An ethnographic study of the experience of everyday life of older people who are living with dementia, and their caregivers, within a Saudi care home

by

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DEDICATION

By the grace and mercy of Allah,

I dedicate this thesis to the soul of my mother, Aisha, the loveliest, tenderest, and most beautiful person I have ever known. She was a pillar of hope in my life. I will never forget her prayers and unrelenting support, which motivated me forward in this life (May Allah rest her soul in eternal peace and grant her the highest place in Jannah).

I also dedicate this thesis to my father, Ali, who is the source of my strength, He encourages and inspires me to fulfil my dream. He did the impossible to get me where I am, and his positive words will never be forgotten.

This research is further dedicated to my husband, for his unrelenting patience during my study, and to my little princess, and my little prince. They are my greatest source of joy and happiness. Their courage, love, and smiles helped me to overcome all the challenges and obstacles I encountered during my PhD journey.

I also want to dedicate this thesis to my sister and my brothers for their love, confidence, and pride in me, which encouraged me to work harder to make them proud.

Lastly, with gratitude for their valuable contributions, I dedicate this study to all the people who agreed to participate in this research and to all nurses and caregivers around the world because I admire, praise, and appreciate the hard work they do every day.

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A Note to the Reader

The content of this thesis may be distressing to read, however, the events reported occur within the specific cultural context of a care home in Saudi Arabia where this ethnographic study was undertaken.

The cultural codes that govern the research setting have been explained in this study so that its findings can be contextualised.

Abstract

Background: Dementia care is integral to the healthcare system in Saudi Arabia, against the backdrop of an ageing population within which the prevalence of dementia is high. The majority of care homes in Saudi Arabia provide dementia care for older people. This trend is expected to continue because care homes are frequently the only alternative available to satisfy the needs of many individuals living with dementia, especially in the latter stages of the disease when a person requires 24-hour care.

Study Aim: To understand the everyday life of older adults living with dementia in the context of a Saudi Arabian care home.

Method: The study used critical ethnography to explore the everyday life experience of older people living with dementia, and their caregivers, within a Saudi care home. Over a period of six months, the researcher spent one-two days per week engaged in fieldwork, totalling 80 hours. Fieldwork involved participant observation, informal conversations and document review. Data were analysed thematically using NVivo 12 computer software as part of a triangulation strategy.

Findings: The findings from this study showed that for both residents and staff, the everyday aspects of caregiving and care-receiving were highly routinised. The daily experiences of residents living with dementia in the care home were shaped by timetables and daily routines, which determined care responsibilities. Understanding these timetables and routines and how these are enacted in practice was crucial for understanding the care setting and how the care home delivered care to the residents. The care home management team used a timetable approach to manage care delivery. However, this approach also created the potential for conflict between the reality of the fixed routines inside the care home and how residents required care. This study found that the organisational culture reflected the power relations and hierarchal values in the home, monitoring and surveillance regimes, as well as practices that led to the obstruction of work. It shaped the workflow of the care home, the underlying values about care and the day-to-day behaviours linked with these in practice, and the ethos of care built around residents with dementia.

Conclusion and Impact: Given that organisational culture shapes care decisions, we can assume that it is embedded in managerial practices and work processes which indirectly uphold or undermine the care of residents with dementia.

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Abbreviations

ADLs: Activity of Daily living

COVID-19: Coronavirus Disease of 2019

DRS: Developmental Research Sequence

MOH: Ministry of Health

PLWD: People Living with Dementia

PPP: Public Private Participation

SA: Saudi Arabia

SHREC: School of Healthcare Sciences Research Ethics Committee

WHO: World Health Organisation

Chapter 1: Introduction to the Study

1.1 Researcher background

This brief overview of the dementia care landscape sets the stage for my personal and professional journey, with this thesis reflecting both external developments and my active engagement with them.

As a Saudi adult nurse, my career began in an adult healthcare department, where I gained diverse experiences and developed a strong interest in adult healthcare. A pivotal moment came when I worked as a trainee for one year in the Adult Surgical Intensive Care Unit (SICU) at King Fahad General Hospital and Medical Unit. During this time, my interest in cognitive impairments, particularly dementia, was significantly influenced by my grandmother's battle with the disease. This personal connection sparked my curiosity about the lives of individuals diagnosed with dementia, the challenges they face, the care they receive within the healthcare system, and the potentially embarrassing situations they might encounter.

Driven by this curiosity and personal connection, I decided to pursue a PhD focused on dementia care. My goal was to delve into the intricacies of care work, exploring the factors that influence how caregivers learn to provide effective care for individuals living with dementia. Through this research, I aimed to enhance the quality of dementia care and elucidate the expertise that underpins exceptional caregiving practices.

1.2 Framing the research question

The genesis of my research can be traced to my initial focus on continence care in the context of older adults living with dementia. In clinical practice dementia is conceptualised as a degenerative disease associated with virtually complete memory and recognition loss, poor or non-existent communication, significant dependency in everyday activities, poor mobility, weight loss, swallowing difficulties and incontinence (De Boaer et al., 2016). Dementia progresses slowly in stages and according to Livingston et al. (2020), severe dementia is the phase during which “the cognitive deficits are of sufficient magnitude as to compromise an otherwise healthy person’s capacities to independently perform basic activities of daily life such as dressing, bathing and toileting” (p.107). My initial interest in urinary continence care in the context of older adults living with dementia stemmed from the evidence which shows that this demographic is vulnerable to developing functional as well as urinary and/or faecal incontinence (Norton et al., 2010; Godman et al., 2017; Edwards et al., 2021).

Furthermore, older adults living with dementia are more likely to be labelled as incontinent (Edwards et al., 2021). According to Abrams (2002), urinary incontinence concerns the “complaint of any involuntary leakage of urine” (p.1622) that is more prevalent in the case of older people. I wanted to explore this topic because despite the growing population of older adults living with dementia in Saudi Arabia (United Nations Population Fund, 2020), and the significance of continence care because of their risk of urinary incontinence (Murphy et al., 2021), there is little research about appropriate interactional strategies as well as management and organisation approaches for such individuals when they are admitted into care homes. Care homes constitute a salient service that caters for the increasing number of older adults diagnosed with dementia who require continuous support and care, in both Western and Middle Eastern countries (Alsulami et al., 2022). Care homes serve as long-term providers of care and accommodate such older adults who lack support with their personal care in their own homes as a result of functional, medical or cognitive problems (Alsulami et al., 2022). They encapsulate both healthcare settings within which on-site nursing provision is available and those where nursing provision is absent (Buswell et al., 2017).

As I engaged with the subject of urinary continence care for older persons living with dementia in Saudi Arabia, it became increasingly apparent to me that there is so much more that goes on outside the bathroom. I thus decided to expand my focus and question to cover the daily experiences of older adults living with dementia within the context of the care home as a whole. My shift in focus partly stemmed from the realisation that care home residents diagnosed with dementia are commonly thought to spend most of their daily life in their rooms, alone, whilst doing little to nothing. My engagement with this line of enquiry, however, revealed how daily life constitutes a multidimensional and dynamic concept that must be holistically understood. Against this backdrop, I came to understand how members of staff, as well as the social and physical environments of care homes, shape the daily lives of residents in various ways including their agency and capacity to make decisions and assert themselves.

1.2.1 Research Aims, Objectives and Questions

In this research, I aimed to provide further clarity about the possibilities, needs and environmental factors which shaped the individual daily experiences of care home residents who had been diagnosed with dementia, since there is a notable academic gap in the context of Saudi Arabia. Thus, I specifically sought to investigate the following research questions from a cultural perspective:

a) How do residents and staff perceive the 'everyday' aspects of caregiving and care receiving in a Saudi care home?
b) How does the ‘culture’ of a Saudi care home influence the experiences of residents and staff members?

By investigating these questions, I aimed to highlight how older adults living with dementia in care homes experienced their bodies, world and life. This lens provides a broad focus on the experience of dementia beyond the corporeal. By answering the research questions outlined above, the overarching aim of my research was to gain a nuanced understanding of the everyday lives of people living with dementia and their caregivers in the context of a Saudi care home. My explicit focus was on the impact of everyday life on individuals with cognitive impairments, specifically dementia, as well as their professional care staff. I sought to investigate how staff in the field understand and influence prevailing norms regarding dementia care. Thus, I aimed to gain a nuanced understanding of life in the care home from the perspectives of the people living and working there. Against this backdrop, the objectives of my study were to:

a) Carry out a critical appraisal of the existing literature to identify current gaps.
b) Conduct non-participant observation in a Saudi care home.
c) Produce detailed field notes that provide insight into the daily experiences of older adults living with dementia in care homes and their staff.
d) Investigate the impact of everyday care on older people and the care home staff.
e) Understand how staff in the field understood and influenced everyday practices of dementia care.
f) Understand the factors that shape the culture of a Saudi care home and how this culture influences the lives of those living and working there.
g) Understand care delivery and interactions in ‘intimate’ situations.

1.3 Methodological Approach

For this study I adopted a constructivist paradigm in order to understand the everyday life of older adults living with dementia in the context of a Saudi care home. This paradigm is predicated on the philosophy that individuals seek an understanding of the world within which they live and work (Berger and Luckmann, 1967; Crotty, 1998) and do subjectively resulting in multiple views and meanings. Consequently, this approach privileges subjective opinions and experiences since the rich and complex experiences of individuals are conceptualised as more insightful than a few strict categories or ideas (Crotty, 1998). The experience of dementia is not singular, thus taking up a constructivist paradigm was crucial for understanding the varied daily experiences of older adults diagnosed with the disease and their care staff. My epistemological roots in constructivism necessitated a research design that is interpretive and supports the daily experiences and contextual aspects of individuals with dementia and their caregivers in the Saudi care facility to be examined. Thus, my research adopted ethnography, this has been widely used in healthcare to understand the subjective experience of illness (see for example, Kleinman, 1992; Soundy et al., 2013; Ljungberg et al., 2015). Specifically, I used critical ethnography, this is distinguished by its aim of challenging the status quo and revealing unequal power dynamics within society, including healthcare settings, by articulating the stories of those often marginalised by their disability, race, sex or class, thus granting them unhindered citizenship (Savage, 2000). Critical ethnography aligned with the objectives of my study, which aimed to reveal the subjective experiences of older people with dementia in a Saudi care home. Data for this study was derived from observing care home residents with dementia and their care staff, as they lived their daily lives in a care home.

1.4 Saudi Culture and Society

The Kingdom of Saudi Arabia was established by Abdulaziz bin Abdul Rahman in 1932 when he unified the territory's four regions into a single state in the aftermath of conquests that began in 1902. Since its founding, the structures and doctrine of the country's religious and by extension, political institutions have been shaped by Wahhabi interpretations of Islamic teachings and texts. Wahhabism has also been enforced by the judiciary in the form of Islamic or Sharia Law, which maintains general jurisdiction (Ayoob and Kosebalaban, 2008; Lacroix, 2005). The centrality of Wahhabism in Saudi culture and society has ensured that the Saudi state has a deeply religious character, which scholars such as Farouk and Brown (2021) argue is changing against the backdrop of reforms introduced by the current Crown Prince, Mohammed bin Salman Al Saud such as the minimised role of Saudi religious institutions which were once salient for the functioning of the monarchy. Wahhabism constitutes a puritanical approach to Sunni Islam (Armanios, 2003), which is derived from the name of Muhammad bin Abd al-Wahhab, a Muslim scholar who proselytised a return to the pure fundamentals of Islam captured in the teachings and life of the Prophet Muhammad, amidst his perceived moral decline of society (Armanios, 2003).

During the 18th century, the founder of modern Saudi Arabia, Muhammad bin Saud, established a partnership with Abd al-Wahhab, as he sought to unify disparate tribes within the Arabian Peninsula. Thus, since the establishment of Saudi Arabia, the Wahhabi religious establishment has been inextricably linked to the Saudi ruling family (Valentine, 2015). Wahhabism gained traction in newly established Saudi Arabia and metamorphosed from a theological doctrine to a philosophy and way of life that underpinned laws and conduct within Saudi society (Nahouza, 2018). In Saudi society this has translated into social restrictions such as the segregation of sexes, which is also practiced within the healthcare setting. Under Crown Prince Mohammed Bin Salman, the governing structures of the state are being reconfigured and centralised, scholars have associated this with the gradual retreat of Wahhabism (Farouk and Brown, 2021). The Saudi governance system is undergoing significant restructuring as the Crown Prince seeks to consolidate the regime via the enhanced centralisation of the state. Saudi religious structures, doctrine and authority are thus evolving but they remain an influential part of the state apparatus and thus, the formulation of laws and policies (Mandaville, 2022).

1.5 Contextualising the Study

My research is situated within the context of a care home in Saudi Arabia, thus it is important to provide an overview of the research setting in order to contextualise its findings. The Kingdom of Saudi Arabia, located in the Middle East, has a population of 36,408,820 which is growing at an annual rate of 1.3% (Saudi Census, 2022). Estimates from 2020 suggest that 84% of the population resides in urban areas, with the majority of the urban population concentrated in cities such as Riyadh (5.5 million), Jeddah (3.6 million), Mecca (1.6 million), Medina (1.14 million) and Ad Dammam (941,000). The Kingdom of Saudi Arabia, according to the United Nations Population Fund (2020), is undergoing a demographic transition, with the number of citizens aged 60 and above expected to increase five-fold from 5.9% of the total population to 23.7% of the total population between 2020 and 2050. In keeping with global population trends, the age of the Saudi population is thus shifting towards the elderly. While in 2016, only 1.3 million Saudi citizens were aged 60 and over, by 2050, it is expected that this age group will surpass the 10 million mark, representing approximately a quarter of the population (UNFPA, 2020). Additionally, the United Nations predicts that life expectancy in the Kingdom will increase from 74 to 82 years; with citizens aged 60 and above living longer lives, there is an expectation that the risk of developing cognitive impairments will also rise (UNFPA, 2020).

1.5.1 Healthcare in Saudi Arabia

Before 1925, Saudi Arabia was characterised by scarce healthcare resources and a weak infrastructure (Al-Hanawi et al., 2019). Only three small private hospitals existed in the Kingdom during the early 1900s, namely, the Al-Shareef, Al-Kaban and Al-Juad hospitals (AlBorie and Tanweer Abdullah, 2013). Healthcare service infrastructure only began to develop in Saudi Arabia from 1925 onwards following the establishment of the country’s first public health department via a royal decree (Al-Hanawi et al., 2019) and subsequently, the creation of the Ministry of Health in 1950. By 1950, Saudi Arabia had hospitals in Riyadh, Madinah, Mecca, Jeddah, Taif and Al-Hasa in addition to several clinics, increasing the number of available beds to 1000 (Sajjad and Qureshi, 2020). Following this period, the provision of both financial and human resources resulted in improved access and service quality in both public and private sector hospitals (Al-Hanawi et al., 2019). In 1978, the Alma Ata Declaration, which introduced primary healthcare reforms, expanded healthcare delivery within the kingdom by identifying primary care as the main conduit for ensuring the health of the Saudi population (Sebai et al., 2001; Al-Yousuf et al., 2002). Importantly, the oil boom between 2003 and 2013 enhanced public spending in the healthcare sector which increased by an annual average of 9.6% during the decade (Al-Hanawi et al., 2019).

Currently, Saudi Arabia has 487 hospitals which provide 72,981 beds (Al-Hanawi et al., 2019). Its beds per capita of the population ranks poorly when compared with countries such as South Korea, Japan, Germany and Austria (Al-Hanawi et al., 2019). The government has asserted its commitment to improving the provision of healthcare in the Kingdom and has prioritised the development of services at all levels (primary, secondary and tertiary) (Al-Hanawi et al., 2019; Almalki et al., 2011). In 2018, the government of Saudi Arabia allocated 15% of its budgetary expenditures or SAR 146.5 billion (1GBP= SAR 4.61) towards health services (Saudi Arabian Monetary Authority, 2018). Currently, Saudi Arabia accounts for 60 percent of healthcare expenditure among the Gulf Cooperation Council (GCC) countries (International Trade Association, 2024). Globally, the healthcare system in Saudi Arabia is ranked 26th out of 191 countries, making it the leading healthcare provider in the Gulf region (Al-Hanawi et al., 2019). Saudi Arabia, via its Ministry of Health, offers older people comprehensive care via its social care homes, these seek to address the social, psychological and health needs of this demographic (Ministry of Health, 2023). There are currently 12 social care homes available for older adults spread across various regions in the Kingdom. In addition to providing in-kind and financial assistance to older people in need and their families via the Social Security Agency. As part of the National Transformation Program, the Ministry of Health and Social Welfare Ministry established initiatives which sought to address the needs of older people via social care homes (Ministry of Health, 2023). These 12 homes accommodate male or female citizens aged 60 or over and who are unable to manage their own affairs. Alternatively, the social care homes also target members of this demographic whose family or relatives are unable to provide care (Ministry of Human Resources and Social Development, 2024). Via these homes, governmental care home which encapsulates medical, social and psychological care, is overseen by a functional body which regulates professional, cultural and recreational activities linked to the provision of care (Ministry of Human Resources and Social Development, 2024). Social care homes in Saudi Arabia, accept residents on the basis of several important conditions. Firstly, they must be Saudi nationals aged 60 and above (Ministry of Human Resources and Social Development, 2024). They must be incapable of managing their own affairs and must be free from contagious, communicable, mental or psychological diseases that threaten their safety and that of others as confirmed via a medical examination (Ministry of Human Resources and Social Development, 2024). The absence of family, or the inability of family members to provide caregiving services is also a necessary prerequisite for acceptance into these social care homes (Ministry of Human Resources and Social Development, 2024).

The healthcare system in Saudi Arabia is compartmentalised into the government and private sectors, the latter of which accounts for 20% of healthcare in the country. The Ministry of Health controls 60% of the governmental sector, which comprises tertiary, secondary and primary care. The remaining segment of government healthcare (20%) is managed by government institutions such as teaching and university hospitals, armed forces medical services, national guards medical services, security forces medical services, and services linked with the state oil company ARAMCO. While the government of Saudi Arabia has made several achievements in healthcare, it is still experiencing challenges in terms of providing enhanced healthcare services for a population which is growing rapidly (Alasiri and Mohammed, 2022). It is projected that the population of Saudi Arabia will reach 39.8 million by 2025, an increase in life expectancy has thus brought new challenges regarding the care of the elderly population (Al-Hanawi et al., 2018). The resultant effect has been an increased burden on the existing infrastructure which points to the need for a boost in both human and financial resources. Aside from the huge demand for enhanced healthcare to cater for the rapidly growing population, Saudi Arabia is also challenged by the lack of trained healthcare professionals in the sector. Currently, the healthcare sector is dominated by foreign workers who are addressing labour shortfalls (Alasiri and Mohammed, 2022). As pointed out by Alasiri and Mohammed (2022), there are significant gaps with regard to the quality of resident services as a result of the poor standardisation of protocols and treatment pathways, this is worsened by a lack of variation in provision, access and investment. This is especially the case when assessments are made based on the population served as opposed to the resident treated, indicating that there are deficits not only in quality but also in value (Alasiri and Mohammed, 2022). The government's strategic plan, Vision 2030 (Alhakami et al., 2023), seeks to address these challenges by creating new opportunities and innovation in the health sector.

1.5.2 The Kafala System

As noted previously, the healthcare system in Saudi Arabia is characterised by the influx of foreign workers. There are currently approximately 232,000 foreign workers in the healthcare sector, who take up roles as doctors, dentists, nurses, pharmacists, paid carers and allied health professionals (Bell, 2023). These foreign workers, who are from countries such as India, Pakistan, Egypt, the Philippines, Yemen and Indonesia, must work within the framework of the Kafala system which is the legal framework in Saudi Arabia and the other Gulf states, it governs the relationship between foreign workers and their employers (Adham and Hammer, 2021). The Kafala system, established in the 1950s, is a sponsorship system whereby Saudi individuals or companies receive government-issued sponsorship permits to recruit foreign workers (Adham, 2023). The work permit is tied to a foreign workers' residence permit, meaning sponsors can terminate or extend it. Under this system, foreign workers must obtain their sponsor's permission to change jobs, terminate their employment, or leave the country (Jureidini and Hassan, 2020). The consequence of this system is that foreign workers are highly dependent on their sponsors. The system was initially established to support the recruitment of cheap labour on a large-scale during periods of unprecedented growth in Saudi Arabia, this growth was the result of the discovery of oil (Jureidini and Hassan, 2020). In the contemporary context, however, the system has been widely criticised for creating an environment where foreign workers are vulnerable to exploitation and oppression due to unequal power relations between workers and their employers (Adham and Hammer, 2021). Further, the system has been linked with poor working conditions, including unpaid and low wages. In 2021, reforms of Saudi Arabia's kafala system came into force as part of efforts to enhance the relationship between employers and employees and to ensure a more transparent labour market which would increase the attractiveness for foreign investors in line with the goals of Saudi Vision 2030 discussed below (Adham, 2023).

The reforms to the Kafala system pertain to exit and re-entry regulations targeted at foreign workers. At the present time foreign workers do not need to seek permission from their employers in order to leave the country when their employment ends (Adham, 2023). Workers also do not need the permission of their previous employers to change jobs. Under certain conditions workers can terminate their jobs, this was not the case previously. Workers can also leave Saudi Arabia temporarily and re-enter it under the sponsorship system (Adham, 2023). In many of these instances permission is required from the government, although an online portal has been set up for this purpose. While these forms have been introduced, the system is still enforced in some sectors for example in the case of domestic workers. Thus, there are questions about whether the reforms will significantly change the working conditions of foreign workers in the country (Hamadah, 2022).

1.5.3 Vision 2030

Saudi Vision 2030 constitutes a strategic framework that has outlined initiatives to mitigate oil dependency. The vision seeks to diversify the economy via economic and social reforms aimed at developing public sectors including health. The government of Saudi Arabia seeks to invest over $65 billion to enhance the country's healthcare infrastructure (Alasiri and Mohammed, 2022). The proposed capital injection is significant because there was a decline in the government's budget expenditure by 4% in 2020 with an allocation of $45.5 billion compared to $46.4 billion in the previous year (Alasiri and Mohammed, 2022). As part of its strategic objective, the government seeks to boost private sector contribution to 65% from 20% by 2030 via the privatisation of 290 hospitals and approximately 2,300 health centres. It will facilitate the privatisation process by leveraging its share in public private participation (PPP) healthcare projects (Alasiri and Mohammed, 2022).

The Ministry of Health, as part of this strategic vision, seeks to promote preventive and integrated care, while also enhancing access to health services. This will be facilitated via the introduction of health clusters throughout the country (Ministry of Health, 2023). These clusters will form part of an integrated network of healthcare providers who will cater to one million people. The MOH has also prioritised the need to increase the number of hospitals that are internationally accredited hospitals whilst also doubling the number of primary healthcare visits per capita. It also seeks to enhance the quality of preventive and therapeutic healthcare services and promote digital healthcare innovation (Ministry of Health, 2023).

1.5.4 Care of Older People in Saudi Arabia

Historically, in Saudi culture, care for the elderly was conceptualised as a religious obligation which young adults are responsible for upholding. In Saudi culture, the family unit was historically regarded as the main carer, supporter and provider for the elderly, especially in the case of elderly people who are unable to care for themselves (Khalil et al., 2020). Thus, from a conservative perspective, placing older relatives with dementia in care homes was frowned upon and viewed as a form of abandonment because the practice contravened the cultural obligations outlined above. Consequently, for a long time community care, as opposed to institutional care, has been the norm. In the contemporary context however, changing demography, caused by population movement to cities by younger people, has led to a new 'nuclear' model of the family which departs from the more traditional extended version (Karlin et al., 2016). The resultant effect of changes in the family structure has been a shift towards informal caregiving (Alshammari et al., 2017). For example, caring for a husband's mother now increasingly falls upon their wife (Khalil et al., 2020). The breakdown in the family structure and population shifts have also made institutionalised care more acceptable. Older women who do not have any sons are less likely to receive communal care making them candidates for institutionalisation (Al Mutair et al., 2020). The new nuclear model of the family and shifting working patterns, in addition to stressors of modern life, have undermined the provision of family or communal care and made institutionalisation a viable option for many Saudi families.

1.5.5 Care homes in Saudi Arabia

The Ministry of Health and Social Welfare aims to provide older people with comprehensive care—health, social, and psychological—through care homes distributed across the Kingdom, currently operating 12 homes. Additionally, it offers financial and in-kind assistance to older individuals in need, and their families, through the Social Security Agency, along with medical devices such as wheelchairs, medical beds, and hearing aids. The Ministry of Health also implements a Care Homes Programme for older people, offering follow-up visits to support care within the family framework (Human Resources and Social Development, 2024).

As part of the National Transformation Programme, the Ministry of Health is working on initiatives to establish five model "oases" for older people, tailored to their needs and offering comprehensive health services, physiotherapy, and recreational care homes (Human Resources and Social Development, 2024). The Ministry of Health and the Social Affairs Council are actively involved in drafting a law to protect the rights of older persons, ensuring their rights are maintained, protecting them from harm and abuse, and providing them with the best possible services (Human Resources and Social Development, 2024). Despite these efforts, the care home which constitutes the research setting for the present study has struggled to meet the Ministry's declared aims. While these findings cannot be generalised to other care homes in Saudi Arabia, the presence of negativity and evidence of poor care in institutionalised settings within the Kingdom cannot be ignored.

It is important to underscore that the challenges faced in the care home under study are not unique to Saudi Arabia. On the contrary, systemic issues in institutional care constitute a global concern and transcend regional boundaries. For example, evidence of poor care has been documented within Western systems, where the regulation of care is comparatively more advanced and oriented towards person-centred services. As a case in point, in the United Kingdom (UK), the *Winterbourne View Progress Report* revealed that institutionalised adults with learning difficulties and autism at Winterbourne View Hospital were subjected to systematic mistreatment by staff, following the abuse of residents (Department of Health, 2012).

It is against this backdrop of global concerns about poor care in institutionalised settings that scholars such as Kitwood (1990, 1992, 1993, 1995, 1997) have highlighted the critical need for care models that prioritise the individuality and dignity of residents. Kitwood's (1990) Person-Centred Care (PCC) framework espouses a more empathetic and personalised approach, which is antithetical to the impersonal and often neglectful practices observed in various institutional settings.

1.5.6 Dementia

Dementia is defined as “the loss of cognitive functioning — thinking, remembering, and reasoning — to such an extent that it interferes with a person’s daily life and activities” (National Institute on Ageing, 2023, para.1). Dementia may range from mild to severe and influence an individual’s functioning in varying ways (Rampioni et al., 2021). In the most severe cases, individuals diagnosed with the disease must depend totally on others to perform basic activities such as eating. There are various forms of dementia (table 1.1), including vascular dementia, frontotemporal dementia, and dementia with Lewy bodies, although Alzheimer’s disease is the most common (Scheltens et al., 2021).

Table 1.1 Variants of Dementia

Dementia Type, Prevalence and Cause	Characteristics
Alzheimer’s Disease • Accounts for approximately 75% of dementia cases. • Entails neurofibrillary tangles, amyloid plaque and atrophy of the brain.	• Associated with a slow and insidious onset and concomitant with a steady albeit progressive decline which causes symptoms to get worse over time. • It is linked with memory loss, language difficulties, word-finding difficulties, impaired daily

	functioning and impaired visuospatial skills.
Vascular Dementia • Accounts for approximately 20-30% of dementia cases. • Associated with an abrupt or gradual onset due the brain's compromised blood supply linked to arterial disease.	• Associated with hypertension, arterial disease, smoking and diabetes mellitus. • It is linked with memory loss, language difficulties, anxiety, apathy, depression and slowed thinking processes.
Lewy Body Dementia • Accounts for approximately 10-15% of dementia cases.	• The characteristics are similar to Alzheimer's disease and Parkinson's disease including visual hallucinations, disturbed sleep and nightmares, recurrent falls, fluctuations in conscious awareness, reduced facial expression, trembling in limbs and shuffling when walking.
Frontotemporal Dementia • Accounts for between 2 and 10% of dementia cases. • This form of dementia affects the frontal regions of the brain that is responsible for emotion, planning, language and motivation.	• This form of dementia affects a younger age group. • Its characteristics include apathy, disinhibited and socially unacceptable behaviours, impaired judgement and decreased motivation.
Mixed Dementia	• This pertains to the coexistence of more than one type of dementia. The most prevalent is the mix of vascular dementia and Alzheimer's.

Source: Adapted from Sandilyan and Dening (2019)

Behavioral and psychological symptoms of dementia, or BPSD, are neuropsychiatric symptoms that accompany the dementia syndrome (Cloak et al., 2024). BPSD includes anxiety, hallucinations, apathy, delusions, disinhibition, and depression, which are prevalent and shape the prognosis and management of dementia (Cloak et al., 2024; Scheltens et al., 2021). BPSD encompasses behavioral, perceptual, and emotional disturbances, which are categorized into five domains. These are the perceptual or cognitive (hallucinations, delusions), verbal (yelling, repetitive speech, calling out, verbal aggression), motor (wandering, pacing, physical aggression, repetitive movements), vegetative (disturbances in appetite and sleep), and emotional (irritability, euphoria, anxiety, apathy, depression) (Bessey and Walaszek, 2019).

The diagnosis of dementia in Saudi Arabia is different from that in Western countries. Explicitly, patients are always diagnosed with either dementia or Alzheimer's disease, and the other forms of dementia are barely acknowledged or diagnosed (Albugami et al., 2018). This disparity in diagnosis can only be explained by the underdevelopment of diagnostic tools and materials available in the region. The diagnostic methods applied tend to be basic and less comprehensive and may not properly differentiate between the different forms of dementia as advanced techniques would. Therefore, general diagnosis among patients suffering from dementia is likely, thus influencing the specific therapeutic and care strategies implemented (Albugami et al., 2018). The limitations in dementia diagnosis highlight systemic issues in care approaches. Thus, the care home, which serves a diverse elderly population, may encounter challenges in addressing the nuanced needs of residents with varying types and stages of cognitive impairment.

Against this backdrop, the care home, which constitutes the research setting for this study, caters to the needs of diverse older people whose characteristics are covered by specific admission criteria. Thus, it is not exclusively designed for older people with cognitive impairment. Residents are admitted into the care home based on established practices and assessment regimes. First, they must be assessed by a psychiatric physician upon admission to the home. However, this assessment, diagnostic criteria, and residents' medical profiles remain unclear. I did not witness any descriptions regarding residents' dementia types or any investigated radiology reports to confirm their brain effects. Furthermore, many other issues such as sleep disorders and disinhibition account for alterations in human behavior (Muller-Spahn, 2003) that were not captured in the assessment. According to the nurses, it has been four years since a psychiatric physician came in to review the residents and update their diagnoses. Thus, they were effectively labeled based on an initial diagnosis made when they entered the home. Concurrently, having mentally healthy aged residents and cognitively impaired residents in the same space could adversely impact their well-being, as has been documented in other studies (see, for example, James and Field, 1992). The implication here is that deterioration is not adequately responded to.

Dementia care in healthcare settings and day-to-day healthcare care practice has historically been influenced by the biomedical model, effectively homogenising the experience of dementia. This causes the diagnosed individual to be excluded from their subjective experience (Sutherland et al., 2019). Social constructionist approaches to dementia care have highlighted the importance of including the voice of individuals in their care (Bosco et al., 2019). According to the clinical psychologist Rampioni et al. (2021), people living with dementia can still express their experiences, even though the symptoms of dementia may slow down the production process and change the structure of the way in which they respond. People with dementia might lose their capacity to reflect and explain their thoughts as their symptoms worsen. Even though the activities and speech of individuals with dementia are restricted or appear to be incoherent, they nevertheless have social value to those who know them, such as their caregivers (Rampioni et al., 2021). As a result, observing and partaking in the practices of people with dementia and their caregivers is a means of understanding how they experience everyday care within a care home. This is particularly the case when investigated via immersive and sustained contact positioned in a defined location relevant to individuals with dementia, which ethnographers mostly refer to as “the field”. In Saudi Arabia, approximately 130,000 of the elderly population has been diagnosed with dementia (Alorfi, 2022).

1.5.7 The context of dementia care in Saudi Arabia

Dementia care in Saudi care homes differs from the British context, which is extremely standardised and tightly regulated. In the UK, licensing requirements are stringent, with regular inspection processes in place as an assurance of good quality care (Alcock and Gregory, 2022). Care homes typically place an emphasis on person-centred care based on tailoring support to the individual needs and preferences of each resident. Care home staff receive specialised education on the management of dementia; for instance, in the UK, there are extensive resources provided by the National Health Service (2022), social care resources stemming from the Care Quality Commission (2024), and other regulatory agencies for the continuous professional development of care home staff (Karas et al., 2020). Furthermore, resident autonomy and dignity are emphasised, with serious regard to the protection of residents' rights and preferences (Elston, 2022). Moreover, UK care homes involve family members within the care process, whereby most care homes have to provide regular updates to families and include families as part of care plans.

The state of dementia care in Saudi Arabia is shaped by the interaction of traditional cultural values with developing regulatory frameworks. Traditionally, older individuals—including those diagnosed with dementia—received family care. That has been changing as modernisation within the country increases the number of families who cannot afford in-home full-time care, increasing the demand for professional homes.

Most care homes in Saudi Arabia blend principles of modern health care with their religious and cultural traditions. Whilst there is growing interest in the person-centred care concept, implementation at different levels can vary based on the extent of personnel training and available resources. Although at present, the regulatory bodies responsible for monitoring care home standards are less strict when compared with their Western counterparts (Alsenany et al., 2018).

What is unique in Saudi Arabia regarding care is the significant degree of cultural influence and, more specifically, family involvement, even in care homes. Families are expected to be highly involved with the care of their loved ones by visiting them regularly and attending decision-making meetings. Within Saudi society, Saudi Arabia has begun to adopt more flexible and liberal practices (Shafi, 2021). For instance, women now have the freedom to choose whether to wear the hijab, reflecting a shift towards individual choice. However, societal norms still place a high value on tradition, and deviations from these norms can be viewed as inappropriate. This cultural context influences the operation of care homes, where practices must align with societal expectations and respect for tradition, even as the legal landscape becomes more liberal. The Kingdom's adherence to Islamic principles and traditional societal norms dictates the separation of genders in various aspects of daily life, including healthcare. Care homes are required to maintain practices that align with these cultural and religious expectations, ensuring that men and women are treated in separate facilities or designated areas (Habib et al., 2022). This segregation aims to respect societal norms and traditions while providing appropriate and respectful care (Habib et al., 2022). Even as the legal landscape in Saudi Arabia becomes more liberal, these traditional values continue to play a crucial role in the daily operation and management of care homes, reflecting the deep-rooted importance of cultural and religious conformity in the provision of care.

In the Kingdom, cultural practices are also embedded within families and communities. For individuals living with dementia in care homes, much of this familiar lifestyle can be lost. The traditional day in Saudi Arabia is characterised by participation in cultural and religious activities, communal meals, and close family interaction—many of which are difficult to replicate within the boundaries of a care home. Thus, the lives of individuals with dementia in the care home setting change, as they must navigate the challenges concomitant with cognitive decline and memory loss whilst being isolated from their social connections and cultural roots. In this regard, the concept of *wasta* is crucial for understanding the types of loss experienced by individuals living with dementia in Saudi care homes. *Wasta* is the practice of leveraging personal connections to access resources and achieve goals (Marktanner and Wilson, 2018). For individuals admitted to care homes, the influence of *wasta* may diminish due to a myriad of reasons. To begin with, the care home is concomitant with a structured environment and typically operates according to formal policies and regulations. This may undermine the effectiveness of personal connections. Once individuals are admitted into a care home, their day-to-day care is handled by professional staff and management who work according to pre-established protocols, mitigating the impact of external influences. Individuals with dementia who live in care homes are also physically separated from their family networks and broader community, so the informal support and influence associated with *wasta* becomes less accessible. Additionally, the social dynamics within a care home do not necessarily mimic social norms. In the care home, there is a shift in focus from individual connections to the collective care needs of patients as staff aim to provide equitable support and treatment for all. Consequently, personalised attention and the advantages that *wasta* might otherwise offer in an informal setting become diluted and curtailed.

1.5.8 Conceptualising the ‘everyday’

In this research I sought to understand the everyday experiences of care for older adults living with dementia in care homes, and their care staff. This focus necessitated that I unpack the meaning of ‘everyday care’. My understanding of ‘the everyday’, is taken from Guillaume and Huysman's (2019) view that it is a central concept with regards to the social and political significance of things that appear to not matter and yet have immense significance when compared with the structural power wielded by elites. According to the scholars however, "adding ignored actors, practices, and things is not all there is to 'the everyday'. The concept also mobilises distinct philosophical, sociological, and literary lineages that organise our understanding of lives and worlds" (Guillaume and Huysman, 2019, p.279). In this study the everyday does not merely pertain to private life, or a site via which certain mundane practices are enacted. Rather, I took it up as a nominalist device that rejects abstract and universal terms to understand the wide-ranging set of practices that provide insight into the meaning of lived lives for older adults living with dementia in the care home setting (Guillame and Huysman, 2019).

1.6 Thesis structure

The remainder of this thesis is structured as follows: Chapter 2, the literature review, presents an integrative review of the published literature to answer the guiding question, "What is the experience of everyday life for older people who are living with dementia and their caregivers within a Saudi care home?"

Chapter 3 presents the methodology for this study. It documents my philosophical positioning and how this, in turn, has informed my methodological choices and the change to a critical ethnographic perspective. In this chapter I provide a detailed overview of my research aims and objectives, the overarching research questions of this study, my research paradigm, design and methodology, and the methods employed for the data collection process. I also provide an overview of the analytical framework underpinning this study and outline my positionality to contextualise the research findings. Chapter 4 enhances this discussion further by presenting the research methods. Descriptions of the study setting and the process for participants' identification sampling, and recruitment are provided. This is followed by the methods used for data collection and analysis in this study. Lastly, the ethical considerations followed in conducting this research are discussed. Following the discussion of my research methods, the findings of the observational study are presented in Chapters 5 to 8.

In Chapter 9, I critically discuss my research findings by unpacking the significant intersections between my thematic process and the existing literature, highlighting the aspects that hold relevance for achieving care for people living with dementia in particular and the consequences these aspects have.

Chapter 10 provides the concluding chapter for this thesis. I present a summary of my findings and discuss the implications for policy, practice and research. I also discuss the existing avenues for future research studies.

1.7 Chapter summary

This chapter has provided a context for understanding the nature and characteristics of healthcare in Saudi Arabia. It also documents the socio-cultural context within which the provision of care is located, this ultimately impinges on the work of care staff and the everyday experiences of care for older adults diagnosed with dementia. The ensuing chapters of this thesis provide additional clarity about the possibilities, needs and environmental factors that shape the individual daily experiences of care home residents who have been diagnosed with dementia, against the backdrop of the existing gaps in the literature.

Chapter 2: Literature Review

2.1 Introduction

This chapter presents an integrative review of the published literature. The research question for the study guided this integrative review: “what is the experience of everyday life for older people who are living with dementia and their caregivers within a Saudi care home?” Key themes were developed from the literature and are presented in this chapter: (1) daily care practices, (2) life disruptions, (3) the organisational structure of care, and (4) meaningful connections and intimate relationships.

2.2 Approach

The integrative review method constitutes an approach that permits the inclusion of both nonexperimental and experimental research, thus contributing to evidence-based practice in the context of nursing (Whittemore and Knafl, 2005). Since integrative reviews encapsulate diverse methodologies, they enable varied perspectives concerning a research phenomenon of interest to be critically examined. Whittemore and Knafl's (2005) methodology has been adopted in this integrative review. This framework was chosen because it has a detailed data analysis framework placed into five sub-categories. Further, in contrast to other frameworks, it permits various methodologies to be combined, producing a strong evidence base (Hopia et al., 2016). It has also been widely used as a basic conceptual structure for many integrative reviews in the field of nursing (Hopia et al., 2016). However, Whittemore and Knafl (2005) updated the framework approximately 18 years ago; thus, a notable limitation is that it is potentially outdated.

This method entails a five-step process designed to encourage rigorous analysis that begins with a clear articulation of the problem via the formulation of a clear research question or questions. Thus, the variables of interest, including the target population and healthcare problem, must be clearly identified as delineating variables of interest will support rigour in all other stages of the review, particularly during the data extraction stage.

The next phase of Whittemore and Knafl’s (2005) approach is to complete a well-defined search of the literature, evaluate the data quality, analyse the data and present its conclusion. The literature search must clearly identify search terms; the databases consulted, and the inclusion and exclusion criteria which were used to identify relevant studies. During the data analysis stage, the resultant data from the search were categorised, coded and summarised to establish an integrated conclusion. In the following sections of this chapter, the search strategy and its components are explained in detail, after which the search results are presented.

2.3 Search Strategy

A comprehensive search was conducted in November 2022 for papers published between 2000 and 2022 via the PsycINFO, PubMed, CINAHL Plus, ScienceDirect, and Google Scholar databases. This search was extended in January 2023. Key terms were entered into Keyword, Subject heading and Ovid .mp searches. In the advanced search engine, the Boolean operators “and” or “or” were used to broaden the results. The adjacency of phrases was maintained by adding (adj) between the words, e.g. “Cognitive impairment adj Elderly adj Care Home”. Moreover, using truncation (*, $) at the end of each keyword allowed the retrieval of all possible results related to that word stem. These strategies enabled the widening of the search results.

Figure 2.1 Search Terms and Keywords

Cognitive Impairment	**Population**	**Setting**	**Context**
Dementia/Dementia.tw.	“Elderly” OR “Older People” OR “Patient” OR “Resident" OR “Senior Resident” OR “People” OR Service user” OR “caregiver” OR “caregivers” OR “care provider” OR “Carer adj2 Carers” OR “Staff’ OR “Nurse” OR “Caring” OR “health professional” OR “healthcare provider” OR “primary care provider”	“Within a care home setting” OR “residential facilities” OR “residential” OR “care institutions” OR “long-term care” OR “nursing homes” OR “care homes” OR “residential care homes” OR “residential aged care”	“Experience*” OR “Main experience” OR “life experience” OR “daylife*” OR “Everyday” OR “Living Perspective” OR “perception” OR “attitude”
(Cognitive adj2 impair).ti.ab.			
(Cognitive adj2 capacity).ti.ab.			
(Cognitive adj2 status).ti.ab.			
(Memory adj2 impaired).tw.			
Alzheimer disease/ (Alzheimer$ adj2 disease).tw. “dementia” OR “Alzheimer’s” OR “Alzheimer’s disease”			

Lateral searches involved checking the references of included studies (snowballing) and further searching; the PubMed and Google Scholar search engines were examined to identify additional studies. The article titles and abstracts were screened against the predefined inclusion-exclusion criteria. Full-text articles were sought for all relevant studies.

2.4 Inclusion and Exclusion Criteria

In line with the conventions of integrative reviews, inclusion and exclusion criteria were designed to achieve a targeted search that could rigorously answer the search questions (Whittemore and Knafl, 2005). The inclusion and exclusion criteria are presented in Table 2.1.

