, values, and experiences may shape the generation and interpretation of knowledge. Through this reflective engagement, the research not only contributes to academic discourse but also reinforces the ethical responsibility to use exploration as a tool for social awareness and positive change within dementia care.

10.8 Broader Significance and Societal Impact

10.8.1 Health Equity and Social Justice

The broader significance of this research lies in its strong alignment with the principles of health equity and social justice, highlighting the urgent need to confront and rectify structural inequalities embedded within healthcare systems. By examining the lived experiences of SAPWD and their families, the study underscores that equitable healthcare is not synonymous with identical treatment for all but requires culturally responsive and contextually sensitive care approaches that address the specific needs of marginalised groups (Karlsen & Nazroo, 2013). The research challenges the pervasive assumption of universality in healthcare models, demonstrating that standardised approaches often neglect the sociocultural dimensions that profoundly influence care access, satisfaction, and outcomes. In doing so, it reframes cultural diversity as a vital asset to healthcare innovation rather than a logistical challenge, reinforcing Bhopal’s (2007) assertion that inclusivity and cultural understanding strengthen the overall quality and humanity of care. Moreover, the study contributes to wider debates on multiculturalism and social cohesion, emphasising that culturally competent healthcare fosters integration, mutual respect, and trust within pluralistic societies (Vertovec, 2007). The implications extend beyond clinical practice to the realm of social policy, where the findings advocate for targeted interventions, inclusive policymaking, and institutional reforms that dismantle inequities and promote collective well-being. Ultimately, the research affirms that advancing health equity is inseparable from advancing social justice; both are essential to building resilient, compassionate, and cohesive communities.

10.8.2 Demographic Transition Implications

The implications of demographic transition highlighted in this research are profound, underscoring the growing urgency for healthcare systems worldwide to adapt to the realities of ageing and increasingly diverse populations. As noted by the World Health Organisation (2023), demographic shifts are reshaping the global health landscape, with longevity gains accompanied by rising rates of dementia and other age-related conditions. This study's examination of SAPWD in UK care settings offers valuable insights that extend far beyond national borders, demonstrating how culturally sensitive care practices can enhance the quality of life, trust, and engagement among minority elders. The theoretical and methodological contributions of this research, rooted in inclusivity, reflexivity, and participatory engagement, hold international relevance, offering adaptable frameworks for countries facing similar multicultural ageing dynamics (Blakemore & Boneham, 1994). Importantly, the findings stress that healthcare systems must move from reactive to proactive strategies in managing cultural diversity, embedding cultural competence and equity into workforce training, care standards, and policy development. As the Office for National Statistics (2023) predicts increasing heterogeneity in older populations, this research provides a timely roadmap for anticipating and addressing future demographic challenges. By integrating lessons learned from the South Asian experience in the UK, global health systems can better prepare to meet the complex, culturally nuanced needs of ageing societies, ensuring dignity, inclusivity, and equality in care delivery across diverse communities.

10.8.3 Innovation and System Change

This research underscores that meaningful innovation and systemic transformation in healthcare frequently originate from efforts to address the needs of marginalised and underserved populations. By focusing on the experiences of SAPWD in UK care homes, the study highlights how initiatives developed to meet culturally specific needs, such as improved communication practices, family-integrated care models, and person-centred environmental designs, can generate scalable solutions that enhance the overall quality of care for all residents, regardless of background (Brooker, 2007). As Williamson (2012) emphasises, innovation driven by inclusivity not only rectifies inequities but also fosters creativity and adaptability within healthcare systems. This study demonstrates that cultural responsiveness can act as a catalyst for systemic learning, prompting institutions to reflect on their practices, policies, and priorities to ensure they are both equitable and effective. The lessons extend beyond dementia care, offering valuable insights for other areas of healthcare where diversity and personalisation are key determinants of patient outcomes. In alignment with NHS England's (2019) vision for a more adaptive and patient-centred system, this research advocates for embedding cultural competence, collaborative learning, and inclusive design into institutional frameworks. Ultimately, the study positions innovation as a transformative process—one that begins with acknowledging diversity and culminates in creating resilient, empathetic, and universally beneficial healthcare systems.

10.9 Final Recommendations

Drawing from the findings of this thesis, the recommendations are structured across policy, practice, education, and research, aligning with immediate, medium-term, and long-term priorities. Together, they support systemic transformation toward culturally responsive dementia care for SAPWD.

10.9.1 Immediate Priorities (Policy and Practice)

Policy-Level Actions

- **Introduce mandatory cultural competency standards in residential dementiacare.**
  National regulatory frameworks should explicitly require culturally responsive practices within care homes, in line with guidance from the Department of Health and Social Care (2021). Embedding cultural competence into inspection criteria would ensure accountability and consistency across services.

- **Allocate ring-fenced funding for culturally responsive care initiatives.** Targeted funding should support interpreter services, culturally appropriate meal provision, religious observance spaces, and culturally adapted activity programmes. Financial commitment signals that equity is a structural priority rather than an optional enhancement.

- **Integrate cultural identity documentation into care planning systems.** Cultural, linguistic, and religious preferences should be formally recorded and reviewed as part of person-centred care documentation, ensuring systematic implementation rather than informal recognition.

Practice-Level Actions

- **Implement structured cultural needs assessments at admission.** Care providers should introduce culturally sensitive assessment tools to identify dietary, spiritual, communication, and family expectations early in the care journey.
- **Strengthen partnerships with local South Asian community and faith organisations.**
  Collaboration with community networks can enhance trust, reduce stigma, and improve culturally congruent support (Patel et al., 2007).
- **Establish regular family forums as co-production platforms.** Structured meetings should be used not only for updates but for shared decision-making, reinforcing the active negotiation model identified in this study.