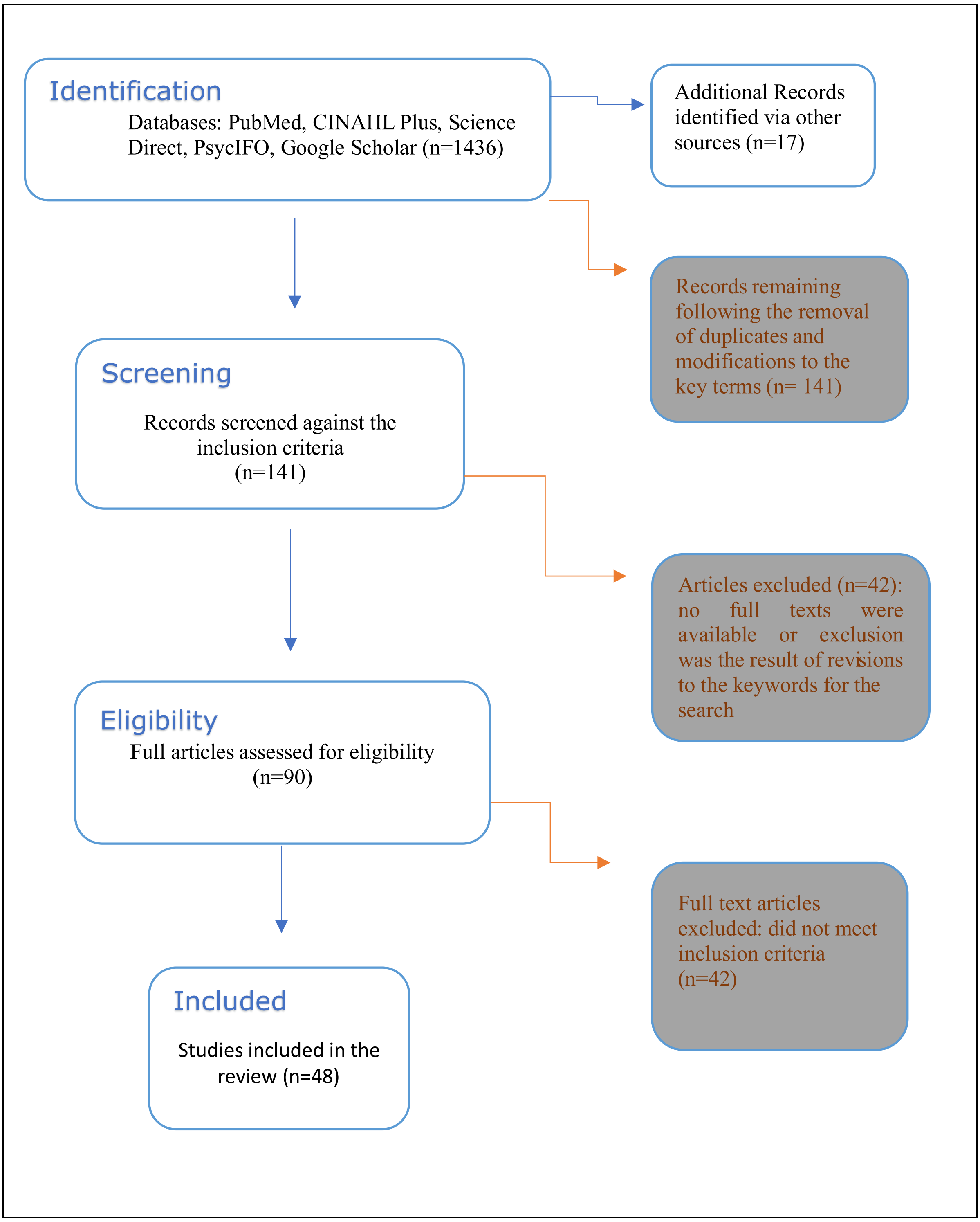
TABLE 2.1 INCLUSION CRITERIA AND 2 EXCLUSION CRITERIA

	Inclusion Criteria	Exclusion Criteria
1	Primary research or evidence syntheses.	Studies that focused on dementia interventions as opposed to exploring experiences of older people living with dementia and/or caregiver experiences.
2	Studies and reviews that focused on older people living with dementia residing in a care home or nursing home.	Studies where the care home was not of interest.
3	Published in English in peer-reviewed journals between 2000 and 2022. Due to existing literature gaps, data filters were not used to restrict the search to a short period so that all relevant studies could be captured.	Studies published before 2000.
4	The experiences of people living with dementia and/or caregivers in a care home setting.	Studies with no abstracts available.
5	Full abstracts available.	Studies not published in English from the grey literature.

2.5 Study Selection

A total of 1436 papers were identified from the database searches, 1128 of which were excluded based on the above exclusion criteria and a review of titles, as they were deemed unrelated to the review topic. Following an abstract review, a further 167 papers were excluded. The reasons for exclusion include the fact that they were unrelated to the review topic, related to non-care home settings, related to scale development, pertained to biomedical, editorial or protocols only, and involved samples of less than ten, evoking questions about their validity and methodological robustness. Following a full-text paper review (N = 90), a further 42 papers were excluded. Forty-eight papers remained for inclusion. Table 2.2 presents the PRISMA flow chart, which summarises the search and study selection process. The research was primarily conducted in the United Kingdom, Australia, New Zealand, and Canada. Cross-country studies included Italy and the Netherlands, and New Zealand; and a paper each from Saudi Arabia, Belgium, Japan, and Taiwan was found. The papers reported studies with quantitative, qualitative (including reviews) or mixed methods methodologies. The study characteristics are presented in Appendix II.

TABLE 2.2 PRISMA (MOHER ET AL., 2009) Chart



2.6 Study Quality Appraisal

The Critical Appraisal Skills Programme (CASP) tools were used to appraise shortlisted studies for inclusion in this review. CASP offers a series of checklists that feature prompt questions to evaluate qualitative studies, randomised controlled trials, reviews, cohort studies, case-control studies, and other research designs. Each of the prompt questions focuses on various methodological aspects which are assessed for rigour. These questions permit the researcher to consider the appropriateness of the methods employed. However, the tool is mainly delineated to elicit 'yes', 'no', or 'can't tell' responses to the questions. Thus, the appraisal results are not typically quantified through rankings or scores. CASP was designed as an educational tool, and the Critical Appraisal Skills Programme (2018) recommends that if positive responses cannot be garnered for the first two to three questions, then the study is likely of poor quality. Tables 1 to 3 in the Appendix capture the results of the appraisal.

2.7 Data Extraction

Following the quality appraisal, a standardised data extraction tool was developed in Microsoft Excel and informed by the review questions. The tool was designed to capture extracted data in the form of author names, study titles, setting, participants, problem, aim, data collection and analysis methods, results, conclusions and contributions. Data were extracted from both the results and discussion sections to capture relevant findings. The write-up stage was enabled via the use of narrative synthesis, which according to Popay et al. (2006) refers to:

> "an approach to the systematic review and synthesis of findings from multiple studies that rely primarily on the use of words and text to summarise and explain the findings of the synthesis" (p.5).

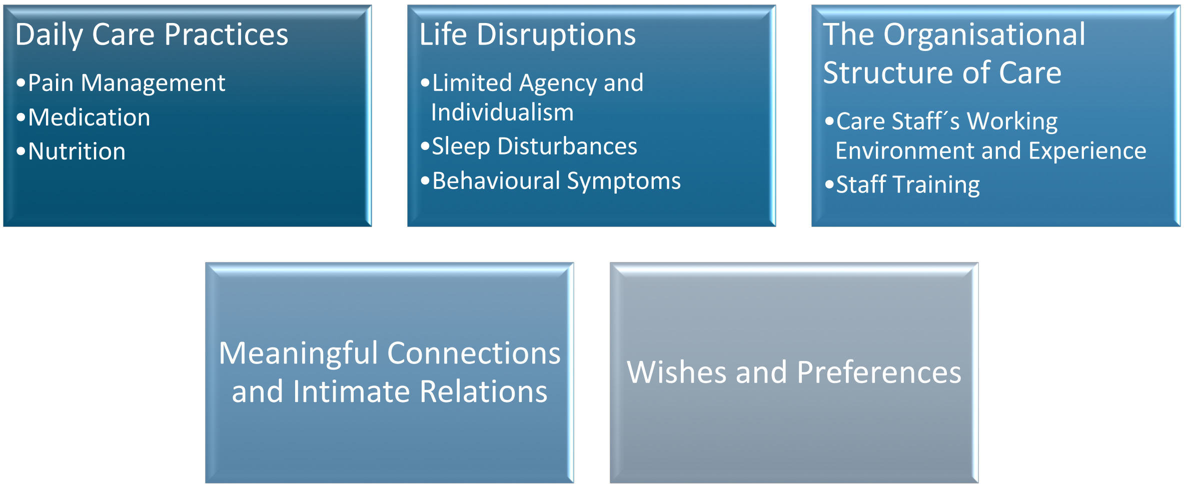
Narrative synthesis does not constitute a summary of findings but involves establishing and synthesising a connection between studies and their findings. The next section presents the characteristics of the shortlisted studies and the emergent themes for each research question that guided the search.

2.8 Themes

All but two of the shortlisted studies stemmed from Western countries such as the UK, USA, The Netherlands, Czech Republic, Australia, Malta and Canada. The remaining two studies were from Saudi Arabia and Taiwan respectively. In total 15 studies were qualitative, 13 adopted quantitative designs, 4 were mixed and 13 were in the form of reviews (see Table 2.1). In response to the question “what is the experience of everyday life for older people who are living with dementia and their caregivers within a Saudi care home?” the following themes and subthemes were developed:

1. Daily care practices: pain management, medication management, and nutrition management;
2. Life disruptions: limited agency and individualisation, sleep disturbances, and behavioural symptoms;
3. The organisational structure of care: staff’s working environment, staff training;
4. Meaning connections and relationships;
5. Wishes and preferences.

Figure 2.3 Visual Representation of Themes and Subthemes



2.8.1 Daily Care Practices

This theme explores 18 papers which identified that older people living in care homes experienced daily care practices related to the management of their pain and symptoms, medication and nutrition. Some studies formulated these practices as routines which are commonly implemented in care homes, whilst others identified lapses and managerial issues in these areas.

Pain management

In nursing homes, it is estimated that approximately 60 to 80% of older adults experience pain (Achterberg et al., 2013). Felton et al. (2021) posits that pain is prevalent in older people, especially in those with advanced dementia who have communication impairments, necessitating pain management as part of their daily care routine. Pain is typically signalled via verbal communication. However, older people with dementia experience a decline in this area. Consequently, in care homes, older adults with dementia may unnecessarily experience pain that is manageable yet unrecognised (Achterberg et al., 2013). In the care home setting, pain management constitutes a challenging endeavour.

Ellis-Smith et al. (2018) identified that care homes practice pain management as part of the day-to-day support offered to older people with dementia. The study adopted a mixed methods approach which focused on three care homes in the United Kingdom, underpinned by an initial theoretical model of mechanisms of action (Ellis-Smith et al. 2018). The measure, the Integrated Palliative care Outcome Scale for Dementia (IPOS-Dem), was introduced into the care of residents with dementia for 12 weeks. Qualitative data comprised focus groups and semi-structured interviews with family (n=6), care home staff (n=15), general practitioners (n=3), district nurses (n=2); and non-participant observations. Quantitative data comprised of IPOS-Dem data. Content analysis was used to analyse qualitative data and descriptive statistics were used for quantitative data. The study found that daily pain management practices comprised the observation of residents, collaborative assessment, devising a comprehensive ‘picture of the person’, systematic record-keeping, review and monitoring, care planning and changes to care provision, and multi-agency communication. In this study, pain management was linked to improved symptom management, improved comprehensive care, and increased family empowerment and engagement.

However, other studies found that pain management was not extensively incorporated into residents’ daily routines, which Petyaeva et al. (2017) attributed to a lack of guidance. Thus, Petyaeva et al.’s (2017) study sought to examine the initial effectiveness of training and support interventions for care staff to improve the pain management practices in people with dementia living in care homes. An evidence-based pain management intervention was developed following a series of qualitative and meta-synthesis phases, with the aim of providing a feasible programme to improve pain management in care homes. The evidence-based pain management intervention consisted of a staff training programme with a simple, evidence-based system for understanding residents’ risk of pain, regular assessment of pain and support for decision-making in providing pain management (Petyaeva et al., 2017). Training in the management of pain for people with dementia living in care homes was delivered to care staff (n=7) in three London care homes, this was followed by intervention support and resources to encourage improved pain management by staff over four weeks. Feasibility was assessed in their study through fidelity to intervention materials and qualitative approaches. Focus group discussions with staff (n=7) explored the use of the pain management intervention in people with dementia living in care homes, and interviews were held with six residents and family carers.

Pain was assessed in all residents at baseline, 3 and 4 weeks, and goal attainment scaling was assessed at 4 weeks. Petyaeva et al.'s (2017) findings revealed that the delivery of training was a key driver for the success and feasibility of the pain management intervention for people with dementia living in care homes. Improvements in pain management behaviour and staff confidence per numerical increases in the validated Abbey Pain Scale (p-value = 0.001 and correlation coefficient r = 0.699) (Abbey et al., 2014) score were observed. Decreases on the non-validated PIS-D and validated MOBID-2 scales, were also seen in homes where training was delivered in a care home setting across the care team with good manager buy-in (Petyaeva et al., 2017). In their study, family involvement in pain management was highlighted as an area for improvement, and goal attainment in residents was significantly improved across the cohort, although no significant change in pain reduction was seen. Petyaeva et al. (2017) concluded that feasibility and impact on staff behaviour were heavily dependent on the contextual setting of training delivery, with major reliance on manager buy-in and involvement of the full staff team. Thus, the challenge of pain and symptom management is only overcome through certain moderating factors including training and management support (Petyaeva et al., 2017). Similarly, a systematic review by Felton et al. (2021) identified lapses in the daily practice of pain management in care homes which were found to be under-assessed and ineffectively managed. Similarly, Black et al. (2006) established that the detection and assessment of pain was hampered by the lack of self-reporting and insight into subjective experiences frequently seen in people with late-stage dementia. According to Petyaeva et al. (2017), the resultant effect is that assessment, therefore, relies on a skilled, knowledgeable workforce to identify behavioural cues and changes in individuals which indicate pain.

Corbett et al. (2016), however, showed that although several simple assessment measures exist, there is no standardised approach for pain assessment in care home residents, and approaches vary considerably between homes. Paulson et al.'s (2014) research aligns with this view and shows that the lack of a standardised approach for pain assessment means that mild and moderate pain is, therefore, frequently not identified, and audits have raised concerns regarding the risk of pain. Achterberg et al. (2013) provide further clarity on the challenges of pain management practices in care homes. The researchers found that care homes presented a unique challenge for the integration of novel interventions and training paradigms because of a combination of complex care needs, limitations in staff skills and financial restrictions.

Thus, while pain management ostensibly constitutes an important daily practice in care homes, there are organisational and managerial issues at play that can undermine its delivery.

Medication management

There was consensus in the included studies that whilst medication management constitutes a central feature of the daily routine for older people living with dementia, it is poorly managed due to a myriad of factors. People living with dementia are often prescribed medication to manage the symptoms of the disease, to control behavioural and psychological symptoms of dementia, or to manage frequently co-morbid conditions such as depression or epilepsy (Jordan et al., 2018). Healthcare professionals have a responsibility to ensure that the debilitating effects of dementia are limited and that their medication and other co-morbid conditions do not negatively impact their overall functioning (Navti and Apampa, 2017). Approximately a third of residents over the age of 65 years in developed countries are prescribed five or more medicines a day (Pazan and Wehling, 2021) and the majority of people living with dementia fall within this age group. The consequences of poly prescribing, especially in the older adult population with comorbidities such as dementia, are functional and cognitive impairment, which can worsen health outcomes (Hilmer and Gnjidic, 2009).

According to La Frenais et al. (2021), care home residents with dementia are frequently prescribed pro re nata (PRN) analgesics, but these are infrequently administered. Some groups of residents (male, with more severe dementia) receive fewer analgesics and may be at risk of insufficient rtreatment for pain (La Frenais et al. 2021). The study found that comparatively, females reported pain more frequently and thus were administered more analgesics. Before prescribing pain relief, clinicians need to consider the risk that PRN analgesics may not be administered, and that pragmatic pain management guidelines specifically for care home residents with dementia and improving medication documentation may optimise analgesic use (La Frenais et al., 2021). La Frenais et al. (2021) aimed at describing the prescription and administration of regular and ‘as required’ (PRN) analgesics in English care homes; and to investigate individual and care home factors associated with analgesic use. La Frenais et al. (2021) collected data in a longitudinal cohort study of 86 English care homes in which residents suffered from diagnosed or probable dementia (n=1483). They found that analgesics were prescribed as regular or PRN medication by class and PRN administration. They explored individual differences, socio demographics and dementia severity using Clinical Dementia Rating (Morris, 1993), and care home differences (type; ownership; the number of beds; dementia-registered/specialist; Care Quality Commission rating) in prescription and administration using multilevel regression models.

At baseline, 967 residents were prescribed analgesics: 426 residents were prescribed regular analgesics and 670 prescribed PRN (Frenais et al. 2021). Paracetamol was the most prescribed analgesic, with PRN prescriptions more common (46.9%) than regular analgesics (29.9%). The researchers found that pain management in English care homes largely relied on PRN paracetamol, which is frequently prescribed but infrequently administered. Care homes differed in how often they administered PRN analgesics. Some care home residents, particularly those with more severe dementia, were likely to have untreated pain. Medical notes for PRN analgesia should include the indication to ensure that care staff have the right information available, this increases the likelihood of residents receiving appropriate pain relief, and clinicians should review PRN use to check it is being administered appropriately (La Frenais et al., 2021).

Moreover, community pharmacists are amongst the most accessible healthcare professionals in primary care and frequently form long-standing relationships with their residents (Chang et al., 2015), thus they play an essential role in the overall health of the community in which they operate. People living with dementia, both in the community and in care homes, can benefit from the expertise of community pharmacists who are trained to understand how medicines affect cognitive function (Navti and Apampa, 2017). Therefore, Navti and Apampa (2017) explored the perceptions of pharmacists about pharmaceutical care practices for people living with dementia in care homes, establishing the nature of pharmaceutical care services provided to these residents. A qualitative study design using a face-to-face semi-structured format was employed to explore the views and perceptions of pharmacists (n=15) who provide services to care homes which provide care for people living with dementia in the United Kingdom.

Navti and Apampa (2017) revealed that the main pharmaceutical service provided by the pharmacists was prescription processing, normally involving the clinical review and supply of medication into monitored dosage systems and delivery to the homes. This was coupled with advice to care homes on the appropriate storage and administration of drugs and appliances supplied. Most community pharmacists interviewed acknowledged that the services they were currently commissioned to provide did not meet the pharmaceutical care needs of older people living with dementia in care homes, including the monitoring of the appropriateness, safety and effectiveness of drug therapy. Navti and Apampa (2017) concluded that dealing with barriers such as time pressures, poor communication with other members of the healthcare profession and training on the pharmaceutical care needs of people living with dementia may lead to more person-centred care from pharmacists; however, the precise pharmaceutical care needs of people living with dementia in care homes still needs to be clearly defined. This is necessary to develop a comprehensive service framework that underpins a cognitive, transformative and well-defined pharmaceutical service to be delivered by pharmacists providing pharmaceutical care to these residents.

Evidently the management of medication in care homes, while part of the daily routine for older people living with dementia, does not necessarily meet their needs.

Nutrition management

Similar concerns were evident in the literature related to nutrition management, which was also identified as a form of routine practice in care homes. Some studies showed that people with dementia experience malnutrition due to eating and drinking difficulties and resistance to care, which can lead to unintentional weight loss (Faraday et al., 2021; Murphy and Aryal, 2020). Faraday et al.'s (2021) systematic review of 18 studies aimed to identify good routine practices in mealtime care for people with dementia living in care homes, by focusing on staff/resident interaction at mealtimes. Some studies in the review assessed mealtime care interventions, others investigated factors contributing to oral intake, whilst others explored the mealtime experience. Faraday et al.'s (2021) synthesis identified four categories of care, staff/resident interaction important to mealtime care: social connection, tailored care, empowering the resident, and responding to food refusal. Faraday et al.'s (2021) findings indicate that good mealtime care involves interactions which facilitate social connection, are tailored to individual residents, empower residents to promote autonomy and independence, and carefully and skilfully respond to the challenge of food refusal.

Likewise, Murphy and Aryal (2020) aimed to evaluate routine care practices in care homes by investigating how care staff (n=45) use nutritional guides to improve the provision of nutritional care for people living with dementia in care homes. Previous work by the same authors explored how to improve the nutritional care of people living with dementia (Murphy et al., 2017), this informed the development of the guide that was used in the subsequent study. An online questionnaire was emailed to care homes that had received copies of the guide between November 2018 and August 2019. Completion of the survey was sought eight weeks after the use of the guide. Care staff (n=45) in Murphy and Aryal's (2020) study reported that the guide had supported them in increasing the appetite and fluid intake of people living with dementia. The guide prompted staff members to monitor for malnutrition using validated screening tools, it also provided strategies to encourage people living with dementia to eat more at mealtimes. Murphy and Aryal's (2020) findings indicated that the guide contributed to changes in the practice of care home staff when providing nutritional care for people with dementia. Murphy and Aryal's (2020) evaluation findings indicated that the use of a nutritional guide improved the appetite and fluid intake of people living with dementia in care homes. The use of this guide may also assist the care staff in monitoring and screening for malnutrition and improve their knowledge and skills. Overall, Murphy and Aryal (2020) concluded that the guide had the potential to make positive changes to nutritional care practices in care homes for people living with dementia.

While Murphy and Aryal (2020) and Faraday et al. (2020) found that people living with dementia in care homes have their nutrition managed as part of their daily routine, they concurrently found that older people living with dementia may experience malnutrition due to eating and drinking difficulties, this can lead to unintentional weight loss. For example, Murphy and Aryal (2020) found that issues with eating and drinking were common in all stages of dementia but were most prevalent in the middle and late stages of the condition. The challenge is that people with dementia who live in care homes often depend on care home staff for help with eating and drinking; thus, where care home staff, have the skills and support they need to provide good care at mealtimes (Faraday et al., 2021). This can lead to unintentional weight loss and malnutrition (Murphy and Aryal, 2020).

Overall, studies under this theme show that older people living with dementia in care homes are governed by routines which revolve around the management of their pain, nutrition and medication. A notable thread that runs through the subthemes concerns the routinised nature of care in all three areas.

2.8.2 Life Disruptions

Twelve articles included in this theme suggested that older people living with dementia in care homes experienced various life disruptions, these manifest themselves in terms of limited agency and individualism, sleep disturbances and behavioural symptoms. Disruptions in the form of limited agency and individualism were directly linked with the experience of confinement in a care home by some studies; however, the remaining life disruptions were framed as concomitant with the ageing process, dementia and environmental factors such as lighting in the care home.

Limited agency and individualism

Lee and Bartlett's (2021) ethnographic study focused on the everyday experiences of people with dementia living in a care home in southern England and found that residents living with dementia in care homes experienced reduced social citizenship, identity cultivation and individualism. Drawing on a framework analysis of observations of daily life, object-elicitation interviews with residents (n=15), in-depth interviews with staff (n=16) and relatives (n=8) and documentary analysis, the study found that object relations are a critical but overlooked site for citizenship. Residents are rarely involved in decision-making relating to their personal possessions, lack control over objects and are often discouraged from material interactions important to the maintenance and cultivation of identity (Lee and Bartlett 2021).

While early research has tended to focus on sentimental or cherished items (such as photographs or keepsakes), Lee and Bartlett's (2021) study focused on functional objects (such as curling tongs or a hairdryer) as a mechanism to actualise citizenship. Their primary objective was to understand how objects manifest in the everyday lives of people with dementia living in care homes, and their secondary objective was to examine whether social citizenship was a useful lens to examine this. Findings from this study suggested that because functional objects are overlooked in the context of care homes, in addition to a lack of guidance for care workers, residents depend upon the whim of individual staff members as to whether they can access a particular object, rather than through an organised and structured care planning and risk management process. The resultant effect is limited on their agency to manage their own lives. Lee and Bartlett's (2021) research findings illustrate the importance of bringing a material lens to sociological and psychological discussions of agency, specifically in the context of persons with dementia in care homes. The researchers suggest that it would be valuable for care practices to combine a material citizenship approach with existing care practices. This would elevate the importance of object–person relations, allowing staff and relatives to recognise that functional objects can help a person maintain identity and rights, as well as influence how they are perceived. Finally, the concept of 'material citizenship' usefully extends our understanding of social citizenship by foregrounding the role of objects in peoples' lives (Lee and Bartlett, 2021). As such, the concept, once it has been more widely applied and assessed in the dementia field, may be useful in other areas of health and social care where object–person relations are important but often overlooked, including hospitals and care homes for people with learning disabilities.

Steele et al. (2019, 2020), like Lee and Bartlett (2021), found that residents living with dementia in care homes experienced limits to their agency, focusing on resident experiences of confinement. Steele et al. (2019, 2020) did not adopt an ethnographic approach but drew on the United Nations Convention on the Rights of Persons with Disabilities to frame confinement as an injustice. The researchers explored how care homes, and specifically, their common features, such as dementia care units and locked doors and gates, impact the agency and individualism of people living with dementia. Taking insights from health sciences literature and observations of the United Nations Special Rapporteur on the right to health as a point of departure, Steele et al. (2019) sought to deepen the current understanding of the drivers and facilitators of confinement in care homes, with the aim of enhancing the agency of older people living with dementia in care homes via a documents analysis of the United Nations Convention on the Rights of Persons with Disabilities. Both studies by Steele et al.

(2019, 2020) respond to growing concerns in the literature about the confinement of people living with dementia in care homes (Borges-Machado et al., 2020; Kontos et al., 2021; Koncul et al., 2023). The study illustrated that socio-cultural constructions of dementia and the experiences of individuals living with dementia inform the assumptions that justify restriction and inform the daily decisions made by care staff and families of older people living with dementia. They showed that unfortunately, these cultural understandings and practices can have adverse impacts on residents. Steele et al.'s (2020) study provides a basis on which to engage policymakers and dementia care stakeholders in reconsidering 'self-evident' and taken-for-granted structural conditions of aged care systems and material aspects of the residential aged care facility built environment that shapes the lives of people with dementia. The study also challenges conventional thinking concerning the political status and capabilities of individuals diagnosed with dementia.

Steele et al. (2020) highlighted that what matters is not merely "good practice in dementia care but also …social justice" (p. 1005). Care is evidently concomitant with broader ethical or philosophical possibilities in providing a framework for how individuals should be treated and how human rights is a unifying factor for all (Cahill, 2018). It is important to note that dementia care practitioners and academics have been oriented towards improving conditions in care homes and that there have been some improvements; however, there is a need to question the moral, ethical and political foundations of segregating people living with dementia in care homes (Steele et al., 2020).

The focus on confinement in this study was, however, antithetical to Lee and Bartlett's (2021) emphasis on confinement and its impact on social citizenship. Rather, Steele et al. (2019, 2020) engaged more extensively with questions of agency in relation to liberty and what this implies with regard to older people's daily experiences in care homes. Moving beyond the existing focus on the role of restrictive practices in confinement, Steele et al.'s (2019) study broadened and nuanced current understandings of confinement by exploring the daily facilitators of confinement in the lives of people with dementia. Here, there are synergies with Lee and Bartlett's (2021) research in terms of the common focus on daily experiences of confinement. Steele et al.'s (2019) findings, however, contrastingly highlighted indirect factors of restriction of liberty that are interrelated and compound one another in a negative spiral. In their exploration of how the common features of care homes such as the locking of dementia care units impact upon the rights of residents living with dementia, the scholars concluded that such practices constitute a form of segregation and rights infringements.

Overall, the studies that discuss this theme evoke important questions about agency and how these are limited due to experiences of confinement. Further scholarly engagement is, however, required to explore the linkages captured under this theme.

Sleep disturbances

Sleep disturbances undermine the daytime functioning of older people living with dementia, this makes their lives and the work of the care staff challenging (Neikrug and Ancoli-Israel, 2010). Six studies found that sleep disturbances were a common experience for older people living with dementia in care homes. In their literature review of 44 studies, Neikrug and Ancoli-Israel (2010) established that when compared to the general population of older adults, sleep disturbances were more common and more severe in institutionalised older adults with dementia. Within the latter population common experiences in the care home included residents dozing off during family visits, meals and activities (Neikrug and Ancoli-Israel, 2010). Aside from excessive sleeping during the day, older people living with dementia in care homes were also susceptible to disturbed night sleep. Neikrug and Ancoli-Israel (2010) found that as dementia progressed older adults were more likely to experience impairment in their capacity to maintain either wakefulness or sleep, this caused sleep and wake fragmentation during the day and night. While the review found that dementia-related depression was a factor that contributed to sleep impairment in this context, environmental and institutional factors were also uncovered, including ambient lighting in the care home.

Martin et al. (2000) and Gehrman et al. (2003) found that reduced sleep efficiency and lighter sleep were common features of dementia. These disruptions are likely to be neurologically based and linked with disturbances in circadian rhythms (Martin et al., 2000; Gehrman et al., 2003), however a limitation of these studies is that they are dated and may not be relevant in the current context. Similarly, Khachiyants et al. (2011) in their systematic review found that people with dementia, along with restlessness, confusion and increased agitation, experienced sleep disturbance and challenges in maintaining wakefulness during the late afternoon and night. Sleep disturbances such as increased daytime napping and sleep-disordered breathing were multifactorial and linked to ageing, dementia, and environmental factors such as ambient lighting. Khachiyants et al. (2011) did not provide a comprehensive overview of their search strategy and results.

Guu et al. (2022) found that older people with dementia in care homes experienced a unique phenomenon linked to sleep impairment, confusion and agitation known as sundowning. Guu et al. (2022) conducted a systematic review of the literature using Cochrane guidelines. They found that poor environmental light contributes to the sundowning syndrome, this is accompanied by diurnal changes in the behavioural and psychological symptoms of dementia. Guu et al. (2022) established the role of light in influencing the sundowning syndrome. Their study found that many countries did not have specific regulations that outlined minimum lighting requirements for care homes, with many care homes using a lighting level of 150 lux and above in their living areas, lower than the recommended illuminance of 200 lux. Poor lighting levels may cause eye strain, present a risk factor for residents' injury and reduce the overall work environment for staff.

Moreover, poor lighting has been linked with eye disease for people living with dementia in care homes. When this disease becomes severe enough, it can lead to Charles Bonnet Syndrome, which pertains to the experience of vivid visual hallucinations (Guu et al., 2022). This disease has been linked to the degeneration of the retina and shapes dementia behaviours and symptoms whilst also altering the pathophysiology of dementia (Gu et al., 2022), these changes have been linked with sundowning syndrome (Gu et al., 2022). In their systematic review, Guu et al. (2022) found contrasting viewpoints concerning the role of light in shaping sleep disturbance, with scholars increasingly focusing on the role of circadian rhythm modulation. Of the nine studies that Guu et al. (2022) analysed however, most studies found that sleep impairment and the worsening of the behavioural and psychological symptoms of depression are due to insufficient natural light exposure. The studies found a lack of clarity about the role of disrupted circadian rhythm.

While 'sundowning' was reported to be a common feature of the experience of dementia in care homes, a study by Martin et al. (2000) found that only 2% of resident older people living with dementia were 'sundowners'. Similar findings were established by Gaugler et al.'s (2000) review, which found discrepancies in the number of residents in care homes reported to experience sundowning by shortlisted studies. Discrepancies in the study reports were attributed to the biases of caregivers who may be heavily impacted during evening shifts. Gaugler et al. (2000) also found that sleep impairment was a strong source of distress for residents and their care staff. In convergence with Martin et al. (2000) and Gaugler et al. (2000), a review by Khachiyants et al. (2011) examined the temporal patterns associated with fatigue and agitation in care homes and found that only a small minority of agitated older people living with dementia showed increased agitation in the afternoons, usually after 4pm. This finding contradicts propositions about sundowning which suggest that the sunset period is concomitant with sleep and behavioural disruptions for older people living with dementia in care homes.

Nevertheless, the study found that residents' poor sleep and confusion, which may manifest as sundowning, could be the effects of disturbed sleep-wake cycles or chronic fatigue (Khachivants et al., 2011). Sleep disturbance was also linked to caregiver fatigue and afternoon fatigue, shifts generally change in the care home at around 3pm which is concomitant with noise and chaos, and environmental overstimulation. Khachiyants et al. (2011) also found that high activity levels in the mornings and during the day can cause afternoon or evening fatigue, this contributes to increased irritability or agitation in older people living with dementia and can cause sleep disturbance.

Behavioural Symptoms

One study found that the experience of specific behavioural symptoms constitutes a common feature in the experiences of older people living with dementia in a care home setting. Studies pertaining to the behavioural symptoms experienced by elderly people in care homes have typically categorised them into three sub-types: aggressive, verbal and physically nonaggressive (Gruber-Baldini et al., 2004). Common aggressive behaviours reported in care homes include grabbing, pushing, kicking and cursing, while common physically nonaggressive behaviours include restlessness, wandering and pacing (Gruber-Baldini et al., 2004). Verbal aggressive behaviours may include complaining, verbal bossiness and constant requests for attention (Gruber-Baldini et al., 2004).

In a quantitative study by Gruber-Baldini et al. (2004) which featured a sample of institutionalised older people living with dementia aged 65 and above (n= 2078), behavioural symptoms were assessed using a modified version of the valid Cohen-Mansfield Agitation

Inventory (Cohen-Mansfield, 1986). The study found that 34% of the research sample showed one or more behavioural symptoms per week. Further, 22% displayed verbal, behavioural symptoms, while 20% showed nonaggressive behavioural symptoms. Additionally, 13% of the sample showed aggressive behavioural symptoms, while 13% also resisted medication or refused to participate in activities linked with daily living care. Gruber-Baldini et al. (2004) found that behavioural symptoms were more common in smaller facilities because staff in these facilities showed more patience with residents with dementia. Further, smaller facilities were more likely to discharge wandering or aggressive residents (Gruber-Baldini et al., 2004). The study also found that behavioural symptoms adversely impacted upon the quality of life via the complication of medical management and assessments due to aggressive behaviour, and increased burden for caregivers (Gruber- Baldini et al., 2004). The quantitative study found that the behavioural symptoms constituted significant risk factors for staff burnout, dissatisfaction and turnover. Further, it was established that among institutionalised older people living with dementia the type of behavioural symptoms displayed, such as wandering and screaming, varies according to the environment and is not experienced in a linear way. For example the tendency for residents to wander may increase as levels of functional impairment increase until their walking is impaired (Gruber-Baldini et al., 2004). While Gruber-Baldini et al. (2004) provided insight into the behavioural symptoms that govern the lives of people living with dementia, the study is outdated, and findings may have changed in the intervening years.

This theme illustrates the way in which older people in care homes experience a myriad of life disruptions that may undermine their agency and autonomy. Some of the disruptions are concomitant with the ageing process and the onset of dementia. The studies however showed that environmental factors such as lighting in the care home impinge on the experiences of older people living with dementia.

2.8.3 The Organisational Structure of Care

The organisational structure of care shapes the nature and provision of care in care homes. Thus, it ultimately impinges on the work of care staff. Eighteen studies alluded to the organisational structure of care, which results in care staff distress, burnout and stress, but is also contingent upon staff knowledge and training as well as monitoring and rapid responses. Some studies discussed under this theme illustrate the potential role that older people living with dementia can play in the design of their care plans by adhering to their wishes about how they want to lead their lives.

Care Staff's Working Environment and Experiences

Five studies highlighted the fact that caring for older people living with dementia constitutes a challenging and demanding job for care staff. Mulders et al. (2018) conducted a study that sought to investigate how care staff experience distress due to residents' neuropsychiatric symptoms in the case of early-onset and late-onset dementia. The study was conducted in a Dutch care home and adopted a retrospective design featuring 382 early-onset older people living with dementia and 261 late-onset older people living with dementia. Using the Neuropsychiatric Inventory (NPI) (Cummings et al., 1994), the scholars evaluated nursing staff distress alongside the frequency and severity of residents' neuropsychiatric symptoms. The study found that their neuropsychiatric symptoms contributed to nurse distress which, in turn, led to sick days, increased workload, lower quality of general health, increased sick days, high staff turnover and high burnout levels (Mulders et al., 2018). Nurses rated delusions, aggression, agitation and night-time behaviour disorders as the most distressing aspect of their work. Via multivariate analyses, Mulders et al. (2018) found that the distress level of nurses increased alongside the frequency and severity of neuropsychiatric symptoms. The levels of distress identified by Mulders et al. (2018) pointed to the urgent requirement of support for professional caregivers.

Similarly, Zwijsen et al. (2014) found evidence of care staff distress linked with their profession. Zwijsen et al. (2014) interviewed care staff responsible for caring for 432 residents across 17 care homes for people with dementia. The care home version of the Neuropsychiatric Inventory (NPI-NH) (Cummings et al., 1994) questionnaire assessed behavioural problems. In contrast, the distress scale of the NPI-NH was used to evaluate experiences of distress among care staff. The study found that aggression and agitation were the highest sources of distress for care staff, also identified as the most prevalent symptom for 52.6% of the respondents. Other symptoms identified as a source of distress by nurses included irritability and disinhibition (Zwijsen et al., 2014). However, apathy, hallucinations and euphoria were not identified as sources of distress for the study. Morandi et al. (2015) conducted a study that focused on caregivers' and staff experiences over the course of three days using a standardised questionnaire and qualitative interviews. A total of 41 healthcare staff, including nurses (n=8), physical therapists (n=2) and healthcare assistants or nurse aides (n=13), were included in the study. Morandi et al. (2015) also included 33 family caregivers in the study. The researchers found that care staff experienced distress in the workplace in response to residents' delusions, incoherence, attention and orientation deficits, and hypokinesia/psychomotor impairment.

McPherson et al. (2016) sampled ten front-line staff, including healthcare assistants (n=2) and nurses (n=8) from three care homes in the United Kingdom, to participate in qualitative interviews about their work. Staff members highlighted their work pressures emanating from interpersonal and structural factors and described how they navigated these. The study found that care staff typically worked long hours in difficult and stressful environments, this undermined their ability to provide compassionate care. McPherson et al. (2016) reported that at the beginning of their training, nurses showed good levels of compassion; however, this soon dwindled as a result of workplace experiences. The study found that participants engaged in various unhelpful strategies to counter their work experiences, such as absenteeism. However, they acknowledged the importance of mindfulness in grappling with their difficult emotions and experiences. McPherson et al. (2016) found that due to professionalism requirements, many care staff processed their difficult emotions outside of work hours, highlighting the importance of organisations giving guidance on and rewarding self-compassion. This is because care staff's lack of self-compassion was linked with burnout and high turnover (McPherson et al., 2016).

The poor processing of emotions impacted upon the ability of staff to show compassion to their residents. Thus, the researchers concluded that professional bodies must promote strong values which refute the idea that emotions should not be displayed at work so that professional conduct may be balanced by an empathetic approach (McPherson et al., 2016). McPherson et al.'s (2016) study was limited by a potential selection bias since the selected staff were required to be English speaking and were predominantly Caucasian. Thus, non-English speaking staff from minority backgrounds were not captured in the study. Aside from the issue of generalisability, one interview was conducted via telephone which might have undermined the quality of interactions.

While studies have shown that care staff experience distress due to the nature of their jobs, Pitfield et al. (2011), in a systematic literature search which resulted in the review of five papers, found that the prevalence rates of staff distress were lower than hypothesised. The study found that care staff in care homes do not experience psychological stress or burnout symptoms. The review found that staff distress was prevalent in 37% of the research sample captured in the study, while only 5% of care staff were at risk of experiencing burnout. However, this study is concomitant with some limitations because the reviewed studies were small or utilised instruments with poor psychometric properties. Consequently, the conclusions of the study need to be interpreted with caution.

Alatram et al. (2023) conducted a cross-sectional study in a Saudi care home that featured 276 caregivers who completed the Carer's Needs Assessment for Dementia (CNA-D) questionnaire (Wancata et al., 2005) to assess their needs as caregivers. The questionnaire contained 13 items, each of which was rated on two subscales. The first subscale assessed the importance of 13 care needs while the second subscale pertained to whether needs rated as important had been met fully, partially or not at all. The findings of the survey via a chi-square test revealed that participants prioritised increased support. They expressed the need for supporting their work with family caregivers who they believed were crucial for assessing residents' needs. The findings are however limited because of the small sample and cross-sectional design as it does not provide a clear view of care staff's needs.

Overall, this theme indicates how caring for older people living with dementia constitutes a challenging and demanding job for care staff who must grapple with unique and sometimes stressful or distressing working conditions linked to the nature of their jobs.

Staff training

Scerri and Scerri (2019) asserted that care settings including care homes require nurses who are knowledgeable, confident and show a positive disposition when caring for the complex needs of residents with dementia. This study found that dementia training programmes for staff working in long-term care settings were effective in improving staff outcomes (Scerri and Scerri, 2019). The researchers investigated the impact of a dementia training programme for all Maltese nursing staff (n=261) working in public nursing/residential homes on their knowledge, attitudes and confidence. Additionally, they identified the predictors of these domains before and after the programme. A 14-hour training programme focusing on dementia management, care and policy was developed for all nursing staff working in public nursing and residential homes in Malta. A pre-test- post-test design was used to evaluate the participants' knowledge of dementia, attitudes and confidence in working with residents with dementia using validated tools. Demographic variables were measured and compared with each staff domain. The majority of nursing staff attended the training programme, with 261 fully completed questionnaires being collected pre-training and 214 post-training.

Scerri and Scerri (2019) found that the programme significantly improved nursing staff knowledge, attitudes and confidence. Stepwise regression analysis of each staff domain showed that the strongest predictor in all models at pre-training was the intensity of previous training programmes. Furthermore, staff who attended previous training continued to improve in their attitudes and confidence following programme completion. Scerri and Scerri's (2019) study continues to shed further evidence on the impact of dementia training programmes on staff outcomes and care. It also indicated that the intensity of previous participation in dementia training programmes is related to the participant's knowledge, attitudes and confidence and that continual exposure to training had a cumulative effect in relation to care.

Building up on Scerri and Scerri's (2019) research which emphasised the importance of both knowledge and training for the provision of care, Leroi et al. (2021) suggest that training is extremely crucial. Leroi et al. (2021) investigated the knowledge, attitudes, and practice of long-term care facility staff in England regarding the sensory-cognitive health of residents with dementia using a self-administered cross-sectional survey. The survey included a stratified random selection of facilities and staff regarding knowledge, attitudes, and practice of sensory-cognitive health. The analysis was descriptive, it was followed by a regression model for predictors of overall knowledge, attitudes, and practice capacity of staff, based on a psychometric Rasch analysis of survey items to interpret their scores. Leroi et al.'s (2021) study revealed that although staff of all grades reported a high knowledge and awareness of sensory-health concerns amongst residents with dementia, training opportunities were infrequent and most front-line staff felt they lacked the skills necessary to support the use of hearing and vision aids.