These immediate actions translate research insights into operational change, ensuring that inclusivity becomes embedded in daily care delivery.

10.9.2 Medium-Term Developments (Workforce and System Integration)

Workforce Development (Education and Training)

- **Make cultural competence a core component of professional dementia training.**
  Training programmes should move beyond awareness toward reflexivity, anti-bias practice, and culturally adapted communication strategies (Sue & Sue, 2019).
- **Create accredited career pathways recognising cultural expertise.** Recognising and rewarding culturally competent practice strengthens workforce motivation and professional identity.

- **Promote diverse recruitment strategies.** Recruiting staff from varied cultural backgrounds enhances linguistic accessibility and cultural literacy within care environments.

Integrated Care Systems (Policy and Practice)

- **Develop integrated cultural care pathways across sectors.** Hospitals, community services, and residential settings should share cultural preference documentation to ensure continuity (NHS England, 2019).
- **Introduce digital care records capturing cultural and spiritual needs.** Standardised information-sharing systems would reduce fragmentation and prevent cultural needs from being overlooked during transitions.

Innovation and Knowledge Exchange (Research and Practice)

- **Establish innovation networks for culturally responsive dementia care.** Peer-learning platforms should enable dissemination of best practices and service models (Tricco et al., 2016).
- **Pilot and evaluate culturally adapted interventions.** Programmes must be tested rigorously and scaled using implementation science frameworks (Munn et al., 2018).

These medium-term developments aim to build a resilient, inclusive infrastructure capable of responding to demographic change.

10.9.3 Long-Term Vision (Structural Transformation and Global Leadership)

System-Level Reform (Policy)

- **Embed equity within funding and quality assurance frameworks.** Cultural responsiveness should be integrated into Care Quality Commission standards and performance indicators (Spector et al., 2020).
- **Reform evaluation metrics to include cultural well-being outcomes.** Measurement tools should assess belonging, dignity, and cultural identity alongside clinical outcomes.

Community Integration (Practice and Social Policy)

- **Transform care homes into community-connected hubs.** Strengthening links with cultural, religious, and voluntary networks enhances relational and participatory care (Ballard, 1994).
- **Promote culturally inclusive public health messaging on dementia.** National campaigns should address stigma and improve early engagement within South Asian communities (Mukadam et al., 2019).

International Leadership (Research and Policy)

- **Position the UK as a leader in culturally responsive dementia care.** Drawing upon WHO (2023) guidance, the UK can leverage its multicultural context to inform global best practice standards.
- **Support longitudinal research into ethnic inequalities in dementia care.** Sustained funding is required to examine outcomes, evaluate policy impact, and inform future reform.

This long-term vision reframes cultural responsiveness as foundational to ethical and socially just healthcare systems.

10.10 Concluding Reflections

The concluding reflections of this thesis encapsulate the core message that achieving culturally responsive dementia care is not an optional enhancement but a moral and professional necessity within an increasingly diverse society. The research has illuminated the systemic barriers faced by SAPWD in UK care homes, revealing how cultural insensitivity, inadequate communication, and lack of representation perpetuate inequity in care delivery (Patel et al., 2007).

However, it also highlights pathways for transformation, demonstrating that when cultural responsiveness is embedded into care practices, it enhances not only the well-being of minority ethnic residents but also the overall quality and inclusivity of care for all (Bhopal, 2007; Brooker, 2007). By amplifying the often-overlooked voices of SAPWD and their families, this study challenges prevailing assumptions of uniformity in healthcare and underscores the necessity of recognising and valuing difference as a foundation for equity (Kitwood, 1997; Mukadam et al., 2019).

The research journey itself has been both intellectually and emotionally enriching, offering lessons on reflexivity, methodological rigour, and prioritising lived experiences (Arksey & O’Malley, 2005; Levac et al., 2010). Moving forward, the findings call for collective action from policymakers, practitioners, and researchers to implement sustained, evidence-based changes that align care systems with the cultural realities of an ageing and heterogeneous population (Department of Health and Social Care, 2021; Office for National Statistics, 2023).

As dementia prevalence rises within South Asian communities, the urgency to act becomes undeniable. Ultimately, the significance of this research extends beyond academic contribution; it represents a call to action for compassionate, equitable, and person-centred care that honours each individual’s cultural identity, spirituality, and humanity. In doing so, it reinforces Kitwood’s (1997) enduring message that genuine dementia care must transcend the medical model to embrace the full dignity and personhood of those it seeks to serve.

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Appendices

Appendix A

Ethical Approval

Faculty of Health Sciences

ETHICAL APPROVAL FEEDBACK

Researcher Name:	**Nisha Babu**
Title of Study:	A qualitative study of the needs of South Asian people with dementia in residential and respite care
Status of approval:	**Approved with Minor Flaws**

Thank you for submitting your application which the panel has now considered. The panel's recommendation is that your application is ***approved with minor flaws.***. See below for details.

Detail required:

This is a comprehensive and considered application. It does not raise any ethical concerns. We have stated some minor revisions below and some points for further consideration.

Minor revision, required before approval can be granted

The application should state that there is no exclusion criteria with regard to the type of dementia.

While there is a sound rationale for conducting the interviews at the point when consent has been obtained, a minimum period should be provided (perhaps one week) to allow all potential respondents to consider their participation – i.e. after they have been provided with information sheets.