The lack of training was found to adversely impact upon the provision of care. The most reported reason for poor use of hearing aids/spectacles is related to a lack of maintenance and care procedures (such as broken and lost devices) and poor adherence support (such as not tolerating the devices). Staff willingness to receive training was high. Most managers in their study reported that training in communication skills and “sensory-friendly” environments was not provided. Finally, higher overall knowledge, attitudes, and practice capacity of staff was predicted by smaller facility size and public, rather than private, facility type. Leroi et al. (2021) concluded that training and practice of sensory health care in residents with dementia in long-term care in England is lacking but highly necessary for the provision of care. To improve sensory-cognitive care for long-term care residents with dementia, there is a clear need for practice recommendations and multifaceted interventions that include staff training, tailored sensory support, and environmental modification (Leroi et al., 2021).

Kupeli et al. (2018) aimed to improve the present understanding of healthcare professionals’ attitudes and knowledge of the barriers to integrated care for people with advanced dementia. They used purposive sampling to recruit healthcare professionals (n=14) across a range of organisations providing care for people with dementia. To gain a thorough and detailed understanding of healthcare professionals’ experiences of providing care, Kupeli et al. (2018) used a realist approach and in-depth interactive interviews. Kupeli et al. (2018) interviewed a range of healthcare professionals (n=14) working for various organisations across London, these included care homes and NHS services such as memory clinics, mental health and commissioning services. Kupeli et al.’s (2018) data suggested that three main factors hindered the development of an integrated approach to palliative care for those with advanced dementia: societal attitudes and governmental policy, the care home organisation and a fragmented approach to care. As per Kupeli et al.’s (2018) findings, care home staff experienced a high role burden associated with demanding working conditions, very low pay and limited professional development opportunities. In his findings he described poor communication and conflictive relationships between HCPs and service settings, poor symptom management, lengthy referral processes, inter-agency ignorance, diffused responsibility amongst care providers and minimal care planning. These factors resulted in a fragmented rather than integrated approach to care.

Kupeli et al. (2018) concluded that the care of people with dementia who are approaching death might be improved through the use of an integrated approach that includes improving the communication and relationships between all care providers and creating multidisciplinary teams who draw on each other’s knowledge to provide optimal care. For this, a top-down approach from policymakers is required so that the funding and resources are available to develop leaders in this field, they could then motivate all care providers to work together at the local level. Successful development of an integrated model could result in an environment and culture where older people are valued and cared for by a proactive, collaborative team of experts who provide health and social care. This study was however concomitant with some limitations, specifically that it did not integrate the views of allied health professionals and general practitioners.

Griffiths et al. (2021) noted that there were implementation challenges linked to staff understanding the experiences of staff trained to lead dementia care. Mapping implementation is crucial to understanding implementation challenges, yet this has rarely been formally explored. Griffiths et al. (2021) aimed to examine the experiences of care home staff trained to lead dementia care, they mapped implementation within a large cluster randomised controlled trial. Process evaluation, including semi-structured interviews with 27 trained mappers from 16 intervention-allocated care homes. Three main themes were identified in Griffiths et al.'s (2021) study, preparedness to take up leadership roles, the transfer of knowledge into practice and the sustenance of dementia care mapping. The scholars found that staff lacked leadership attributes and that there were gaps in dementia care mapping training for equipping staff with these attributes. The complex nature of dementia care mapping also implied that knowledge transfer was limited. Griffiths et al. (2021) concluded that many care homes might not have staff with the requisite skills to lead practice change using dementia care mapping or the requisite staffing, resources or leadership support required for sustainable implementation.

Staff training also pertains to monitoring and rapid responses concerning residents' vital signs. Studies show the monitoring function of care staff, focusing on the surveillance of residents' vital signs including heart rate variability. Heart rate variability is a physiological indicator of autonomic function, whereby reduced vagally-mediated heart rate variability is associated with a variety of anxiety symptoms and disorders (Quinci and Astell, 2021). Quinci and Astell (2021) evaluated the feasibility of collecting heart rate variability data within this population, presented heart rate variability data for older adults with dementia living in a care home, and examined heart rate variability in the context of self-reported anxiety. Heart rate variability data in Quinci and Astell's (2021) study, in the form of log-transformed root, mean square of the successive differences, were in line with transformed data from previous research by Albinet et al. (2010). These data provide a promising direction for the use of wrist-worn devices in future heart rate variability research undertaken on people living with dementia in care homes. Data presented in Quinci and Astell's (2021) study adds to the current body of literature assessing autonomic functioning in older adults with dementia. Quinci and Astell's (2021) research also investigated the use of wrist worn devices, these have previously been used to explore autonomic functioning in older adults with dementia over the course of their daily routine. The study found that people living with dementia in care homes have reduced heartrate variability, however it is possible that the sample size of the study undermined the ability to detect any significant findings regarding the relationship between heartrate variability and anxiety. Furthermore, the participants in the study consumed medications such as antidepressants which could have had an impact on their heartrate variability.

This theme reveals that in care settings nurses must be knowledgeable and have the technical capacity to manage the complex needs of residents with dementia including those pertaining to their vital signs since they experience unique medical conditions such as reduced heart rate variability.

2.8.4 Meaningful Connections and Relationships

Some studies (n=3) revealed that the caregiving of care home residents living with dementia was characterised by meaningful connections and relationships between staff and residents, sometimes mediated by family members. Most people with dementia die in long-term care homes (McCleary et al., 2018), where palliative approaches are practised; however, there is limited understanding of staff and family experiences of dying and bereavement in this context (McCleary et al., 2018). McCleary et al. (2018) conducted a descriptive qualitative study in Canada, they explored family and staff experiences of end-of-life and end-of-life care for persons with dementia in long-term care homes. They conducted focus groups with 77 staff members and 19 relatives of dementia residents at four long-term care homes in four Canadian provinces. Three themes were developed from their data: knowing the residents, the understanding that they are all human beings, and the long slow decline and death of residents with dementia. McCleary et al. (2018) concluded that longstanding intimate relationships enhanced end-of-life care but left healthcare aides with unmet bereavement support needs. As per McCleary et al. (2018), staff in long-term care homes should be supported to answer questions about the trajectory of the decline of dementia and death. Further research about residents' experiences of the deaths of other residents is needed. They maintained that intimate knowledge of the person with dementia, obtained through longstanding relationships, was foundational for person-centred end-of-life care. Healthcare aides need to be included in end-of-life care planning to take advantage of their knowledge of residents with dementia. McCleary et al.'s (2018) findings revealed that there were unmet bereavement support needs among staff, particularly health care aides. Persons with dementia in McCleary et al. (2018) were affected by death around them, and existing rituals for marking deaths in long-term care homes may not fit their needs, staff indicated that they were uncomfortable answering relatives' questions about the end of life.

Furthermore, people with advanced dementia living in care homes may experience social death before their physical death (Watson, 2019). Social death occurs when a person is no longer recognised as being an active agent within their relationships, this necessitates a shift in how activity in people living with dementia is conceptualised (Watson, 2019). According to Watson (2019), a focus on embodied and inter-embodied selfhood enables a more nuanced understanding of dementia and thus helps to foster better relationships with individuals diagnosed with the illness. Watson's (2019) study examined the role of embodied and inter-embodied selfhood within caregiving/ care-receiving relationships in a specialist dementia care home. It adopted an ethnographic approach with an appreciative intent. They aimed to understand what worked in interactions between care staff and residents in day-to-day life in the care home. Their aim was not to ignore problems but to achieve a better understanding of practice within the context of care homes.

Three overarching themes which shaped the face-to-face relationship between care staff and residents in the care home emerged in their study. These themes were hands-on care or 'body work', which includes care in the dying phase but also during the prolonged period of care before this phase is reached; recognising and supporting selfhood; and witnessing and responding to distress. Using the 'body' as an analytical lens, Watson (2019) showed the ways that people with advanced dementia continue to be fully present, experiencing people and interacting with those who care for them until the end of life. It also shows what we can learn from care home staff through their experience of the human encounter with people with advanced dementia. Watson's (2019) findings provide a deeper understanding of the complex nature of dementia care in care homes.

At present, there is little knowledge about how resilience in people in later life with dementia might be understood or even whether such an outcome is possible (Newman et al., 2019). An understanding of this is important in order to improve the care of the high number of people living with dementia around the world. This is particularly important as in countries such as Saudi Arabia and others, the aged population at risk of dementia is expected to grow. Newman et al. (2019) examined how visual arts enrichment activities might improve care for people in later life with dementia and their care staff via a mixed methods study featuring 48 older people living with dementia and 37 care staff or family members. They applied an Eco psychosocial framework of resilience, theorising that those sources of resilience may be personal, social and structural. It also viewed the creative practice as a way of providing new perspectives on a topic, and it is seen as a methodology in itself (Hope 2016). The analysis of a range of visual arts enrichment activities, run by participatory artists, enabled the processes of adaptation leading to resilience within the social-cultural context of the care home to be analysed. This was in an attempt to improve the lives of people in later life with dementia rather than preventing or treating the condition. Newman et al.'s (2019) results showed that visual arts enrichment activities supported the resilience of those with dementia through creative expression, increased communication and improved self-esteem, and that they influenced relationships with care staff and family members. Newman et al. (2019) concluded that even those with advanced dementia were capable of demonstrating resilience which could be supported by, and explored through, visual arts enrichment activities. The data collection approach used in the study, art activity, did not however provide insight into the meaning of having dementia since the condition was not mentioned explicitly by the artists or respondents. Notably, dementia was not reflected in the art that was created by the respondents from the care homes.

In summary, this theme demonstrates that meaningful connections and relationships between staff and residents, are crucial to the daily functioning of older persons diagnosed with dementia although sometimes they must be mediated by family members.

2.8.5 Wishes and Preferences

Three studies showed that older people with dementia, despite their cognitive impairments, were able to articulate their needs pointing to how their wishes must be respected. In a study by Groenvynck et al. (2023), the researchers reported the lived experiences of institutionalisation of older people living with dementia and found that the experience of moving into a nursing home was linked with negative emotions and outcomes. The study adopted a qualitative phenomenological methodology which involved administering semi-structured interviews to 18 community-dwelling older people living with dementia. The participants expressed fear and anxiety about the prospect of moving into a nursing home, fearing reduced social contact with family members, exposure to impersonal care and limitations to independence and agency (Groenvynck et al., 2023).

Explicitly, the researchers found that in general, older people living with dementia were able to express their care wishes (Groenvynck et al., 2023). The analysis of their stories about the present, past and future identified that “the potential, future nursing home residents wished for care that enables them to remain (a) individuals; (b)who were autonomous; and (c) in contact with others” (Groenvynck et al., 2023, p.4). The findings of this study showed that older people living with dementia were not passive recipients of care merely because of their impairment but could articulate their care needs and expectations. Shiels et al. (2020) also conducted a scoping review of the literature and analysed 41 articles to assess the self-reported experiences and needs of older people living with dementia. Older people living with dementia voiced their needs and experiences with regard to end-of-life care, meaningful relationships, support with grief and loss, the need for choice and freedom, the need to maintain previous roles, the desire for an appropriate environment, reminiscence and the desire for social activities. This study also illustrated how older people living with dementia could describe their experiences and also communicate their care needs, which is crucial for evidence-based practice that seeks to provide person-centred care.

In agreement with Groenynck et al. (2023) and Shiels et al. (2020), Hadjri et al. (2015) demonstrated the autonomy of older people living with dementia when making choices about their housing. In this study, which interviewed 22 managers of care homes, Hadjri et al. (2015) noted the role of older people living with dementia in identifying issues related to the design of care homes based on their needs. The needs of older people living with dementia revolve around their desire for accessibility, social connectivity and independence. Older people living with dementia also played a role in illustrating how new housing environments constitute a stressful experience that culminates in anger, withdrawal and shock. The study showed that older people living with dementia are able to self-report their housing needs, with this demographic illustrating varying choices, which are contingent upon their varying levels of care. Specifically, they noted that “the choice of care homes relates to the atmosphere of a home as some occupants favour a homely or relaxing environment and others prefer dynamic settings” (Hadjri et al., 2015, p.80).

2.9 Summary: Literature Gaps and Research Focus

In response to the question “what is the experience of everyday life for older people who are living with dementia and their caregivers within a Saudi care home?” this chapter showed that the following themes emerged: daily care practices, life disruptions, experiences of agitation, the organisational structure of care and meaningful connections and intimate relationships. The included studies showed that older people living in care homes experience daily care practices related to the management of their pain and symptoms, medication and nutrition. Some studies formulated these practices as routines that are commonly implemented in care homes, while others identified lapses and managerial issues in these areas. The included studies also showed that older people living with dementia in care homes experienced various life disruptions, these presented in a myriad of ways, including limited agency and individualism, sleep disturbances and behavioural symptoms. Disruptions in the form of limited agency and individualism were directly linked with the experience of confinement in a care home by some studies; however, the remaining life disruptions were framed as concomitant with the ageing process, dementia and environmental factors. Five studies found that people living with dementia in care homes had high levels of needs arising from a range of factors, including moderate to severe levels of cognitive impairment; high frequencies of concurrent neuropsychiatric symptoms such as agitation, aggression, and apathy; and medical and other mental health comorbidities. Thus, aggression was framed as an experience linked with older people with dementia in care homes. Some studies alluded to the organisational structure of care and how it is contingent upon staff knowledge and training, family involvement, as well as monitoring and rapid responses. Finally, some studies revealed that the caregiving of care home residents living with dementia is characterised by meaningful connections and intimate relationships.

A limitation of the existing studies, however, is that they were primarily conducted in Western countries thus, there is a large literature gap with respect to the care experiences of older people living with dementia in Saudi Arabia. Only one study in the review pertained to Saudi Arabia (Alatram et al., 2023). A limitation of the present review, therefore, is that it is not culturally variegated and does not account for the nuances of care home experiences in other cultures. Since this review focused on studies published in English, it is possible that studies published in Arabic which could have provided insight into the Saudi context were missed. The present study nevertheless seeks to make an original contribution to the literature through its research enquiry. This review identified a need for future qualitative studies which explore the everyday life experiences of older people living with dementia and their care staff in care homes. Presently many of the studies included in this review are outdated as they were published in the early to mid-2000s. Addressing this gap was a stimulus for this study, it will be the first to qualitatively explore the experience of everyday life for older people living with dementia and their caregivers within a Saudi care home.

Chapter 3. Methodology

3.1 Introduction

The previous chapter examined the literature and what is known about caring for people living with dementia in care homes. As previously mentioned, my original research question focused on the way in which continence care for people living with dementia (PLWD) was carried out in a care home in Saudi Arabia. As I engaged with the subject of urinary continence care for older persons living with dementia in Saudi Arabia, it became increasingly apparent to me that there is so much more that goes on outside of the bathroom. I thus decided to expand my focus and question to cover the daily experiences of older adults living with dementia within the context of the care home as a whole. This chapter outlines my philosophical positioning and how this informed my methodological choices and the adoption of a critical ethnographic perspective. In this chapter I provide a detailed overview of my research aims and objectives, the overarching research questions of this study, my research paradigm, design and methodology, and the methods employed for the data collection process. I also provide an overview of the analytical framework underpinning this study and outline my positionality to contextualise the research findings. Further, I provide a thorough discussion of ethical considerations.

3.2 Research Aims, Questions and Objective

The overarching aim of my research is to gain a nuanced understanding of the everyday lives of people living with dementia and their caregivers in the context of a Saudi care home. I seek to answer the questions: a) How do residents and staff perceive the 'everyday' aspects of caregiving and care-receiving in a Saudi care home? b) How does the 'culture' of a Saudi care home influence the experiences of residents and staff members? The aims of my study are as follows:

- To explore the everyday experiences of older people with dementia and care home staff.
- To investigate the impact of everyday care on older people and the care home staff.
- To understand how staff in the field understand and influence everyday practices of dementia care.

My explicit focus is on the impact of everyday life on individuals with dementia, as well as their professional care staff. I seek to investigate how staff in the field understand and influence prevailing norms regarding dementia care. Against this backdrop, Pink (2012) contends that anthropologists have always investigated “everyday life”, and it is neither a disregarded area of practice that ought to be highlighted nor a subcategory that necessitates a definition. Pink (2012) advocates for everyday life research which considers everyday practices, materials, and the settings within which everyday life occurs. The feeling of the ordinary is what I am interested in, the patterns and interactions of everyday life which are vital for comprehending the experience of everyday living in care institutions on a micro level (Hughes et al., 2006; Nettleton and Watson, 1998). For people living with dementia, whereby some aspects of everyday life might become more challenging to participate in or perform without assistance, it is critical to consider how they experience everyday life in a new phase of their lives or under changed situations. Kontos’ (2003, 2004) work focuses on the embodied and pre-reflective processes and deeply embedded cultural performances of everyday life. Kontos (2003, 2004) takes up a phenomenological approach that focuses on the embodied experience and conceptualises the body as a site of understanding and knowledge. This approach offers a voice to people living with dementia, she underscores their agency via intentional actions such as using the body in terms of movements, gestures and sounds. Via the concept of embodied selfhood, she highlights the role of the body in dementia care, shifting away from traditional notions of personhood as cognitively driven and shedding light on the agency and intentionality of the body (Kontos, 2004). My work will also explore the embodied aspects of everyday life for people with dementia.

3.3 Research Paradigm

The term paradigm pertains to a philosophical way of thinking (Kivunja and Kuyini, 2017) that encapsulates researchers’ philosophical viewpoints, vision, and understanding of world reality (Mackenzie and Knipe, 2006). It is a set of ideas, beliefs, and practices that serve as a philosophical lens through which the research framework, design, and analytical approach are viewed (Weaver and Olson, 2006). A research paradigm comprises three main components: ontology, epistemology, and axiology (Creswell, 1998). The present study employs a constructivist paradigm to understand the everyday lives of people living with dementia in the context of a Saudi care home.

Constructivism proposes that people seek an understanding of the world in which they live and work (Berger and Luckmann, 1967; Crotty, 1998). Individuals develop subjective meanings of their experiences to understand their world, which is directed toward specific objects or people (Crotty, 1998). These meanings are varied and multiple. Therefore, the constructivist viewpoint proposes that researchers acknowledge and embrace the complexity of points of view rather than narrow them down to a few strict categories or ideas (Crotty, 1998). Indeed, the constructivist researcher intends to interpret the meanings others have about the world rather than attempting to categorise this experience solely based on the researcher's meaning (Crotty, 1998). Such views fit well with my current research aims; exploring the life of people living with dementia in long-term care in Saudi care homes and the impact of everyday life on individuals living with dementia and their caregivers. Constructivism emphasises how humans perceive social reality rather than only direct observations, as positivist and postpositivist methods do (Murphy et al., 1998). Individuals, according to constructivists, create their own world (Ormston et al., 2014). As a result, reality cannot be precisely recorded, yet it is more or less true (Guba and Lincoln, 1994). Individuals' experiences are central to this paradigm. Constructivism takes an inductive method to study but recognises that theories can impact the researcher's ideas and assumptions. The technique also implies that researchers might be actively involved in the research rather than merely observing what is being examined (Silverman, 2010). The constructivist paradigm which I have adopted in this research is inextricably linked with a subjectivist ontological position which I discuss further in the next section of this chapter.

3.3.1 Ontology

The social world must be understood as one constituted of multiple interrelated 'realities' that exist simultaneously, each of which can be regarded as 'true' in some sense (Rubin and Rubin, 2005). The study of being or existence is referred to as ontology (Guizzardi, 2005). Scotland (2012) defines ontology as "a set of assumptions or beliefs that we make in order to understand the essence of a specific society and culture that we study" (p.9). Ontology is concerned with nature and reality, focusing on what there is to know and understand about reality and how reality should be conceptualised (Guba and Lincoln, 1994). Is there a social reality that exists apart from human perception and interpretation? Are the things we analyse in research merely made up of our thoughts (subjectivism), or do they exist independently of our ideas (objectivism)? Ontology addresses the question of whether there is a singular reality or numerous realities that are context-specific (Giacomini, 2013); there are two major ontological viewpoints: objectivism and subjectivism (Ormston et al., 2014).

Objectivism believes that reality exists independently of people's views or understandings. This ontological viewpoint privileges scientific knowledge and espouses the notion of a singular, universal truth. Thus, objectivists suggest that knowledge about reality exists independently from human cognition. Proponents of this ontological position strive towards universal truth via logic and deduction. On the other hand, subjectivism holds that reality is socially produced and exists solely in the consciousness of individuals (Rolfe, 2006). Reality and truth are derived from the intersubjective experiences of individuals based on the premise that reality is socially constructed and rooted in sociocultural experiences (Geertz, 1989; Gin, 2023). Subjectivists and objectivists are engaged in polemical debates about the parallels and contrasts between the physical and social worlds. These debates concern whether the physical and social worlds operate in comparable ways or whether social reality is distinct since it is up to individual interpretation. Some scholars believe that the physical and social worlds coexist and are regulated by the same rules (Ormston et al., 2014). Others believe that because humans can make decisions, the social world cannot be ruled by the same rules that govern the physical world (Giddens, 1984, Hughes and Sharrock, 1997, Patton, 2002). According to Ormston et al. (2014), qualitative researchers gravitate towards the latter viewpoint, which espouses the idea that the social and physical worlds exist in distinct ways.

In this research, I adopt a subjectivist ontological position since it enables me to comprehend the unique experience of PLWD and to investigate their life within their setting based on their subjective experiences. Only via this lens and its focus on social constructions of reality can I gain a nuanced understanding of how this setting influences their daily lives and shapes their subjective meanings in relation to their experiences. A wealth of studies underscore the fact that the experience of illness is subjective (Cummins, 2001), which is antithetical to objectivism's view of reality as singular and universal. I have adopted a subjectivist ontological lens because it offers the possibility of investigating context-specific meanings, experiences, and practices. As noted by Boyland (1999), here, the focus is on:

> provisional rather than essential patterns of meaning construction; [the framework] considers knowledge to be the production of social and personal processes of making meaning; and is more concerned with the pragmatic utility of validity of application than with validity per se. (p.5).

A subjectivist ontological position is suitable for this research as it makes no presumptions about universality, enabling the subjective experience of disability to be unpacked.

Further, in ethnographic research, the possibility of a researcher being completely objective has been a subject of scholarly debate. Various researchers have expressed the idea of shared reality between the researcher and research participants. There is the suggestion that reality, in this context, is mainly understood based on the intersubjective constructions of all social subjects, including the researcher (Gullion, 2015). Based on this logic, reflexivity constitutes a salient feature in ethnographic research to draw out the biases and standpoint of the researcher in relation to the subject matter and participants (Gullion, 2015). This aspect of the present study will be discussed in the ensuing sections.

3.3.2 Epistemology

My ontological position invariably shaped the epistemological framework that I adopted in this study. Petty et al. (2012) define epistemology as "a theory of knowledge of what can be known and what criteria it uses to justify it being knowledge" (p.378). Epistemology pertains to how researchers gain insight into truth and knowledge and encapsulates their worldview (Crotty, 1998). As noted by Creswell (1998), all researchers are motivated by assumptions about the world, although in most cases, these assumptions may be latent. Nevertheless, these assumptions impinge upon the research process as researchers deliberate upon their choice of methods and approaches in unpacking knowledge claims. Bateson (1997) clarifies that all researchers consider the question:

> how do I know the world? What is the relationship between the inquirer and the known? Every epistemology…implies an ethical–moral stance towards the world and the self of the researcher. (p.157)

The subjectivist lens that underpins this study suggests that one cannot separate individuals' experiences of reality from the social contexts in which they exist (Rubin and Rubin, 2005). My understanding of knowledge, therefore, is interpretive, and I conceptualise knowledge as a lens to represent people's experiences (Marcus, 1986). As a researcher, I place value on meaning-making in specific contexts and what this might mean for knowledge generation (Marcus, 1986; Rainbow and Sullivan, 1979; Fetterman, 2010). Against this backdrop, my research is rooted in social constructivist epistemology (Gergen, 2001; Lincoln and Guba, 2005). According to Owen (1992), social constructivism is the notion that knowledge is derived from culture and other metaphysical factors which are often taken for granted but contribute to learning.

Social constructivists focus on the subjective experiences of reality to interrogate the lived experiences of social subjects, drawing from their unique experiences. Indeed in this research I intend to interpret the meanings others have about the world, rather than attempting to categorise this experience only according to a singular understanding of reality (Crotty, 1998). Social constructivism fits well with this current research aim, which is to explore the lives of people living with dementia in long-term care in Saudi care homes and the impact of everyday life on individuals living with dementia and on their caregivers. My epistemological framework is predicated by the view that subjective meanings are created through interaction with others and the historical and cultural norms in individuals' lives (Creswell, 2013). Thus, in this study, I explore the interaction among individuals and focus on the specific contexts in which people enact these interactions (Creswell, 2013). My epistemological framework suggests that the subjective experiences of my research participants are my primary source of knowledge in this study.

To investigate how people living with dementia and their caregivers go about their everyday lives in a care home, which I conceptualise as an observable practice, I must first account for how these people interact on a regular basis. Dementia is diagnosed by clinical practitioners based on a range of bio-psychosocial factors (World Health Organisation, 2017). Because different types of dementia lead to varying rates, levels, and impacted symptoms of deterioration, each individual might experience dementia in somewhat differing ways (Yeo et al., 2014). Caregivers may engage in behaviours that differ from those of the persons with dementia for whom they care. Being labelled as a 'caregiver' implies a manner of positioning oneself in the world based on one's own particular practices that cannot be identical to those of the person living with dementia. In this relationship, their societal function as caregivers is about 'giving care' rather than receiving care. As a result the way in which people living with dementia and their caregivers view and incorporate their daily lives into their care methods may differ greatly. People's behaviours, which are formed by their interactions with others and with the world around them, will reflect and repeat their knowledge of social reality. Individuals with dementia and their caregivers might seem to engage in identical behaviour, but how they perceive this behaviour may indicate different ways of perceiving or understanding those interactions within the context of their life. Using a social constructivist epistemological viewpoint, based on individuals' interpretations of their perspective of reality, thus enabled me to comprehend such subjective aspects of practice and the numerous constructions of practice these may give rise to.

This perspective allowed me to connect with and comprehend the many constructs of how people perceive their own world. As a naive observer of the way dementia care was delivered at the care home when this research began, this position provided me with an opportunity to investigate the research context whilst staying open to observing variance in the range of practices of people with dementia and the ways that people could perhaps express their perceptions of reality. In other words, I would not 'medicalise' (Conrad, 2007; Bond, 1992) the practices of people living with dementia as a sign of their condition. I concentrated on the way in which people with dementia and caregivers went about their daily routines in the care home, to see how they made meaning of their own practices within the care home. Via my epistemological position, I sought to comprehend people with dementia and their caregivers' daily behaviour and how they described, interpreted and positioned themselves. Attending to the way in which people with dementia conduct everyday tasks, and making meaning of these tasks, necessitates a study technique which can address the ordinary and implicit relevance of everyday existence. Everyday life is made up of social ties, as well as social and material interactions which help shape our habits. These aspects of daily life are based on how individuals perceive their surroundings and interact with one another through social activities. Exploring the various behaviours and interpretations of them by individuals with dementia, and their caregivers, is critical for determining how they 'fit' into their daily life.

3.3.3 Axiology

While epistemology and ontology concern understanding reality, axiology pertains to the researcher's values, beliefs and ethical concerns (Mingers, 2003). Researchers' ontological and epistemological stances influence axiology. For instance, objectivists believe that reality is single and objective, so the researcher's subjectivity and value judgments must be constrained. On the contrary, social constructivists argue that reality is socially relative and has multiple dimensions. Hence, subjectivity cannot be avoided since the researcher's values are intrinsically tied to their own participation (Lehman, 2011). Individual bias may be reduced in qualitative studies if the researchers are conscious of their values and subjectivities (Aliyu et al., 2015). Social constructivism attends to an individual's values, beliefs, interactions, and interpretations and how they contribute to the co-constructed account of the setting under study (Rubin and Rubin, 2005; Hammersley and Atkinson, 2007). Researchers cannot remove themselves and their values from the exploration because every researcher's action is infused with those values (Lincoln, 1990). Based on this reality, reflexivity constitutes a crucial feature of this approach to research, this will be explored in-depth in the ensuing sections of this chapter.

As a social constructivist researcher, I do not give an impartial, unbiased description of the data under investigation. Within this thesis, I, as the researcher, have an impact on the data generated. Likewise, my interpretations and preconceptions about the data will impact the analysis. Thus, excluding my personal bias during data interpretation may be difficult. While conducting this research, I was aware of the impact of my beliefs, values, expertise, preferences, and expectations. As a result, I practised transparency by keeping a diary expressing my inner thoughts and emotions throughout the study process as recommended by Etherington (2004), this assisted me in remaining aware of my own biases and subjectivity. Therefore, reflecting upon how the researcher is an active participant will be discussed in this chapter.

3.4 Study Design

My research is predicated on a qualitative design, this is defined as a process of inquiry that relies on information derived from the naturalistic setting to understand social and human problems (Creswell and Poth, 2016). Qualitative research is thus a naturalistic and interpretive technique that investigates phenomena from the inside out (Flick, 2009). According to Ormston et al. (2014), researchers approach qualitative research differently, with many distinct assumptions about the social environment and qualitative research prevailing. Further, myriad methods are employed in qualitative research, including informal conversation, focus group discussions, field notes, observational techniques and life narratives, among others (Denzin and Lincoln, 2011; Ormston et al., 2014). In contrast to quantitative studies which explore “how many” questions, qualitative research questions often explore the question of “how and why” (Murphy et al., 1998). Instead of the hypothesis driving the study and data analysis for scientific testing and confirmation, qualitative research is frequently stated as offering richer data from which theory may be created and developed inductively (Silverman, 2011).

Qualitative approaches enable researchers to solve ‘intellectual problems’ by investigating mechanical and processual phenomena. Everyday actions can be characterised through “how and why” queries regarding social reality (Mason, 2002). Qualitative methodologies are inherently interpretivist, since quantitative approaches minimise the specificity of the investigated phenomena via their focus on deduction and scientific knowledge. Qualitative research, and its focus on meaning-making in specific contexts, supports the exploration of multiple, complex phenomena in their naturalistic setting (Creswell, 1998). This research design was chosen because it is especially relevant to investigating the intricacies inherent in the nuances of how people with dementia, and their caregivers, understand their everyday behaviours and perceptions within a Saudi care home.

Further, the continual linguistic and cognitive issues that a person with dementia might well have, added a layer of complication to their own expression in structuring their life and connections (McCleary et al., 2018), including any contact with the researcher. Qualitative research, which is focused on social construction, supports the quest to understand the lived realities of research participants, despite the complexities of their lives and expression. It was also important to adopt a methodology that supported the interpretative analysis of the behaviours of individuals with dementia and their caregivers in their daily lives in a Saudi care facility. The methodological approach is structured throughout by that proposed by Carspecken (1996). This method is suitable since it presents a five-stage critical qualitative research strategy for conducting ethnographic research. This study was based on Carspecken's critical ethnography (Carspecken, 1996, 2001; Carspecken and Walford, 2001), although its five steps were carried out iteratively rather than linearly. Against this backdrop I have adopted an ethnographic methodology, this will be explained in the following section.

3.5 Methodology

The research ontology, epistemology, and design outlined above necessitates a qualitative approach that is iterative and interpretive, allowing for the daily experiences and contextual aspects of individuals with dementia and their caregivers in the Saudi care facility to be examined. Methodologies based on objectivist frameworks would be in direct opposition to the worldview of this research; thus, an approach based on critical ethnography has been adopted. Prior to delineating this approach, a general overview of ethnography as a methodology is provided.

3.5.1 Ethnography

Compared with other qualitative approaches, ethnographic research permits researchers to directly experience the culture and experiences of a specific group on a first-hand basis (Hammersely and Atkinson, 2019); it was thus apt to take up this approach in the research to understand the everyday experiences of older persons diagnosed with dementia. Ethnography is varyingly referred to as a method, methodology, or the written product among those approaches in which the researcher or the ethnographer investigates the 'culture' of a particular group through a focus on their attributes, social systems and ritual practices (Hammersley and Atkinson, 2019; Bryman, 2008). This method is based on first-hand immersion with group members, typically over a long period (Hammersley and Atkinson, 2019; Bryman, 2008). Over the past 130 years, ethnographers have used many ways to describe local populations in their varied research endeavours. A brief history of ethnography and its various turns, wherever applicable to the current research, is offered to demonstrate how the essential aspects of ethnography and the commitments an ethnographer makes concerning philosophical assumptions (ontology and epistemology), analytical predispositions, methodologies, and, probably most significantly, connections with people being documented are ever shifting. Ethnography may be understood in a variety of ways and is constantly debated and modified in social and cultural anthropology, sociology, and other related social sciences.

In the late nineteenth and early twentieth centuries, ethnography evolved as a methodological tradition in social and cultural anthropology (Eriksen and Nielsen, 2013). Anthropology was envisioned by the Founders of Modern Anthropology school as a 'science of humans' predicated on the same premises as the natural sciences, in that cultures were 'out there' to be discovered, documented, and characterised in comparable ways to thermodynamics, gravity, and chemical processes. This early kind of ethnography sought to gather everything (Bernard, 2011). Ethnography, meaning 'writing about people', was a way for anthropologists to codify civilisations throughout the world into specialised domains, describing their behaviours, belief systems, and subsistence tactics, amongst other things (Bernard 2011; Murdock, 1971).

In the early twentieth century, the Chicago School of Sociology also established its own ethnographic tradition (Hammersley, 2006; Apter et al., 2009). These sociologists and social anthropologists continued to study society and cultural systems, but there was a greater emphasis on how and who collected the data, as well as how it was portrayed (Apter et al., 2009). Within anthropology and sociology critiques of how academics depicted culture and how ethnographers learned about a cultural or social group, were brought to the forefront of scholarly debates (Wolcott, 2008). This resulted in the first significant shift in the way anthropologists conducted ethnography, known as the 'interpretive turn' in anthropology and other social sciences (Rabinow and Sullivan, 1979).

Interpretivist ethnography is an approach derived from hermeneutics, this is a human sciences framework that seeks to understand human life via interpretation (Taylor, 1971, 1985). Hermeneutics challenges the objectivist view of human phenomena within which interpretation is not prioritised. Drawing from the principles of hermeneutics, interpretivist ethnography supports the examination of local and social imaginaries that shape how norms, practices and structures are understood in local contexts, enabling the experiences of specific groups to be captured. In other words, in interpretivist ethnography, knowledge is contextualised, and culture is no longer reduced to a set of structures and functions. Culture is defined as:

> a system of inherited conceptions expressed in symbolic forms by means of which men communicate, perpetuate, and develop their knowledge about and attitudes toward life (Geertz, 1973, p.89)

Interpretivists believe that practical understanding is gained by the ethnographer thinking about his own activities in the world as a subject of experiencing as well as deliberate action (Rabinow and Sullivan, 1979). In other words, culture cannot be lowered to a series of interconnected systems based on an objectivist science approach; rather, all investigations are moulded by how the ethnographer intentionally attends to, participates in and builds relationships with specific people doing and saying specific things. Whereas various pioneering anthropologists and sociologists of the traditional ethnographic traditions (i.e., structuralism, functionalism) learned through spending time with a specific community, this was countered by a new paradigm which advocated portraying the culture via one's own first-person vantage point instead of a third-person omniscient narrator in order to show their authorial authority (Hammersley and Atkinson, 2019). In interpretivist ethnography, this concept is characterised as ‘being there’ (Geertz, 1988), in which the ethnographer articulates their absorption in the action taking place.

Nevertheless, writing about an event necessitates translation or 'textualisation' (Ricoeur, 1971), in which social realities are reproduced as focused, autonomous, and categorised text (Van Maanen, 2001, p. 91). Clifford and Marcus (2010) argued that culture cannot be gathered; rather, it is inscribed by active and conscious writers depending on how they perceive their cultural experience. Writing description based on extended and intensive interaction with a group of people remains fundamental to ethnography, but the manner in which ethnographers communicate these experiences through their writing has evolved.

In the contemporary context the motives that underpinned early ethnographic work and the concomitant neutrality of the ethnographer have been increasingly viewed with scepticism (Hammersley and Atkinson, 2019). Processes of political change within academia and throughout the world have inspired debates in relation to previously dominant views about the ethnographer's authority as the most legitimate account in ethnographic research. This account no longer prevails, with the issue of authority not only being defused by a change of location in ethnographic research but a change in focus for many ethnographic researchers (Savage, 2000). From a locational perspective, many ethnographic researchers have shifted focus from remote settings and communities to settings at home, including healthcare facilities. The advent of new information technology, as well as the emergence of new local and national identities, has increasingly challenged traditional views which conceptualise culture as rooted in shared beliefs and practices (Hammersley and Atkinson, 2019; Savage, 2000). The challenging of such traditional views has been supported by the emergence of theoretical perspectives that reject discourses of social coherence, instead focusing on the differences that exist between social groups so that culture now connotes a "process of struggle to determine meaning on the part of individuals with unequal access to power" (Savage, 2000, p.1400).

Against this backdrop ethnography has been applied to the study of healthcare and health in myriad ways. It has been applied as a methodology that permits assessing practices and beliefs, thereby supporting an understanding of illness, health and health-related behaviours (Savage, 2006). Ethnography is thus especially valuable for gaining nuanced insight into residents' perspectives of illness as well as their experience of it. Ethnography, for example, can illustrate how care staff's approach to illness is influenced by their cultural practices or how specific assumptions on the part of healthcare professionals can undermine effective health promotion (Kelly et al., 2018, Gerrish et al., 2013).

In considering ethnography as methodologically acceptable for research studies, the following principles are typically shared throughout most and even experimental versions of the approach:

1) immersion in the field to understand people's everyday behaviours and the situations in which they are located;
2) data gathered mostly through participant-observation and talks;
3) concentration on a few individual instances or a small-scale community;
4) unstructured approach wherein concepts arise during analysis (Hammersley and Atkinson, 2019).

This research emphasises how residents with dementia and their caregivers experience daily care in a Saudi care facility. Against this backdrop, a longitudinal approach is necessary to investigate how people with dementia and their caregivers view their daily lives in a care facility. Most ethnographic designs are longitudinal and qualitative, whereby spending a long time with a group of individuals is a basic premise of ethnography, particularly in anthropology (Ingold, 2014). The purpose of this approach is to learn as much as possible; such persistent and extended engagement has been suggested in order to create rapport and negotiate access to distinct groups of individuals or behaviours that would be difficult to examine via a single visit, exemplified by a cross-sectional design (Hammersley and Atkinson, 2019; Bryman, 2008; Bernard, 2011). Longer time allows for the development of connections, trust between ethnographer and participant, and the development of a more authoritative presentation of findings.

3.5.2 Critical Ethnography

As noted in the previous section, ethnography constitutes a qualitative methodology that is used to understand the world of participants and elicit their points of view (Bryman, 2008). Critical methodologists expand further on the goals of ethnography by adopting a political lens (Marshall and Rossman, 1995). Thus, according to Schwandt (1997), critical ethnography concerns “ethnographic studies that engage in cultural critique by examining larger political, social and economic issues that focus on oppression, conflict, struggle, power, and praxis" (p. 22). The tenets of critical ethnography are rooted in the paradigm of the Chicago School, this focused on researching marginalised populations as a strategy for shifting the focus of research towards an assessment of cultural dominance and minorities (Cook, 2005). While conventional ethnography speaks for the research subject via a description of 'what is', critical ethnography speaks on their behalf by outlining not only 'what is' by 'why this is' and the steps that can be taken to change the status quo (Cook, 2005). Thus, the goal of critical ethnography is to study culture with the objective of changing it; "criticalists find contemporary society to be unfair, unequal, and both subtly and overtly oppressive for many people. We do not like it, and we want to change it" (Carspecken, 1996, p.7).

Critical ethnography's core is a quest to challenge the status quo and unequal power dynamics within society by articulating the stories of those often marginalised by their disability, race, sex or class, thus granting them unhindered citizenship (Bryman, 2008). These aims align with the goals of this study, which seeks to highlight the experiences of older people living with dementia in a Saudi care home as an avenue for devising meaningful health promotion practices. For people living in care homes, much of their daily experience revolves around their bodily practices of illness and disability, particularly for people living with dementia. In this context, the experience of illness means that wishes and desires may become more difficult to convey through spoken language, and the perception of time is limited (Campbell and Ward, 2017; Keady, 2010). Within this research a critical approach was adopted, for instance, relying on Ahmed (2013) to understand how issues of power are perceived at spatial and bodily levels. On a daily basis, power dynamics in dementia care homes revolve around how bodies are handled, monitored, and cared for. Place and space have consequences for who owns them, and Ahmed's (2013) concept of bodily space is valuable for understanding the everyday power dynamics of such settings. Ahmed (2013) employs the concept of bodily space to describe "the way strange bodies are produced through tactile encounters with other bodies: differences are not marked on the stranger's body, but come to materialise in the relationship of touch between bodies" (p.15).

This PhD study emphasises how differentiation between healthy and sick bodies, or the production of 'strange bodies' (Ahmed, 2013), is enacted in everyday life via a focus on the experience of living with dementia. This entails considering how the spaces are organised and connect to the realities of daily living within the care home. It also indicates that external factors that enter the care home, and impinge on the experience of daily life, are considered through the many social and healthcare policies that exist and are implemented at the care level (Armstrong and Bradley, 2013). Critical ethnography taught ethnography that there is no single dominating culture among many communities and cultures, but rather diverse voices (Quantz and O'Connor, 1988). It is thus necessary for a critical ethnographer to be aware of how power systems affect lives and the various experiences of this. According to Madison (2011), critical ethnographers must acknowledge their ethnographic positionality, or the researcher's own power and privilege in the process, because it expresses concern regarding representations and how participants' voices will be represented.

There are complicated feelings of power in this research; the people living with dementia live in a care facility where they no longer have much control over what happens to them. Care homes are responsible for implementing care practices and monitoring residents' health. There are clearly distinct power dynamics and multiple voices within those care institutions; for instance, individuals working directly in care delivery are most typically female employees in the lowest-paid jobs (Armstrong and Bradley, 2013). Armstrong and Bradley's (2013) findings about gender imbalances in care delivery align with the Saudi context, whereby the staff in the care home studied were predominantly female. Dementia is an illness which is frequently connected with the loss of individual agency (Bosco et al., 2019), and people living with dementia might also be subjected to legislation that restricts their agency, or limits their agency, when their capacity to provide consent is reduced. In the United Kingdom, for example, the Mental Capacity Act (Department of Constitutional Affairs, 2005) designates guardians to make decisions for people with dementia who have lost their mental capacity to make certain decisions, following requisite assessments by healthcare agents. Saudi Arabia's Mental Health Law (2014) similarly enables residents to make decisions if they are capable (Article 9:1), without discrimination to the presence of dementia which might impact a resident's decision-making functions. Further, under the law, guardians of residents are allowed to consent to experimental treatment.