It could be made more explicit in the application what role the carer/family member will undertake during the interview with the person with dementia. (Are they only present in case there is a problem, or are they actively contributing to the data gathering process?)

The Next of Kin Information sheet reads the same as the SAPWD Information Sheet. Nisha might want to amend this to reflect the nature of the interview with this participant group.

The consent form can be streamlined in terms of questions and need reformatting (e.g. the addition of boxes for the participant to initial).

The information sheets also require proofreading.

Advisory points for consideration (optional)

Do transcripts require checking by participants? If this is a feature of study design you wish to retain then a simple form can be devised so the respondent can confirm the transcript is a faithful representation of the interview.

Demographic information is collected from the SAPWD and their next of kin/family member. Should this data also be collected from the care staff? This could be used to highlight not only cultural similarities/differences, but also generational differences which might impact on care.

The type of dementia can be obtained when acquiring participant details. It might also be worth obtaining their principal occupation (even if they are retired) and education level. Duration of relationship could also be useful to obtain if spousal couples are taking part. (These details could be requested by reviewers if you seek to publish articles later).

The role of consultee could be considered. As there is no ongoing empirical process (in terms of a single participant's engagement) then fluctuating capacity, outside the management of the interview process itself, isn't an ethical concern. If you feel a consultee is required, then a specific information sheet and (proxy) consent form would be required.

Just a general query: does the person to contact if there is a complaint need to be independent of the project? (It currently states a supervisor).

Action now needed:

Please revise your proposal to take account of the feedback provided by the ethics committee which is listed above.

You should arrange to meet with your supervisor as soon as possible to discuss the revision of your proposal. When you have addressed all the comments, please **email the revised form**, and a **covering letter** indicating how you have addressed the points raised to Peter Kevern **p.kevern@staffs.ac.uk.**

Please make sure that **all appropriate signatures** (Researcher Signature and Supervisor Signature) are included on the amended Ethics Form.

You are reminded that you cannot commence the implementation phase of your study until you have received a written response from the Faculty Panel confirming approval.

PM Kevern

Signed: Dr Peter Kevern **Date: 9.3.18**
Chair of the Faculty of Health Sciences Ethics Panel

STAFFORDSHIRE
UNIVERSITY

ETHICAL APPROVAL FEEDBACK

Researcher name:	Nisha Babu
Title of Study:	A qualitative study of the needs of South Asian people with dementia in residential and respite care
Status of approval:	Approved

Thank you for addressing the committee's comments. Your research proposal has now been approved by the University Ethics Panel and you may commence the implementation phase of your study. You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

You should arrange to meet with your supervisor for support during the process of completing your study and writing your dissertation.

When your study is complete, please send the ethics committee an end of study report. A template can be found on the ethics BlackBoard site.

PM Kevern

Signed: Dr Peter Kevern **Date: 19.3.18**
Ethics Coordinator, School of Health and Social Care

Appendix B

COVERING LETTER FOR THE MANAGER OF CARE HOMES

Dear Manager

Re: Research Project

Title of the study:

The needs of people with dementia from South Asian origins in residential or respite care

I am Nisha Kudiyirippil Babu, a PhD student from Staffordshire University. The purpose of the study is to explore the opportunities and barriers to meeting the needs of South Asian people with dementia (SAPWD) in residential care and respite care. I would like to talk with South Asian people with dementia (specifically, those who can give consent), care staff and next of kin.

Attached is a general information leaflet detailing the project. If you are willing to help with this research, I would like to meet with you at a time and location in the nursing home that is convenient for you and the participants. If you, your care staff, SAPWD, or next of kin would be willing to speak, please let me know when I visit next time. Following this, I will contact you and the participants, and I will provide more detailed information. All information will be treated with the strictest confidence, and no one will be identified personally. Thank you for reading this letter.

Yours sincerely

Nisha Kudiyirippil Babu

nishakudiyirippilbabu@research.staffs.ac.uk

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Appendix C

UNIVERSITY OF STAFFORDSHIRE

Title of the study:

The needs of people with dementia from South Asian origins in residential care settings.

GENERAL INFORMATION SHEET

What is the project about?

The purpose of the project is to explore the opportunities and barriers to meeting the needs of South Asian people with dementia in residential care and respite care.

Why I would like to talk to you.

I am particularly interested in talking with South Asian people with dementia, nursing home care staff and next of kin regarding their experiences and perspectives in meeting the needs of South Asian People with Dementia.

How will I go about doing this?

I aim to interview people with dementia from South Asian backgrounds, care staff and next of kin, and ask them to share their thoughts and feelings about needs, services and care which South Asian People with Dementia receive. For example, do you think that services and care provided for South Asian People with Dementia meet their needs? Is there anything about the care you have witnessed or received that was inappropriate to your culture or that you did not like? Is there anything good about the care/services that you have used? If you are willing to be interviewed, the researcher will contact you to arrange a time and location in the nursing home to suit you. The interview will last between 30 minutes and one hour.

Do I have to take part?

Anyone taking part is free to withdraw at any time. This will not affect any help or care you or your family member is receiving, now or in the future. This study does not involve treatment.

What will happen to the information and digital recordings?

All information will be strictly confidential and referred to anonymously in the reports and articles. Any information you give us will be kept in a secure environment and destroyed after 10 years, in accordance with university policy.

What happens if I change my mind?

If you wish to withdraw from the project, you can do so at any time up to 1 month after the interview. To withdraw your data from the study, please email the researcher at the address given below.

Are you interested in helping us with the project?

YES NO

If yes, please write your name and pass it on to the Manager. Alternatively, please email me at the email address below. The Researcher will contact you shortly to arrange an interview.

Name –

Thank you very much for reading this.

Nisha Kudiyirippil Babu

nishakudiyirippilbabu@research.staffs.ac.uk

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Appendix D

UNIVERSITY OF STAFFORDSHIRE

Title of the study:

The needs of people with dementia from South Asian origins in residential or respite care

INFORMATION SHEET -1

Participant Information Sheet - SAPWD

My name is Nisha Kudiyirippil Babu, and I am studying for my Doctorate in Health Studies at Staffordshire University. You are being invited to take part in a research project. Before you decide, you need to understand why the research is being done and what it will involve. Please feel free to ask if anything is unclear or if you would like more information.

What is the purpose of the study?

The purpose of the project is to explore the opportunities and barriers to meeting the needs of South Asian people with dementia in residential care and respite care.

Why have I been asked to take part?

You have been asked to take part as you are diagnosed with dementia (memory problem) and are from a South Asian background. The manager of the residential care home has suggested you might be interested in taking part.

Do I have to take part?

You do not have to take part if you do not wish to. If you decide to take part, you are still free to withdraw at any time, without having to give a reason. Whatever you decide, it will not affect the care you are receiving.

What does taking part involve?

I will come to visit you and ask some questions about yourself and your experience of staying in the care home. A family member or a member of the care staff will be with you. We will talk for 30 minutes to an hour. I will record our talk on a digital recorder.

What are the possible disadvantages and risks of taking part?

You may become upset during the interview, and if this happens, you can ask the interviewer to stop the interview. If this happens, a member of staff or a family member will be there to help you.

What are the possible benefits of taking part?

Participating in this study will allow you to talk about your experience of dementia/memory problems and needs, which may be beneficial.

Confidentiality and Anonymity

I may write down some of what you say for inclusion in my thesis or a published paper. If this happens, I will not use your original name so that nobody will know what you said.

All information you provide will be kept securely and destroyed after ten years. Only I and the supervisors will have access to the information.

Who has reviewed the study?

The Staffordshire University Research Ethics Committee has approved this study.

Where can I get more information or sign up for the study?

If you are interested in hearing more about the study, please tell a member of the care home staff. The staff will contact me, and then I will contact you.

What happens if I change my mind?

If you wish to withdraw from the project, you can do so at any time up to 1 month after the interview. To withdraw your data from the study, please inform the care staff so that they can email the researcher at the address given below.

Nisha Kudiyirippil Babu

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Appendix E

STAFFORDSHIRE UNIVERSITY

UNIVERSITY OF STAFFORDSHIRE

INFORMATION SHEET -2

Participant Information Sheet for Staff

Title of the study:

The needs of people with dementia from South Asian origins in residential care settings.

My name is Nisha Kudiyirippil Babu, and I am studying for my Doctorate in Health Studies at Staffordshire University. You are being invited to take part in this research project. Before you decide, you need to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please feel free to ask if anything is unclear or if you would like more information. Thank you for reading this.

What is the purpose of the study?

The study hopes to gather information from some different sources by interviewing residents, care home staff and next of kin to identify best practice in meeting the needs of South Asian people with dementia. I aim to explore opportunities and potential barriers to meeting needs, and ways in which care staff and family could work together to address them. The study's findings can then be used to identify how service provision could be improved for South Asian people in residential care homes.

Why have I been invited?

You have been invited to take part as you are one of the care staff in this care home, which has agreed to the study.

Do I have to take part?

You do not have to take part if you do not wish to. If you decide to take part, you will be given this information sheet and asked to sign a consent form.

What do I have to do?

If you are interested in taking part in the study, you will be asked some basic background information (age, experience), and I will come and talk with you in an interview lasting about 30 minutes to 1 hour. During the interview, you will be asked to talk about your experiences of identifying problems in South Asian residents with dementia, any difficulties or challenges you have had in meeting the problems, language as a communication barrier and any ideas/suggestions of how these challenges could be overcome. The interview will be digitally recorded and will take place at a time and place convenient for you in the nursing home.

What happens to the information I give at the interview?

The interview will be digitally recorded, so the interviewer can listen to what you have to say without taking notes. Following the interview, it will be typed up from the tape recording. Your personal details and any names or people you mention will remain confidential. The recordings will be destroyed once the interview has been transcribed. A written report will be produced at the end of the researcher's time in your care home and shared with others to better understand what is happening in efforts to meet the needs of South Asian residents with dementia and to improve service provision. Whilst the report may contain quotes of what has been said during interviews, these quotes will be anonymised, and so no one will be able to identify who said what, including your employers.

What will happen if I do not want to carry on with the study?

If you decide to take part, you are still free to withdraw at any time, without having to give a reason. This includes your right to stop an interview at any time. Any decision to withdraw, or not to take part, will have no effect on your job in the care home.

If you wish to withdraw from the project, you can do so at any time up to 1 month after the interview. To withdraw your data from the study, please email the researcher at the address given below.

What happens if there is a problem?

If you have a concern about any part of the study, you should email the researcher, who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do so through your supervisor, Dr Peter Kevern at Staffordshire University, at p.kevern@staffs.ac.uk.

What will happen to the results of the study?

The results of the study will be used to help improve the care provision of South Asian people with dementia at a local and national level. To make sure that care homes routinely offer good, personalised, culturally and respectful care to older people with dementia from South Asian communities. The findings and possible service improvements will be published in various ways, for example, at a local workshop, in journal articles, and through guidance on improving services to care homes in caring for South Asian people with dementia.