Authority is transferred from external societal and cultural systems to care organisations, based on similar logic, concerning the capacity of people with dementia to care for themselves. Care institutions do not exist in a vacuum; they are embedded in historical systems and power structures. This implies that power dynamics impact the everyday level of relationships, care methods, and the lived experience of daily living (Armstrong and Bradley, 2013). The articulation of such power dynamics constitutes the premise of this study, it was thus imperative to adopt a critical lens when studying the everyday lives of the study participants to interrogate them. As a result, this study has produced an ethnographic technique that includes critical ethnographic framings. According to Sumartojo and Pink (2018), this strategy allows for an approach that considers communal experiences and the configurations of everyday life. They also contend that such research may aid in understanding power dynamics by revealing who is included and excluded.

3.6 Chapter Summary

This chapter has established the theoretical and methodological foundations of this investigation. I have explained how I came to understand the principles adopted in my study to investigate the experiences of location in the lives of persons living with dementia in a care home environment. This chapter addressed critical factors in supporting the ethnographic methodology choice to investigate how the behaviours of individuals with dementia, and their caregivers, may alter experiences of living with dementia, meanings and practices of care, and relationships with the care home. To address this research dilemma I proposed ethnography as a research methodology, relying on the ethnographer's reflective and interpretative accounts. These accounts were the result of continuous engagement and observation in the everyday lives of individuals with dementia and their caregivers in a care home as a socially and physically restricted study field.

Fieldwork has been utilised to provide dense descriptions in which the ethnographer analyses, not just content analysis but also methodological thoughts on how these analytical assertions and linkages are formed. However, I argued that traditional ethnography techniques were inappropriate for the study's research environment. A methodological difficulty was identified when comparing this study to other ethnographic studies: how restricted contacts and signs of dementia may impair the quality of connections formed with participants in this research. To address methodological obstacles, modern ideas from social science ethnographers were applied to the study's essential characteristics: targeted, short-term, collaborative, and embedded ethnography. Those modifications contributed to a unique ethnographic strategy for this study which could address the intricacies of modern contexts, such as the behaviours and experiences of persons with dementia and their caregivers within a Saudi care facility.

Chapter 4. Research Methods

4.1 Introduction

This chapter presents the methods used for implementing critical ethnography in this study. The data collection process and analysis used in this study are also presented. This includes descriptions of the setting and the sampling process. Lastly, the ethical considerations of this study are discussed.

4.2 Methods

4.2.1 The care home setting

The care home was owned and managed by the government; the government wholly funded it under the Social Welfare Ministry's budget, which also oversaw employee recruitment. It oversaw the employment of administrative staff, physicians, nurses, supervisors, home monitors, and care staff. The function of this care home was to serve older Saudi citizens who could no longer care for themselves for reasons of either physical, mental, or financial disability. They were only admitted to the home if they were Saudi nationals. At the time of fieldwork, there were 29 residents in the care home and 34 carers, as shown in Table 5.1.

The number of residents and caregivers in other care homes in Saudi Arabia was unknown (not published). In order to understand how the studied care home in this research compares to others in the kingdom in terms of function, the researcher attempted to contact the Social Welfare Ministry. However, I did not receive a response.

In the studied care home, the home doctor was responsible for making decisions on admission to the care home. When the home received a referral from the hospital or social welfare, a committee consisting of one of the care home nurses and a social worker assessed the case from a social perspective. The parameters for admission revolved around whether the prospective resident was:

1. A Saudi national,
2. Had no close relative (that is, a son) who could care for them, and
3. Had no private home.

Within Saudi Arabia, adults are held responsible for their parents' essential needs, health, and safety. If they cannot care for their parents due to physical, financial, or psychological problems, then a social welfare professional will assess their condition and provide the parents with the support they need, which includes 10,400 SAR per year, equivalent to 2,220.63 GBP. Further, they receive in-kind assistance, which includes food supplies. Therefore, older people with children who are able, both physically and psychologically, to look after them are refused admission. Where older persons have private homes, they are provided with a private care assistant without admission to a care home.

Conversely, older people aged 60 years and above who have no adult children to take care of them are eligible for social support in social care homes. When the committee approves a case, the home doctor assesses their medical and physical status. The individual must not have any psychological behaviours such as depression, anxiety, bipolar disorder, schizophrenia, or any contagious diseases that could be transmitted to other residents.

Figure 4.1 provides an illustration of the research setting. In the nurses' room, there was one desk facing the door at the end of the room with three chairs; a Dina-map ProCare electronic blood pressure monitor next to a filing cupboard on the right side, along with a dressing trolley and a small narcotic medication cupboard. On the left side was a large regular medication cupboard, followed by a small dressing and catheterisation shelf and a small fridge. However, the room had no emergency crash cart or observation bed.

Figure 4.1 Illustration of the Care Home Facility

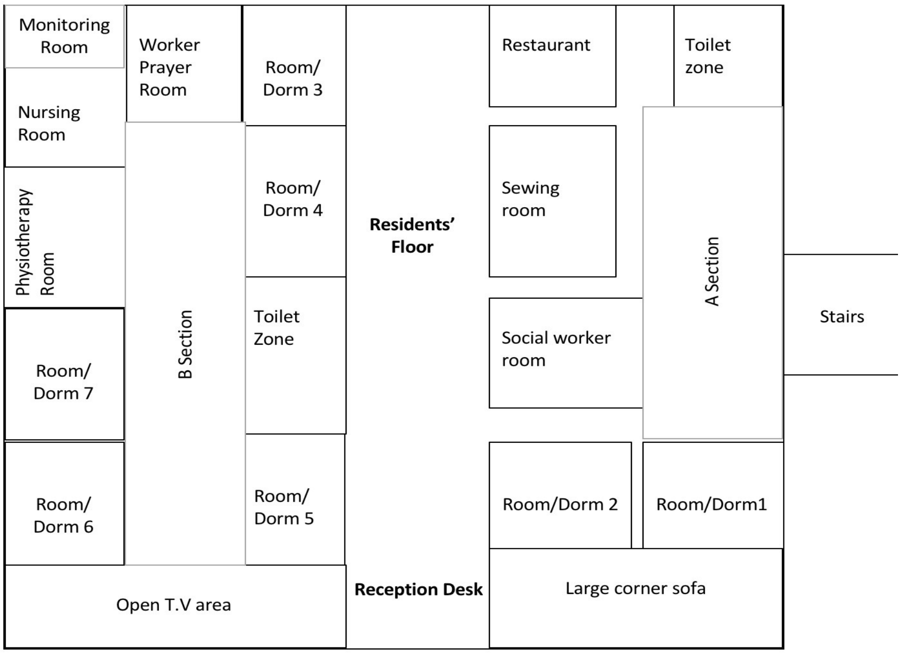
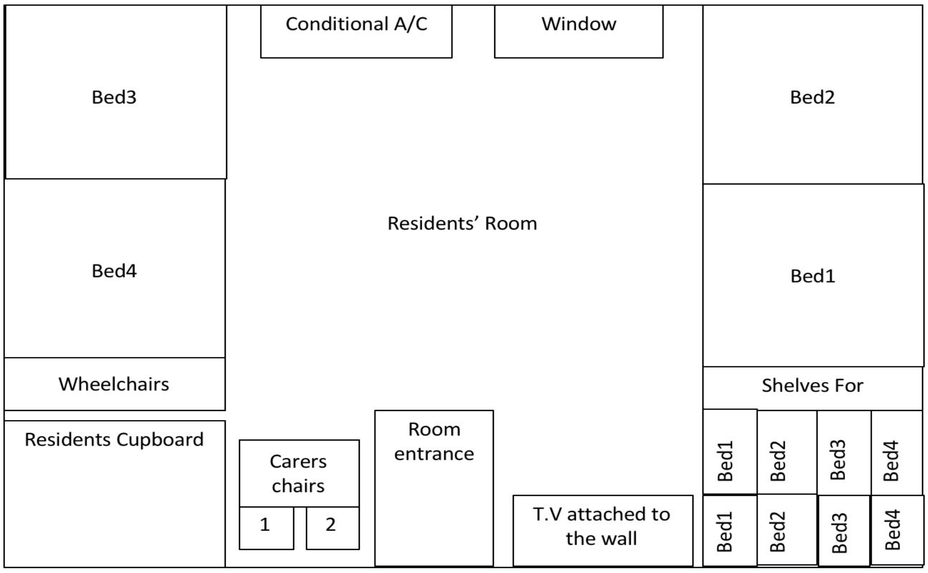


Figure 4.2 Illustration of Residents' Dorm Rooms



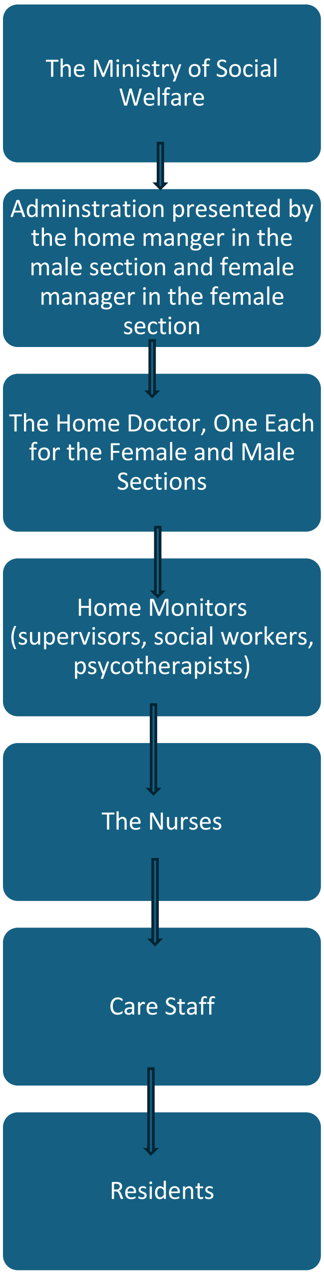
The care home consisted of seven resident rooms or ‘dorms,’ five on the left and two on the right. Each room had four residents, except one which had five residents, with two beds on each side (see Figure 4.2). All rooms had a mosquito net above each bed to protect the residents from insects. All the bed sheets and covers were white, and the single window in each room was covered by a white curtain. There was a television on the wall facing the beds, two wheelchairs next to the doors, which the carers informed me were used to move residents, and one cupboard in each room for the residents’ clothes. All the rooms looked very clean and tidy, and the doors were open. According to the home manager's policy, the doors should never be closed. There was also an intensive care room with five beds for nasogastric intubation. Residents must always be supervised, according to the home manager.

4.3.1. The Hierarchy Within the Care Home

The care home was characterised by observable power hierarchies, with the Ministry of Social Welfare, which manages and funds the care home, at the top. This was followed by the home doctors, who oversaw medical care in the female section. The power they wielded was by virtue of their medical knowledge and, thus, standing within the health community of the care home. Beneath the home doctors were the home monitors, who were comprised of supervisors, social workers, and psychotherapists. The power they wielded was also by virtue of their professional standing and experience compared to the nurses beneath them. Due to their professional expertise, they were assigned to supervisory roles. At the bottom of the hierarchy were the care staff, who were directly answerable to the nurses. They had to negotiate the power dynamics emanating from the top as part of their daily experiences, as this study will show.

This hierarchical organisational structure, whereby a doctor to whom subordinates must answer was placed in charge of the home, reflected the cultural set-up of work in Saudi Arabia and was not particular to this specific care home. Aside from being a typical set-up in a Saudi care home, this organisational structure also reflected the characteristics of the Saudi healthcare system described in Chapter 1, whereby it was mainly doctors who lacked specialisations in a field. From a cultural perspective, doctors are highly regarded, which explains why the doctor oversaw the care home's management despite having no specialisation in psychiatric or geriatric care. Further, due to the lack of specialisation in the Saudi healthcare system, doctors who are placed in charge of wards occupy significant positions of power. This presents them as credible from the perspective of the general public, who do not interrogate their decision-making.

Figure 4.3: Illustration of the Hierarchy of Power in the Care Home



4.3.2 Study Participants

Study participants were chosen for observation via purposive sampling. Purposive sampling constitutes the deliberate choice of a participant because of their knowledge or experience regarding the research subject (Etikan et al., 2016). Research participants were observed from the study population described in Table 4.1. Out of 34 care staff and watchers, 19 consented to participate in the present study. With regard to the female residents, a total of 29 were observed.

The care home under investigation had six nurses, one of whom was Saudi; she was the head nurse and worked eight hours per day during the week. The remaining nurses, including the deputy nurse, were overseas workers and, despite their varying nationalities, were all Muslims, which was a requirement of employment.

From my observation, I perceived that the duties of the nurses included administering medications, checking vital signs, observing toilet care, and preparing blended food. Usually, the home doctor decided which residents must be placed on blended food based on the observation of care staff. The role of nurses, on the other hand, was to observe residents during feeding, administer nasogastric food, refill medications, arrange residents' follow-up appointments, and accompany residents during hospital transfers or visits. Furthermore, nurses' roles extended beyond administering medications and other therapies; they were responsible for the holistic care of residents, which encompassed the individual's psychosocial, developmental, cultural, and spiritual needs.

In addition, care staff worked twelve hours per day, six days per week. They had no specific room in the home and were not permitted to leave residents' rooms except to have a meal. They took on more of a custodial role rather than a caring one. Residents had to always be supervised. The roles and remits of nurses and care staff are captured in Table 4.1.

Table 4.1 The Study Population

Positions	**Peoples**	**Description**
HOME	Older adults centre	Older people who can no longer care for themselves.

THE DOCTOR (n=1)	Although not a geriatrician, she was head doctor for the western region social welfare centres, it included elderly homes, orphanage homes, and specialised secured centres for young girls who have committed a crime.	She was responsible for residents' admission, and managing their health and conditions, including conducting physical assessments making diagnoses, prescribing medications, making referrals and determining nutrition status and the type of food served. She was the most important person in the care home from the authority point of view.
HOME GENERAL SUPERVISOR/MANAGER (n=1)	A Saudi national, from social service personnel but not a healthcare professional.	She was the manager of the female section and the second most important person at the care home from the authority point of view.
THE HOME NURSES (n=6)	A head nurse from Saudi A non- Saudi deputy nurse 4 non- Saudi nurses Each shift had 2 nurses, they worked 12h shifts, except the head nurse who worked 8h	They were responsible for administering residents' medication, measuring their vital signs, performing nursing procedures, and observing and maintaining residents' general health and conditions; they were the fourth important group from an authority point of view.
SUPERVISORS/ HOME MONITORS (n=6)	All were Saudi nationals from social service personnel but not healthcare professionals; each shift had 2 home monitors on the floor and 1 in the monitoring room where the security screen was located. They worked 8hour shifts.	They were the third most important group from an authority point of view. They were responsible for monitoring the care staff to ensure that they perform their duties appropriately. They did not participate in direct resident care; they observed toilet care, food, and feeding, and they monitored and assessed all care delivered to residents as part of a quality and safety control strategy. The care staff could not administer any care without home monitors or supervisors.

CARE STAFF/ WATCHER (n=34)	All were non-Saudi nationals; they were Muslim women from overseas; each shift had 16 care staff plus one general helpers who called emergency care staff. They worked 12h shifts. (The ratio was 1 carer for 2 residents). 19 care staff participated in the study	They were the least important group from an authority point of view, but they were the backbone of the care home. Each carer was responsible for two residents. They were known as care staff, caregivers, and watchers. They were responsible for administering residents' direct care which included feeding, cleaning, washing, toileting and monitoring residents' safety. They were positioned in residents' rooms.
SOCIAL WORKERS (n=4)	Each shift had 2 social workers on the floor. They worked 8h shifts. All of them were Saudi nationals.	They maintained communication between the residents and their families, and they facilitated entertainment and activities.
GOVERNMENT COMMITTEE GROUP (n=3)	Three Saudi female from The Ministry of Worker and Social Welfare with social service background.	They were responsible for monitoring care in the homes by conducting visits and checking how the residents are being treated.
RESIDENTS in Female unite (n=29)	29 female residents, all were Saudi nationals aged 60 years and above. For the present study, all 29 female residents were observed, including 5 who were in a coma.	

During the fieldwork, the staff informed me that caregivers were generally recruited by a private company from overseas, which supports them in accessing work visas. These companies are selected through a tendering process before the operational contract with the Ministry is established.

Table 4.2 Participants' pseudonyms- Residents and Caregivers

Residents' names/ages	**Care staff/watchers' names**
Salha- 72years old	Bath
Sharon- 65years old	Huly
Aisha-70 years old	Emma
Khadija-81 years old	Mia
Fatimah-79 years old	Sali
Reem-65 years old	Logayen
Hessa-85 years old	Roze
Laila-90 years old	Rozilina
Sadia- 84 years old	Hadeel
Alia-80 years old	Moss
Norah-72 years old	Lina
Abrar-62 years old	Tolina
Samar-75 years old	Sofia
Amal-81 years old	Samiah
Monirah-75 years old	Ayah
Zainab-83 years old	Awatif
Halima-91 years old	Shafa
Amanyl-72y years old	Mary
Jumana -90 years old	Sue
Marzoga-92 years old	
Jumaa- 81 years old	
Ashwaq- 68 years old	
Amal- 72 years old	
Jumana- 90 years old	
Marzoga- 92 years old	
Jumaa- 81 years old	
Ashwaq- 68 years old	
Maha- 70 years old	
Monirah- 86 years old	

TABLE 4.3 PARTICIPANTS' PSEUDONYMS

Nurses	Supervisors/Home monitors	Home Doctor	Home Manager	Social Worker	Nutritionist
Wahida Salma Um Nisrean Judith Fofa	Samira Maryam Hajar Noor Kareem Sara	Dr. Fifi	Mrs. Shamah	Amirah	Misha

4.3.3 Data Collection Process

The scholarship I received allowed for a maximum data collection period of three months. To maximize the potential of this opportunity and enhance the study findings, I strategically aligned this period with my summer break, thereby extending the data collection phase to a total of six months. Data collection was conducted two days per week, resulting in a total of 44 days of data collection. The period between August 1st and August 17th was excluded due to the Hajj season, a significant religious occasion in Islam. Within this timeframe, days were randomly selected during the weekdays, and arrival times at the site were also randomly chosen to ensure comprehensive coverage of activities throughout the entire day and night. In keeping with Hammersley and Atkinson's (2019) observations that ethnographers cannot undertake fieldwork at all times of the day, weekends were excluded. The study primarily utilized participant observation, complemented by conversational methods, to explore actions and interactions within the cultural framework of the care home. Each visit comprised five hours on-site, including a one-hour break, allowing for an in-depth observation of the daily routines and practices within the care home. As noted by Hammersley and Atkinson (2019), it is imperative that the length of observations is appropriately balanced to achieve manageable amounts of data.

My visits varied in length, and I focused on recording different aspects of everyday life at the care home to accommodate practicalities and other commitments, resulting in the data types/volume shown in Table 4.4.

TABLE 4.4 DATA TYPE AND VOLUME BY CARE HOME IN THIS STUDY

DATA TYPE	**CARE HOME SE**	
	Day	**Night**
Hours of observation	40 Hours	5 Hours
Number of informal conversations	20 Hours	2 Hours
Hours in Documents review	3 Hours	0 hour

As noted by Carspecken (1996), the first stage of critical ethnography is to develop a record of data collected and analysed from an outsider's point of view. This requires methods that can elicit unobtrusive observational data in the form of participant observation and field notes, for example. Observation and field notes were the primary methods employed in this research to capture the research participants' everyday experiences, behaviours and activities while immersed in the field. "The field" refers to the methods in which the ethnographer conceptualises and circumscribes their society. It is a socially and materially constructed space where the ethnographer spends time with a group of people. Traditionally, ethnography addressed understanding indigenous knowledge and ways of life by accessing and participating in the field, defined as places specified by the presence of a certain group. Ethnicity, or association with a certain group of people located in a given geographic location, was related to the work of various classic anthropological ethnographies (see, for example, Malinowski (1922) and Evans-Pritchard (1951)). This conceptual design may be seen in modern ethnographies such as Alice Goffman's (2014) study on institutional racism and Montoya's (2011) study on racial politics. Although a century divides the oldest and most current work, geography remains an important means of defining participation in ethnographies and where data collection fieldwork will take place.

4.3.4 Observations and Field Notes

Participant observation is recommended by Cook (2005) as a useful strategy for examining everyday life, or a community's "culture," as a primary focus of anthropological research. In this form of research, the researcher works closely with the research subject such that they are all conceptualised as participants and evidence is derived inductively from observation data (McKnight, 2006). Gold (1958) suggests that an observer can take one of four strategic roles: complete participant, complete observer, participant-observer, and observer-as-participant. My role as a participant was limited to a specific scope, the role varied but observations generally involved sitting in private areas of the home or walking between areas, occasionally making notes in a research diary. Notes, or "jottings," serve as an aide-memoire, from which I could develop "rich descriptions" (Geertz, 1973) of field notes that explained and contextualised what I saw and did during my time with the person with dementia and her caregiver. The depth and attention to context give birth to "thickness." As a result, densely detailed field notes give readers the impression that they are "there" (Geertz, 1988).

This research entailed spending time with individuals with dementia and their caregivers as they went about their daily lives in the care facility. It also entailed the observation of five residents in a coma, all of whom received the same care as conscious residents. The accounts generated did not necessarily follow a chronological sequence but followed a logical order, such as by themes or concepts comprised of the language spoken by individuals with dementia and/or their caregivers throughout observations. Data gathering was, therefore, an interpretive act rather than a neutral recording of events (Emerson, Fretz, and Shaw, 2001; Taylor, 2002; Hammersley and Atkinson, 2007; Fetterman, 2010). As a participant observer, I accompanied on-duty nurses and carers. I helped the care staff participants with small tasks, such as moving a resident or answering a resident's question while the nurse participant was present. At one point I alerted a care staff participant when a resident was in distress.

It is imperative to highlight that no formal interviews were conducted for this study. On the contrary, data gathering involved informal conversations as part of fieldwork. These conversations were designed to ensure that respondents were at ease and encouraged to express themselves freely about their experiences related to my research objectives, as they are akin to everyday conversations (Rinaldo and Guhin, 2022; Spradley, 2019). Further, informal conversations encouraged a fluid and organic exchange of ideas, as the style afforded respondents the opportunity to express themselves freely without feeling handicapped by a rigid framework of questions. This method aligned with the objectives of this study in capturing the authentic and nuanced perspectives of participants.

Conversations with people with dementia and their caregivers regarding their daily lives in the Saudi care home produced in-depth data. This related to practices linked to the institution that provides care to people living with disabilities, as well as differing representational priorities. I took part in activities and conversations if I judged that it might enhance my insight or help maintain my 'unobtrusiveness' in the home. In terms of observation I began by seeking a variety of events and people to avoid making assumptions. This developed into efforts to observe 'strangeness' (such as what happened following an unusual event) or focusing on 'familiarity' (such as probing or taking part in something that had become routine). I also focused on the prevalence of certain languages and communications between staff and residents and what needs to be done for residents. I therefore chose to explore this by using the language myself with staff and probing whether I had the right understanding. This contrast is common in ethnographic studies as a way to ensure both breadth and depth of what is being observed (Carspecken, 1996; Hammersley and Atkinson, 2007; Miles et al., 2014).

The choice to visibly record notes may have affected the data I collected as it would have made people more aware of my presence. Emerson et al. (2011) highlighted the possibilities of 'observer effects' and the potential for invalidating research findings due to biases. Methodologists such as Patton (2014) however advised that the potential for observer effects should be documented in research studies and incorporated as caveats in accounts of the fieldwork process. I therefore approached the potential for 'observer effects' as an ethical consideration. My handwritten in-situ notes were typed as soon as possible after the event, together with my reflective and analytic thoughts. The purpose was to enable me, long after the visit itself, to understand the care home as a whole, the events I referred to, and the content of conversations. Hammersley and Atkinson (2007) noted that this approach is an effective way to ensure both the breadth and depth of what is being observed.

In structuring notes several layers of description per the guidance of Spradley's (1979) Developmental Research Sequence (DRS) method which approaches ethnographic study as a sequence to guide the researcher via the process of knowing and describing what is being observed:

- The location of the observation (unit, area, room, time, date);
- The interactions between others and the interactions of myself with others in that setting;
- My reflections on what I was seeing, hearing, and feeling.

For analysis purposes the observations were transcribed and translated from Arabic to English directly before writing them in my diary. I followed Squires' (2008) guidance and did not only perform a literal translation of the language but also focused on the cultural context of the participants' words. To do this, I considered the structure of the phrases and words that were spoken while concurrently placing them in the context within which they were spoken when performing the translation (Squires, 2008). In addition, it was valuable for me to self-transcribe and translate the informal conversations to enhance my analytical thoughts and allow the writing of memos about the initially generated codes and categories.

4.3.5 Challenges in the Field

Some challenges were experienced during the data collection process which must be noted, these enabled the research findings to be contextualised. How my journey from first meeting participants to leaving the field influenced my understanding of a specific group's way of life is one function that evolved. It evolved from my beginnings as a relatively naive "cultural outsider" through to my departure as a relative "cultural insider" who presents a descriptive and analytical account of my interactions with study participants. These roles are sometimes referred to as the emic, or cultural insider, and the etic, or cultural outsider (Headland et al., 1990). The ethnographer might typically begin research as a complete observer with limited knowledge of the culture and progressively create rapport with the community's members, who instruct the ethnographer in the group's customs and enable her to take part in particular cultural practices until they are able to participate fully. This transformation is made possible by the ethnographer's extensive time spent with individuals of another culture. This concept of civilisation, nevertheless, is questioned here. The simple opposing categorical reduction of a cultural outsider and cultural insider depicts cultures as objectified objects that can be gathered rather than as something that involves the ethnographer in observation, writing, and interpretation processes. According to Strathern (2004), how people created their identities in relation to the group under study was based on partial and contextual links instead of unchanging traits. To adopt these more recent constructions of the ethnographer role, I regarded and recognised my position in relation to how and to what extent I participated in the practices of people with dementia and their caregivers rather than strictly concentrating on my insider/outsider position based on how this study's participants and I as a researcher might affiliate with any specific group in the local research setting. As indicated previously in this chapter, ethnographers might occupy and continually move between the positions of a full observer, observer-as-participant, participant-as-observer, and complete participant, depending on the context and their aim. When and how these adjustments occur might provide the ethnographer with analytically meaningful information regarding their standing and interaction with research participants. Talk and persistent engagement imply a more contextual awareness of how I may co-construct my position with participants purposefully and/or coincidentally during and after fieldwork. How I see my relationships with participants, or how people perceive me, will mirror and shape my interaction with research participants.

Managing research interactions with persons with dementia and their carers proved challenging. The potentially restricted time I spent sharing a place with participants might have hindered my ability to develop and sustain meaningful relationships with them. Restricted or disrupted social interactions might impact the quality of data and what I can obtain throughout fieldwork. When possibilities to develop rapport are reduced, the distance between the researcher and the researched grows. Using a "collaborative" ethnographic method in this circumstance assisted with overcoming the limited possibilities to create trust and build rapport with participants in this study who have dementia and their caregivers. Lassiter's (2005) definition of cooperation in ethnography is based on participants sharing authorship. While authorship is not acceptable for this study owing to the inclusion of people with dementia and their caregivers, ethnographic partnerships may still be explored in a variety of ways by taking into account the viewpoints of both people with dementia and their caregivers. People with dementia are frequently excluded from dementia research, even though the phenomenon of interest is directly tied to decisions that impact upon them (Gibson et al., 2004). People with dementia usually have difficulty retaining material and organising it into a narrative; therefore, research that includes them may limit their capacity to participate by employing retrospective informal conversation to extract their experiences. People with dementia might also experience aphasia, this further inhibits their capacity to express themselves verbally. Compared with other approaches and practices used by health and social researchers, an ethnography which includes people with dementia as participants is already collaborative.

4.4 Researcher Positionality

As an observer I must consider the impact that my presence and interactions may have had on the persons with dementia and their caregivers, as they went about their daily lives. Earlier work in sociology by Gold (1958) argued that an observer can take one of four strategic roles: complete participant, complete observer, participant-observer, and observer-as-participant. Observational researchers might shift between various roles assessed here in terms of their potential applicability to this situation and how these judgments influenced orienting myself and my attention whilst spending time with people with dementia and their caregivers.

The "complete participant" function focuses on completely participating in the observed person's daily activities to learn how certain actions are completed. As a researcher aiming to connect with and understand the daily lives and practices of caregivers and persons with dementia within a care home I felt that acting as a complete participant would be improper, due to my lack of professional clinical or care-providing expertise in this setting. Furthermore, full engagement might disturb a person with dementia who is accustomed to a certain schedule with recognised caregivers. It would also have been challenging to fully immerse myself in the daily practices of people with dementia and their caregivers whilst also being able to capture what I saw if I actively participated in these activities with individuals with dementia and their caregivers.

The second position, "full observer," focuses solely on monitoring participants in research instead of participating in their behaviours. The full observer would have been a better position for me to take in this study because it would have allowed me to attend to the specific practices of people with dementia and their caregivers, whilst reducing my direct intervention with how they perceive routine care in the care home. Nevertheless, I contend that it would have been improper not to engage when the participants were explicitly addressed. Both the individual who has dementia, and his or her caregiver, would have been conscious of my overt research position when observing their daily routines, they might have asked questions that I felt bound to answer. I further claim that by doing an overt observational study, my presence implied a certain level of engagement in people's daily lives. People with dementia and their caregivers saw me when I observed them; I am not an invisible presence. I am a human being whose views, feelings, and behaviours are predicated on how I try to “fit in” with persons with dementia and their caregivers in a care home-based context. As a result, observation is inextricably linked to engagement, although, how, and to what extent, I was able to engage was an issue that I experienced during my fieldwork.

The last two roles, “participant-as-observer” and “observer-as-participant,” vary in that they emphasise either engaging in the practices of people with dementia and their caregivers, or witnessing those activities as the major technique for understanding how people with dementia and their caregivers perceive the everyday caretakers inside a care home. The hybrid roles of participant-as-observer and observer-as-participant are useful for connecting more directly with persons with dementia and their caregivers. Discussing their experiences with them could have offered further information about the activities I was observing. As a result, casual discussions must be used to extract additional information about how people with dementia and their caregivers view the world around them, their place in it, and how and what they do in it. These talks are intended to elicit more information regarding their activities and how they interpret them in the present. In other words, they are a method which enables people with dementia, their caregivers, and myself to develop and communicate how we interpret our experiences as they occur.

4.5 Data Analysis

The last criterion for this study’s approach was to allow interpretation of how people with dementia and their caregivers engaged in daily care in a care facility. By the 1970s, most ethnographies were characterised by interpretivism (Bernard, 2011), as researchers discovered that their work was being challenged to accommodate diverse understandings. Writing is a key component of interpretative analysis, both in documenting field notes on all phenomena seen during fieldwork and in inscribing them for analysis. Ethnographers collect data by assigning meaningful action to certain occurrences or behaviours. Nevertheless, there still needs to be more clarity between the difference and the conclusions in anthropology about how contextual, local information may assist in establishing universal human patterns (Ingold, 2014). An interpretive approach with the support of NVivo constituted the analytical framework for this study, drawing from both transcripts of informant conversations and field notes. This study was a critical ethnography aiming to critically explore the care home institution, the experiences of people with dementia in the home, and their caregivers' expressions.

Therefore, analytic tools were employed to move beyond description, develop understandings from within the data itself, and consider the context. The analytic approach used was, therefore, inductive and thematic. Braun and Clarke (2021) described reflexive thematic analysis (TA) as capturing qualitative approaches that consider the positionality and values of a researcher within the context of inductive analysis, ensuring that it is situated within an interpretative reflexive process. Via this process, themes and codes are generated. It constitutes an analytical approach that permits researchers to derive meaning from a data set by focusing on common patterns about how a particular topic is talked or written about.

It is important to highlight that TA assists researchers to uncover patterns of meaning which are crucial for addressing the research question under exploration. Via this analytical framework, answers to the questions become evident through the process of meaning-making stemming from the identification of themes, patterns and codes. With regards to the thematic analysis process used in this study, I began by reading and rereading the data set to reacquaint and immerse myself, this time with a solely analytical perspective (Morse, 1994; Fereday and Muir-Cochrane, 2006; Braun and Clarke, 2013). After re-examining the data I looked for similarities (resemblances and common traits) and coded them by writing the phrase in the margin. Ryan and Bernard (2003b), Corbin and Strauss (2008), Braun and Clarke (2013) as well as Maxwell and Chmiel (2014) define this as open/descriptive coding. This process required me to label my observations whether using my own vocabulary or the terms of the participants. As a result there is a wide variety of codes relating to two broad areas: 'What is care here?' and 'How is that care learned here?'. My original coding list had more than 30 categories; In Table 4.5, I present some examples of the original codes.

TABLE 4.5 EXAMPLE OF ORIGINAL CODES

Code	*Example of data*	*Code*	*Example of results*

Timetables	"Everything is the same, nothing new?" (informal conversation)	**Culture**	The nurses worked twelve hours shifts. The normal working week was 72 hours, six days a week, and this served as a major barrier to the daily tasks of the homecare nurses: (observation)

I then examined the data for a third time, this time looking for patterns (as linkages or connections) within and between the descriptive codes (Braun and Clarke, 2013; Maxwell and Chmiel, 2014). This is known as analytic coding, and it resulted in the combination of comparable codes and the identification of candidate themes: central organising concepts that make sense in their own right to explain data patterns (van Manen, 1979; Braun and Clarke, 2013; Al Sayah et al., 2014). The number of codes was reduced, but the complexity and interconnectedness increased (Braun and Clarke, 2013; Maxwell and Chmiel, 2014). For example, analytic coding reduced my initial codes to 8 themes, but each had various elements and connections. A simplified example of this is shown below in Table 4.6.

TABLE 4.6 AN EXAMPLE OF THE ANALYTIC CODING PROCESS

Theme	**Sub-theme**	**Elements- Codes**	**Relationship to other themes**
1. Resistance	1. Unmet needs and related behaviour, shouting screaming, anger, and agitation 2. Resistance towards the timetabled, mealtime, food, and drinks 3. Resistance toward personal care 4. Resistance toward timetabled bedside	1. Resistance to care and escalation of emotions 2. Lack of privacy and personal dignity	Behaviours interfere with everyday care

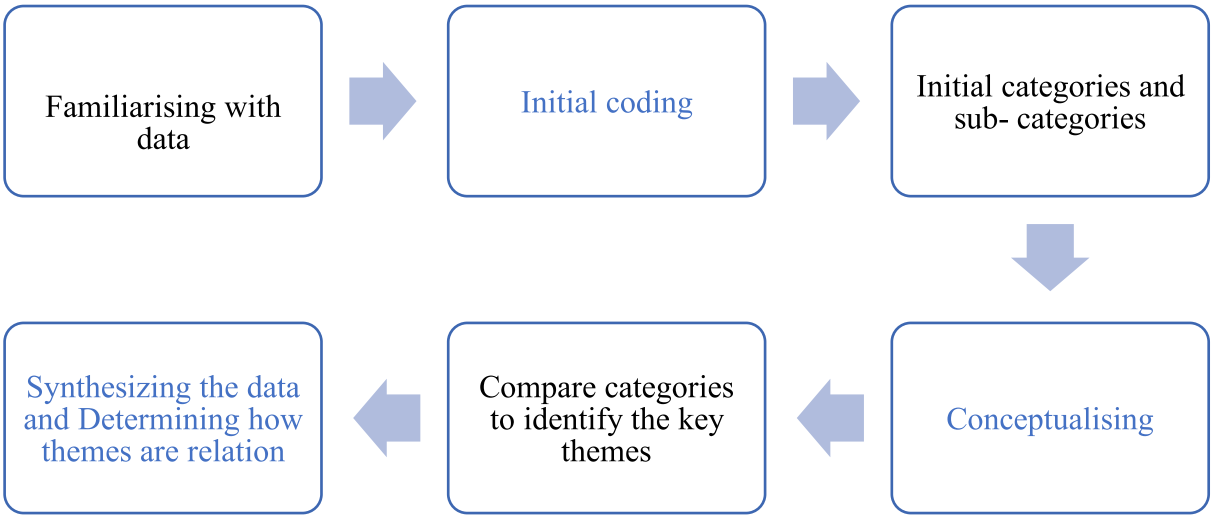
To test my readings of the data in this third stage, I employed a variety of strategies such as cross-checking the codes with the data-set. This was necessary to avoid falling into the trap of seeing only what served my purpose or making statements unsupported by evidence (Thomas, 1993; Miles, Huberman, and Saldana, 2014). I inspected each code in order to write a summary so that someone unfamiliar with my work could comprehend what I had discovered. This was performed by reviewing all the data obtained within that code again. I examined code contingencies across data kinds and sources (Hammersley and Atkinson, 2007; Zulfikar, 2014; Rashid, Caine, and Goez, 2015). Within an ethnographic study, triangulating in this way is not about validating the validity of data (as it would be in a positivist study) but rather about deepening data and my understanding of it (Hammersley, 1998; Holthe, Thorsen, and Josephsson, 2007). For example, an initial learning code was “strike”. I examined all incidences of that code to determine when, where, and why it occurred. This code was only found in the case of senior staff. What I saw in practice and what I was told by care personnel should be reviewed. This technique was also beneficial in identifying areas where a code had been influenced by ‘elite bias,’ in which participants who supply more eloquent data are over-represented (Miles, Huberman, and Saldana, 2014). Also, I examined correlations and patterns between each theme and its codes by examining what other themes or codes were commonly cited within similar data. For example, I noticed a substantial relationship between “Power Relations and Hierarchical Values” and other codes related to “Monitoring and Surveillance.” I could then segregate this data and investigate how and when the two interacted. Finally, I searched the data for anomalous situations or examples that were substantially different from anything else I had seen or which contradicted the patterns which appeared to be emerging. This helped ensure that my findings did not fall victim to “holistic fallacy,” in which data is viewed as more important than it truly is (Leininger, 1994; Silverman, 2011; Miles, Huberman and Saldana, 2014).

My fourth level of analysis was the creation of flowcharts to visually express the various themes, subthemes, and relationships. While not explicitly part of thematic analysis, this alternate approach to describing the data helped me discover trends or erroneous assumptions (Wheeldon and Faubert, 2009; Braun and Clarke, 2013; Maxwell and Chmiel, 2014). Furthermore, by maintaining each iteration of these diagrams, I could monitor the evolution of my thoughts through time. Furthermore, a useful tool was questioning my thoughts; this assisted me in determining why discrepancies may have occurred and highlighting when these were due to my actions rather than the care home and its actors.

The final analysis stage occurred due to an unanticipated hiatus in my study, which meant I had to re-familiarize myself with my data when I returned to analysis. I used this opportunity to apply a complementary method, coding data again, but this time with NVivo 12 software. This allowed me to verify my themes again, examining them in different ways, such as searching for word frequency or volume of coding, which is considerably easier to do electronically (Corbin and Strauss, 2008; Braun and Clarke, 2013). Figure 4.3, depicts the process for generating emergent themes from the data.

4.5.1 Process of generating themes

Figure 4.4 The Theme Generation Process



The themes following the generation process are captured in Figure 4.5.

Figure 4.5: Summary of Themes

Theme 1: Culture

- Power Relations and Hierarchical Values
- Monitoring and Surveillance
- Obstruction of Work
- Communication, Management and Transparency
- Inspection of the Home
- Approach to care
- Restrictive Practice
- Practices and Habits in the Workplace

Theme 2: Timetables

- Handover and Recording Activities
- Morning Routines
- Afternoon and Evening Routines
- Shift Change

Theme 3: Resistance

- Unmet needs and related, shouting screaming, anger, and agitation, anger and agitation
- Resistance towards timetabled Mealtime
- Resistance towards timetabled Personal Care
- Resistance timetabled Bedside Care

Theme 4: Containment

- Permissions and privileges
- Punishment
- Restrictive practice

4.6 Ethical Considerations

There are many ethical issues, nuances, and complexities when conducting dementia-related research. Ethically, the vulnerability of dementia patients presents a significant challenge. Informed consent is a tenet of ethical research; however, it can be difficult to achieve this from dementia patients because of their cognitive impairments (Dresser, 2000). That often necessitates reliance on proxy consent from care homes or family members, which further complicates the ethical frame. The preservation of the rights and well-being of these vulnerable participants requires meticulous care in the implementation of ethical guidelines and a compassionate approach (Hodge et al., 2020).

Conducting research in care homes logistically can be fraught with difficulty. Accessing care homes involves gaining permission on multiple fronts, such as bureaucratic procedures and clearance from the management, healthcare givers, and, in some cases, the government (Johnson & Karlawish, 2015). Access then needs to facilitate the scheduling and carrying out of informal conversations or observations, with a view to observing the daily routines and medical needs of residents, which can sometimes be unpredictable. In the context of the present study, access was facilitated via the Home Manager.

Methodologically, researchers must face the variability in the progression and symptoms of dementia, which makes the collection of consistent data quite complicated (West et al., 2017). The emotional toll of working closely with residents with dementia is also significant (Johnson & Karlawish, 2015). Researchers must prepare for the emotional strain of decline, which is witnessed in the residents, and the stress associated with this experience. There is thus a need for strong support systems for researchers, such as the provision of counseling and peer support systems.

This research was reviewed and approved by the School of Healthcare Sciences Research Ethics Committee (SHREC) at Cardiff University as well as the administration of the care home research site, which reviewed the participation in Saudi Arabia. I subsequently followed the ethical considerations of informed consent, confidentiality and autonomy to support the research participants, as outlined by Polit and Beck (2010).

4.6.1 Informed consent

Informed consent to conduct research in care homes is approached differently in Saudi Arabia when compared with countries such as the UK. The process of seeking informed consent is tightly regulated and surrounded by strict ethical guidelines in the UK, so that participants' rights are safeguarded. Ethically, the researcher has to seek informed consent directly from participants or their legal guardians, explaining what the research is about and the risks concomitant with it. There is an increased focus on patient consent and autonomy; each resident or their representative has to personally agree that they are willing to be involved in research. Crucially, the care home manager cannot sign any paper on their behalf without their direct consent. Ethical review boards regulate the procedures during consent to ensure the procedures conform to these requirements.

Alternatively, in Saudi Arabia, there may be a more centralized approach, although general guidelines pertaining to ethics in the conduct of research do exist (Woodman et al., 2022). Often, the case is that once a researcher has obtained approval from the Ministry of Health or the local ethics committee of a specific hospital, it is quite common for consent to be signed by the care home manager on behalf of the staff and residents, at the potential cost of compromising participant autonomy and informed consent. The manager's permission is taken to represent consent for the whole facility, which mirrors a more hierarchical approach to decision-making. Thus, for both conscious and unconscious patients featured in the present study, the manager’s permission represented their consent. Furthermore, care homes in Saudi Arabia serve a legal guardianship role for residents once they are admitted. This means that the resident's relatives sign a form stating that the care home manager can make decisions on behalf of the resident, including signing consent forms for medical procedures or hospital admissions. This arrangement reflects the power hierarchy within the care home, where significant authority is vested in the care home manager and staff. The staff members in this hierarchy wield enormous power over the lives and treatment of the residents.