Who is organising and funding the study?

This study is being carried out as part of a PhD which the researcher is undertaking at Staffordshire University. Dr Peter Kevern and Professor Wilfred McSherry are the supervisors and are overseeing the study.

Who has approved the study?

Staffordshire University Research Ethics Committee has granted ethical approval

Contact for further information

Nisha Kudiyirippil Babu

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Appendix F

UNIVERSITY OF STAFFORDSHIRE

INFORMATION SHEET- 3

Participant information sheet for family

Title of the study:

The needs of people with dementia from South Asian origins in residential care settings.

My name is Nisha Kudiyirippil Babu, and I am studying for my Doctorate in Health and Social Science at Staffordshire University. You are being invited to take part in this project, through which it is hoped to improve how next of kin/relatives can help to meet the needs of South Asian people with dementia in residential care homes. Before you decide to take part, you must understand why this study is being done and what it will involve. Please take a moment to read the following information and discuss it with others if you wish. Please ask the researcher anything that is unclear to you or if you would like more information. Take time to decide if you wish to take part. Thank you for reading this. I am required to undertake a project as part of my course, and I am currently recruiting participants for my study.

What is the purpose of the study?

The purpose of the project is to explore the opportunities and barriers to meeting the needs of South Asian people with dementia in residential care and respite care. The study hopes to gather information from some different sources by interviewing residents, care home staff and next of kin of SAPWD to discover whether the needs of South Asian people with dementia are being fully met. To explore what is stopping needs from being met, experiences and views of SAPWD, and whether there are better ways for care staff and family to work together to meet these needs. Positive and negative aspects of staying in a nursing home. The study's findings can then be used to identify how service provision could be improved for South Asian people in residential care homes. To develop culturally competent care and enhance good practice with South Asian minority groups across the home sector.

Why have I been asked to take part?

You have been asked to take part because you are the next of kin/relative of SAPWD and know the service user best, who has agreed to take part in the study.

Do I have to take part?

You do not have to take part if you do not wish to. If you decide to take part, you are still free to withdraw at any time, without having to give a reason. Whatever you decide, it will not affect the care services provided to the service user (South Asian People with Dementia).

What does taking part involve?

I will come to visit you and ask some questions about yourself and your relationship to the service user. In the interview, you will be asked about your experience and views on meeting the needs (met or unmet) of South Asian people with dementia in the care home. We will talk for 30 minutes to an hour. I will record our talk on a digital recorder, and the interview will take place at a time and place convenient to you.

What are the possible disadvantages and risks of taking part?

You may become upset during the interview, and if this happens, you can ask the interviewer to stop the interview. If you require further support, this would be arranged with the most appropriate member of the nursing home staff.

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What are the possible benefits of taking part?

Participating in this study will give you the opportunity to talk about your experience of dementia/memory problems and needs, which may be beneficial. Encourages you to think about how you can help to meet the needs of service users (SAPWD) with the staff. Hopefully, you will find participating in the process engaging, enjoyable, and positive as you share your views and needs.

Confidentiality

All the information you provide to the researcher will be kept anonymous and confidential, in accordance with standard clinical guidelines. That means the information will not be reported back to the nursing home care team. However, if you tell me that someone else might be at risk of harm, I will have to pass the information to the appropriate health professional.

The information you will give in this study will be stored securely and anonymously according to the Data Protection Act. I may write down some of what you say for inclusion in my thesis or a published paper. If this happens, I will remove your name so that nobody will know what you said.

All information you provide will be kept securely and destroyed after ten years. Only I and the supervisors will have access to the information.

Who has reviewed the study?

The Staffordshire University Research Ethics Committee has approved this study.

Where can I get more information or sign up for the study?

If you are interested in hearing more about the study, please tell a member of the care home staff. The staff will contact me, and then I will contact you.

What happens if I change my mind?

If you wish to withdraw from the project, you can do so at any time up to 1 month after the interview. To withdraw your data from the study, please inform the care staff so that they can email the researcher at the address given below.

Contact for further information

Nisha Kudiyirippil Babu

nishakudiyirippilbabu@research.staffs.ac.uk

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Appendix G

CONSENT FORM FOR SAPWD

Project Title: The needs of South Asian people with dementia in residential care settings.

Name of Researcher ……………………………………………..

Thank you for reading the information about the research project. If you would like to take part, please read and sign this form.

Participant Name:……………………..

Please initial

the box

I have read and understand the information sheet and have had the opportunity to ask questions. ☐

I understand that taking part is voluntary and that I am free to withdraw at any time, without giving any reason, without any medical care or legal rights being affected. ☐

I can ask for the interview to be stopped at any time without giving a reason. ☐

I can ask for my interview data to be removed from the study at any time up to one month after giving the interview. ☐

All the information I provided in the study will be anonymous. However, if I reveal information about future harm to myself or others, that information will be passed on to the appropriate ☐

healthcare professional.

I understand the interviews will be recorded and typed word for word. I give permission for this to be done. ☐

I understand that direct quotes may be used in future publications, but will be anonymised. ☐

I understand the recordings will be destroyed once the interviews have been analysed. ☐

I understand that individuals from the regulatory authorities may look at relevant sections of data collected during the study (Staffordshire University), where it is appropriate. I grant those individuals access to my data.