I acquired approval from the Saudi care home to conduct my study, however, I also sought consent from the care staff by way of a consent form attached to an information sheet (see Appendix VI). The information sheet (Appendix V) provided a comprehensive overview of the research study so that prospective participants could make an informed decision about participating in the research. As part of the consent form, participants were informed of their right to withdraw from the study on a no-questions asked basis at any time during the research, and they were assured confidentiality and anonymity via the use of pseudonyms in the present study. Participants also provided consent for their activities in the home to be observed. Due to the exigencies of taking consent from individuals lacking cognitive capacity, it was important to practice process consent (Dewing, 2007) in addition to informed consent and proxy agreement from the care home's manager in cases where residents lacked capacity. I used a form of 'process consent' (Dewing 2007) and, irrespective of residents' mental capacity at the time of recruitment, verbal agreement to undertake the observations was always sought from the resident prior to the period of observation. Process consent has been purposely designed to be used in the case of older adults that have cognitive impairments and thus have a reduced capacity to provide consent (Dewing, 2007). This approach is predicated on ethical decision-making values that recognise the importance of context-specific actions since capacity is situational. Consequently, it supports a particular as opposed to a universal approach to consent (Dewing, 2007). As part of this process, I firstly clarified that permission to access the residents had been gained from the manager. Then I established the basis for consent by referring to the care home manager about residents' capacity. Initial consent was then sought from residents based on their capacity, either in the form of single words, pictorial information or props. Feedback was also garnered from staff and this process was not linear but ongoing.

In this study the presence of people living with dementia and my presence in a person's home in particular, where participants are dependent on the setting (the institution caregivers and staff) in some manner, meant that I needed to maximise participants' ability to express their wishes throughout if I were to be an ethical researcher. Studies have shown that in ethnographic research that involves participants with a cognitively impairing condition which undermines their ability to consent, it is important to combine procedural ethics with lived ethics (Balkin et al., 2023). This was achieved by adopting behaviour that regularly reminded people I was a researcher, such as keeping my notebook visible. This behaviour allowed me to consider verbal and non-verbal communication from participants and react accordingly, removing myself if I felt consent was unclear. This approach served both staff and residents, but it was most significant concerning residents living with dementia. It was not unusual for residents to confuse me with staff, even following formal introductions. By showing that I was ‘different’ in these regular ways, I enabled residents to react to that difference and thus gave myself the opportunity to interpret that as unhappiness with my presence.

4.6.2 Privacy and Confidentiality

In qualitative research, the researcher should respect the participants’ privacy by assuring anonymity and confidentiality (Creswell and Poth, 2018); this can be complex, particularly in institutional settings. This is because these concepts are already challenged by the nature of care needs and behaviours that blur the boundaries between public and private spaces (Hammersley and Atkinson, 2007; Tinney, 2008), especially in private care, personal care, and toilet care. In order to protect resident privacy during personal care activities, I observed only in public places. But for the transparency and data saturation of this research it was necessary to obtain approval to enter the toilet zone. However, in reality private activities were often treated as public by staff, this necessitated action by myself to ensure I did not take advantage of the situation. This was because the bed’s positioning meant that the caregiver could see me watching from the corridor as she attempted to remove any incontinence protection. As I was sure she could distinguish me from a staff member I felt this was an invasion of her privacy, even though this was caused more by the institution (staff routinely left the dorm door open) than my research. Having a sufficiently flexible approach to ensure the maintenance of high ethical standards without compromising the study is important for any researcher (Watts, 2011).

Therefore, in addition to adapting my behaviour during fieldwork, I used several techniques to preserve privacy and confidentiality in the field and in writing this thesis. Firstly I was mindful of using shorthand and pseudonyms when taking notes in the field, so that if someone read my notes it would be difficult to identify individuals (Watts, 2011; Braun and Clarke, 2013). Secondly, pseudonyms for individuals and homes have been used throughout this thesis as a recommended way to avoid identification (Hammersley and Atkinson, 2007; Braun and Clarke, 2013). Nonetheless, an absolute guarantee of anonymity is problematic as individuals are likely to be able to identify themselves (Murphy and Dingwall, 2001). I therefore aimed to show respect to participants and settings in my writing. I also safeguarded participants’ privacy and confidentiality by storing my field data on a password-protected device in line with university requirements and the Data Protection Act 2018. The password-protected device is only accessible by myself and the stored data will be destroyed following the grading of the present study.

4.6.3 Ethical Duty

Using participant observation as a method to explore the daily experiences of residents with dementia in the care home setting required that I take up a dual role. Bloomer et al. (2012) highlighted the methodological challenges linked with this approach, in terms of balancing the position of nurse and researcher and determining what the research limits and boundaries are. As a nurse I had an ethical duty to report any accidents and instances of abuse which I observed during fieldwork as stipulated on the information sheet (see Appendix V) issued to participants. I upheld this duty of care by reporting such instances to the relevant managers when I observed them, based on the established protocols for reporting in the care home. Specifically, two incidents of abuse during toilet care were reported verbally to the home manager as required on my written pledge form.

4.7 Pre-Fieldwork and Entering the Field

Before I entered the field, I created a fieldwork diary to document my research experiences and the process of identifying and gaining access to the site of study. My fieldwork diary enabled me to organise the administrative aspects of my research, who I had spoken to, what had been said, and what I had observed. It constituted a form of data collection via which I documented the processes of entering the field, the care home. During the pre-fieldwork stage, I gathered information about the home's management practices, its administrative set-up, the personal characteristics of its staff and residents as demographic data, and my initial perceptions of the home's culture and practices. My field notes remained a critical tool after I had gained entry into the field.

4.8 Rigour

According to Morse et al. (2002), rigour in qualitative research is vital to the significance of the study and the contribution of knowledge. Credibility was maintained throughout this study by ensuring that residents' views were faithfully transcribed, described, and interpreted (Sandelowski, 1986). I made sure to stay sensitive to the experiences and views shared by the residents and caregivers to enable clear and true representation of their perceptions. Moreover, peer debriefing was also used to ensure credibility by discussing methodology, data analysis, and interpretations with supervisors who had expertise in qualitative research (Hadi and Closs, 2016; Lincoln and Guba, 1985). This debriefing evoked deep analytical thoughts and enhanced criticality in data interpretation, this helped me to ensure that the interpretations were grounded in the data with reasonable links and relationships (Long and Johnson, 2000).

Credibility is used to determine the study's internal accuracy. It addresses the consistency of the study findings with the observed phenomenon. It also establishes the researcher's level of confidence in the findings based on the research design, informants, context, and reviewed documents (Lincoln and Guba, 1985). According to Krefting (1991), the truth criterion determines credibility, this is supported by the researcher's belief in the veracity of the findings. The following strategies were used to confirm credibility: first, the audit trail required a detailed account of the research process which provides an overview of the coding process. It describes how data were collected, conclusions were reached, themes were developed, and decisions were made (Merriam, 2009). It was used to reflect the study's evolving nature, reveal bias, connect research questions and data, outline steps in data analysis, and present an interpretation of the findings in a logical and synthesised manner (Carcary, 2009). It aided in reflecting evolving thoughts and perceptions. Another strategy used to ensure credibility was thick description. Denzin (1989) defines thick description as "detailing the context of an act, stating the intentions and meanings that organise the action, tracing the evolution and development of the act, and presenting the action as a text that can then be interpreted" (p. 33).

Transferability refers to the study's external validity and the extent to which it can be applied in other contexts, where "the original enquire cannot know the sites, but the applications can and do" (Lincoln and Guba, 1985, p.298). Readers, not the researcher, bore the burden of proof (Merriam, 2009). The respondents and research site were carefully sampled in order to aid readers' decision-making in other contexts (Merriam, 2009). While the sample size was small, the goal of purposive sampling is to derive data from a group of individuals who can provide knowledge for answering research questions, based on their expertise or experiences (Etikan et al., 2016). Thus, purposive sampling is not underpinned by quantitative goals.

In qualitative research, dependability refers to consistency. It corresponds to reliability in quantitative research because it focuses on "how can an inquirer persuade his or her audience that the inquiry's research findings are worth paying attention to" (Lincoln and Guba, p. 290). It is about the consistency of the research findings for others to replicate, which is based on extensive original research (Merriam, 2009). I articulated the research design in such a way that it was consistent across time, researchers, and analysis techniques (Guba and Lincoln, 1985) by going back and forth between my research and existing studies in the literature through a triangulation process, to illustrate external validity.

Confirmability refers to how collected data supports qualitative study findings to confirm their credibility. It is about how easily other readers or reviewers can confirm the findings. In this regard, conformability allows readers to concentrate on the uniqueness of the study context (Denzin, 1994). I promoted confirmability by providing detailed data transcripts as a testament to my findings and running back my findings with the participants.

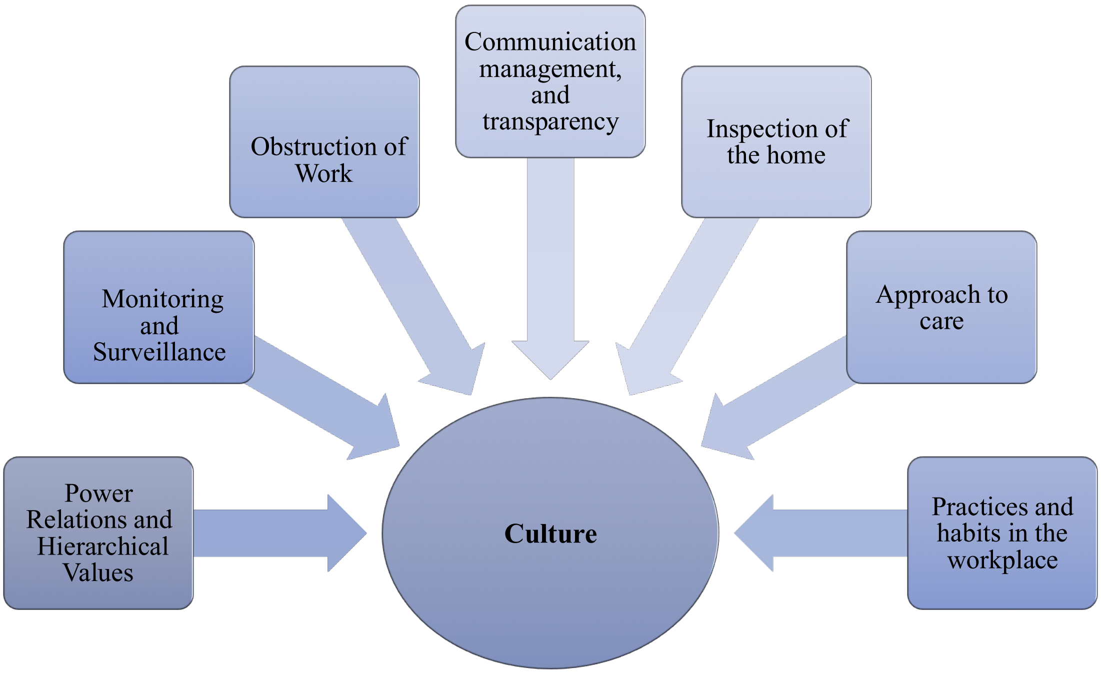
4.9 Chapter Summary

This chapter has provided a comprehensive overview of the research methods that have been employed in this study. The chapter has outlined my philosophical positioning and how this has influenced the methodological choices and research process as a whole. The contextualised overview of the research process enables the research findings presented in the next chapter to be situated within the boundaries of my research, which I have outlined in this chapter.

Chapter 5: Theme 1: Culture

When examining the daily experiences of residents with dementia and their care staff in the residential home setting, the organisational culture must be considered in keeping with the ethnographic approach of this study. The organisational culture reflects the power relations and hierarchal values in the home, monitoring and surveillance regimes, as well as practices that lead to difficulties in working. It shapes the workflow of in- care home, the underlying values about care and the day-to-day behaviours linked with these in practice, as well as the ethos of care built around residents with dementia. Organisational culture shapes decisions about care, it is embedded in managerial practices and work processes which indirectly shape the care of residents with dementia. For this reason I began by exploring the power relations and hierarchal values that permeate all relationships and practices in the home. Next, I considered how monitoring and surveillance regimes embody the symbolic culture of work at the home. In this chapter, I explore how daily routines and rituals of care are conveyed in toilet care and snack time, for example, structure the care staff's work and dementia residents' experience of care. In doing so, I offer an account of the normative organisational culture at the care home.

Figure 5.1 Overview of Theme 1



5.1 Power Relations and Hierarchical Values

During my fieldwork at the care home there were several occasions when I observed healthcare practices between doctors and nurses that appeared to be configured based on specific power relations; a hierarchical structure with relationships of order, roles and levels of importance characterised the care home. This was made clear during an afternoon shift when I walked into the nursing room as the doctor sat behind the nurses' desk with Wahida, the Indian nurse, standing next to her. The doctor elevated her head a little, looked at me from above her glasses, then continued to work on some papers, but she did not talk to me. The desk was full of papers and residents' profiles. As I sat down to talk to her, she asked nurse Wahida:

> Doctor Fifi: *"Where is the paper? What is this? What kind of nurses have I got?"* with an aggressive and accusatory tone while she searched the file.
> Wahida appeared nervous and tried to find the paper while the file was in the doctor's hands. I did not know what this was all about. Nurse Wahida found the paper, and in a soft tone she said: *"Here it is Doctor. It was here, but you could not see it!"* She handed it to the doctor. The doctor took the paper, looked at it, and wrote on it. I found out later that it was a medication sheet. Once she finished, she closed the file, and Wahida left the room. (Observation)

The interaction above was evidently predicated on the dominance of the doctor who leveraged a simple request for a medication sheet to exert her authority by displaying controlling and commanding behaviour over the nurse. She also failed to respect professional boundaries by speaking aggressively to the nurse and denigrating her competence as well as that of her peers in general, in an unconstructive way. The dominance of doctors was also made clear in decision-making scenarios about healthcare, for example, when I questioned a nurse about healthcare instructions documented on a whiteboard in the nurse's room:

> Researcher: "*Can you tell me about all these instructions?*" pointing to the white board.
> Salma: [with a wry face] "*Doctor's instructions!*"
> Researcher: "Y*ah, I can see her signature below. But what do they mean?*"
> The board has instructions dealing with insolation times, opening window times, diluting mashed food in milk for the residents who are unable to eat, starting an IV fluid line in the event that any resident vomits more than three times, with a table that shows the fluid name and the calculation, and a paper for the lab work due for each resident.
> I was curious about the window and isolation time.
> They laughed sarcastically which made me laugh too.
> Researcher: "*What?*" in a surprised voice.
> Salma: "*Did you notice that today is different? It's very relaxed. We do the work calmly because she is on leave*." Salma was referring to the Home doctor." (Informal Conversation)

Salma's response to my enquiry shows how doctors constitute the dominant health profession in the care home, with the authority to prescribe medicines and provide guidance on nutrition and care plans. We can also assume from the interaction that nurses' perception of doctors as hierarchically superior leads them to frequently recourse to using doctors' advice so that they have little or no input in healthcare decision making as nurse Salma recounted. Thus, opportunities for professional collaboration via consensus building are undermined because of formal authority flows. Salma's statement above about working more calmly as a result of the doctor's absence also illustrates how power exercised by doctors, who are at the top of the hierarchical structure, contributes to tense interpersonal working relationships with nurses, as was also highlighted during a conversation I had with nurse Nisrean:

> Researcher: "*What is wrong, Nisrean*?"
> Nurse Nisrean: "*I do not want to see the doctor*."
> Researcher: "*Why*?"
> Nurse Nisrean: "*We're having some trouble but don't worry*."
> Nurse Nisrean, with a smile: "*It is not a secret. Everyone here knows. Wait until she leaves then we can talk*" (Informal Conversation)
>
> The doctor passed along the corridor and left the floor and we were able to see her go. I looked at nurse Nisrean and I said: "*She's left. Is it a tense relationship*?"

> Nurse Nisrean (talking after taking a deep breath): "*You may have noticed how she treats us, with a lack of respect. She always says 'stupid nurse' and we had a clash one day when she said it to my face. I replied to her and told her that she was disrespectful, what do you think we are working for you? Then she caught herself and said 'No I don't mean that, I am sorry.' Since then our relationship has not been good. She is the one who does our evaluations and in the last 3 years I have had a bad evaluation, and my salary has been decreased because of her. We all knew she had been through a lot of negative circumstances in her private life, and we tried to give her excuses all the time, but we get tired. What is really the matter is how she is behaving towards us. Is that right*?" (Informal Conversation)

The dominant leadership style of the doctor meant that she did not communicate professionally and effectively with nurses, resulting in perceived bullying and the use of offensive language. The doctors' crossing of professional boundaries created new obstacles to positive communication and undermined nurses' trust and respect. Despite conflictual relationships, power was constituted in working relationships in ways that afforded professionals with perceived greater knowledge and legal authority a privileged position including the right to make demands or requests of others working within the home even when these demands did not align with acceptable healthcare practices. This became apparent when for the first time in the lunchroom I saw nurses preparing mashed food for residents who were unable to eat and asked for an explanation for this practice:

> Researcher to Nurse Um: "*I thought the food was prepared in the kitchen*?"
> Nurse Um (in an angry voice): "*This is the doctor's orders!"*
> Researcher: "*Could you explain*?"
> Nurse Um: "*The food arrived from the kitchen, as you see on this trolley*" (she points to the food trolley- two layers trolley with wheels covered with blue sheet).
> Researcher: "*OK*."
> Nurse Um: "*Then we mashed the food in the blender on the doctor's orders*."
> Researcher: "*Why is the kitchen not preparing it*?"
> Nurse Um: "*The kitchen used to do it in the past, but then the doctor decided that we 'the nurses' have to do this duty*."
> Researcher: "*Was there any incident behind this order*?"
> Nurse Um: "*No, she just wants us to do some work!"* (Informal Conversation)

It is the doctor who bears primary legal responsibility for the residents in the care home; thus, the role of the nurse is subservient to theirs. The doctor sometimes misappropriated the power they exerted in the care home's vertical relationships as shown in the following example, where the home doctor Fifi asked a nurse to visit her at short notice in her own private home to provide her, her family, and her guests with a private nursing service (an influenza vaccination). A senior nurse Judith recounted her story during our lunch break. Judith has been working in the country for over ten years, she can speak Arabic clearly, and she is fully cognisant of Saudi culture:

> Nurse Judith: "*She (home doctor) called me on my off day and asked me to prepare myself because she would come and pick me up from my accommodation to go to her home. There was a family gathering, and she wanted me to administer the vaccination to them! She had a lot of vaccination ampules, and there were almost 20 people. I did not expect that*."
> Researcher: "*What did you not expect*?"
> Nurse Judith: "*I do not know; it is not my duty to do this!! I am not her private nurse!! They treated me very well when I was there, she was friendly, and she gave me money for it*."
> Researcher: "*Why did you not refuse to go?"*
> Judith, with a surprised face: "*No, I cannot"*
> Researcher: "*Why do you think you cannot?"*
> Nurse Judith: "*She [home doctor] will be mad at me! (pause) I would not mind because if I did not do it, someone else would do it, right? But in my opinion, I still think this is not my job!"* (Informal Conversation)
>
> Judith raised her shoulders frequently with startled facial expressions when she was telling her story.

In the discourse above, power differentials where doctors exercise their authority not only at the time of care procedures but also in the private domain is evident. In this account, the seeming misuse of authority to take action in a personal interest is conducted by a person in a superior position, "the home doctor", which implicitly emphasises the direction of power in the care home. When I enquired later about the norms pertaining to re-directing care towards the private domain, or jobs outside the care home with Samira, a supervisor, she remarked as follows:

> Samira: "*No one is tracking! These things may happen, but it is rare"* (Informal Conversation)

A consequence of the organisational culture was that some nurses became disillusioned by their work which led them to adopt impersonal attitudes in the care home, adversely impacting the care of people with dementia. Nurses became detached from their duties and thus, performed them in a highly routinised way. Professional roles were delineated between the home team, care staff and 'watchers'. The caregivers are also called 'watchers' by the care home staff because they are responsible for watching residents for the duration of their whole shift; they have limited qualifications. This offers another example of how power is constituted in professional roles in ways that afford those with greater knowledge a privileged position. Watchers who transferred from children's rehabilitation had received basic assistance training in the areas of bathing, cleaning, dressing and feeding, while the others had not; they learned on the job from the senior care staff, as the carer Bath explicitly stated:

> Bath: "*I do not have a certificate; I trained for two weeks for basic needs before I worked at the children's rehabilitation centre*." (Informal Conversation)

Power was also constituted in professional roles on the basis of nationality; I took the following field note after observing staff interactions during an afternoon shift:

> There are some unwritten hierarchies in the home. These are nationality-based. The Saudi nurse is the head nurse because she is the only Saudi nurse in the home. Nurse Salma is the second in charge. I noticed that when they gave orders to the caregivers, the latter have to obey them; even the administration and the supervisors respect them more than the other nurses. I will say that Salma is even more powerful than the head nurse because she lives with the staff at their shelter. As a foreigner working for a company, she does a 12-hour shift, as do the other caregivers. She also works on the weekend.
>
> As a result, other workers feel she is one of them. On the other hand, the Saudi nurse, a government employee, has the civil right to only work for 8 hours/day with the weekend off. The other nurses do not possess the same power. They do their nursing duties. From the outside, it looks like a family relationship. However, the interrelationship conflict can be seen when you spend time in the home. I want to reflect further on the people and power aspect and consider how people in power can shape the working environment. I was shocked when I found out from the staff that the home doctor is not a geriatric doctor. However, she has full power in shaping the home as a supposed expert in every major area. She takes on the nutrition role and the physiotherapy role. She indicates what people can eat and their portions of food and drink. She is the one who orders the time spent outdoors. The funny thing is that the home manager and the supervisors know about this, and they said that she would leave the home soon so her lack of speciality should be ignored. Concerning the personal side, I wouldn't say I liked her attitude and how she speaks to the caregivers. (Field Notes)

Power differentials constituted a source of interpersonal conflict in the care home. The interdepartmental tension at the managerial level led to friction where nurses and care staff were made to understand that they should accept all the doctors' personal behaviours with no questions asked. They were tasked to focus on their professional roles as carers and ignore perceived personal offences:

> Head Nurse Nisrean**: "***She, referring' to the home physician, and called me a 'stupid nurse*'!" (Informal Conversation)

Language is a barrier to communication between the care staff and residents within the home, it can cause interpersonal conflict between staff and between staff and residents. I talked to many of the care staff during my fieldwork, they would chat with their colleagues in their mother language (Indonesian) before responding and answering my question. I did not know whether they were talking about me or were filtering and discussing what they wanted to tell me. The caregivers communicated with the residents in broken Arabic most of the time and did not understand what the residents were saying, this created misunderstandings of problematic issues, here is an example:

> Resident Halima: "*I want cold water*."
> Caregiver Sue: "*No more*." (Observation)
>
> The resident gets angry and shouts at the caregiver's face, "*how could you say this, it is not from your wallet*", because 'no more' in Arabic suggests that there is cold water, it is available, but I don't want to give it to you. On the other hand, the caregiver did not mean it in this way, she wanted to tell her that the available water is not yet cold enough. (Observation)

Language groups are dominant in the care home; caregivers have their native language, while the rest of the staff speak in Arabic. Any issue raised with native language usage turns into a battle of languages as captured in my field notes:

> There was a conflict between one of the social workers and one of the caregivers. The caregiver began speaking with colleagues in her own language, and they were responding to her. Although I could not understand what they were saying, I had a feeling it was not good, and although we could not understand their speech, their voices start to rise up, the social worker returned to them, and she said in a sharp tone do not keep talking about this now, do not wake the residents with your voices, she added "Hamajia", which in the Arabic language means barbarism.
>
> The carer looked at the researcher and asked: "*What does this mean*?" (Field Notes)

Thus, while existing power relations adversely shape relationships within the care home, there are also other mediating factors such as language which impact upon inter-personal relationships among healthcare professionals, and between healthcare professionals and residents.

5.1.2 Autocratic system

Care staff's work in the home was regulated by an autocratic system which was inextricably linked to the power hierarchies in the organisational culture. The autocratic system, while symbolic of the organisational culture, was manifested normatively through the micromanagement of care staff's work, lack of managerial support and a surveillance and discipline culture that permeated workplace habits and practices.

5.1.2.1 Micromanagement Style

Within the care home environment, the staff who delivered direct resident care were answerable to two departments: the nursing and the caregivers' departments. Although the caregivers' evaluations were completed by their supervisor, the nurses' evaluations were completed by the home doctor, who was not privy to their daily undertakings. The dilemma of falling between two departments was described by the nurses as meaning they struggled to obtain appropriate support or to obtain an evaluation that would support and lead to the progression of their careers.

> Head nurse Nisrean: "*The most confusing part is that our annual performance appraisal is conducted by the home doctor. We struggle to ask the question of who is our boss? What shall we do in case of conflicts? We are not supported by the nursing department*" (Informal Conversation)

At the care home, this relationship between a perceived high-status worker (the home doctor) who holds the authority and low-status worker (a care worker) who has no power is complicated. Indeed, it is the cultural norm of the autocratic system. This power imbalance was referred to and had an influence on workers' thoughts, feelings, and behaviours.

> Head nurse Nisrean added: "*I do not even have the authority as a head nurse to evaluate my nurses, I have no role except making the monthly nurses' rotation schedule*" (Informal Conversation)

As mentioned earlier, the doctor, who has higher status and therefore, power, said she had been evaluating the head nurse's performance and found it unsatisfactory in the annual report for the last three years. This limited the head nurse's salary and ended her chances of promotion. The head nurse described that this happened to her because she had a voice and refused to accept any disrespectful behaviours. Negative reinforcement and punishment were used to enforce the rules. In this observational quote, the home doctor has abused her power in a personal issue and she has violated the head nurse's rights in promotions:

> Nisrean: **"***Everything is under the control of one person, she [the doctor] is like an Octopus*!" (Informal Conversation)

The care home staff felt that the administration failed to support them when they experienced complex life events. Some of them lost a family member, and another described being unable to obtain approval to spend a night outside the dorm with a family member who visited the country.

> Caregiver Samiah: "*I left my country to support my family financially, my son was six months when I left him, but he died while I was here in Saudi. He got a respiratory infection, my contract states that I cannot leave the country once I arrive until I finish my two years, I talked to the administration if they can help, but they could not!"*
> Another caregiver Ayah commented: "*We are just carers, they see us as a machine, nothing more*." (Informal Conversation)

This caregiver spoke with tears in her eyes and pain in her voice. She had to work in conditions which in turn influenced her performance, so as a response to this, she was transferred to work in the kitchen as a chef assistant. This micromanagement approach led the care home nurses to feel a stifling of agency as they felt that they were without autonomy. All the decisions were made without considering the staff's input, which had a negative influence on their reported job satisfaction and their satisfaction with life in general.

In a hierarchical, bureaucratic organisational culture, senior managers have direct control over the goal orientation of their subordinates. Consequently, the subordinates follow a fixed daily routine to control and adjust their daily work, this was observed in the care home. This structure afforded fewer opportunities for the transfer of valuable knowledge and arose as a result of this recourse to formal control mechanisms. From a cultural conflict side, foreign staff also experienced difficulties in interacting with physicians' behaviour and dealing with unsupportive administration. Their knowledge of Arabic was not as strong as the native and Arabic staff; as such they felt that the administration team were not as friendly with them as they were with the Arabic staff:

> Carer Hadeel: "*I felt negative about continued contribution; our effort was disregarded; foreign staff are vulnerable to managerial sanctions despite the existence of the contract, as they were protected least due to their foreign status*."

> Carer Lina: "*I don't take the risk to convince any person here because of the language; Saudi staff had more power to go against conformity as they did not share the same fears*." (Informal Conversation)

These frictions frayed the relationships between the teams further and caused the care home staff to be sceptical about their organisation. Due to this, the care staff and native nurses had little motivation to reach across and work together to improve the residents' wellbeing. In conclusion, interpersonal conflict is a consequence of accumulated problems at the management level and the organisational level; it is rooted in organisational differences and socio-cultural differences, this may need further research to ensure causality is accurately revealed. Evidently, as shown in this section, culture in the care home is rooted in hierarchal power relations that impinge on healthcare practices; as the subsequent section will show, the care home culture is also shaped by specific monitoring and surveillance practices.

5.2 Monitoring and Surveillance

A monitoring and surveillance culture in the care home was evident, it was designed to regulate care staff's work. Surveillance was an ongoing process to identify potential threats to residents, in the form of staff abuse. Surveillance was performed by the home supervisors, who do not play a role in providing direct resident care. Thus, home supervisors utilised their expertise, early recognition skills and analytical skills to identify threats to residents' health and safety potentially emanating from staff.

A secondary purpose of surveillance and monitoring was to ensure that care staff upheld the rules, procedures, principles and values underpinning the home's approach to wearing uniforms and adhering to dress codes in keeping with social care standards. Against this backdrop the purpose of monitoring and surveillance was to ensure that care staff presented a professional and suitable image, to support infection prevention and control and food hygiene measures delineated in keeping with relevant policies and procedures. Monitoring and surveillance also supported the health and safety of staff who might have been impaired by inappropriate clothing or footwear. Monitoring and surveillance procedures ensured that all care staff subscribed to existing policies and procedures. It is well recognised across Saudi Arabia that some foreign workers violated the rules concomitant with their 'iqama'. This is unique to the Gulf countries and is similar to the residency cards in western countries by leaving the work that they have been recruited for to work illegally in the country in a different job. It is very common for foreign workers to take up posts as domestic workers in private households where salaries are higher. There is a history of such occurrences in the care home, whereby care staff were described as “escaping”. Through surveillance practices, the behaviour of care staff was monitored to ostensibly inform safety practices although safety was not guaranteed by some of the policies put in place. One such action was to lock all but one emergency exit in the care home. The only emergency exit door at the care home was locked by the senior team, and the key was held by the main home supervisor during shifts:

> Supervisor Maryam: **“***The door was open before, but we had an incident with the care staff; they escaped. This exit has a direct path to the street; it doesn’t go through the main entrance door, so they escape and join the violators of the residency regulation system across the country.”* (Informal Conversation)

During an afternoon shift when I was moving around in the care home halls, I noticed an orange door that had a green label above it. I found that the door was locked with a big padlock. I asked Supervisor Maryam why this was the case, she explained and took out a key from a pocket which was inside her black handbag. This constitutes a serious safety threat since in the event of an emergency, access to the door will be contingent upon an individual (Maryam) possessing the key or not. For the care home, however, locking the main exit doors is an example of how monitoring and surveillance constitutes a preventive solution aimed at curbing care staff from running away. However, actions in response to the identified threat in the form of locking emergency exit doors place the residents and staff at risk. All the residents were immobile within their rooms or ‘dorms’ on the second floor. Furthermore, only one bed at a time can go through this emergency door, and the home only has one sledge, which is used to roll the bed wheels to evacuate residents. As per the exchange below, care staff also lack the requisite skills and knowledge to perform evacuations correctly, which is risky:

> When I was standing at the lobby doorway with two of the care home staff and watching committee members from the Ministry of Social Welfare, who were visiting the care home as inspectors. Moving between residents' wheelchairs nodding while they were passing the corridors and their heads with smiles on their faces saying in a low voice “*how are you*” to the residents, I remembered the locked door story so I decided to ask her.
>
> Researcher: *“Do you know how to evacuate the residents in case of emergency?”* in a shocked face with half a smile she replied “*what do you mean*?” while turning her head away and checking her residents with her eyes.
>
> I repeated my question “*do you know how to evacuate the resident in case of emergency*?” Carer Emma: “*No, we do not know! No one has told us!”*

> She left me with no additional comments she walked to the resident's bedside and started playing with her by holding her hands and counting the numbers in her fingers. (Observation documented and fieldnotes)

As I have noted, a secondary purpose of surveillance and monitoring was to ensure that care staff uphold the rules, procedures, principles and values underpinning the home’s approach to wearing uniforms and adhere to dress codes in keeping with social care standards. Care staff were expected to comply with a number of regulations. For example, they were not allowed to have cosmetic products on their faces and were not allowed to carry any camera or cell phone inside the home:

> While I was checking the residents’ dorms, Mia, one of the care staff, was holding her lipstick in her right hand and facing the opposite side of the wall, so you could not see her front when you entered the room when she saw me she looked irritated and tried to hide what was in her hand (a lipstick and eyeliner) in her pocket quickly, she looked at me and smiled. I was able to see what was in her hand before she hid it, so I said:
>
> Researcher: “*You look pretty with this lipstick colour*.”
> Mia replied: **“***No, we should not have this; we should not have any cosmetics on our faces; this is the protocol here! Before the shift starts, they check our handbags and our face. If we have any make-up on, they will remove it, but today I’m hiding it because I was so tired, and I want to look good*” (Observation documented and field notes)

Conversely the home supervisors, who do not provide resident care but oversee working practices to ensure that care staff present a professional and suitable image and enact infection prevention and control and food hygiene measures delineated in keeping with relevant policies and procedures, are exempt from this regulation.

The care home has a video monitoring system that is used for observing and watching caregivers and monitoring nurses to ensure they do not abuse elderly residents. In an informal conversation with the home general supervisor in regard to the monitoring system in the care home, she felt that it was important and beneficial to ensure the residents’ safety:

> Mrs Shamah, the Manager: “*One of our residents had an abscess on her tooth, and during toilet time, her caregiver held the resident’s mouth on the painful side and pushed it, trying to increase her pain and make it worse. I was watching her in silence; when she noticed I was there, she acted as if she was playing with the resident and said, ‘I love you, Mamma’, referring to the resident as Mamma. This is one of the incidents that I saw; I am sure there were a lot of others that we could not see.”*

> Researcher: "*I acknowledge that you have been very open in talking about the abuse the residents were exposed to.*"
> Mrs Shamah replied: "*It is our role; we should identify it and prevent it. Some of the residents were complaining about caregiver violence, and during our assessment, we saw some bruises on their skin. However, we cannot determine whether that happened because of caregiver violence or for some other reason. Also, some of the residents were complaining about the caregivers' behaviour in the toilets during cleaning and the diaper change. So yes, the cameras and monitoring systems clearly help us limit the possibility of such incidents against the residents and limit the caregivers' abusive behaviours; they have the feeling that they are watched, so they control themselves*."
> (Informal Conversation)

Although the care home manager stated that the monitoring system limited the abusive behaviour against the older people in the care home, residents were still exposed to harm in the individual toilets inside the toilet zone. The cameras were removed from the inside because of privacy concerns. Cameras may be reviewed by males, such as the inspector and control committee, which raises the issue of privacy and ethical duty. One of the residents indicated she was exposed to the abuse in the following example:

> While I was walking in the corridor, a slim lady with beautiful brown eyes, resident Salha, who has paraphasia and immobility was sitting in her wheelchair in dorm five, she waved to me with her tiny hand to come. When I came closer to her, I bent my head so that I could hear her low voice which trembled. She asked me for water, so I brought a small water bottle, and I opened it before I handed it to her. She drank just a few sips and handed it back to me.
>
> The caregiver looked on in silence, but her facial expression indicated she was not comfortable.
>
> I asked the resident: "*Are you ok?*"
> Resident Salha: waved her head to indicate "*Yes*."
> Researcher: "*Do you want to tell me something?*"
> Resident Salha: "*No*".
> Researcher: "*Did she, the caregiver, do something to you in the toilet*?"
>
> (I asked because Salha had just finished having her continence pad changed in the toilet, and she was looking at her caregiver with frightened eyes)
> The Resident looked back to make sure the caregiver could not see her
> Researcher in a reassuring voice: "*Do not worry, she cannot see you, and she cannot hear us*."
> Resident Salha moved her right hand toward her left breast and made a tweak gesture to show that the caregiver had tweaked her during the changing time.
> Researcher: "*Did she pinch you?*"
> Resident Salha nodded to indicate yes

> Researcher: “*Was it the first time?”*
> Resident Salha: “*No”*
> Researcher: “*Did you tell any of the supervisors’ home monitors’ before?”*
> Resident Salha shakes her head emphatically to indicate no
> Researcher: “*I am sorry for what happened to you; I will try to tell the supervisor, ‘home monitor’. Is that ok?”*
> Resident Salha: “*Maybe she will tweak me more!”*
> Researcher: “*Do not worry; I promise I will not let her know that you said anything about it, ok?”*
> Resident Salha: “*waved, ok.”* (Informal Conversation)

In response to this conversation, I had an ethical duty according to the Written Pledge form (see appendix) to report the incident to the supervisor to ensure that the resident would be protected from the abuse. Thus, I engaged with the supervisor Sara and reported what I had heard from the resident, Salha;

> Supervisor Sara said; ‘*oh, ok, I will keep my eyes on them.”*
>
> Sara was not shocked by what she heard from me; her face was calm and not surprised as if the abuse had happened before, however;
>
> Sara added; that “*we have heard similar stories from the resident against this particular caregiver, so I will make sure that my colleagues are focusing their eyes on her too*.” (Informal Conversation)

Unfortunately, it is clear that everyone in the care home is experiencing abuse and violence but in a different form; the residents are experiencing either physical or behaviour violence, while the care workers are mainly exposed to control.

Although care staff are the backbone of the home, their duties are fixed. They are responsible for the overall care of residents, including personal care, continence care, dressing, feeding, room tidiness and physical assistance as I captured in my field notes:

> The watcher finished cleaning Huly and asked her to stand. Again the resident stood alone by herself without any support, while the watcher wiped up the area with the towel and applied a new diaper while the resident was standing and facing the wall. (Field Notes)

Overall, they serve as a porter to the residents. Staff nurses and the home supervisors are responsible for observing the care staff and ensuring that they maintain the daily scheduled routine. Alongside their duties of assisting the residents with feeding, toileting, and cleaning, the care staff begin each shift by arranging the residents’ clothes on the shelves in a specific order, cleaning their rooms, tidying their beds, washing their wheelchairs, cleaning the floors, the kitchen, and the toilets.

Each is assigned a room and must watch the residents for the entire shift (see table 5.1). They are not allowed to leave their residents' rooms under any circumstances because the rules state that residents must never be left unattended as is clear from my field observations:

> What grabbed my attention was that the caregiver was sitting at the entrance to the room on an uncomfortable chair, watching the residents. Why was she sitting like that as an officer, as if the residents were inmates? This was true of all the other rooms. We were in room 5 when I asked nurse Salma why the caregivers sat like that. She replied that it was their duty to stay in the room watching the residents and providing them with what they needed. They were there if the residents needed a drink, to change their diapers or clothing, and to ensure their safety by preventing them from falling. I nodded, but in my heart, I felt sorry for these caregivers. (Field Notes)

On every shift, two emergency care staff do not directly handle residents' care but assist in transferring/lifting them and act as substitutes for the care staff when they need to leave their designated room.

5.3 Obstruction of Work

Work in the care home is occasionally obstructed due to unsatisfactory labour conditions, sometimes resulting in staff strikes. The organisational culture is unable to attend to the care staff's demands for better conditions and flexibility, and the inability to address these tensions via trade-offs culminated in work strikes.

The conditions of work present a risk to care staff's physical and mental health, they must work long hours while ensuring the residents health and safety. This was evident in the case of nurse Salma during an afternoon shift when I entered the room of a resident with dementia who had been recently diagnosed with metastatic cancer. Nurses' experiences are exacerbated by their separation from their families, this can lead to resentment and a lack of empathy and impacts the quality of care they provide:

> Researcher: "*Hi Salma, how is she*?"
> Nurse Salma: "*Don't think about them, think about us, these elderly have lived their life and they are here to die! Think about us, we also want to live our life before we reach this stage*!" She was very angry.
>
> I was shocked and speechless. I did my best to hide this.

Researcher: "*Why do you feel like that*?"

She ignored me, and with tears in her eyes, left the room. I was worried about her. She was not the Salma I had observed previously. Something had happened, so I went to the nursing room to check. Nurse Um and the Indian nurse Wahida were there when I entered the nursing room.

Researcher: "*Nurse Salma looks unwell, do you know what's happened with her*?"
Nurse Wahida: "*They refused to let her husband visit*."
Researcher: "*What do you mean*?"
Wahida: "*We are not allowed to leave the dormitory except for grocery shopping, and if we want to leave for any other reason, we have to submit a request. So her husband wanted to visit her this next weekend, but her request was refused. I was on vacation in India and I just arrived yesterday, do you know what I am thinking about*?"
Researcher: "*No*."
Wahida: "*About my husband too, these people do not understand that we are human like them*."
I nodded. I had nothing to say. (Informal Conversation)

Punitive measures are in place for care staff who cannot keep up with excessive workloads which they view as inhumane. Staff are separated from their families due to the nature of their work, thus the inhumane conditions have an exacerbating effect. Strikes, therefore, constituted a response to these conditions, as care staff sought to ensure a balance in company policy, their need for safety at work and humane working conditions, and residents' health and safety. The caregivers in the home worked six days per week with one day off. Every two weeks, they alternate from day duties to night shifts. Care home policy states that caregivers must stay awake during day and night shifts, irrespective of whether their residents are asleep or awake. Care staff complained about the impact of excessive workloads on their physical health and how this impaired their ability to perform their duties efficiently:

Researcher: "*You looked tired, what's happened*?"
Caregiver Sali: "*They brought us here too early because night shift refused to work, they woke us at 2am. We finished our duty yesterday at 7pm, we went to our apartment at almost 8pm. We went to bed at almost 11pm, after we had had a shower, dinner and washed our clothes*."
Caregiver Logayen intervened: "*If we do not get a good night's sleep we will not have the strength to work*." I nodded in agreement.
Caregiver Logayen "*How can we hold the elderly, bathe them, change their diapers and feed them if we are weak. We may lose hold of them, and then who will be blamed, we will be in trouble*!"
She looked at me and said, "*Is that alright*??"

Again, I nodded. I did not know what I should say. In my heart I supported them completely, but I could not say it.

Researcher: "*What do you think about that*?"

> Caregiver Logayen: "*They should treat us as human beings. What they are doing is inhumane, none of us will renew their contract when it is finished*."
> Researcher: "*What happened last night, did your colleagues on the night shift refuse to work*?"
> Caregiver Logayen "*Yes, we agreed with what they asked for, routinely the shift changed every two weeks, between the night and the morning staff. At night, between 12.00am and 4.00am there is no work. We just sit on the chairs and watch the residents while they sleep. Why can't we sleep at this time? We did not ask for a lot, we will sleep on the floor, or even put our heads on the desk! We will rotate between us so the elderly will be watched, and if they need something the caregiver in the next room will respond*" (Informal Conversation)

Illustrating their dissatisfaction with this rule, the care staff went on strike for one night to demand their right to sleep at night when the residents slept. However, no advance warning was made by the caregivers. Therefore, the administration and staff were not prepared with an alternative care plan. During the strike, residents' continence pads were not changed, and odours permeated the home in an unprecedented way. Residents grumbled and looked unhappy; they were upset about the delay in their care. When I was walking in the corridor, I heard one of them saying, "When can we bathe?" but no one responded to her. The residents' frustration was very clear to the staff:

> Resident Sharon, who has a mild-dementia and immobility, looked frustrated, angry, and frightened of the non-responsiveness as she repeatedly called out her caregiver's name, but no response came. None of the care home staff personnel talked with the residents about what was happening, so they were left with no information. Therefore, the residents' missed their caregivers, and they felt frustrated without them around.
>
> I go over to Sharon and say: "*hello, your caregiver is not around. Can I help you?*"
> Sharon, in a sad voice: "*Where she was gone! No one told me she is going, oh.. what shall I do now without her*."
>
> Sharon is laying on her bed, wearing a white dress and covering her head with a black scarf. I assured her that we were all around her, that she was not alone, and that I would call one of the staff members to come and talk to her.
>
> I talked with supervisor Sara, who emphasised that this was not the first time, and the caregivers will be back soon to their residents.
>
> I asked whether the residents would need to wait for the caregivers to provide personal care, and Sara raised her shoulders up, stating, "*What is the other option*!" Researcher: "*Can you talk to Sharon? She needs reassurance from you*." Sara: "*No, no*", and she walked away. (Informal Conversation)

The exchange above illustrated how the organisational culture embedded in management's behaviours and attitudes towards care staff's work is unable to meet care staff's demands for better conditions and flexibility, with the inability to address these tensions via trade-offs culminating in work obstructions. At the end of the strike, which lasted for five hours until 1pm, the administration agreed to allow the care staff to sleep at night between 12.00 am and 4.00 am on a rota, therefore; the staff returned to their care duty starting with the residents' personal care.

Thus, management evidently responded to collective bargaining on this occasion.

5.4 Communication; management, and transparency

Overall, staff reported that there was a lack of job descriptions within the workplace, and the absence of clear structures of care. During my observational fieldwork, it was clear that staff often received a number of competing priorities and instructions on how to deliver care. Staff expressed their confusion about their individual roles within the home, what reflects good care, and who they should follow:

> Carer Tolina: *Here, we (the care staff) received different orders from everyone; it is confusing we do not know who we should follow.* (Informal Conversation)

The more senior staff, also described a lack of autonomy and recognition of their expertise. The home doctor is described as regularly intervening in the nutritionist's work:

Nutritionist Misha: "*she (referring to the home doctor) reviews the food menu she orders what the blended food should include as if I am not professional enough to do my work.*" (Informal Conversation)

The head of the administrative team also discussed this but did not appear to consider this could cause any issues for staff. Although the manager and doctor in charge of the home did meet regularly, albeit informally, there were no formal, organised meetings with staff, and the employees' opinions were not considered:

> Mrs. Shamah, the home manager**: "***Usually, the doctor and I have unofficial scheduled meetings; we meet when it is necessary to discuss resident updates. We do not have a meeting with the staff, but if any of them need anything, they can come and talk.*" (Informal Conversation)

> Samira the home supervisor was standing in the lobby when the committee group passed her without speaking to her; she looked at me with a sad face. When they left,

> she sat in the chair, turned her face to me and said: "*they do not respect us at all",* she was referring to herself and her colleagues. (Informal Conversation)

Some caregivers reported that because communication with them was scarce, the importance of expressing their opinions was devalued, thus causing them to feel dejected. Communication for them was closely linked with valuing the care that they delivered:

> Carer Sofia: *I have been here for 10 years now, no one asked me about my problems or opinions in regard to the care.* (Informal Conversation)

For the staff this lack of communication between the managerial and the care home staff was interpreted as disrespectful and deceptive.

> Home supervisor Maryam: "*We are spending six hours shifts with the residents every day; we know more about the residents' health and the care delivered to them, we are the ones who management should talk to*" (Informal Conversation)

The majority of care home staff, despite their different roles, had mentioned the lack of managerial and interdepartmental communication as being one of the barriers to improving the residents' care delivery.

5.5 Inspection of the Home

During the fieldwork one of the government committees visited the care home for an inspection. The Ministry of Worker and Social Welfare has a committee that is responsible for monitoring care in the homes by conducting visits and checking how the residents are being treated. The visit was carried out by three women who stayed in the administration office for around two hours. They then came to the residents' floor to make their rounds, along with the home deputy supervisor and the home psychotherapist. I noticed that this committee did not speak with any of the care staff or the direct supervisors. Instead, they walked around the home and tried to talk with the residents; however, only three were able to speak and respond to them. The questions they asked included very general questions, including: "How are you? How do you feel? Are you comfortable here? Do you need anything." Then they left. I asked the home monitors and nurses if they had ever been asked by this committee about their opinions or problems in the home or their suggestions to improve residents' hospitality. I asked them whether any committee member had talked to them since they began working at the home. All answered no. I was able to talk to one member of this committee after introducing myself and my research work, and I asked her about the aim and outline of this monitoring visit:

> The committee member: "*We meet the administration (home manager, the deputy of the home manager, and the home doctor) to see what updates there are regarding the residents' health and needs. We also meet the residents and hear from them directly, when I asked her why they didn't talk to staff and get their opinions and hear their troubles, she said it is okay as 'we were able to know it', referring to the staff's opinion, through their manager*." (Informal Conversation)

The staff reported that the committee reaction emphasizes the disrupted relationship between leaders and subordinate staff in the care home and clarifies the perception of the general environmental behaviour in the care home which includes the personal attitude of staff.

5.6 Approach to care

5.6.1 Nurses

Nurses' workload was dependent on the size of the care staff team and the different sites they were required to work. Typically, there were two nurses covering each shift; one focussed on taking residents to their clinic appointments and refilling their medication from the hospital pharmacy, while the other took care of the residents in the care home setting. The nurses worked twelve hour shifts. The normal working week was 72 hours, six days a week which meant a significant workload:

> Nurse Judith: "*Every month I go to the hospital and wait hours outside the consultant clinic to get medication refills for my residents; if he is not around I have to come the next day, and so on until I found him otherwise, the resident will be left without medication and I will be claimed responsible for that*."
> Nurse Um: **"***We have to take the resident to the hospital for their follow-up, the specialist never came to check up on them here [meaning the care home], also when we go with the resident, we have to wait in the waiting area and based on the number of the clinic visitors, it takes hours. Yesterday, I was at the internal medicine clinic waiting with my resident who needed medical assessment, I was there from 8 a.m. until 11 a.m., after she was seen by the physician I had to take the resident to the laboratory department, we were finished and return to the home at 1 p.m., the resident was very agitated and tired*." (Informal Conversation)

Additionally, in certain circumstances, the nurses also have to work twenty-four hour shifts once per month to cover the shift gap between the day and night duties, this meant seven day shifts per week without a break:

> Nurse Um: "*Every two years, started from the contract signing date, we are allowed to get annual leave of four months to travel to our country, so when it is the time for the annual leave for one of us (the nurses), we have to sign a statement paper that said we are committed to cover our colleagues' duty under any circumstances because the administration wants the work to flow smoothly without*

> *any obstacles, but this leaves us under workload pressure as the head nurse is now on maternity leave, it means only four nurses on duty, we will work two nurses in each shift every day without a break to cover this period*."
> Researcher: "*Do you, as nurses, complain to the administration about this shortage*?" Um: "*We did, they said we requested to recruit more nurses, but until they come, we cannot help unless withholding the annual leave until further notice*" (Informal Conversation)

5.6.2 Care Staff

The workload of care staff also led to consequences where there were apparent barriers preventing them from supporting residents' independence. For example during toilet care, I asked the home supervisor, Samar, why the care staff were not allowing the residents who were able to help themselves and carry out their own personal care to do so, instead of care staff doing it for them:

> Home Supervisor Noor**:** "*There is no time, I wish we could do it because this will help the resident to move their muscles, but unfortunately, this means every resident will take at least one hour of toilet care and another hour to get dressed with another hour to comb her hair, the care staff have no time for this, they need to finish quickly to move on to the next resident"*
> Researcher: "*Do you think this care strategy will lead to the resident lethargy*?" Supervisor Noor, pointing to one of the residents who just entered the toilet zone in the wheelchair: "*Do you see resident Abrar she is still able to walk by herself, and she did not need a continence pad; she is dripping but can manage if we could assign one care staff for her, however; this is impossible because we have a staff shortage*." (Informal Conversation)

The staff reported that it was not possible to prioritise a self-care approach among residents. This caused the care home staff to feel dejected and not heard. Some staff felt that because meaningful communication with the care home administration was scarce, this devalued the needs of residents and devalued the importance of advocacy by staff towards the residents. This appeared to result in lack of motivation amongst the nurses and the care staff and stifled any initiative. One wonders if this could be the reason why the care home staff had such negative perceptions of the progression of both the residents' holistic care needs and their own professional development.

5.7 Practices and habits in the workplace

There was no voice for the care home staff to contribute to the workplace, thus there was no individual with power that could identify the obstacles to their jobs and provide the residents with holistic care. In addition, they felt that their comments would be misunderstood as deconstructive complaints:

> Caregiver Mia: "*When we are the ones always going to them to complain, they tell us that we are messing around and not taking our work seriously. So, we decided to stay silent and get on with things*." (Informal Conversation)

During my observation and discussions, the nurses and caregivers frequently expressed a powerful sense of job insecurity as well as job dissatisfaction. Much of this stemmed from feeling that they lacked managerial support. The nurses and the caregivers are all non-Saudis except the head nurse; thus, they raised the concern of job security, and they described feeling less protected in the Saudi workplace. These nurses and caregivers, therefore, once explicitly told to stop arguing with and questioning the administrative decisions, stopped intervening in the residents' daily routine and instead adhered to instructions despite the potential negative impact on residents.

> Nisrean: "*To be honest, I lost my excitement and I feel bored every morning. I took a step back, and I decided to benefit into consideration and not risk my salary*." (Informal Conversation)

Regarding job security, care home staff also had fears that they were required to register their attendance in the care home reception daily in the morning, and in the evening, even if they had hospital duty with the resident before starting their workday. Although this was an added inconvenience to their working day, they feared this could result in a salary deduction if they went straight to the hospital, as they would be held personally accountable.

> Carer Samiah**: "***We have to sign in the dorm before we leave, and we have to sign again here at the home when we arrived and so on at the leaving time; I am someone who has been questioned when I did not sign before I leave at the end of my duty and I was informed to return to the home to sign because it is systematic and if I did not return to sign the day wouldn't count.*" (Informal Conversation)

5.8 Conclusion

In conclusion, this lack of cooperation between the care home staff and the administration has added to a culture of workplace blame that inhibited motivation and impeded the development of comprehensive care for the residents. The organisational culture in the care home was embedded in the problematic issues that the residents and their care workers are exposed to every day; it informs and regulates the everyday activities in the home. Against this backdrop, work in the care home is occasionally obstructed due to unsatisfactory labour conditions, sometimes resulting in strikes. The organisational culture is unable to attend to the demands of care staff for better conditions and flexibility, and is unable to address these tensions via trade-offs, leading to disruption in the home. In the next chapter, I explore timetables and daily routines that residents and caregivers in the care home are exposed to on a daily basis.

Chapter 6: Theme 2: Timetables

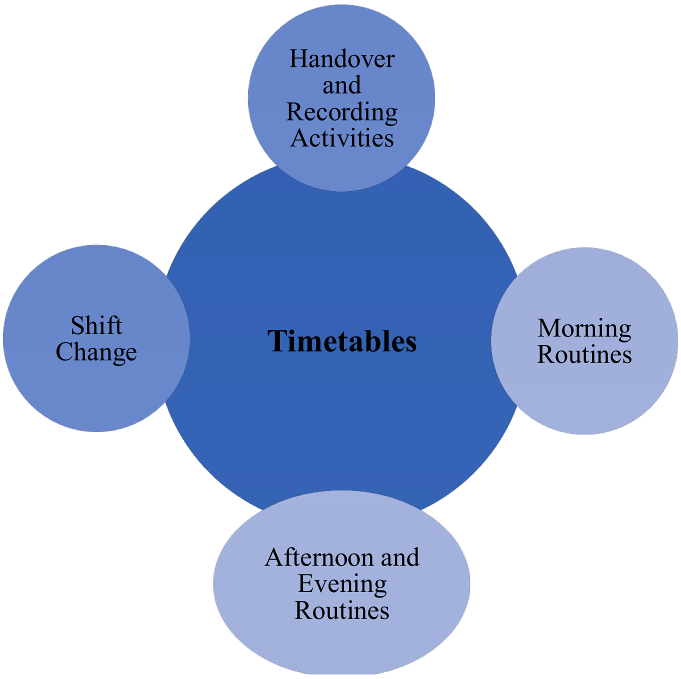
The daily experiences of people living with dementia in the care home are shaped by timetables and daily routines as presented in Table 6.1, these determine care responsibilities. In this chapter, I explore these timetables and daily routines, starting with an examination of handover and recording activities, followed by morning and afternoon routines. I also explore the daily routines concomitant with shift changes in the home. Understanding these timetables and routines and how these are enacted in practice is crucial for understanding the care setting and how care is delivered to residents. Furthermore, I will show how the care home management team used the timetable approach to manage care delivery. I will then demonstrate how this approach created the potential for conflict between the reality of the fixed routines inside the care home and how residents required care.

TABLE 6.1 AN OVERVIEW OF DAILY ROUTINES

Daily Routines
7:00 A.M: The day starts when the morning shift begins, which commences with breakfast. Tea and coffee is then made available in the lobby.
9:00 A.M: Residents' rest time, sometimes the residents receive visitors, usually school and university students in the morning. All the visits are followed by a report to the Ministry of Social Welfare as a part of the residents' activities.
10:00 A.M Toilet time when sanitary pads care changed (continence pads/diaper). This is followed by nap time.
12:00 P.M. Lunch time,
Lunch is followed by residents' rest time, and a fruit and juice snack around 2 p.m.
3:00 P.M Toilet time, followed by bath time.
Bath time is followed by tea and coffee in the lobby.
Tea and coffee is usually then followed by a visit from charities and association, usually the visit organised by the activity department to maintain the social interaction between the residents and the society. Evening time visits are reserved for charities and associations. These visits are usually organised to mark international days, events, ceremonies and holidays.
7:00 P.M: The night shift starts with the serving of dinner
9:00 P.M. Bedtime
12:00 A.M Toilet time; sanitary pads are changed (continence pads/diaper) and a snack is given to diabetic residents.

4:00 A.M Toilet time followed by a morning bath.
Morning bath is followed by a fruit and juice snack.

Figure 6.1 Overview of Theme 2



6.1 Handover and Recording Activities

In the home, the day starts when the morning caregivers and nurses enter the front door at 7:00. It is usually a very quiet and calm environment; the light is not off but dimmed, and the residents are in their beds. The night caregivers are preparing to leave; they wear their abaya, which they usually wear when they are outside, at 6:40 the nurses prepare to finalise their shift documentation. The caregivers do not fill in any documentation or perform handover tasks. On the other hand, the nurses oversee the handover, transferring all the residents' information from one shift to another to inform them of the changes and ensure a smooth transition. The handover process is not performed at the residents' bedside but in the nurses' room. Incoming care staff are informed about new developments including medication changes (changes in dose or refills) wound care needs, and updates on vital signs, blood sugar, bowel motion, and any resistance to care. Below, I present an example of the routine handover in the day and the night shifts:

> At the start of the day shift, the head nurse entered the nurses' room, and she asked loudly:
>
> Head Nurse Nisrean: "*Everything is the same, nothing new*?"
> The other Senior Night Shift Nurse Judith replied to her: "*Nothing new*."
> The Head Nurse looked at the documentation book quickly and said: "*Ok, go*."
> The staff are already prepared to leave; they are wearing their abaya and holding their bags in their hands; once the new shift staff enters the corridor, the caregivers leave quickly in small groupings while the nurses leave after them. Then, the new shift staff starts their duty immediately by preparing the residents for their breakfast while they speak loudly to each other in the Indonesian language. (Informal Conversation)

Recording activities also constitutes a salient feature of care delivery in the home. It encompasses what the nurses write in their documentation "outlook book" during and at the end of the shift. This consists of a page with every resident's name and biographic data, followed by a medical and physical assessment, diagnosis, and records of medications. There is also a documentation book for recording their 'daily activity', and that includes the date at the top of the page, with the observation and activity outlines. Nurses also write up residents' vital signs, new medical orders (if they exist), any hospital transfer or referral, and if any of the residents have a hospital follow-up clinic appointment. What they write in the documentation book is what they hand over during the next shift. Recording activities are also performed via the keeping of files which I evaluated during an afternoon shift after being granted permission by a nurse:

> I start looking at the residents' files one by one. The admissions page was at the front of each one. The second page contained the doctor's notes, the resident's medical history, and the final diagnosis. The third page had the medication chart, and the last page had the family contact details and social notes. I reviewed 29 files. All residents were diagnosed with dementia and all the residents were on memantine medication (for Alzheimer's Disease) in addition to the other chronic disease medications. (Informal Conversation)

Similarly, I did not see any diagnostic criteria included in the residents' outlook book or the results of any diagnostic tests. During the staff change in the morning shift, I asked the deputy nurse Salma:

> Researcher: "*How can you differentiate between the residents with no diagnostic label in their files*?"

> Salma looked at me with a puzzled face: "*There's no need as all the residents have dementia residents added to a different diagnostic disease*." She laughed and turned her back to me as she continued chatting with the other nurses. (Informal Conversation)

Although the diagnostic test is not captured in the residents' file, it is captured in the electronic system that connects residents' file numbers with their records at the main hospital. After two minutes Salma returned to me and I asked her how diagnoses are made. She responded that it is via the resident review and examinations conducted by the psychologist prior to admission:

> Researcher: "*What is the frequency of evaluating the diagnosis*?"
> Salma: "*Before 4 years every 9 months, but now it is not updated, we don't have psychologist doctor visit in 4 years*." (Informal Conversation)

6.2 Morning Routines

Daily objectives and duties are determined by a timetable designed to facilitate routines and ensure that they are performed efficiently. After the night shift leaves, the day shift prepares and gets ready to start their day. All the lights in the residents' room and in the corridors are turned on at 7:00, and the staff can be heard conversing loudly as they open and close cupboards to put away belongings and move chairs around. Below, I provide an account of the typical morning routine in the home.

> In dorm number five, the resident in bed one covered her face with a blanket to avoid the light and to continue sleeping, while the resident in bed two asked her caregivers, "where is the breakfast? We do not have breakfast," the other two residents in the room stared at the caregiver in silence. Two of the residents looked ready for their meal, they sat on their beds, and asked for breakfast, while the other two residents lay in a sleeping position and refused to wake up. All the residents must wake up and start the day to fit into the timetable; there is no option. The head nurse and one of the nurses walked to the residents' kitchen while the other nurse went to the main kitchen on the first floor to bring the blended food for some of the residents who were unable to chew food. While this was happening, the caregivers transferred residents who are 'mobile' from their beds to their wheelchairs and then took them to the kitchen for breakfast, while the residents who eat the blended food stayed in their beds. The breakfast trolley was already in the kitchen; the night shift brought it in before the end of their shift. The kitchen has a long dining table covered with a white sheet and bulbs hanging light from above. Two nurses and three monitors must attend to observe the

> residents' nutrition during mealtime. The breakfast menu is variable based on the day's schedule and includes foods such as beans, hummus, eggs, and cheese, with either milk or juice. The meal is prepared and served on plastic plates and covered with a plastic wrap; the menu of the day is beans, white and yellow cheese, boiled eggs, and green salad. The monitors offer warm bread slices to all the residents and some honey for non-diabetic residents; fruit, banana, and apple are also available for all. During this moment, the caregivers distribute the plates among the residents; the residents' weak voices can be heard across the room, "*give me more bread*", "*where is my tea*", and "*I want a little honey*". It seemed easy for the residents to help themselves and to eat without assistance, using their hands instead of cutlery. Once the food has been served the residents start eating, the nurse then starts distributing the oral medication to all. She stands next to them to make sure they swallow it and do not throw it away, the monitor in an encouraging tone can be heard asking residents, "*more bread and cheese*?", "*let's finish your plate*". After breakfast, the residents are taken to the sink to wash their hands and mouth. Some of the residents prefer to return to their beds after the breakfast meal, while others are moved on their wheelchairs to the lobby. In the lobby, the large television is tuned to the Saudi morning programme, there is a beautiful Arabic coffee smell across the floor, and the staff offer all residents either a cup of coffee or tea with biscuits. When they finish their snack time, they are taken to the outside patio, which is off an empty hallway after the main care home entrance. It is what they call a fire safety 'evacuation centre point'. The team told me that residents need to be exposed to the sun for 30 minutes. They describe this as a doctor's order to expose them to the fresh air and receive vitamin D. However, this order does not distinguish between the seasonal impacts of the weather. One resident removed her scarf and started screaming, "*Uh, people, have mercy on us, it is hot, it is hot*", while the others sat in silence but exhaled loudly. The physiotherapist who supervised residents during this activity looked at the caregivers and said, "*yes, it is hot; take them inside*." (Field Notes)

Typically, the staff return residents indoors after five minutes due to the hostile weather. During the period of observation, it was typically 42°C. The western Saudi region weather has a desert climate, and summer (April to October) has extremely hot days. Between November and March it is warm; the summers are long, sweltering, arid, and partly cloudy, and the winters are short, comfortable, dry, and mostly clear. Over the course of the year, the temperature typically varies from 16°C to 41°C and is rarely below 12° C or above 44°C. It is usually around 9 a.m. when the residents return to their rooms to get some rest. At this time, as a part of daily routines, the weekday visitors arrive, a group of school and university students who come as a part of social solidarity initiatives. This visit is organised between the schools and the activity department in the care home. The visitors, as they call them at the care home, bring with them gifts for the residents and some traditional food. The visitors are not allowed to go to the residents' floor due to privacy concerns; instead, the residents meet with them in the visitor room, a very big room at the end of the first-floor hallway. They perform some activities including talking and singing but the residents get bored quickly, and some fall asleep in their wheelchairs. However, during the weekends, national holidays, and the students' vacations, this part of the routine is absent, and the residents stay in their rooms while some of them prefer to watch the television in the lobby.

At 10 a.m., the caregivers take the residents to the toilet for continence pad changes. It is imperative to clarify that all the residents are in pads as part of their ritualised care. As the home doctor said, as part of the care home routine all residents must wear pads to manage (in)continence and potential falls during toilet care. Toilet time is the most important time in the care home; it cannot be delayed or changed as any delay causes frustration for both staff and residents. Care staff oversee toilet time systematically, caring for the residents four in a row in the toilet zone. The zone itself has no door, but inside the zone, there are individual toilets, although the individual toilet doors should not be closed when the resident is inside undermining residents´ dignity. Per regulations, one of the home monitors (they also call them 'supervisors') and one of the nurses should stay with the caregivers in the zone while the caregivers give direct care. However, neither the monitors (supervisors) nor the nurses participate directly in residents' toilet care; their role is to observe and supervise the caregivers who directly provide toilet care. So, each resident has one caregiver with her inside the toilet, in addition to one supervisor and one nurse in each zone.

In the toilet zone, the residents look away, their eyes are looking down, and they never look at the faces of the staff; they are not happy and appear 'agitated' during personal care time, but they also surrender to the authority. Residents' angry voices are ignored during toileting time; some of the residents raise their voices with unclear speech, but from their tone, their exasperation is clear. The toilet zone is unsanitary as I documented in my field notes:

> There is an increasingly bad smell coming from the toilet zone as this work continues, and it turns into a big mess; waste pads are put immediately in a yellow waste bag and then thrown in a trash bag located inside the toilet zone; this big bin is taken by the cleaner at the end of each care rotation to be disposed of outside the healthcare building, but faeces mixed with dirty water and other body secretions is on the floor. For this reason some of the monitors do not enter the zone during this point in the timetable, as they feel discomfort and irritation from the smell even though they wear a facial mask. Consequently they do not observe and monitor the caregivers during the continence pad changes and the bathing. The toilet zone is then cleaned and there is an apparent smell of bleach. Routinely toilet care takes 30 minutes because the staff are usually in a rush and aim to finish it quickly, but it can take an hour sometimes which equates to one to two minutes for each resident. There are six dorms; each one has four residents, and two caregivers cover it. They assist each other when they transfer the resident from the bed to the wheelchair, then one of them goes to the toilet with the resident while the other stays in the room with the other residents as the dorm should not be left unattended under any circumstances. The residents are then taken to their rooms, where the routine for the day determines the type of dress to be worn. All the residents wear the same dress colour, design, and scarf which is variable from day to day, to promote uniformity; they all look the same in their daily outfits. They are then put into their beds for a nap as they are tired by this time. The light is turned off inside the rooms, and the whole place becomes quiet. It is the time when the staff take their coffee break. (Field Notes)

The care staff deliver personal care in a highly routinised way; residents are dressed identically regardless of their personal preferences and they participate in the same activities at the same times, regardless of their unique needs and wants. Aside from the implications for their agency, there is also the issue that person-centred care is non-existent which undermines their personhood (Kitwood, 1990, 1992, 1993, 1995, 1997). According to Kitwood (1990, 1992, 1993, 1997), dementia is not solely a medical condition or neurological process. Based on his propositions on malignant social psychology, he underscores how the lived experience of individuals with dementia is often overlooked via malignant positioning (Kitwood, 1990, 1992, 1993, 1997). Consequently, they are denied their primary social rights and are conceptualized by others merely as patients with less status and ability.

6.3 Afternoon and Evening Routines

Mealtime is at noon. The lunch trolley arrives and fills the place with an aroma. It is sweet and pungent, usually pleasing. Two nurses and three monitors (supervisors) must be present in the kitchen to observe the residents' nutrition. Mealtimes are a key aspect of routine timetabled care; it is the time when the residents are taken from their rooms to the dining room in their wheelchairs to attend to their nutritional needs. Their wheelchairs are lined next to each other around the long kitchen dining table, and the residents are easily observable. All the caregivers wear white disposable aprons and place a similar one on all the residents without exception to protect their clothing from the expected 'mess'. The dishes are then distributed. The food is served in stainless steel trays divided into 4 sections; on the day of observation, the meal of the day is a slice of fish, rice, salad and yoghurt covered with plastic wrap. Different types of juice and water are also offered. The food is mostly blended. On this particular occasion, the lunch plate consisted of boiled rice and medium grilled chicken and green salad with wheat soup, bread, and one banana in addition to either a choice of yoghurt or juice to drink. Residents have limited opportunities to exert their individuality as the food options are standardised.

The residents then began eating their meals with the caregivers' assistance, they were fed even though they were able to eat by themselves as shown at breakfast, when residents ate independently. The staff would perceive the residents as highly dependent and in need of their help in their daily activities, although the residents did not necessarily ask for it; it is seen as a feature of their condition. In some instances staff members adopted a formulaic approach to assisting residents with their daily activities, which removed any degree of agency for the resident. In the example below, the staff were efficient during mealtime without considering the resident's needs and limited communication to small and short words, preventing an enjoyable mealtime experience:

> One of the residents, her name is Khadija, 81 years old, whose hair was nicely braided, said once she had her food, "*I don't feel like eating".* The supervisor Tolina who was standing next to her replied, *"no, you should eat; let's do it together*." She took the spoon and tried to feed the resident the pureed food. Five spoonsful of food were inserted into the resident's mouth despite her resistance. Another assistant also advised

> one of the residents to hurry and finish the whole meal, with repeated attempts to spoon puree into the resident's mouth, despite her saying, "*I am finished*". The resident was clearly unhappy and uncomfortable. She said nothing more but looked around the room silently with anxious eyes. (Observation)

Even when residents were resistant to food staff always encouraged them to eat, which they reported was to prevent hunger between meals and safeguard their nutrition. It was noticeable that during mealtimes all caregivers, nurses, and monitors typically repeated certain phrases such as, "*come on, let's eat", "let's finish it quickly", "let's eat."* These phrases were repeated in an assertive but encouraging tone, and sometimes, they were uttered with a hand clap to encourage and emphasise the importance of eating. I noticed that this gesture constituted a type of motivation to support residents and their nutrition but indicates to them that the staff want to finish their task quickly. Mealtimes are not a pleasant time within the home; discomfort is evident on the faces of both staff and residents. Staff speed up the mealtime, which appeared to be a bullying tactic that triggers residents' anxiety and distress.

From my observation, finding a resident who finished her meal was rare, although it could be because of the portion size as the caregivers mentioned "*Residents' stomachs get smaller like the babies, therefore, they are not able to finish their meals"* (Informal Conversation). When mealtime is finished, the disposable aprons are taken and thrown away before they leave the kitchen; the residents are then taken to the toilet to clean their hands because some residents resist caregivers to feed them, so they use their hands to eat by themselves instead of the spoons; eating by hand is part of Saudi culture. Residents then have their teeth brushed for them.

Later in the early afternoon, the residents return to their rooms; some of them prefer to stay in their wheelchairs and some return to their beds for a rest. This is the time when the staff eat their lunch. However, it is also usually "the noisy time", as the staff call it. It is the time when some residents start to become distressed and shout loudly or behave aggressively towards staff. Sometimes, they sing loudly. The staff in the care home call this 'hyper' behaviour. Usually, this hyperactivity lasts for no more than an hour:

> A resident Fatimah who is 79 years old sits in her wheelchair. She used to be a farmer and grazer in the past. She is calling after her sheep 'herd calls' and singing to the sheep in a very loud voice. She asks every person who passes her if they have seen

> her land. She asks, is the land fruitful or not yet? Some of the staff responded to her and recalled her memories to make her happy because she loves talking about her sheep, while others preferred to orient her with reality by talking to her about her day and her 'new home', as they call it in the care home. (Observation)

Throughout residents' apparent agitation phases, the staff continued to direct them to calm down without assessing the underlying reasons for this agitation.

> Another dementia resident Reem, who is around 65 years old and has been in the care home for years as her sisters are unable to take care of her. She is angry and shouting loudly because she wants to see the care home manager and the staff will not allow her to do so. The staff said that she saw her yesterday, and all she did was talk about herself and her sisters, which the manager found annoying. As a consequence of the staff's refusal, she screams and shouts loudly and verbally abuses her caregiver by calling her *'a whore'*. The staff continue to ignore her, and as a result, in what appears to be an attempt to grasp their attention, she falls or throws herself out of bed to the floor while she continues crying and screaming. The caregivers lift her up and return her to her bed again, after which they call the home monitors, who, in turn, call the home psychologist. Once the psychologist arrives, she asks me to leave the room immediately, and she closes the dorm door. I can hear the resident's screaming getting louder, but her speech was unclear. (Observation)

At around 14.00, fresh apple juice and slices of orange fruits arrive from the kitchen on a portable hospital trolley. The nurse is responsible for distributing snacks to the residents, and the remaining food is given to the staff. I asked why snack time is the responsibility of nurses and not care staff, but the nurses said they did not know; it was the routine. The nurses check if the residents have eaten their fruit safely and if they can chew by themselves; on the other hand, the caregivers are responsible for assisting residents while they eat and for maintaining their cleanliness.

6.3.1 Mealtimes and the practices adopted by the staff to encourage eating

Care home staff typically prioritised speed, efficiency, and consumption, which meant that mealtimes could often become a battle of wills between residents and staff. The impact of repeated attempts to encourage people to eat and the often invasive approaches staff used to try to '*feed'* someone typically made residents angry, increasing their anxiety and distrust of staff, as demonstrated in the examples below. Food for the residents who were unable to chew and had difficulty eating solid food was served in blended form. This food is composed of the day meal menus added to ensure milk to liquefy the meal, and sometimes they added Persian fruit for the residents who suffer from a low haemoglobin level:

> Norah, a 72-year-old woman with right-side hemiplegia, is unable to speak. The caregiver brought her lunch in a small white plastic bowl, and it was covered by a white plastic cover; the resident's name was written on the cover with a clear black pen. The meal included separate plain yoghurt, 50 ml of milk and 50 ml of orange juice; the caregiver dressed the resident in a disposable plastic apron to maintain the cleanliness of her dress whilst preparing for the meal. It commences when the lunch meal arrives at the resident's room, the resident was lying on her bed, and the head of the bed was elevated to 90 degrees. The caregiver held up the bowl and opens it, then she starts pushing a spoon full of food into the resident's mouth; the resident's facial expression was full of resentment, and she responded by closing her lips and waving her head right and left as a sign of *'No'*. The caregiver said, '*you do not want it? You can try it, it is good'*, but the resident continues shaking her head right and left, signalling *'No'*. At this point, the head nurse enters the room and calls the resident loudly by her name, '*Norah Norah'* in order to grasp the resident's attention, but in a soft and kind tone, and starts by encouraging the resident to eat. She said '*why don't you eat your lunch, honey'*, then she holds the spoon and fills it with the pureed food and pushes it again to the resident mouth while she said, "*open up, you have to eat, take one for me, try it",* resident opened her mouth and takes it with an expression of displeasure. The head nurse made another attempt to spoon puree, but the resident refused to respond; then they asked her to choose between the plain yoghurt and the milk, and she waved her head toward the milk. The head nurse turned to me and took a deep breath she looks disappointed and said 'she did not like this blended food'.
>
> I ask her: "*did anyone from the staff taste this food before*?"
> She said: "*No"* (Informal Conversation)

Mixing the food together without paying any attention to its taste and presentation is a common approach in the care home; the staff emphasise the nutritional value of the meal and the cost of missing it, whether the resident likes it or not. They are however increasing the risk of choking and food aspiration by pushing food into residents´ mouths.

> Caregiver Sofia: "*There are no different meal options available, and therefore, it does not matter whether the resident likes the meal of the day or not; there are no other choices for them*." (Informal Conversation)

The lack of options available to the residents, as well as the poor taste of the food is made clear in my field notes capturing the experience of Samar, a 75-year-old resident who has low haemoglobin.

> During dinner and when the resident was in the dining room, the staff nurse brought Persian fruit in a small jar and poured it on the resident's dish of rice and chicken. The resident stopped eating, she was very annoyed and anxious; the staff nurse encouraged her to eat by saying it tastes good and to try it. All the staff in the room - two supervisors and eight caregivers - looked extremely disgusted, but they were silent. The staff nurse leans low over to talk to the resident: *'will you eat this because your haemoglobin is low, it tastes good, I promise'*. The resident now looks very, very, anxious and said '*no, I feel full'*. The staff nurse ignores what the resident has said and takes the spoon, and tries to put the food directly into the resident's mouth. The resident pushes the spoon away with her hand, and in a low voice she repeated, '*I feel full'*, and she looks at her caregiver and said "*take me to my room."* (Field Notes)

The impact of repeated forceful attempts used to encourage the residents to eat, as in the example above, increased the conflict and made the residents angry and anxious; at the same time, it made the staff disappointed and frustrated. The staff were highly focused on delivering mealtimes as timetabled, so when residents did not comply it was seen as resistance that must be overcome. Mealtimes were considered essential care by the staff, and the residents were verbally warned of the risks of not eating their meals.

6.3.2 Personal Hygiene

The routine is similar to the morning toilet care, particularly the continence pad change. When the residents arrive at the toilet, the caregiver starts showering their lower body with shower gel. Their upper body is washed without shampooing their hair. Verbal communication from staff during this personal care, which includes touching genitals, is totally absent; the caregivers do not tell the resident what they are going to do, which appears to increase the anxiety and discomfort level among these residents. In this example, the residents clearly felt shamed due to being visible to their care staff during personal care. Further, touching their sensitive areas without psychological preparation by verbal communication violated the residents' dignity and rights. During one of my observation days, I noted:

> Aisha who was around 70 years old, underweight, had paraplegia and a nasogastric tube inserted in her right nostril, was brought to the toilet zone for an afternoon bath on a toilet wheelchair. This resident, who never left her dorm except for the toilet or hospital appointments, looked very anxious, her eyes looking around, her head turning right and lifted, looking at people's faces. They were taking her to change her clothes and continence pad. Once they had moved her wheelchair into the individual toilet, the resident started making incomprehensible sounds. Although these were not comprehensible, the caregiver ignored these sounds and continued to provide toilet care. The resident's voice got louder, and she became more agitated and tried to move her body, but her caregiver continued in silence. The care staff then directed water onto the resident's body without checking the temperature. The resident started screaming, her voice getting louder. I do not know if she was shouting because of the uncomfortable water temperature or because she was threatened when the caregiver directed the water to her face and head. The care staff scrubbed the residents' skin hard; she continued by putting shampoo in her hair and washing it with her hands, which were covered by gloves. Once she arrived at the genital area and started washing it, the resident got very, very anxious and her screaming became louder. She tried to close her legs to prevent her caregiver from touching her, but she failed. The caregiver forced open her legs and washed her. When she finished, she wiped the resident's body with a towel and opened a bottle of baby powder which she tossed up the resident's body. She then covered her with a new gown and moved the wheelchair to return to the dorm. There, two caregivers transferred the resident to her bed, where a sanitary pad was spread on the bed. Once the resident was on the bed, the care staff closed the pad tape and covered her body with a blanket and her head with a headband. (Field Notes)

In this example, the care staff did not communicate with the resident, let alone reassure her that she would be fine; further to this, the resident was shocked and scared from the pouring of water on her body without warning, and perhaps she might have been hurt by the temperature of the water. The interaction seemed almost inhumane as the resident's body was treated as an object during cleaning and scrubbing. The carer behaved as if she were treating an inanimate object as opposed to the body of a human being.

The caregivers delivered personal care as functional care in a horrific way and this functional approach to care placed a huge psychological burden on the residents.

After being washed they are wiped with a towel and then dressed in a sleeveless cotton t-shirt. Their lower body is covered with a towel, and then they are moved to their rooms. In the room, they are dressed with pads and cloth; they are prepared for the afternoon visiting time because some of the residents have a family visit scheduled. After the bath and whilst I am walking through the corridor, a very tiny woman in a long blue dress and short haircut down to the level of her neck says in a loud voice, "*ice, cold, cold. Cover my head!"* She reached her room (dorm number three, bed number one); her caregiver went to fetch a scarf for the resident from the white wardrobe on the right-hand side. The wardrobe was divided inside into four racks. Each resident has her belongings organised on a rack. At that time, the resident was trying to remove her pad, but the pad was taped strongly with extra adhesive tape. At the same time, she was trying to scrub her genital area with her two hands. I thought that she had an itch, perhaps an allergy from the Vaseline that they rubbed on the residents after their bath to moisturise their bodies. She was unable to rest, literally jumping on the bed. The caregiver was trying to prevent her from moving and stop her from scratching by removing her hand instead of calming her down. I went quickly to the nurses' room and asked one of the nurses to come with me. When we arrived at the room, I asked her:

Researcher: "*Do you know what's happening to this resident*?"
Nurse Wahida replied, "*Yes, she always tries to remove her diaper*."
Researcher: "*She has an itch?"*
Nurse Wahida, *"Yes, we examined the skin in her genital area, and it was clear*."
Researcher: "*Do you think she maybe needs to be seen by the dermatologist*?"
Nurse Wahida: "*She was seen before, and he prescribed Zintec olive cream for 3 months.*
It did her good, but when she was finished, her itching returned."
Researcher: "Might she need a follow-up?"
Nurse Wahida, "*Maybe. However, this is the doctor's job; it's not ours*."
Researcher: "*Does the doctor know about it?"*
Nurse Wahida: "*Yes, but she did not pay it any attention*."
Researcher: "*Why not give her a break from the diaper to allow the skin to ventilate? The residents are in diapers 24 hours a day*."
Nurse Wahida: "*No. We had an incident with her, and she took her faeces in her hand and threw it at us*!" (Field Notes)

In this example, the dominant routines over the resident's individual needs restricts their personal liberties, they are pushed into this routine without any other available options and they respond by resisting care as per the scenario above. Once bath time is finished, the cleaner starts cleaning the toilet zone with bleach, and the caregivers start cleaning and washing the dorms floors with an antiseptic cleaning solution. Immediately after they finish this, they take residents to the lobby in front of the television for a prepared snack table where biscuits, Arabic coffee, and tea are available. The residents watch the TV and spend an hour there.

6.3.3 Entertainment

After 17:00, the visitors arrive. Visits are either by immediate family, relatives, or charity workers. The residents go down to the first floor to meet their visitors, no one is allowed up to the residents' floor except officials so that residents' privacy can be maintained. Privacy breaches, however, sometimes occur. On one occasion, a Saudi staff member who facilitates entertainment and activities, brought her family and relatives to the residents' floor during the month of Ramadan to socialise with them during the Iftar time. This is the evening meal with which Muslims end their daily Ramadan fast at sunset. During an afternoon shift as I walked along a passage in the care home, a staff member with a layered hairstyle dressed in traditional southern female dress caught my attention. She was organising the tables in the reception hall. I went to her and asked if she was preparing for breakfast, because it was almost sunset, but the residents were not fasting:

> Hajar: "*Yes, we are having guests today*!"
> Researcher: "*That's nice. Who is coming*?"
> Hajar: "*My relatives*." She was referring to her female relative, her sisters with their daughters and her cousins. She had invited them and they were happy to come.
> Researcher: "*Good. I see you have food containers, so you have already brought the food*." She replied that she had, and that they would bring more with them.
> Hajar: "*You are welcome to join us*."
> Researcher: "*Thank you, maybe next time, but may I ask; what is the process of inviting people to visit the home*?"
> Hajar: "*No one is allowed to come to this floor except workers, student and trainers*."
> Researcher: "*What about your family*?"
> Hajar: "*It's Ok, workers' relatives are fine because we know them*." (Informal Conversation)

Residents' families were denied access to the floor to maintain their privacy, however, care staff's families were permitted access, which constituted a breach of residents' confidentiality and privacy. During the afternoon visit on the weekdays, which starts from 16:30 to 18:30, the residents look more active than during the morning visit as I captured in my field notes below:

In the visiting room people were sitting on the corner sofa which can seat almost 12 people. Eight residents were sitting in wheelchairs, and four caregivers accompanied them. On the left side of the room there was a corner table covered with a sheet with traditional red and blue paint on it. The table was full of traditional food, Arabic coffee, and tea, which the visitors from recreational neighbourhood club intermediate and high school neighbourhood students, had brought. The activity supervisor was responsible for arranging the visit. A deputy nurse was standing in the middle of the room with two of the visitors. I moved to the back where I could see clearly. I noticed four mature women; from their appearance, I would say they were above the age of thirty. One of them (a woman with dark glasses who was blind) had the microphone and sang a traditional song while two residents were clapping hands. The deputy nurse was very happy, clapping with a big smile on her face. I sat next to a university student who appeared very smart.

Researcher: "*Who are you*?"
She said: "*We are a charity group. It is a group of different aged girls from all parts of the western region, as you can see*," pointing to her colleague. Researcher: "*OK. Who leads this charity? Is it a government one*?"
The student: "*No. Our leader is a lady from Makkah City. She and her husband thought of raising this charity to support all people in need. We don't give money or any kind of donations. Instead, our aim is to spread happiness. We want people to be aware that we are thinking of them. That way, when we visit them, we want them to laugh. Our leader will come. She is just late*."