I agree to take part in the above study. ☐

Name of participant	Signature	Date
Witnessed	Signature	Date
Name of person taking consent	Signature	Date

Contact Details:

Nisha Kudiyirippil Babu
nishakudiyirippilbabu@research.staffs.ac.uk
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Appendix H

STAFFORDSHIRE UNIVERSITY

CONSENT FORM FOR STAFF

Project Title: The needs of South Asian people with dementia in residential care settings.

Name of Researcher ………………………………………………..

Thank you for reading the information about research project. If you would like to take part, please read and sign this form.

Participant Name:……………………..

Please initial

the box

I have read and understand the information sheet and have had the opportunity to ask questions. ☐

I understand that taking part is voluntary and that I am free to withdraw at any time, without giving any reason, without any medical care or legal rights being affected. ☐

I can ask for the interview to be stopped at any time without giving a reason. ☐

I can ask for my interview data to be removed from the study at any time up to one month after giving the interview. ☐

All the information I provided in the study will be anonymous. However, if I reveal information about future harm to myself or others, that information will be passed on to the appropriate healthcare professional. ☐

I understand the interviews will be recorded and typed word-for-word. I give permission for this to be done. ☐

I understand that direct quotes may be used in future publications, but will be anonymised. ☐

I understand the recordings will be destroyed once the interviews have been analysed. ☐

I understand that individuals from the regulatory authorities may look at relevant sections of data collected during the study (Staffordshire University), where it is appropriate. I give permissions for those individuals to have access to my data.

I agree to take part in the above study. ☐

Name of participant Signature Date

Contact Details:

Nisha Kudiyirippil Babu

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Appendix I

CONSENT FORM FOR FAMILY

Project Title: The needs of South Asian people with dementia in residential care settings.

Name of Researcher ……………………………………………..

Thank you for reading the information about research project. If you would like to take part, please read and sign this form.

Participant Name: ……………………..

Please initial

the box

I have read and understand the information sheet and have had the opportunity to ask questions.	☐
I understand that taking part is voluntary and that I am free to withdraw at any time, without giving any reason, without any medical care or legal rights being affected.	☐
I can ask for the interview to be stopped at any time without giving a reason.	☐
I can ask for my interview data to be removed from the study at any time up to one month after giving the interview.	☐
All the information I provided in the study will be anonymous. However, if I reveal information about future harm to myself or others, that information will be passed on to the appropriate healthcare professional.	☐
I understand the interviews will be recorded and typed word	☐

for word. I give permission for this to be done.

I understand that direct quotes may be used in future publications, but will be anonymised. ☐

I understand the recordings will be destroyed once the interviews have been analysed. ☐

I understand that relevant sections of data collected during the study may be looked at by individuals from the regulatory authorities (Staffordshire University), where it is appropriate. ☐

I give permissions for those individuals to have access to my data. ☐

I agree to take part in the above study. ☐

Name of participant Signature Date

Contact Details:
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Staffordshire University
College Rd, Stoke-on-Trent
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Appendix J

Demographic Information Sheet

Family/relative Details

Age:

Gender:

Religion:

Education:

Occupation:

Marital Status:

Relationship to person with dementia:

Country of birth:

Country of upbringing (if different from above):

First Language:

Languages known:

Year which you came to the UK if applicable:

Appendix K

Demographic Information Sheet

SAPWD Details:

Age:

Gender:

Education:

Occupation:

Marital Status:

Religion:

Country of birth:

Country of upbringing (if different from above):

Languages known:

Year which you came to the UK:

Type of dementia (if known):

Appendix L

Demographic Information Sheet

Care Home staff details:

Name:

Age:

Gender:

Ethnicity:

Religion:

Job Title:

Qualifications:

First Language:

Languages Known:

Appendix M

Interview Guide for Care Home Staff

Can you tell me a little about yourself and how long you have worked in this care home?

Can you tell me about your experience and views on providing care to the SAPWD?

Do you have problems getting all the information (previous history/life history of the resident) ?

What do you think is your role in managing the needs of residents?

Do you have any problems communicating with the residents?

Do you think culturally appropriate care is provided?

Have you had any training for dementia care and cultural diversity? Does this help to understand the SAPWD?

Did you get any training to communicate with South Asian people with dementia? (verbal/non-verbal)

Did you have any problems communicating with SAPWD, and what training do you think may help you meet these needs?

How do you work with senior staff to manage a SAPWD needs?

What has been your experience in getting the support that you need?

Is there any support that you would value?

Looking to the future

What do you think could be better done to meet the needs and improve care provision for South Asian residents with dementia?

Do you have any ideas, based on your own experiences, about how to improve the collaboration between staff from different disciplines and families?

Is there anything else I have not covered that you would like to say?

Appendix N

INTERVIEW GUIDE FOR SAPWD

Can you tell me a little about yourself?

Can you tell me about your experience living in this nursing home?

Can you tell me about the care and services provided?
Likes and dislikes of the services?

What are your views on the needs of a South Asian individual with a memory problem?

Do you have any problem communicating with the care staff?

Needs that are met and unmet eg, culturally appropriate food, activities, religious belief

Do you think that your needs are met?

Would you like to come back again to this nursing home or recommend to others (for SAPWD respite care)

Any suggestions to improve the needs

End

Okay, that was the last question I had for you. Thank you so much for taking the time to talk with me. How are you feeling now?

Is there anything we have not covered that feels important to share?

Is there anything you would like to ask me about the study?

(Check for the sensitivity for using the term ‘dementia’ prior to interview, not to distress the SAPWD, state it as a memory problem)

Appendix O

INTERVIEW GUIDE FOR FAMILY

Can you tell me about yourself and the relationship to the individual with a memory problem?