The visitors started to serve residents coffee. The caregivers noticed, so they acted quickly, taking all the coffee cups and returning them. The deputy nurse said that not all residents were allowed to drink coffee, and those who were allowed should have it served warm rather than hot because they could scald themselves. The deputy nurse also advised that it was best to give them half a cup rather than a full cup. The woman with the microphone asked some questions regarding, what we call in Islam, the *'Biography of the Prophet Muhammed, peace be upon him'.* She asked the question, *"where was the Prophet Muhammed, peace be upon him, born*?" She then gave the microphone to one of the residents to answer. The resident was silent but looked around at the people's faces; the audience loudly told her the answer, which the resident heard and repeated loudly. When she answered, she felt excited and happy and clapped her hands. She then received a gift which she admired with a smile on her face. She rolled it around in her hand; then she put it in her small white fabric bag

> that she carried. I had never seen the residents so happy, so much so that they ate their meals enthusiastically. (Field Notes)

This socialising activity fulfilled their psychological needs for an enjoyable social engagement, and their mood changed as a result. Social activities such as trips to the mosque also had a positive influence on the residents' moods:

> Researcher: "*How are you today?"*
> Resident Hessa: *"I am very well; we are going to the holy mosque."*
> Researcher: "*Are you happy?"*
> Resident Hessa.: "*I am very happy; I cannot express it* [with tears in her eyes]. *I miss it."* "*Do you know, it has been a year now!"* [since she had last visited the holy mosque.] (Informal Conversation)

This is supported by studies that have found that socio-environmental factors, including spiritual status, can improve an individual's health (Thoresen, 1999). Spiritual well-being is significantly related to mental and physical health; Flannelly and Inouye (2001) found that religious faith and religious affiliation contributed to improved general health. Kirkland and McIlveen (1999) studied the effects of spiritual therapy on people with dementia; they found that maintaining a relationship with God and having an inner sense of peace might benefit older people and residents with dementia. Additionally, Laukhuf and Werner (1998) found that people with dementia definitely needed spiritual care and that such people were able to reaffirm God's past activity in their lives and sometimes receive healing in the present.

6.4 Shift Change

When the night staff arrive for their shift, it is similar to the day shift routine. The caregivers leave the floor, and the nurses update the residents' notes in their room. However, the staff shift changes every two weeks, between the night and the morning staff. Once the night shift starts they take the residents to the kitchen for their dinner; however, I observed that if any residents needed the toilet for continence pad changes after the visiting time, this was done before the dinner meal.

Evening meals are usually traditional food, and it could be brought by either visitors or care home staff. This may be Kabsa which is rice and chicken; Harees, which is similar to porridge; or Makaronia, with yogurt and juice or milk. Evening meals are an aspect of routinised care and highlight both residents´ and carers´ lack of agency; it is the time when the residents are again taken from their room to the kitchen in their wheelchairs. Residents are positioned next to each other around the long kitchen dining table where they are easily observable. The caregivers place disposable aprons on all the residents to protect their clothes from the mess, and then the dishes are distributed. Two nurses and three monitors (supervisors) must attend in the kitchen to observe the residents' nutrition. However, evening is a less controlled time when residents are not forced to finish their dishes if they do not want to. This is because the carers keep the remaining food so hungry residents who wake up late at night can eat it.

After the meal, they take the residents to the sink to give them mouth care before bedtime, followed by a pad change. They are taken in a row to the toilet, similar to the morning routine. Around 21:00, the caregiver moves the residents to their rooms, where they change the residents’ clothes and place them on their beds. The lights are turned off, and the home becomes quiet again. Some staff members go for a dinner break, and caregivers divide themselves into mini-groups in front of residents’ rooms. While the doors are open, they start talking in their mother language (Indonesian) and socialising in a soft and low tone in a way that does not disturb residents’ sleep. The Saudi staff and the monitors (supervisors) also group themselves together and socialise in the lobby in a low and soft tone; they usually talk about their families and their private lives.

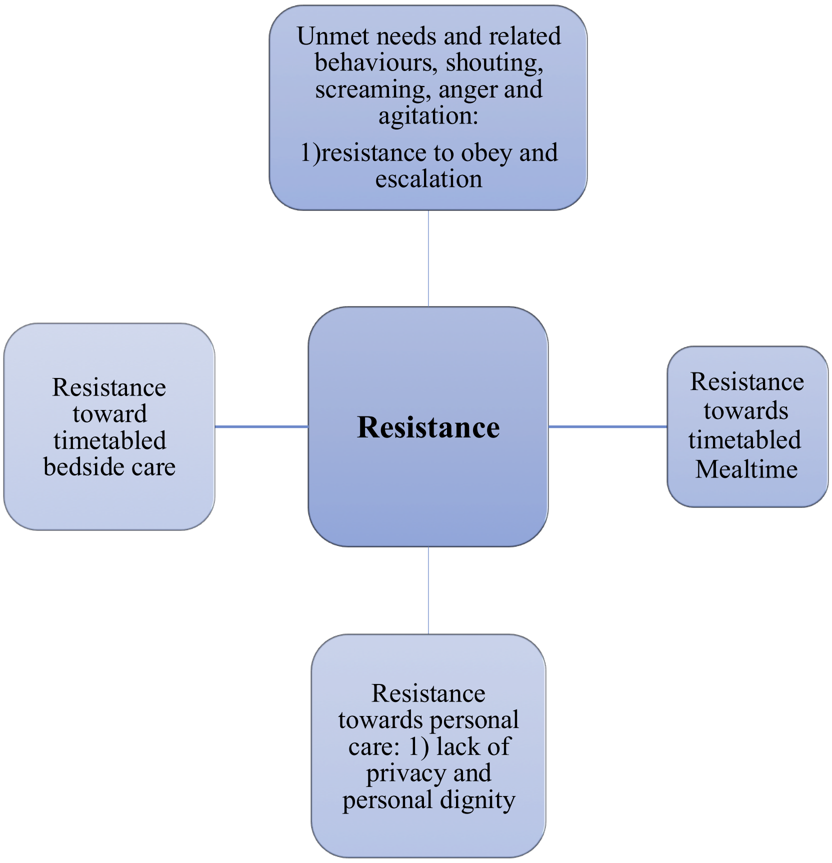
I could not observe routines between 00:00 and 07:00. Still, based on the care home timetable, residents typically sleep during night-time; however, at 04:00, they are woken up for a full body bath from head to toe, after which snacks are offered to diabetic residents. I wondered why this time was chosen for a bath, so I asked the supervisor Noor, and their answer was, “*it is the only time that fits the schedule, probably as the morning shift is busy*.”

In conclusion, the dominant routine that arose from the care home’s timetable was concomitant with some limitations and challenges, these are reflective of dominant power relations whereby individuals with the greatest power exert the most influence on residents’ everyday experiences in the care home. Separating dominance and the influence of managerial direction was missing in the provision of care, and both carers and residents lacked agency and personal autonomy to enable change. The resulting effect was that some residents displayed resistance to care, this theme is discussed in the next chapter.

Chapter 7 Theme 3: Resistance

Resistance to care was part of everyday life in the care home. It was defined by care home staff as any behaviour by residents that staff interpreted as resisting or refusing care. During my observational period in the care home, this seemed to include any behaviour that prevented or interfered with the care provider performing or assisting with activities of daily living (ADLs), including bathing, eating, toileting, and dressing. The pattern of resistance throughout the shifts varied, it could be verbal or physical, and the levels of resistance were highly variable. In addition, the way in which staff made sense of this behaviour as being 'resistant' to care varied considerably. In this chapter I classify the refusal of care by the care home residents into categories, this provides a broader understanding of the refusal incidents and offers a detailed contextual analysis of the events. I begin with a focus on verbal forms of resistance, after which I discuss resistance to timetabled activities. Next, I focus on resistance to personal care which I locate within issues such as lack of privacy and personal dignity.

Figure 7.1 Overview of Theme 3



7.1 Unmet needs and related behaviours: shouting, screaming, anger and agitation

Behaviours relating to unmet needs were seen by staff members as a normal feature of cognitive impairment and the staff described it as "hyper-behaviour". Care home residents who were verbally resisting due to unmet needs or a disproval of routinised care typically received less attention from the staff. This often resulted in the individual being ignored by the staff during the shift. As a consequence of this, the residents were more forceful in their resistance as evident in the example below:

> Hessa, an 85-year old resident with black hair who always kept her hair braided on her shoulder, is sitting in her wheelchair wearing a long colourful dress without a scarf on her head, holding her Barbie doll to her chest. This resident used to spend the month of Ramadan and Eid with her sisters in their family home. The caregiver said that the resident wanted to see the home manager, but the manager was busy and the time was not suitable, and the caregiver continued to say Hessa was always in a bad mood and kept annoying staff when she came back from her family visit.

Researcher to her caregiver Hadeel: "*Are you going to take her down to the manager's office*?"
The caregiver replied that there was no need because she (the resident) would calm down and relax by herself for a while.

I tried to talk to the resident myself, but she was not listening, nor could I understand what she was saying; she was screaming and crying loudly, and I could not understand her. One of the home monitors was present and she joined us, talking directly to the resident, as the team's response was to 'rationalise' with the resident. The resident however continued to cry and talk unclearly.

Supervisor Kareem said: "*No, I am not listening to you when you talk in this way in an aggressive tone! You should stop crying so I can hear you*!"
The resident stayed in silence for a few seconds; then she said in a tear-filled voice: "*I want to talk with the manager "the Ablah*"", then she continued crying while speaking unclearly.
Supervisor Karem: "*I told you don't cry. If you continue crying, I will leave*."
The resident continued crying, so the home monitor left her.

I stood there in silence, not knowing what I should do. Her caregiver was trying to take her inside the room and put her to bed to get some rest; this action led to more resident anxiety as she felt that her request was being ignored, so she screamed louder and louder and started using offensive language by cursing and insulting the caregivers. Two of the caregivers pushed her wheelchair to the room whilst whispering to each other in their own language; they looked very angry with her, when they reached her bed one of them held her by her shoulder while the other one held her feet and they put her on the bed by force. Hessa immediately threw herself onto the floor because the caregiver had forgotten to raise the bedside rails. The rails are made of metal, and very difficult to move. The caregivers looked very scared, they tried to pull her up while they continued talking to each other in their own language, Hessa was now silent and the monitors were running to the room to check up on her as they watched her via the Closed Circuit Television (CCTV). Three monitors were now in the room with the caregivers, they raised her up and lay her on the bed, she seemed fine but she was silent and there was no reaction on her face. There was a small injury on the right side of her forehead. (Field Notes)

She was unhappy, and the staff failed to communicate with her properly; her agitation and frustration was raised unconsciously by them.

> I could see the fear on their faces, they called the psychologist to come and speak to the resident, it took another five minutes for the psychologist to arrive. Once again she asked me to leave the room immediately without giving any reason, and closed the door. I responded to the psychologist and I decided to go and take off my abaya and drop my handbag, then return to her. When I returned the resident was lying on her bed, she was sleeping in a foetal position and holding her baby doll who she called 'Fatima'. I thought she was perhaps missing her family, and I felt that she might need attention. I looked at her caregiver and said:
>
> Researcher: "*Does she behave like this after every home visit*?"
> The caregiver, Moss, said, "*Yes, it will take a few days before she returns to normal*."
> The researcher: "*Do you know why she is unable to stay with her family*?"
> The caregiver replied that they were unable to tolerate her behaviour. They have their work to do and their own life, but during Ramadan and Eid, they have her on holiday. But sometimes, they return her before Eid if she is not behaving well. She added, "*That is sad*."
> I asked, "*but what do you mean by behaving well*?"
> Caregiver Moss**;** "*as you see, unreasonable crying, night screaming without any reason, refusing to eat and refusing to take her medicine, and being aggressive by pinching and spitting on them*." (Informal Conversation)

Throughout these resistance phases some of the care staff, who were responsible for delivering residents' care, would communicate verbally with the residents to calm them down. However, this performative approach required a supervisor's approval. This meant any physical action or reaction needed to be cleared by the supervisor; for example, transferring the residents from their rooms to the other home sections such as lobbies or kitchens or restraining them by not allowing them to move out of their bed. All of these actions required verbal approval from the supervision staff. The supervisor assessed the residents' status, physically, if they were able to sit in the wheelchair, and psychologically if they were not agitated in order to prevent disruption, following this they made a conclusion. Unfortunately, this process had no protocol that staff could follow, this process was done according to personal evaluation and diligence.

7.1.1 Resistance to Compliance and Escalation

In the care home the staff linked behavioural disorders with cognitive impairment. Common features associated with this were agitation, aggression, paranoid delusions, hallucinations, sleep disorders, including incontinence, and vocalisations or screaming. Therefore they focused on controlling this behaviour, rather than focusing on the feeling that triggers the behaviour. Staff viewed this behaviour as unintentional but in order for the daily routine to run smoothly, the residents' behaviour must be disciplined to the point of blind obedience whereby they do as they are told without thinking for themselves. However, staff were typically not bothered by this resistance, it was seen by them as normal behaviour for people who have cognitive impairment, specifically Alzheimer's disease and other dementias. Sometimes resistance increased the tension between the staff and the residents during care delivery. The care home staff believed that they had to manage, even improve, the behaviour of residents with cognitive impairment as I observed in my field notes:

> When I walked down the corridor to the nurses' room, a tiny resident with grey hair in dorm number two, Laila who was 90 years old, grabbed my attention. She was sitting on her bed, eating her snack of tea and cake. I was watching when the resident took the cake with her right hand and started to eat it. However, she was scattering the cake on her red dress and her bed. Her caregiver did not like this, so she took the cake and started feeding the resident with her hand, but the resident wanted to eat by herself.
>
> The resident starts screaming loudly, "*Give it to me; I will eat by myself.*" When she tried to pull the cake back from the caregiver's hand, the caregiver said: "*No, you messed up the dress and the bed, and we have just changed it."* And she continued feeding the resident. But the resident was extremely unhappy at this point, and she refused to open her mouth for more cake; the caregiver stopped trying to feed her and puts the cake on the tray out of her reach; the resident started talking to herself in a low voice before she put her head down on the bed and covered her full body including her head in her brown fur blanket. I watched in silence. (Field Notes)

This is another example of treating the residents as though they did not have agency, infantilising them:

> A very tiny woman, a resident called Sadia, who was 84 years old and had a short hairstyle (the staff usually cut the resident's hair to a neck level, which made it easier

> to clean and ensure tidiness), screamed, "*I want a pillow*!! *Where is my pillow*?" and called the caregiver "*a bitch woman*". Then she stopped, and her anxiety seemed to increase; it seemed that her fear increased and she started a high-pitched cry.
>
> When I looked at her, she already had two pillows, one under her head and the other next to her. So I asked the caregiver who was sitting in the room,
>
> Researcher: "*Why is she asking about the pillow when she already has two of them*?"
>
> The Caregiver Moss replied: "*She's fine. She was admitted to the hospital last month, and there the nurses ignored her when she asked for a pillow, so, since then, she has screamed frequently and asks for a pillow*."
>
> Researcher: "*Won't you remind her that she has her pillow under her*?"
>
> The Caregiver Moss: *"It is an unending cycle; she will stop by herself. I tried for the last two days, but she is not listening."* (Field Notes)

The interactions with care home residents show that there is a range and pattern of resistance to care, and it is an everyday feature. The caregivers, however, seemed to believe the home's authority was legitimate and more powerful than theirs as staff members. Ultimately, it results in resistance. For the staff, the residents are not validated and do not realise what is most beneficial for them, therefore they made choices on behalf of residents. This was seen as a normal feature for older people with cognitive impairment. The issues around compliance and resistance to staff orders were raised every shift, it could not be prevented, and it came in different forms.

7.2 Resistance to timetabled mealtime

Mealtimes are evidently a critical trigger for resistance after personal care and are the routine activity where resistance is most visible. Often this appears in the form of a clear sign that the resident does not want to eat and is evident both verbally and physically. This was almost always viewed by staff as resistive and a feature of the cognitively impaired person which had to be overcome. Below is an account of 80-year-old Alia, she refused the staff order to sit in the kitchen room during lunchtime, as a response she threw herself on the kitchen floor because the staff did not listen to her and did not return her to her bedroom:

> During lunchtime, the resident returned from a private home visit; she covered her face with a "niqab", (a veil worn by some Muslim women in public). She refused to take it off. Looking at her eyes, she appeared sad. The staff wanted her to engage with the group in the hope that she could forget the sadness of leaving her family home.

> She was brought to the dining room by her caregiver, who served her lunch with the other residents. She however started to scream. The staff ignored her reaction and began serving the lunch trays. In response to being ignored, the resident threw herself on the floor. She was able to do so because the care staff forgot to put the wheelchair safety belt on. The staff ran to her and tried to return her to her wheelchair. The resident refused to cooperate with them and the staff shouted at her "*get up- get up*". Three care staff with the attending supervisors held her up and put her on the wheelchair. This resident was able to walk, but she refused to do so. She preferred the wheelchair she used permanently. (Field Notes)

7.3 Resistance towards timetabled Personal Care

The care staff appeared to consider it their duty to carry out personal and intimate care without the permission of the residents. Often, care staff did not talk to the residents, instead they started working on the resident's body without any verbal communication. It is not considered necessary to obtain their consent. However any response the residents made to this type of action would frequently take the form of physical or verbal resistance, while staff typically continued their focus on completing care. For staff, meeting the timetable and routines of the care home, and the expectations of the institution, is the priority over the psychological and social needs of the residents. Salha, a 72-year-old woman who used to be independent, worked on her farm before admission to the care home 'diagnosed with dementia':

> During personal care, when she was moved on her wheelchair to the toilet zone she said, "*Hah people where are you taking me? Hah, hah stop I don't want to go, I am clean*" her caregiver replied to her "*no, you are not we have to change your pad, it won't take long time I promise*". Once they arrived at the individual toilet, the caregiver starts taking off the woman's dress, in response, Salha gives a high-pitched scream, "*leave my clothes; what do you want to do for me? Fuck you, you are such a moron, why do you want to expose my body? Son of bitch".*
>
> The caregiver was working in complete silence, she did not respond to what the resident said, but when the caregiver removed the continence pad the resident punched the caregiver's hand and spat in her face while she continued to insult her. Eventually, the caregiver got angry and said, '*don't do this to me'*, and she called the supervisor loudly by name and asked her to come to the toilet. When the supervisor arrived she

> is told what happened and what the resident has done and said to her; resident Salha starts saying,
>
> '*because you remove my clothes, I am naked, cover my body, give me trousers, give me my underwear'*.
>
> The resident now looks very angry, so the supervisor starts talking to her and calms her down while the caregiver continues doing her task. When they have finished and have dressed her and were about to return her to the room, Salha refused to move into her wheelchair, and when they forced her, she was about to throw herself on the toilet floor, in loud voices, they said '*no, no'*, while they were holding her shoulders up, the supervisor said
>
> '*if you fall you will break your bones and you will get hurt, you will be in pain, you don't want to do this to yourself, won't you*?'
>
> Salha was affected by what the supervisor said, and as a response, she holds herself up and moves to sit in the wheelchair. However, it is unclear why the caregivers behave like this as it is distressing for the residents and also for the caregivers themselves. (Field Notes)

7.3.1 Lack of privacy and personal dignity

Dignity and privacy were not fully maintained during personal and private care; residents are exposed to the supervisors because they are permitted to be inside the toilet during intimate care. They assume responsibility for checking residents' hygiene and are also responsible for maintaining their safety against any physical abuse while they receive care. An example of the inability to maintain personal dignity is seen in the case of Samar, a 75-year-old, who was admitted to a care home with 'confusion' as captured in my field notes:

> Samar requested to be the last resident who enters the toilet zone, as she said there would be no one watching her when she is naked. Once when she was moved to the toilet early, 'not the last', she refused to allow the caregiver to take off her dress.
>
> Samar said: "*as a human, we have sanctity! Respect that*."
>
> Then, when talking to the supervisor, Samar: "*why you are here? Why you are you watching us*?"
>
> Supervisor Noor: "*to protect the other residents from harm and abuse during the care',* she continues directing her speech to the resident; *'you are able to express yourself, but the other residents as you see are not able to".*
>
> The resident Samar: "*I need my privacy"*,
>
> Supervisor Noor: *"ok", you have it; we are not looking at you",* then she directed the speech to the caregiver,

> Supervisor Noor: “*finish quickly*”.
> Resident Samar, in an annoyed tone: “*no, no I want to defecate; stop watching and talking, leave*!”
> Supervisor Noor, with an irate face, turns herself around. (Field Notes)

The staff are highly focused on delivering care without considering the essential need to maintain the personal dignity of residents. Therefore, the carer did not uphold the resident Samar's privacy during the hygiene time.

7.4 Resistance toward timetabled bedside care

A classic example of routinised practices is checking vital signs, blood pressure, temperature, heart rate, and oxygen saturation, these are an essential feature of the organisation timetable and must be checked once per shift. For some residents, the blood pressure cuffs cause a lot of discomfort and pain, especially for the residents who have tiny arms or fragile skin. Resistance to the BP cuff can be seen as verbal resistance by screaming and crying, as well as physical resistance by pulling, removing, and throwing the cuff on the floor, which I documented in my field notes:

> It is evening, the staff nurse was carrying the Dinamap machine, a monitor designed to check vital signs, she was checking and recording the residents' observations ritually while they are sitting in their wheelchairs watching the television in the lobby. When she reached an 81-year-old resident named Amal, who is a hypertensive resident, she tried to put the BP cuff on her arm and the resident started screaming, *‘No, no, I do not want it’*, the resident tried to remove the cuff but she could not loosen it. Amal became increasingly agitated and the nurse was holding the cuff around her arm with her hand, nurse Aisha tried to reassure her and calm her down; ‘it’s not hurting, it wouldn’t cause any pain, just relax’; but the resident's anxiety increased, Amal looked very distressed, then she said; 'please I do not want it, please take it off’, her tears were running, and she looked very scared of it. The staff nurse was sympathetic, and took the cuff off and said 'ok, relax now', nurse Aisha wiped her hand over the resident's shoulder and she whispered ‘I will do it later’. This situation continues with this resident every observation round, and the staff, in the end, always leave her. They resort to checking her BP when she is sleeping which is just another ritual during the duty of the nurse's shift. (Field Notes)

Another example is a 75-year-old resident Monirah who is diabetic, she requires an insulin injection, and staff have to check her blood sugar levels frequently. I was present in her room when a staff nurse brought a disposable kidney dish from the staff nurse's room, this was loaded with the blood glucose monitor to check her sugar levels. This required the resident to be woken up from a nap:

> The staff nurse Fofa: “*darling, I need to check your blood sugar*”
> Monirah took a deep breath: “*not again*.”
> The staff nurse held Monirah’s right thumb, cleaned it with an alcohol swap, and inserted the needle stick.
> Monirah opened her eyes widely and screamed: “*you hurt me*”, she repeats “*you hurt me*.” The staff nurse Fofa: “*I won’t do it again promise*.” She squeezed Monirah’s thumb to promote circulation and got some blood for the test strip, then she applied a cotton ball and held it for a second before she left.
> Monirah held her injured thumb with the other hand and said: “*Wow*”
>
> The staff nurse returned to the room within a minute with the same disposable kidney dish but with an insulin syringe in it. When she came closer to the resident bed, Monirah said, in a loud voice: “*No, no*”
>
> The staff nurse Fofa: “*You have to take your insulin, your blood sugar is high, and you will eat your lunch*.”
> Monirah: “*I will not eat, I don't want food*.”
> Monirah was very clear that she would not take this insulin shot, she looked very intense. The staff nurse ignored her and tried to hold her arm to insert the medication. At this moment, Monirah pinched the staff nurse's hand. As a way of response the staff nurse became very exasperated.
> The staff nurse Fofa: “*No, this is not allowed*,” then Monirah tried to slap her face with her tiny and weak hand, which had a mild tremor, but the staff nurse moved her head quickly after she administered the medication.
> The staff nurse Fofa: “*No*” (directed to Monirah, who looked very annoyed and anxious).
>
> The staff nurse also looked very frustrated, and on her way out she said to me,
>
> The staff nurse Fofa: “*I will be questioned by the doctor if I did not give it*.” (Field Notes)

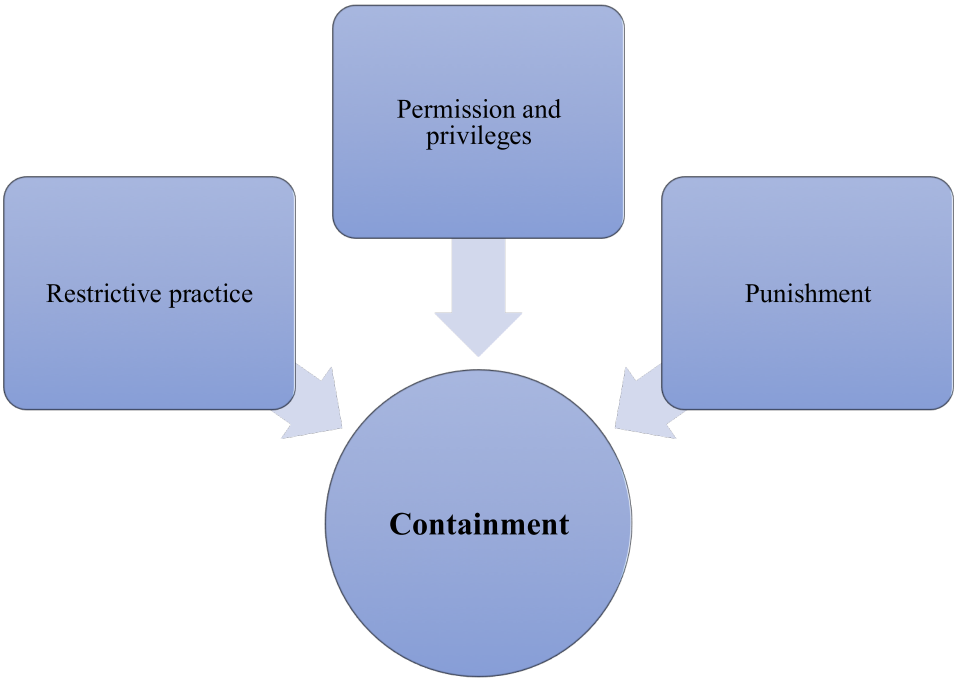
The refusal to take her medication was part of her wider rejection of the care that she received. However, it is repeated every shift leading to escalated conflict and frustration between the staff and the residents.

In conclusion, home healthcare staff often presume that residents with cognitive impairments are unable to walk independently, are at high risk of falling, are frequently incontinent, and require assistance during mealtimes. These assumptions lead to routine care practices that increase caregivers' workloads while simultaneously restricting residents' opportunities for rehabilitation and independence. The perceived incompetency and dependency trigger residents' resistance to care, with staff typically overlooking low-risk behaviours such as refusing to eat and using offensive language. However, these patterns of resistance are problematic as they can escalate and disrupt the delivery of routine care. Consequently, daily routinised practices create a less demanding environment which reduces physical activity, leading to deconditioning and the loss of personal skills. This negatively impacts upon residents' quality of life. This emerging theme will be explored further in the next analytical section.

Chapter 8. Theme 4: Containment

I identified institutional timetables and the care home routines as a critical catalyst in containment among the residents, it appeared to be focused on isolating them, preventing them from socialising with their peers and decreasing their physical activity. Consequently, in this chapter I explore containment further and focus on the major factor leading to it and the resulting loss of motor skills: containment. For example, the prescribing of bed rest had an impact on increasing the residents' dependency on the caregivers in undertaking their daily care tasks. Most of the residents were classified as non-mobile, the home doctor is the one who classifies them, and they rely on the caregivers in their daily activities. Consequently, I consider how, and to what extent, the care home routine has adapted the residents to a dependent status in general, which leads to a decline in their self-reliance. Understanding the daily experiences of people living with dementia necessitates for containment and its associated problems to be unpacked, which I seek to do in this chapter.

Figure 8.1 Overview of Theme 4



8.1 Permissions and privileges

The care home allows external trips as a privilege for the residents; these trips are usually to tourist areas, malls, or restaurants. They are arranged by the home activity team which is comprised of four staff members, two of whom are in the female section. They receive the invitations, contact the person in the visited area and manage the transportation. The home activity team receive their funding directly from the ministry office; furthermore, the permission for these trips should be received by direct written clearance from the ministry office. There is no fixed schedule as it is based on the weather, transportation, and funds. The length of the trip is variable, but it is an average of four to five hours as the residents are non-mobile and sitting for more than this time makes them uncomfortable. Sometimes residents are invited to attend a charitable organisation. Here is an example of this;

> Resident Zainab is 83 years old, and is described by the staff as an ‘annoying woman’ because she talks a lot. Zainab may hold people's hands and ask members of the public for their personal belongings, their bags, pens, watches, and so on. During a religious festival, Zainab was dressed up in the traditional Saudi women's dress (residents can wear special clothes for particular occasions), which was decorated on feast days with tribal patterns, coins, sequins, metal threads and appliques. She sat in her wheelchair in the lobby and told the monitors who passed her,
>
> Resident Zainab: “*I want to go with you*”, repeatedly “*take me with you*”
> The caregivers said “*ok, we will*”, but they left without taking her.
> Supervisor Karem said: “*we do not want to embarrass her and embarrass ourselves with her; she would not be able to represent the care home perfectly in front of the public!”*(Field Notes)

Unfortunately, not all the residents are allowed to go on these trips, residents who staff perceive to be “well behaved” (quiet, undemanding and easily managed) are allowed to go. Usually, one caregiver attends for every two residents, as well as two home supervisors and one member of the activity team. The residents on these trips wear their abayas and their scarf on top of their regular clothes and sports shoes to protect their feet from any injuries. Residents do receive cash in their hands (100 S.R., which is equivalent to £20); these monies are non-returnable. If they do not use it, they can save it for themselves with the supervisor.
One of the specific outings that I attended was the International Day for Older Persons which was provided by charities. The setting was in the lobby of the main city hospital; at around 6

pm four of the residents were prepared to go, they dressed up in their abayas and the scarves. While they were waiting in the care home lobby, to be transferred to the event, the home supervisor noticed that one of the residents was wearing shoes that were not similar to the other three residents, so immediately she called the caregiver and asked her to change it:

> Caregiver Lina responded: "*this is the resident choice; she chose these specific shoes*."
> Supervisor Maryam**;** "*go and change it quietly*."
> When I asked what the reason behind this is, she said: "*they are representing the care home, and they should look similar, that makes them more tidy and organised!"*
> This is not a written policy; however, when the caregiver returned to change the resident's shoes, the resident looks surprised, and she furrowed her eyebrows and said "*Why? Leave it."* The caregiver replied while she changes the shoes, "*no, we have to*." The transportation arrived, it is similar to the disabled bus where the residents can go inside the vehicle with their wheelchairs. When we arrived at the ceremony, the place was decorated with flowers. There was a reception that had seven sections, each one covered one of the Saudi cultures. After the reception we found a group of volunteers who were preparing fun activities for the residents, these included a singing competition and a heritage dance performed by volunteers. The residents were happy, and they laughed all the time. After three hours they were tired, and they asked the home supervisors if they could leave and return to the care home. I noticed that the male residents who were attending were mobile, none of them were using wheelchairs. I do not know whether they are using wheelchairs while in the care home or not. (Field Notes)

8.2 Punishment

Residents viewed by staff as not behaving well were isolated from other people. These residents were expected to "behave", not behaving resulted in removal from the group. Ostensibly this was for the safety of the group or to prevent others from being "influenced". As I captured in my field notes, residents who shout or who speak outside of respectful boundaries will be excluded because they may behave poorly in front of 'society'. A resident who is physically violent (beating, biting, and pinching) against the staff, and any resident who asks the public for money or food:

> During school student visits, resident Salha was not allowed to attend with the other residents because of her 'inappropriate behaviour'. Resident Salha was insulting staff

> with the name of their mum and dad, e.g. son of bitch, and she named the care staff 'whore ladies'. There was an expectation that Salha would not "behave well", and not behaving well resulted in her being left in the lobby rather than allowing her to engage with the visitors. However, the staff members were the ones who made this decision, the staff conducted an evaluation of residents' previous behaviour and made their judgments; there was no regulatory process controlling this. (Field Notes)

A person with dementia and Alzheimer's disease may have fluctuations in their level of mental capacity from day to day or throughout the day. In Saudi Arabia, power of attorney is applied, however in this care home staff are legally given power of attorney. While staff understand the impact of dementia on the behaviour of residents, they are more concerned about the image of the care home. This is because they reported that the home will be evaluated by society based on the residents' behaviour which is justification for their 'rules'.

For instance, one of the residents was never allowed to go to the visiting room (where the care home received the visitor from society and schools) because she always, as the staff reported, asked people for "*money, food, anything".* As a result, she would not be able to represent the home 'perfectly' in front of the visitors. I recorded an incident where the staff member was not permitted to leave the visiting room:

> It is a visiting time when I saw Sadia sitting in her wheelchair at the lobby corner and bending forward; she was wearing a white polka dot dress with short sleeves, she was looking around and turning her head right and left, I can see in her eyes a kind of confusion, while I was pushing another resident in a wheelchair to the visitor room, helping the caregiver, she said "*take me with you*'? I replied "*ok I will return to take you*", the home supervisor Noor was sitting on the sofa next to the lobby desk, she said '*no, resident Sadia is not coming*', I come closer to her and ask her 'why?' she said, "*it is the admin decision, you know she will keep asking people*; (referring to the visitor) *to take from them what they have money, food, drink, and even their bags if she likes it, she will not stop*." (Field Notes)

8.3 Restrictive practice

In the care home, restraints come in three different forms. The first pertains to a safety restraints system to secure the wheelchair used by staff to protect the older person from falling out of the chair. Once the residents are in their wheelchairs, they are always wearing the safety restraint system, it is similar to the car seatbelt, and it protects them from falling down the chair under any circumstances. The care home had an incident of a resident who threw herself from the wheelchair to the floor; therefore, they are very clear that wheelchair restraints are used. The second pertains to limb restraints to minimise some behaviours such as nasogastric tube removal, continence pad removal, scratching the skin resulting in bleeding, biting nails, or sucking fingers. These restraints include either tying the hand to the bedside rails by soft foam medical strap; the mitten restraint style which holds the finger inside, or by the knot that is made at the end of the resident's dress by tying the sleeves of their dress. During an observation, a social worker approached a resident and witnessed the use of such restraints:

> The social worker Amirah to the caregiver; "*you are not allowed to do this? Not without permission*" and she started opening the knot that the caregiver made at the end of the resident's dress (the caregiver Logayen was tying the edges of the dress together and making a knot).
> I understood later that this resident used to remove her dress and pull down her inner trouser and open the diaper; they told me that one day she threw her faeces on them, so they used this way as an alternative restraint instead of restraining her hand.
> Caregiver Logayen was very emotional; she said "*I am the one who came up with this idea, it is better than holding her hand.*"
> After opening the dress knot, the social worker brought non-finger gloves, which had a rope at the end and used it to restrain the resident's left hand; the resident has right hemiplegia.
> Social worker Amirah left the room after pointing her finger to the caregiver and said: "*next time, you just listen to the order!"* (Observation)

The third method of restraint pertains to the use of bedside rails to hold residents and keep them on the bed. The use of bed rails should be risk assessed, as it can simply lead to residents falling further over the top of the bed rails. Further, it is used to protect them from falling out the bed:

> Resident Amal was holding the bedside rails: "*Do you think I can move it by myself, it is like a cage*?" When I looked at it, I could see it was very strong, made with strong

> metal, which opened from the outside only with no possibility of being opened from inside the bed. (Informal Conversation)

Many residents have lost their muscle elasticity due to immobility and the use of a wheelchair over a long period of time. The residents who are independent in their movement are viewed by staff as being at high risk of falls. However, these limitations are powerfully felt by the residents. Resident Amal described feeling as if they are “being trapped in a cage”; she expressed loneliness, dissatisfaction, and depression.

In conclusion, in the containment the care home routine traps the staff and residents. They find themselves lacking support to prevent them from losing personal skills and instead trapped in an organisational culture of bedside care that provokes and escalates the deconditioning of losing skills and containment, as well as incontinence, depression, and anxiety.

Chapter 9: Discussion

9.1 Introduction

This chapter firstly reiterates how the research was conducted and then moves on to discuss institutionalisation and the role this plays in the development of cultures of care. Gidden's theory of structuration is used as a theoretical framework through which to explore the idea of how cultures of care are developed through structuration. Gidden's ideas about how agency and power can generate institutional change are also discussed, in reference to how cultural change is precipitated and maintained. Power dynamics and the way these are reinforced through institutionalised practices are also discussed, in relation to conformity and obedience and how these contribute to the overall culture in place in care homes.

Carspecken (1996) is used throughout to structure the methodological approach. This approach is appropriate because it introduces a five-stage critical qualitative research method for undertaking ethnographical research. This study was based on Carspecken's critical ethnography (Carspecken, 1996, 2001; Carspecken and Walford, 2001), although its five stages were not conducted linearly but, rather, in an iterative manner.

Stage One

Primary records compiled from an outsider, or etic perspective, involve making passive observations while in the field, concurrently recording notes for the primary data record and the field journal (Carspecken, 1996). I collected primary participant observations via comprehensive field notes, which Carspecken conceptualises as the "primary record". Stage One involved observational data collection in the care home. Within the primary record, the researcher records thick descriptions that capture speech acts, gestures, movements and postures. I also collected secondary participant observations via a comparatively informal set of notes, which Carspecken (1996) conceptualises as the "field journal" (p.45). These notes were taken using my observations of care home routines and interpersonal interactions at various levels of the hierarchy within the home. As part of these notes I recorded my perceptions and thoughts about my observations and/or informal conversations for the day, such as feelings of shock when I witnessed a carer provide intimate toilet care without the consent of the resident. Parts of the journal were completed while I was still in the field, at the care home, while others were completed outside of the field. In my observations for the primary record and field journal I adopted a passive approach, taking on the role of an observer and recording my observations from the viewpoint of an "uninvolved observer" (Carspecken, 1996, p. 42). Moreover, Carspecken advises that the researcher must take up an unobtrusive stance so that comparisons can be made between the data collected by the passive observer and that collected when the researcher adopts the role of a facilitator of data construction during the informal conversations.

Stage Two

Stage Two, according to Carspecken (1996), constitutes the preliminary reconstructive analysis, which is the stage at which the researcher attempts to unpack emerging patterns of power relations and roles to identify the key issues and further explore them in the next stage. As part of the preliminary reconstructive analysis I entered my observational data, and the data garnered from my field notes, into a Word document after transcribing my notes. I then read and re-read to draw out any underlying meanings from the data. I created a list of codes and sub-codes. In line with Carspecken's (1996) approach, the codes that emerged during the preliminary analysis were low-level codes similar to the objective notes recorded. Following this, I reflected on the emergent patterns to identify the data that might be useful for the analysis.

Stage Three

During the third phase of Carspecken's (1996) framework, he advocates for a shift from an outsider researcher to an insider researcher or emic perspective, a process termed "dialogical data generation" (p.155). Researchers produce dialogical data via the informal conversation with participants, this enables the latter to have an active voice in the research process. Through dialogue, participants may challenge or confirm the observational data collected by the researcher, enabling initial patterns to be observed. During this phase, the data collection process revolves around the informal conversation. Informal dialogue with the carers and care home staff occurred during the fieldwork to facilitate a participant perspective of the events observed. The data gathered from this informal dialogue was incorporated into the primary record, encouraging critical reflection via a dialogical process. This dialogical process has an overriding centrality for ensuring that actors are empowered in social settings (Lather, 1986). Analysing the dialogical data involved applying the same analytic tools used in stage two, specifically, the two-level approach to coding adopted and categorising codes into hierarchical schemes (Carspecken, 1996). This stage also involved comparing the collected data from stages one and three to achieve high-level codes.

Stages Four and Five

Stage Four of Carspecken's (1996) framework involves a system analysis that seeks to critically examine the relationships that exist between the research group and other groups. I conducted this system analysis by comparing my research findings to findings in the existing literature in the form of peer-reviewed academic journals, grey literature and academic books on the everyday experiences of dementia residents in care homes. This approach to conducting a system analysis enables the social site of the study to be linked to others through the relationships established between them (Hardcastle et al., 2006). Establishing a relationship between this study's findings and those of other studies in the literature will enable this research to be established within a particular cultural, political and economic context.

Stage Five of Carspecken's (1996) framework involves using system relations to explain research findings with the assistance of a sociological theory. The sociological theory enables the researcher to explain how the social phenomena observed are reproduced (Hardcastle et al., 2006). In this study, I apply Giddens's (1981) structuration theory of systems to unpack relations between the structures of domination (i.e., of overarching power), signification (of creating meaning), and legitimation (i.e. of establishing legitimacy) (Whittington, 2015, p. 148).

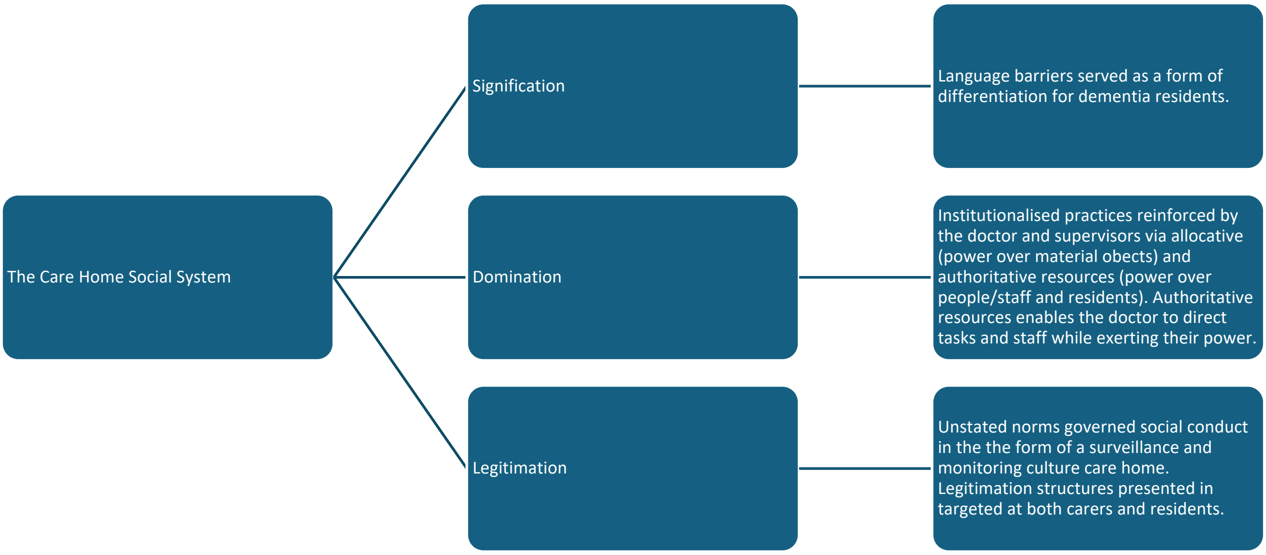
I applied Giddens' theory to the structures of domination, signification and legitimation that constrained or supported the everyday experiences of residents diagnosed with dementia in a care home. In particular, I examined the system relationships that influenced the home's routines and schedules of care and the emergent associated concepts, including institutionalisation, routines, surveillance, regulation, resistance to care, conformity and obedience, restraint and signification structures. The key finding of this study was the system reproduction of routinised care among care home staff, this was enabled through unequal power dynamics which established asymmetrical domination that is legitimised by certain structures in specific ways (see Figure 10.1). Giddens (1979) noted that the process of system reproduction relates to the dynamics through which individuals have a tendency to act in certain ways regarding specific social conditions.