Can you tell me about your experience with the care provided to the person?

Do the care/services help to meet the needs of the SAPWD?

Likes and dislikes of the services?

What are your views about needs met or unmet?

How can you help to meet the needs of the individual?

Do you have difficulty understanding the individual with a memory problem?

Do you have any problem communicating with the staff?

Do you discuss any concerns, and are they solved?

Would you like to take admission for the individual in future to this nursing home or recommend to others (for SAPWD respite care)

Any suggestions to improve the needs

End

Okay, that was the last question I had for you. Thank you so much for taking the time to talk with me.

Is there anything I have not covered that feels important to share?

Is there anything you would like to ask me about the study?

(Check for the sensitivity for using the term ‘dementia’ prior to interview, not to distress the SAPWD/next of kin, state it as a memory problem)

Appendix P

Medical Care Needs of Residents

Resident 1 (R1)

Location: Unit 1 (Nursing Home)

Diagnosis: Vascular Dementia

Comorbidities: Angina, hypertension, type 2 Diabetes, ischaemic heart disease, osteoarthritis affecting the knees and hip, left leg ulcer and a history of falls.

Physical Health needs: Monitor vital signs and Blood glucose (BM) daily; catheter care; medication dispensing and administration by a registered nurse. Left leg ulcer dressing change needed (every 3 days).

Diet and Fluids: Normal diabetic diet and fluids

Mobility: Requires a rollator frame and the assistance of 1 staff.

Continence: Catheter in situ.

Personal Care needs: Assistance of 1 staff member in shower/ bath or wash, changing clothes and toileting.

Resident 2 (R2)

Location: Unit 1 (Nursing Home)

Diagnosis: Alzheimer's Dementia

Comorbidities: Excision of basal cell carcinoma, previous delirium, previous AKI, paroxysmal atrial fibrillation, Pulmonary embolism, Chronic Kidney Disease stage 3b, fragility fracture, osteoporosis, pre-diabetes, essential hypertension, spinal stenosis, rectal prolapse, anaemia, hypertension, urinary tract infection, fracture, Neck of femur fracture, Hemiarthroplasty, bilateral hip replacement, multiple falls.

Physical Health needs: Monitor vital signs and Blood glucose, medication administered by a registered nurse.

Diet and Fluids: Diabetic diet, Level 1 Thickened Fluids and Level 6 Diet. Support of 1 staff in feeding, on diet and fluid charts to monitor intake of diet and fluids.

Mobility: Unsteady on feet. Assistance of 2 staff + Hoist

Continence: Incontinent of urine and faeces.

Personal Care needs: Assistance of 2 staff.

Resident 3 (R3)

Location: Unit 2 (Nursing Home)

Diagnosis: Vascular Dementia

Comorbidities: Multifactorial fall, Postural hypotension, Vitamin D deficiency, Lumbar disc degeneration, Stroke, Mild hyponatremia, Hypertension, COPD, Asthma, Mild left-sided pleural effusion, diabetes, bilateral leg ulcers.

Physical Health needs: Medications administered by a registered nurse, leg wound ulcers dressing every two days.

Diet and Fluids: Normal diabetic diet and fluids

Mobility: Sara Stedy and assistance of two staff members.

Continence: Incontinent of urine

Personal Care needs: Two staff members for personal care and toileting

Resident 4 (R4)

Location: Unit 2 (Nursing Home)

Diagnosis: Frontotemporal

Comorbidities: Type 2 diabetes, Chronic obstructive pulmonary disease (COPD), coronary heart disease, Hyperlipidaemia, Osteoporosis, and Previous vertebrae fractures.

Physical Health needs: Regular blood glucose monitoring and insulin administration. Medication administered by a registered nurse

Diet and Fluids: Normal diabetic diet and fluids

Mobility: Assistance of 2 staff for short distances and a wheelchair for long distances. High risk of falls.

Continence: continent.

Personal Care needs: Assistance of two staff in shower/bath and toileting due to poor coordination.

Resident 5 (R5)

Location: Unit 3 (Residential Home)

Diagnosis: Alzheimer’s

Comorbidities: Chronic kidney disease stage 3, Hypertension, Type 2 Diabetes, Angina (Stable), Ischaemic heart disease, Peripheral nerve disease, Right inguinal hernia, Anxiety, Fracture of the thoracic spine, constipation, Iron deficiency

Physical Health needs: medication administered by senior care staff.

Diet and Fluids: Normal diabetic diet and fluids.

Mobility: Requires a rollator frame and the assistance of 1 staff member when walking at risk of falls, independent with bed and chair transfers.

Continence: Continent.

Personal Care needs: Requires the assistance of 1 member of staff to support him during personal care; when getting changed, showering or going to the toilet.

Resident 6 (R6)

Location: Unit 4 (Residential Home)

Diagnosis: Vascular Dementia

Comorbidities: Angina, Hypertension, Asthma, Bilateral Cataracts, Frozen shoulder, Total abdominal hysterectomy, Ex-smoker, Osteoarthritis, Diverticular Disease, Eczema, CCF, Decompensated HF, Paroxysmal AF, CKD stage 3.

Physical Health needs: Medication administration by senior care staff.

Diet and Fluids: Normal diet and fluids

Mobility: Independent

Continence: Continent

Personal Care needs: Supervision of one staff member for personal care, toileting and with his safety.

Resident 7 (R7)

Location: Unit 4 (Residential Home)

Diagnosis: Alzheimer's

Comorbidities: Hypertension, Hypercholesterolemia, arthritis.

Physical Health needs: Medication dispensing and administration by a senior care staff.

Diet and Fluids: Normal diet and fluids

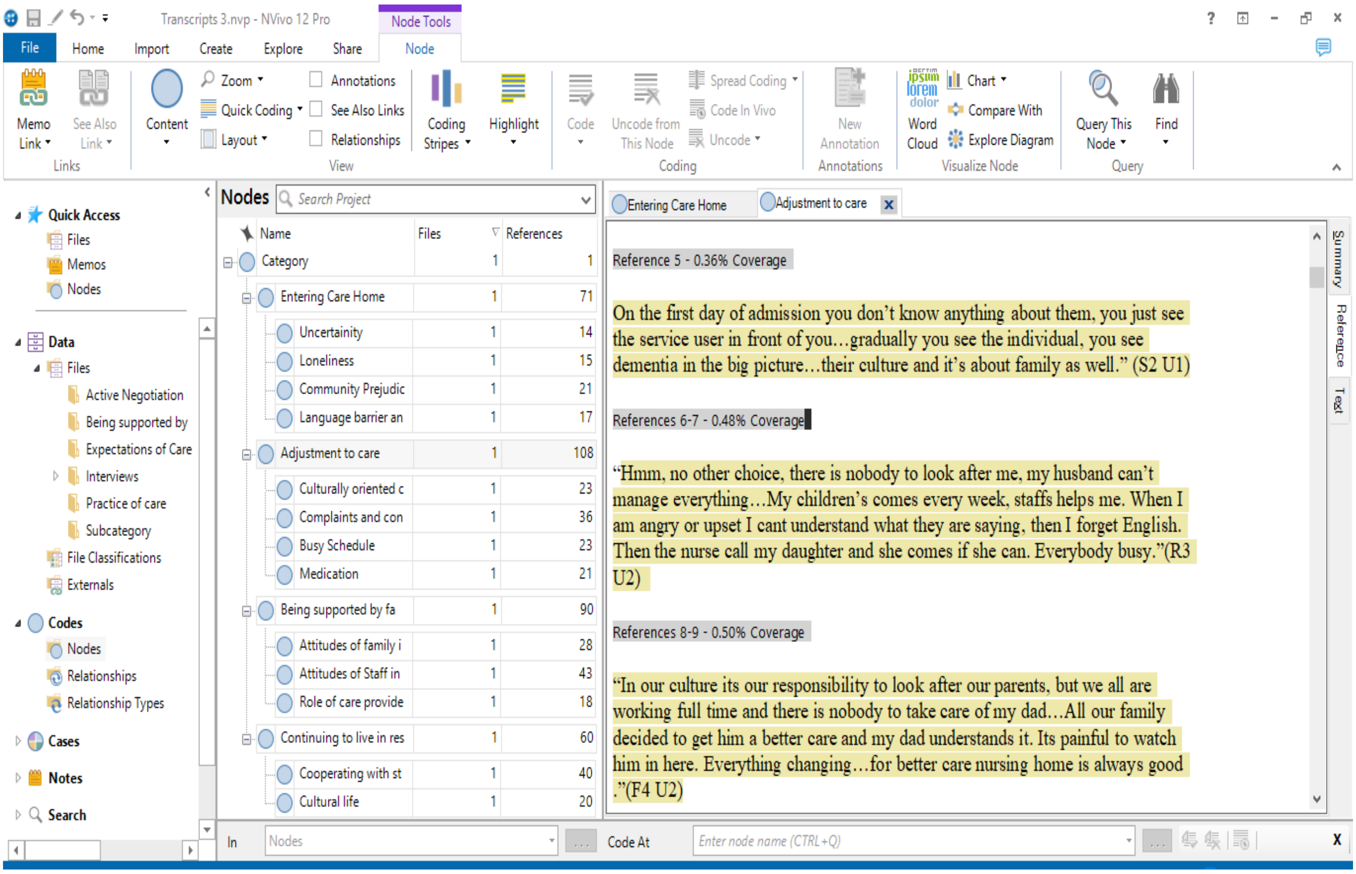
Mobility: Independent

Continence: Continent

Personal Care needs: Assistance of 1 staff member.

Appendix Q

Examples for data analysis in NVivo



Name	Files	References
Category	1	1
Entering Care Home	1	71
Uncertainity	1	14
Loneliness	1	15
Community Prejudic	1	21
Language barrier an	1	17
Adjustment to care	1	108
Culturally oriented c	1	23
Complaints and con	1	36
Busy Schedule	1	23
Medication	1	21
Being supported by fa	1	90
Attitudes of family i	1	28
Attitudes of Staff in	1	43
Role of care provide	1	18
Continuing to live in res	1	60
Cooperating with st	1	40
Cultural life	1	20

Reference 5 - 0.36% Coverage

On the first day of admission you don't know anything about them, you just see the service user in front of you…gradually you see the individual, you see dementia in the big picture…their culture and it's about family as well." (S2 U1)

References 6-7 - 0.48% Coverage

"Hmm, no other choice, there is nobody to look after me, my husband can't manage everything…My children's comes every week, staffs helps me. When I am angry or upset I cant understand what they are saying, then I forget English. Then the nurse call my daughter and she comes if she can. Everybody busy."(R3 U2)

References 8-9 - 0.50% Coverage

"In our culture its our responsibility to look after our parents, but we all are working full time and there is nobody to take care of my dad…All our family decided to get him a better care and my dad understands it. Its painful to watch him in here. Everything changing…for better care nursing home is always good ."(F4 U2)