Reflecting on the Saudi cultural context, it is apparent that cultural norms significantly impact upon the perceptions of dementia care. The constructivist approach used in this study highlights how these perceptions shaped the caregiving practices and the experiences of residents. The findings suggest that improving care for people with dementia in Saudi Arabia requires a culturally sensitive approach that considers the unique social dynamics and values of Saudi society. When the Saudi context is compared with global practices in dementia care, such as the UK, where rights and agency are prioritized, it becomes clear that there are opportunities to adopt more person-centered approaches that have been successful in the Western context (Rosengren et al., 2021; McCormack et al., 2021). For instance, integrating more flexible care routines and enhancing staff training to focus on cultural competence could significantly improve the quality of care. These changes could lead to better outcomes for residents, as seen in other cultural contexts, such as the UK, where individual agency and dignity in care are prioritized. Advocating for policy reforms that support the adoption of best practices in dementia care, while concurrently emphasizing the importance of cultural sensitivity and the adoption of international care standards, can assist in addressing the challenges delineated in this study.

By addressing these areas, care homes in Saudi Arabia can enhance their caregiving practices to better accommodate the needs and preferences of their residents, ultimately leading to more humane and effective care settings. This chapter sets the stage for concluding discussions on the broader implications of this research for dementia care in Saudi Arabia, underscoring the need for continued inquiry and adaptation of global best practices to local cultural contexts.

The structuration theory offers a robust framework for analysing how care routines are not merely habitual but are deeply entrenched in the power structures and cultural narratives of the Saudi context. These routines are instrumental in establishing a culture of care that both constrains and enables certain behaviours by staff and residents. The dual nature of structures as both enabling and constraining becomes evident in the daily interactions and the institutional responses to individual agency.

Figure 9.1 The Care Home System using Giddens' Structuration Theory (Giddens, 1984)



Language barriers served as a form of differentiation for dementia residents.

Institutionalised practices reinforced by the doctor and supervisors via allocative (power over material obects) and authoritative resources (power over people/staff and residents). Authoritative resources enables the doctor to direct tasks and staff while exerting their power.

Unstated norms governed social conduct in the the form of a surveillance and monitoring culture care home. Legitimation structures presented in targeted at both carers and residents.

The problem of routinised care, hierarchal working structures, and surveillance cultures was examined within the context of the care home, but in this chapter are situated within national and global systems to understand events and routines as they occur within interrelated social sites (Carspecken, 1996, p.201). The analysis of systems relations in this chapter, is the product of a dialogical data set or data derived from the dialogue of the research participants who were conceptualised as the sole experts in this study. Following Carspecken's framework as outlined in Carspecken (1996, p. 190), priority has been given to participants' experiences and life situations, which were revealed when conducting Stages Four and Five. Epistemologically, Carspecken stipulates that social system models must be generated from an insider perspective, and the data were thus generated from within the care home.

In the following content, I will critically discuss my research findings by unpacking the significant intersections between my research findings and the existing literature, highlighting the aspects that hold relevance for achieving care for people living with dementia. These are outlined under the following headings: 1) Institutionalisation, 2) Routines, 3) Power, 4) Surveillance, 5) Management, 6) Resistance to Care, 7) Conformity and Obedience, 8) Restraint, 9) Communication.

There are notable linkages between the themes established in the present study, including institutionalisation, routines, power, and surveillance, revealing a complex interplay where each element influences and is influenced by others. For example, the routinisation of care practices is closely linked to the exercise of power and control, reflecting broader societal norms that value conformity and obedience. These routines not only structure the daily lives of residents but also reflect deeper cultural values that prioritise efficiency and control over individualized care.

9.1.1 Institutionalisation

Giddens (1979) conceptualised institutions as significant features of society which concurrently enable and constrain action. In the care home and regarding the individuals that work and populate them, there is an adherence to a specific set of values, rules, norms and beliefs which define their world and how it should be. Institutionalisation provided a blueprint for the organisational culture, placing constraints on the options available to care staff and residents alike. Institutionalisation was communicated via cultures of care revolving around the routinisation and depersonalisation of care and the micromanagement of staff. Giddens' (1979) theory of structuration explains how structures (institutions), through their enabling and constraining characteristics, impinge on the daily practices of agents, with power being the capacity of these agents to draw upon these structures to achieve specific outcomes.

The powerful interactions between how care was organised and delivered at the care home and how residents living with dementia responded and reacted to care encapsulate the cultures of care (Featherstone and Northcott, 2021), which were constraining. These constraining cultures of care shaped how people enacted power, communicated and determined the types of behaviour to be sanctioned or rewarded. I found that organisational culture impinged on older people's experiences in the care home, whereby the workflow of in- care home, the underlying values about care, and the day-to-day behaviours linked with these in practice informed the ethos of care built around residents living with dementia. Ultimately, organisational culture impacts upon health practitioners within the care home, who, in turn, play an active role in re-creating this culture through their work practices and networking with their cohorts. The observed organisational culture had limited interaction with members of the communal society outside of the care home. In this context, residents living with dementia were passive recipients of care; thus, it was mainly the healthcare practitioners within the care home that created the culture. Micro, meso and macro power dynamics shaped this organisational culture.

The findings of this study aligned with studies about care home culture which critique institutionalisation and how it is mainly shaped and maintained by power interactions. Scholars such as Artner (2018) have adopted Goffman's (1961) notion of a 'total institution' within which all members of the institution have the same fate as "like-situated individuals, cut off from the wider society for an appreciable period of time…together [leading] an enclosed, formally administered life" (p.xi), to criticise institutionalisation in care homes. Similar to the current study, Artner's (2018) study demonstrated how residents' daily experiences are determined by care home staff so that everyday life is scheduled and residents are compelled to follow the same institutional rules. Koch-Straube (2003) conceptualised the care home as a total institution almost entirely controlled by staff. Compared to the present study, however, studies on care homes as total institutions in the literature (see for example, Shield, 2018; White et al., 2019; Fernandez-Carro, 2016) do not provide detail on the rigid control exercised by staff or their display of patronising behaviour. This study thus provides insight into how an impersonal atmosphere is achieved in daily practice by analysing the micro-level—specifically, the interaction and actions in the Saudi care home.

9.1.2 Routines

Giddens (1979) proposed that agency and power can generate institutional change. Explicitly, through their agency, he proposed that individuals can either produce change within an institution or maintain and reinforce it via routines and similar reproducing practices. The resultant effect is a recursive interaction between agency and structure (Giddens, 1979). In this study, care home staff effectively acted as institutional entrepreneurs (in the sense of Garud et al. (2007), actors who maintain institutional arrangements through their actions and behaviours) who wielded significant authority and resources to exert influence on residents. They maintained and reinforced institutionalisation through the development of routines, which assisted them in navigating the complexity of providing dementia care. Routines provided a predictable and orderly framework deemed essential for managing the complexities of care efficiently. However, these routines transcended mere organization; they constituted manifestations of institutional power that enforced conformity and suppressed individual agency. In the care home, routines simplified management and ensured compliance from both staff and residents. For staff, adherence to routines was monitored and tied to performance evaluations, while for residents, routines culminated in a paternalistic approach where residents' personal preferences and spontaneity were significantly curtailed.

The emphasis on routines also reflected broader cultural and societal norms that value obedience, respect for authority, and conformity. Within the Saudi context, where social and familial hierarchies are pronounced, replicating these hierarchies within care homes through strict routines reinforced societal expectations and cultural values. The power dynamics within the care home were intricately linked to these enforced routines. Institutional power was exerted through the imposition of routines, which often prioritized institutional needs over individual care needs. This rigid application of routines reduced autonomy for residents, regulating when they ate, slept, and engaged in activities. Surveillance practices reinforced the power of the institution (the care home) and contributed to a culture of oversight where privacy was compromised. The cyclical reinforcement of routines and institutionalization contributed to a culture where individual needs and spontaneous human interactions were often side lined in favour of maintaining order and predictability. This dynamic can be particularly detrimental in dementia care, where person-centered approaches are crucial for enhancing the quality of life of residents (McCormack et al., 2021). While routines provide structure and can reduce confusion for dementia patients, they need to be flexible enough to accommodate the varying needs and daily realities of residents, allowing for adjustments that recognise and respect their individuality and humanity (Rosengren et al., 2021).

Person-centered care (Kitwood, 1990) and resident-centered care (RCC) (Nolan et al., 2006) are two evidence-based approaches whose focus is different in emphasis but complementary in terms of focal points to manage and support persons living with dementia. In person-centered care, there is a focus on the individuality of each person as a person with his or her history, preferences, and needs rather than one with medical conditions. This approach takes into account the personal experiences, cultural background, and values of a person in order to offer treatment that will enhance his or her quality of life. On the other hand, RCC adopts the principles of person-centered care and mainly focuses on the relationships between the person living with dementia (PLWD) and their carers, as well as on their social network in general, since good health and well-being for all involved can be assured only through quality interactions. It respects mutual esteem, shared decision-making, and emotional support within the relationship and underlines the interdependence between all those involved in the care.

Training carers for this type of person-centered care is essential in dementia care. It starts with education around the various forms of dementia, so carers understand that the behaviour of a person with dementia is a communication rather than a symptom. Effective communication skills are paramount, involving the use of clear and simple language and non-verbal cues to understand the needs of PLWD and to react appropriately. Carers should learn methods to identify the triggers for distress behaviours and develop tailored interventions. For example, if certain environments or activities cause anxiety in a case, then carers can modify the setting or routine to minimize distress. Empathy and patience are the cornerstones of person-centered training, as carers should understand that, in most cases, the behaviour results from confusion, fear, or frustration, and hence need to act with compassion.

The second critical element of person-centered care is the involvement of PLWD in care decisions as much as possible, which empowers control and choice. This might relate to selection concerning daily activities or more general decisions about care, hence ensuring that his or her voice is truly recognised and respected. It is also important that carers are culturally sensitive, since the background of the person influences how they feel and express distress. A person-centered approach in this regard may create an enabling and appreciative environment, addressing the emotional and spiritual needs of people living with dementia, improving their quality of life and reducing distress behaviour.

I found that the daily experiences of dementia residents in the care home were shaped by timetables and daily routines which determined care responsibilities and were used to manage care delivery. There were lapses in this approach due to tensions between the reality of the fixed routines inside the care home and how residents required care. Similar findings have been established by studies of care homes, where routines and timetables have been criticised for regulating and controlling the experiences of elderly residents, inhibiting their agency (Cobo, 2014; Moilanen et al., 2021; Hillcoat-Nallétamby, 2014; Quine and Morrell, 2007; Fjordside and Morville, 2016).

I also found that care staff tried to exercise control due to timetables and routinised care. The exercising of control is invariably rooted in prevailing assumptions about the cognitive and physical abilities of dementia residents. The care home I observed was designed to compensate residents for their lost cognitive and physical functions via the provision of assistance. The challenge is that due to this focus, residents inadvertently became vulnerable to erroneous assumptions that care staff made about their level of competence or function. The resultant effect was that there was little room for their remaining levels of autonomy to be attended to. As discussed in the previous chapter, I found that home healthcare staff appeared to hold assumptions that residents with cognitive impairments were unable to walk independently, were at high risk of falling, had presumed incontinence and needed support at mealtimes. Furthermore, caregivers seemed to believe that the home's authority was legitimate and more powerful than that of residents, who were not recognised as individuals in terms of their unique needs. Thus they were treated passively and care staff were expected to make decisions on their behalf, this was perceived as a normal feature among older people with cognitive impairment. This led to routine practices of care that increased caregivers' workloads while also restricting the residents' opportunity to rehabilitate and increase their independence. Threats to residents' autonomy, therefore, do not only occur with regard to medical decision-making, which has been focused upon in the literature (Featherstone et al., 2019), but with regard to other aspects concerning the daily care of residents with dementia.

There are similarities between these research findings and the research of Watson (2019), discussed in Chapter 2, which showed that people with advanced dementia living in care homes could experience social death before their physical death. This occurs when a person is no longer recognised as being an active agent within their relationships. In the present study however, social death is enforced via routinised care. This indicates the importance of a shift in the way older people with dementia are perceived within the care home setting, so that the ways in which they can assert their autonomy and play an active role in their lives is acknowledged. The present study's findings also align with previous research that considers the adverse impacts of routinised care. Burke and Veliz-Reyes (2021) propose that there is a need to not only include residents' perspectives in the design of their own care environments but also co-construct a theoretical model, through interactions with residents and their support networks including care workers, so that they become active agents in their care routines. Nunez et al. (2018), who explored current practices and challenges in night-time care for people with dementia living in care homes in the UK, asserted that care homes require practices and guidelines to strike a fine balance between individualisation and institutionalised care. Finally, similar findings were established by Webster et al. (2020).

9.1.3 Power

Giddens (1979) proposed that domination is contingent upon allocative and authoritative resources. While allocative resources are material, authoritative resources capture command over individuals. Through agency, both allocative and authoritative resources are reproduced. I found that care home leaders (the doctor and nurses) and their decision-making capacity were predicated on a myriad of factors, including the practising of their agency and dimensions of the social structure, including rules for safe care and other institutional protocols. Leaders at the top of the hierarchy enforced institutionalised practices through their legitimation as leaders. Since they had both allocative and authoritative resources, they had the capacity to command resources, direct tasks and staff, and exert the authority vested in them via the structure of the organisation. In doing so, they sustained the structure of the care home and reinforced it.

Healthcare practices between the doctor, nurses and carers were configured based on specific power relations; a hierarchical structure with relationships of order, roles and levels of importance characterised the care home. The power exercised by the doctor, who was at the top of the hierarchical structure, contributed to developing tense interpersonal working relationships with nurses as it was sometimes misappropriated. Power was constituted in working relationships in ways that afforded professionals with greater knowledge and legal authority a privileged position. Within this setting, a doctor has certain powers by virtue of their legal authority and position, with most of the wider staff appearing to accept the hierarchical structure. This included accepting the doctors' authority and right to make demands or requests of others working within the home. It is the doctor who bears primary legal responsibility for the residents in the care home; thus, the role of the nurse is subservient to theirs. Power imbalances between doctor and nurses created situations in which nurses' needs were not considered by the doctor, resulting in tension on the part of the nurses.

There are various studies that examine working relations between doctors and nurses, they confirm these unequal power relations and instances of power abuse such as Porter (1991), Adib et al. (2004), Lockhart-Wood (2000), Coombs (2004) and Noyes (2021). In their Iran-based study which adopted a grounded-theory approach for example, Adib et al. (2004) found that nurses across four hospitals in Tehran lacked the power to control their practice due to the fact that doctors and their managers did not respect their decision-making capabilities. In this study, unequal power relations meant that nurses lacked authority, confidence and support, undermining their professional practice and causing them to avoid independent interventions (Adib et al., 2004). While these studies align with the findings of this research, the majority are however outdated. Further, my research findings indicate how power dynamics and organisational structures within the care home act as contextual constraints that limit the actions of care staff. The staff have to grapple with multiple competing demands from residents while also adhering to the requirements of routinised care, as delineated by care managers, with negative implications for resident experiences. On the contrary, much of the existing research is situated outside of the care home setting, focusing on hospital settings and interpersonal dynamics instead. Both Adib et al.'s (2004) and Coombs' (2004) research for example, were situated within hospital settings and emphasised how competing knowledge bases and decision-making capabilities between doctors and nurses undermined the work of the nurses. I similarly found that power is mainly concentrated in the professional roles of the doctor due to their professional knowledge and experiences, thus, care staff are limited in their actions with respect to delivering person-centred care. A novel aspect of my research however, is the finding that many residents in the care home have needs or realities that are not conducive to the organisational structure of care, but this is largely out of their control. The work of care staff is directed from 'above', but this also leads to power inequities manifested in uncaring attitudes and poor communication that cause residents to feel as if they are not valued or listened to. As Noyes (2021) suggests, interdisciplinary healthcare groups can face multiple issues relating to the issues of power and authority, this can lead to tensions and conflict in the workplace. Yet, the goal of healthcare teams should be power sharing in order to achieve communication that is nuanced and allows for a high quality, safe and collaborative care home characterised by shared decision-making (Noyes, 2021).

Carers also enforced institutionalised practices through their legitimation as staff members. Since they had both allocative (power over material objects) and authoritative resources (power over people) (Giddens, 1979), they had the capacity to exert the authority vested in them via the structure of the organisation through the provision of routinised care. The power relations I observed within inter-staff relations trickled down to shape power relations between dementia residents and their care staff through controlling care practices. Organisational contexts linked to power hierarchies affect the implementation of resident care. Yet, within the care home, issues concerning power are not sufficiently considered as part of models of resident experience against the backdrop of person-centred care. Power is mainly concentrated in the professional role of the doctor due to her professional knowledge and experience. Thus, care staff are limited in their actions with respect to delivering person-centred care. Many residents in the care home have needs or realities that are not conducive to the organisational structure of care, but this is largely out of their control. My findings illustrate how resident empowerment is not necessarily translated into the everyday experiences of dementia residents. These findings converge with other studies that suggest that dementia residents are not involved in decisions about their care as much as they would like because of the power dynamics in care homes and the attitudes that are concomitant with them (Elwyn et al., 2010; Van Corven et al., 2021).

A weakness of the organisational culture in the care home that I observed is that there is no consideration for the adverse consequences of power differentials between the various groups of staff and what this means for residents. Interpersonal skills are rooted in power relations, which ultimately strengthen and weaken the sense of individual and professional power. The complex interplay of power in the organisational culture of the care home, and how it impinges on interpersonal relationships, manifested itself in poor interdisciplinary relationships between the doctor and nurses and between supervisors and care staff. Due to power inequities, care practices are not approached in a collaborative way based on pillars of trust, respect and confidence in each other (Ocloo et al., 2020). On the contrary, power suppresses the role of lower-ranked staff, such as care staff and this hinders efforts to achieve common goals. As I have noted previously, care staff appeared to hold assumptions about dementia residents and old age so that they are infantilised and silenced. This finding converges with the work of Ojanen (2016), who noted that the infantilisation of dementia residents and older adults, in general, goes hand in hand with failures in interpersonal communication because at the heart of these assumptions is the notion that they are not competent individuals. Ojanen (2016) clarifies that older residents rarely produce this ‘silence’ by themselves. Rather, they are silenced via cultural narratives which espouse specific ideas about what it means to be old and how old people act; these cultural narratives inevitably permeate the healthcare sector.

9.1.4 Surveillance

Legitimation is a criterion that governs systems analysis and captures the procedures of action or rules that support social practices to be reproduced (Giddens, 1984). Legitimation structures may be in the form of unstated norms for social conduct or formal laws and sanctions which regulate modes of social conduct (Giddens, 1984). Legitimation structures in the care home were in the form of a formal surveillance culture that governed the social conduct of carers, in addition to unstated norms and expectations concerning carers' work. Importantly, these norms were reinforced by formal legitimation structures which were discursive in nature through the use of cameras and other monitoring mechanisms. These legitimation structures which sanctioned modes of conduct, played a powerful role in the system reproduction of institutionalised care. It ensured that carers' behaviour aligned with organisational policies, which underpinned organisational culture and, to some degree, dictated the action that staff took (Haunch et al., 2021). Policies relating to meal times and toilet care for example, supported the system reproduction of institutionalised care by ensuring that all residents ate and showered at specific times, regardless of their preferences. Formal legitimation structures ensured that care staff upheld the rules, procedures, principles and values underpinning the home's approach to wearing uniforms and dress codes, in keeping with social care standards. The purpose of monitoring and surveillance was to ensure that care staff presented a professional and suitable image to support infection prevention and control and food hygiene measures, delineated in keeping with relevant policies and procedures. Monitoring and surveillance also supported the health and safety of staff who might have been impaired by inappropriate clothing or footwear. Monitoring and surveillance procedures ensured that all care staff subscribed to existing policies and procedures.

The surveillance of staff through monitoring, according to Wiener (2003), can lead to a breakdown in trust at the organisational level. Ultimately, direct care staff do extremely challenging work for low wages and long hours. The use of cameras for the purpose of staff surveillance can be interpreted as a trust problem on the part of care staff, but it also signals a breakdown in the social and structural support which they need to do their work. The possibility of staff isolation due to monitoring regimes has been captured in some studies. Niemeijer et al. (2011), for example, raised concerns about the use of cameras to monitor staff, which they believed could foster mistrust and culminate in staff isolation and disappointment. Additionally, Robinovitch et al. (2013) and Woolrych et al. (2013, 2015) noted the ethical challenges linked with informed consent and privacy concerning the use of staff monitoring cameras. Mortenson et al. (2015) criticised this approach and perceived this form of surveillance as the embodiment of the negative aspects of institutionalisation. Ultimately, my research findings, along with these concerns, illustrate the tensions between obviating risk and safeguarding the freedom of staff. During my observations and in discussion with the nurses and caregivers, they frequently expressed a powerful sense of job insecurity as well as job dissatisfaction linked to this surveillance regime. Much of this stemmed from a feeling that they experienced a lack of managerial support. The nurses (except the head nurse) and the caregivers are all "foreigners" who are regulated within the kafala system; thus, they raised the concern of job security, and they described feeling less protected in the Saudi workplace. Whenever they expressed concerns, they were told not to question administrative decisions or to interfere with the residents' daily routine, and instead adhere to instructions despite the potential negative impact on residents. This points to how lack of support is at the root of surveillance, which also suggests that organisational efforts must be directed in this area if staff retention presents a challenge. To recall, this study found that the organisational desire to prevent staff leaving was one of the justifications provided by management for monitoring staff.

Various studies have highlighted similar legitimation structures within care homes as part of resident safety practices, such as the research of Fisk (2015) which found that there were seven principles required for surveillance to be supported in care homes. In contrast to the findings from Fisk (2015), however, this research showed that these monitoring solutions were not only used to monitor dementia residents' activity or health status remotely, but rather as a preventive solution aimed at preventing care staff from running away and averting the abuse of residents. It is imperative that I reiterate the nuances in the distinctions between the monitoring and surveillance practices that I observed and noted in the previous chapter. Through surveillance practices, the behaviour of care staff was monitored to inform safety practices and inform actions taken based on this form of analytical work. I found that surveillance was an ongoing process to identify potential threats to residents, in the form of staff abuse, and to the care home itself, in the form of staff attrition. Surveillance was performed by the home supervisors, who do not play a role in providing direct resident care. Thus, home supervisors utilised their expertise, early recognition skills and analytical skills to identify threats to resident health and safety potentially emanating from staff. Consequently, legitimation structures in the form of unstated norms for social conduct regulated modes of social conduct regarding residents' safety with the support of surveillance practices.

This research finding evokes important questions about privacy and dignity at various levels. As noted by Berridge et al. (2019), care homes are complex spaces within which privacy must be regulated because they are both private and public spaces. It is widely accepted that work practices in care homes are highly regulated because, ultimately, institutions are susceptible to liability risks for any incident of resident abuse. Moreover, resident abuse is a serious violation of human rights that must never be allowed. Concurrently, within the care home, various intimate activities occur, including using the toilet and medical care. Although I found that cameras are not installed in toilets, a dignity issue still presents itself for both care staff and residents. While the care home manager stated that the monitoring system limited the abusive behaviour against the older people in the care home, the individual toilet inside the toilet zone is the place where the residents are still exposed to potential harm. The cameras were removed from the inside because of privacy concerns. The problem of consent in the case of dementia residents has been discussed extensively in the literature by Berridge et al. (2019) and Mulvenna et al. (2017), alongside questions about autonomy in the context of bioethics, which has often ignored individuals with cognitive impairments.

9.1.5 Management

There is generally a poor understanding of the experiences of caregivers in care homes for dementia residents, and this study is one of the few (including Fisk (2015), Livingston et al. (2012), Mallon et al. (2019) and Rapaport et al. (2018)) that delineates the nature of their work. In the previous chapter, I highlighted how nurses and care staff constitute the foundation of the care home, as they are responsible for residents' personal and health care, yet there are various challenges concomitant with their role. Firstly, the work of care staff in the care home is occasionally obstructed due to unsatisfactory working conditions, sometimes resulting in strikes. The organisational culture is unable to attend to their demands for better conditions and flexibility, and the inability to address these tensions via trade-offs culminated in work obstructions. The conditions of work present a risk to the physical and mental health of care staff as they must work long hours while ensuring the health and safety of the residents. Moreover, punitive measures are in place for care staff who cannot keep up with excessive workloads, which they view as inhumane.

Engaging in strike activity therefore constituted a response to these conditions, as care staff sought to ensure a balance in company policy, their need for safety at work and humane working conditions, and residents’ health and safety, the option to strike was one of the only viable options available to them. The workload of the nurses was dependent on the size of the care staff team and the different sites within which they were required to work. Nurses worked laborious 12-hour shifts, six days a week, this sometimes interfered with their capacity to perform daily tasks and support residents’ independence. Moreover as described earlier, care staff work within a micromanaged system, this is led by the care home doctor and supervisors and is defined by a monitoring and surveillance culture that regulates their work and violates their privacy and dignity. Cleary et al. (2015) have similarly highlighted the dangers of micromanagement, which culminates in the loss of productivity, reductions in staff morale, and declining staff creativity (Cleary et al., 2015). Micromanagement has also been linked with increases in staff turnover (Cleary et al., 2015). Despite this evidence, I found that within the care home environment, the staff who delivered direct resident care were answerable to two departments: the nursing and the caregivers' departments. Although the caregivers' evaluations were completed by their supervisor, the nurses' evaluations were completed by the home doctor, who was not privy to their daily undertakings. Both nurses and care staff occupy a subordinate position within the hierarchy however the experiences of care staff are markedly distinct and characterised by a higher degree of micromanagement. The dilemma of falling between two departments was described by the nurses, they struggled to obtain appropriate support or to obtain an evaluation that would support and lead to the progression of their careers. My research findings show how the autonomy of care staff as professionals is undermined in a manner that is linked to their status as migrants within the kafala system. Autonomy has however been identified in the literature as an invaluable asset in healthcare that supports staff to independently face the challenges they encounter in the professional setting (Mookerjee et al., 2022). Ultimately micromanagement in healthcare settings occurs due to complex dynamics between autonomy, trust and accountability (Mookerjee et al., 2022).

9.1.6 Resistance to Care

Although power relations inside the care home appeared to favour carers and care home staff, some residents attempted to exert their agency by resisting routinised care. Giddens (1984) conceptualises this process as a dialectic of control, which involves a complex amalgamation of the determinism and voluntarism of the actors (Kaspersen, 2000). Resistance to care was invariably linked to infringements on autonomy. For example, I found that the dominant routines over the resident individuals with respect to toilet care and mealtimes restricted their personal liberties, they are pushed into this routine without any available options. This makes them socially lonely while causing some residents to become aggressive because their emotions are neglected. Mealtimes are especially a trigger for resistance, with residents showing resistance both verbally and physically. Routinised care practices in the home mean that care home staff typically prioritised speed, efficiency, and consumption, which meant that mealtimes could often become a battle of wills between residents and staff.

Giddens (1984) notes that "all social actors, no matter how lowly, have some degree of penetration of the social forms which oppress them" (p.72). Thus, the impact of routinised care, for example, the often-invasive approaches staff used to try to 'feed' someone, typically made residents angry, increasing their anxiety and distrust of staff. The impact of repeated forceful attempts to encourage the residents to eat was shown by the data presented in Chapter 8. Following Giddens (1976), the dialectic of control is engrained within the inherent nature of human agency or within the relations between autonomy and dependence, which are reproduced via the enactment of practices through the duality of structure. While resistance to care constitutes an exertion of resident's agency, it must be highlighted as a source of increased conflict and anxiety for residents. Further, while resistance to care is typically conceptualised by staff in terms of low-risk behaviour, it is problematic because it results in a vicious cycle that obstructs the delivery of care. As Konno et al. (2012) suggested, decreasing resistance to care is fundamentally important for the safety of both residents and staff, with Mast (2022) suggesting that person-centred assessment of both apathy and resistance-to-care can reduce this, resulting in an improved experience for both residents and staff.

9.1.7 Conformity and Obedience

For staff, meeting the timetable and routines of the care home, and the expectations of the institution, takes precedence over the psychological and social needs of the residents. It is important that residents feel their needs are being adequately met without care staff rushing off to complete their next task, as the literature shows this can leave residents feeling helpless and vulnerable (Bradshaw et al., 2012). Illustrating diagnostic overshadowing, the regimented timetable means that when residents resist routinised care, it is interpreted by staff erroneously as a feature of the cognitive impairment diagnosis and interpreted as the person lacking capacity, forming behaviours that must be challenged and overcome. In the care home, the staff linked the behavioural disorders with cognitive impairments; common features associated with this in this setting are agitation, aggression, paranoid delusions, hallucinations, sleep disorders, including incontinence, and vocalisations or screaming; therefore, they focused on controlling this behaviour rather than focusing on the feeling that triggers the behaviour. Mast (2022) suggests that person-centred assessment can improve detection of the root causes of resistance-to-care, with Cook (2019) finding that certain steps can be undertaken to understand the behaviour of such residents.

For the staff this behaviour comes across as unintentional, but to officiate the daily routine smoothly the residents' behaviour must be disciplined to the point of blind obedience, whereby they do as they are told without thinking for themselves. This is another example of how control and the lack of person-centred care in the care home, with regard to the provision of routinised care, is informed by erroneous assumptions that also shape unequal power relations between residents and their care staff. Contrastingly a recent study by Nakanishi and Yamaga (2021) found that this form of control and routinisation is concomitant with positive outcomes for residents and the long-term care burden for staff since routines lead to a reduction in the behavioural and psychological symptoms of dementia. The present study however found that prevailing power relations meant that individuals with the greatest power exert the most influence on residents' everyday experiences in the care home. Separating dominance and the influence of managerial direction was missing in the provision of care, and residents lacked agency and personal autonomy to create a change although they expressed their agency. Furthermore, assumptions inhibited a true understanding of residents' needs. A study of eleven non-dementia residents in a nursing home located in Norway found that while residents acknowledged the importance of adhering to nursing home norms and surrendering to dependency, they wanted to be included in the decision-making process to exert their agency (Mortensen et al., 2023).

9.1.8 Restraint

Dementia residents experience a myriad of difficulties in expressing their needs, frustrations and problems; therefore they express their discontent or their unmet needs, which may be in the form of aggression, leading to the use of physical restraint by care staff. As with my research findings, various studies have focused on the use of physical restraint in dementia care and the risk of harm to self and others (Kettles et al., 2004; Woods and Lasiuk, 2008; Pu and Moyle, 2022; Laboni et al., 2020). Physical restraint does not necessarily mitigate difficult behaviour and it places dementia residents at additional risk while also denying them their basic human rights (Steele et al., 2019, 2020). The use of physical restraint is invariably a form of formal risk management that seeks to balance the potential repercussions of resident aggression, but it also informs clinical decision-making processes and shapes the delivery of care to residents. There is an ongoing debate in the literature about the use of restraint, with some scholars conceptualising the use of physical restraints as a sign that healthcare services have become increasingly risk averse due to a fear of litigation (Kettles et al., 2004). The resultant effect in this study is that care staff experienced competing demands to ensure resident safety on one hand while also avoiding harm on the other. Concerning healthcare ethics and the implications of using restraint in caring for older adults, the law is unclear in Saudi Arabia. The Ministry Of Health has delineated the right to healthcare for all Saudi citizens under Articles 27 and 32 of the Basic Laws of Saudi Arabia (Al-Amoudi, 2017).

In 2006, a Patient’s Bill of Rights or PBR was issued by the ministry, this reiterates that all residents have the right to access healthcare that is suitable for their needs, to be treated with respect, to participate in their treatment options, to have personal privacy and to receive information. The bill permits residents to refuse or change their treatment although there are guidelines on informed consent for individuals who cannot make decisions (Al-Amoudi, 2017). Saudi Arabia falls behind other countries in regulating the use of restraint and developing ethical standards to govern nursing practice and protect residents' rights delineated in the PBR. In the United Kingdom, for example, the Mental Capacity Act 2005 permits the use of restraint, but only if it is necessary and proportionate, and in the resident's interest (Cooper and Livingston, 2020).

During this study three main forms of restraint were observed. As discussed in Chapter 2 and as found in Pu and Moyle (2022) and Weiner et al. (2003), safety restraints were used to secure the wheelchair and were used by staff to protect the older person from falling out of the chair. Once the residents are in their wheelchairs, they always wear the safety restraint system; it is similar to the car seatbelt; it protects them from falling down the chair. I also observed the use of limb restraints to minimise behaviour such as nasogastric tube removal, continence pad removal, scratching the skin to the bleeding level, cutting nails with their mouth, or sucking fingers. These restraints included either tying the hand to the bedside rails using a soft foam medical scraper; the mitten restraints style, which holds the finger inside, or by a knot that is made at the end of the resident’s clothes. Beds were also used for the purposes of restraint, whereby care staff used the bedside rails to hold residents during incidences of aggression or to protect them from falling down the bed. Finally, a physical restraint was also used to interfere with residents' ability to make a decision, such as using a wheelchair to protect residents from falls and injuries, using incontinence pads for all the residents, and treating all the admitted residents the same rather than individualising cases. Furthermore, the residents were not allowed to move freely around the care home floors if they chose to do so. They were also not permitted to go outside the building if they wanted and had to remain on their floor, they could only go outside during a family visit when their family requested this.

Another form of physical restraint which I observed was tying residents' hands to the bedside rails during incidents where they were pulling out nasogastric tubes. Furthermore, care staff used the mitten restraint style on some of the residents to prevent them from opening and removing incontinence pads. Another form of physical restraint used to protect the residents from harm was described by the care home staff, they used the bedside rails to prevent the residents from falling out of bed, especially when the resident was in "a hyperactive mood" where they chose to fall on the floor intentionally to show their refusal to the transaction methods the staff used to treat them. There is an argument to be made that while the use of restraints in a medical setting can assist in the prevention of harm, it is also a source of harm that infringes on the rights of residents (Testad et al., 2005). My findings reinforce the research of Steele et al. (2019, 2020) and Lee and Bartlett (2021) who found that residents living with dementia in care homes experienced infringements on their rights, focusing on resident experiences of confinement. Although both studies were situated in the Western context where there are clearer guidelines about the use of restraint than in Saudi Arabia. Steele et al. (2019, 2020) show that there is a global concern about the confinement of people living with dementia in care homes. However, while Lee and Bartlett's (2021) study places emphasis on confinement and its impact on social citizenship, my study focuses on confinement.

Educating staff about the limits and dangers of physical restraint, as well as other alternatives to the use of restraint, can enhance the quality of care provided to dementia residents (Testad et al., 2005). Care staff must also be made aware of the legal and ethical risks that are present with the use of restraints (Ljunggren et al., 1997; Testad et al., 2005). As noted by Bellis et al. (2011; p.6), the application of restraint-free practices offers benefits to both residents and staff which means that the gold standard – using no restraints – could be achieved through education and training. These education and training programmes require multidisciplinary approaches to aid implementation and also ongoing support from management.

Drawing from Testad et al. (2005), it is important that care homes in Saudi Arabia invest in training that focuses on reconfiguring perceptions of aggressive behaviour as problematic and something to be managed rather than understood.

There is evidence from Testad et al. (2005) that following such educational programmes enable care staff to become more tolerant in the face of resident agitation. In Bellis et al. (2011), it was also found that an educational programme mitigated the use of restraint among staff. Aside from these educational programmes, the successful implementation of restraint-free policies in care homes necessitates strategies that can foment attitudinal changes for staff who are involved in the provision of direct care. Bellis et al. (2011) also found that an educational programme successfully improved staff attitudes and behaviours concerning the use of physical restraint. Bellis et al. (2011), however highlighted the importance of continuous education despite the behavioural changes observed, to achieve long term changes in attitudes via knowledge of the legal ramifications of restraint use. There is significant support for the role of education on restraints for mitigating the practice, while alternatives have also been proposed by scholars such as Lee et al. (1999), De Bellis et al. (2009), Brooker (2007).

9.1.9 Communication

Giddens' (1984) systems analysis focuses on signification structures (modes of discourse) which embody assumptions that legitimise specific power relations. In the care home, the most powerful signification structure that shaped the system was language barriers which worked as a form of differentiation for dementia residents, marginalising their needs. I found that caregivers communicated with residents in broken Arabic and struggled to interpret residents' requests due to a lack of language proficiency. As also found in other studies such as Al Shamsi et al. (2020), Meuter et al. (2015) and Steinberg et al. (2016), language barriers culminate in communication errors between care staff and residents, this presents a risk for life-threatening medical errors whilst also enhancing the risk of poor help-seeking, less confidence and dissatisfaction with care. Similar to this research, Al-Ahmadi and Roland (2005) found that language barriers are prevalent in Saudi healthcare settings and constitute a key element that shapes resident dissatisfaction with care quality. In their study, the scholars found that 40% of the residents that participated in the study complained about language barriers during their treatment. Further, the study found variations in the quality of interpersonal care due to these barriers. These variations were determined by experiences of communication breakdown due to language barriers (Al-Ahmadi and Roland, 2005).

My research findings also converge with the study of Almutairi (2015), this study investigated the impact of language barriers on healthcare in Saudi Arabia. They found that language barriers are concomitant with cultural discrepancies which collectively contribute to the impediment of person-centred care. Similar to the present study, Albougami (2019) found that poor health outcomes in Saudi Arabia are reflective of foreign nurses' lack of knowledge about the nuances of cultural practices. Research by Gany et al. (2013) highlighted how people from different cultural groups expressed experiences of pain and distress in varying ways, which I also found in this study. Residents, in some instances, used culturally specific terms and expressions which care staff found difficult to navigate, this compromised the quality of care for residents.

In my research I found evidence of the way dementia residents are treated in silence, including during the provision of toilet care. This is a deeply personal experience that requires some form of communication to safeguard their dignity, integrity, respect and independence. It is clear that the lack of communication around toilet care violated residents, caregivers delivered personal care as functional care instead of humanised care, placing a huge psychological burden on the residents. A study by Northcott et al. (2022) similarly found that routinised toilet care juxtaposed with the stigma attached to incontinence, discredits the autonomy of residents in care homes, attacking their sense of self and creating a lack of agency around their bodies.

The lack of interpersonal skills and communication during the provision of care was inextricably linked to the fact that care home staff appeared to consider it their right to carry out personal and intimate care without the permission of residents. This is another example of the controlling care practices which occurred within the home. Often, staff started working on residents’ bodies without any verbal communication, regardless of whether the resident consented or not. However, any response the residents had to this type of request would frequently take the form of physical or verbal resistance, while staff typically continued their focus on completing care regardless of the response. The lack of appropriate verbal communication when preparing the resident for a task resulted in negative responses from residents. This often manifested itself in the form of the physical act of resistance (hitting out and pinching) and/or verbal (screaming and saying inappropriate words to the staff). These questions evoke important questions about care routines and autonomy and how effective communication can help mitigate some of the tensions that arise in the provision of care for residents who are cognitively impaired. Northcott et al. (2022) produced similar findings and concluded that the care of people with dementia might be improved by using an integrated approach that includes improving the communication and relationships between all care providers and creating multidisciplinary teams who draw on each other's knowledge to provide optimal care.

My findings converge with that of Kupeli et al. (2018), as discussed in Chapter 2, which noted that care home staff experience a high role burden associated with demanding working conditions, very low pay and limited professional development opportunities linked with poor communication. Kupeli et al.'s (2018) findings illustrate poor communication and conflicting relationships between health care professionals and service settings, poor symptom management, lengthy referral processes, inter-agency ignorance, diffused responsibility amongst care providers and minimal care planning. These factors result in a fragmented rather than integrated approach to care.

It was found that poor communication reinforces the hierarchical, bureaucratic organisational style observed in this study, where the senior managers have direct control over the goal orientation of their subordinates. Consequently, the subordinates follow a fixed daily routine to control and adjust their daily work. This structure affords fewer opportunities for the transfer of valuable knowledge and may arise as a result of this recourse to formal control mechanisms. In such an organisational structure, workers' needs seem to be secondary to the needs of the wider system.

As a signification structure that shaped the system, language barriers also worked as a form of differentiation for carers. I found that language barriers resulted in workplace conflicts due to communication lapses and misunderstandings. The performance of care staff is evaluated on a daily basis, and the process of getting feedback about their performance requires them to interact with managers and supervisors who are native speakers of Arabic. Studies have shown that interpersonal communication between healthcare staff is an important component of the delivery of person-centred care (Abdulla and Al-Doghaiter, 2000). When care staff cannot receive feedback from senior staff to ensure that they have fulfilled their duty of care to residents, and when there are general barriers to communication, this results in work-related stress and conflict. Relationships between staff become frustrated because of language barriers which culminate in adversarial relationships with other staff in the care home, creating a vicious cycle of work-related stress. Further, there is the issue of language barriers which contribute to the formation of cliques among staff, this points to the importance of diversity training for staff as shown in Runci et al. (2005).

Interpersonal skills are rooted in power relations which ultimately strengthen and weaken the sense of individual and professional power. The complex interplay of power in the organisational culture of the care home and how it impinges on interpersonal relationships is manifested in poor interdisciplinary relationships between the doctor and nurses and between supervisors and care staff. Existing power inequities between care staff and residents undermine the provision of collaborative care since there is an underlying lack of trust and respect between the two parties. Further, these power relations also adversely impact the independence and agency of lower-ranked staff, which hinders efforts to achieve common goals. As this study found, power hierarchies mean that senior staff lack the interpersonal skills to support collaborative care goals, these deficiencies are also replicated at another level between care staff and dementia residents. When dementia residents and older adults, in general, are infantilised it suggests underlying failures in interpersonal communication, since there is the implicit suggestion that they lack competency as individuals (Jongsma and Schweda, 2018).

9.2 Reflections on the research process

While this study has made important contributions to the literature, it is concomitant with some limitations, which must be highlighted so that the findings can be contextualised. The primary limitation of this study is inherent to the nature of critical ethnography. In critical ethnography, the researcher assumes the role of an advocate for the research population that is being studied (Thomas, 1993). Thus, the researcher effectively speaks on behalf of typically a marginalised community, with the goal of ensuring that their voices are heard (Thomas, 1993). The main challenge associated with this role is that it constitutes a form of negotiation, especially as I adopted the hybrid roles of participant-as-observer and observer-as-participant between the boundaries of healthcare practitioner (in my role as a nurse) and academic. I constantly had to translate from the real world to data, back and forth, which ultimately shaped my research findings and how I interpreted my data. Moreover, the data interpretation with regard to this approach is rooted in a subjective opinion (Lincoln and Guba, 1985). A limitation in this regard is that subjective opinions cannot be meaningfully detached from the cultural codes that shape my realities and that inspire my critical evaluation and interrogation of dementia residents' daily experiences. Critical ethnographers typically address this limitation by reverting to reflexivity (Mueke, 1994).

In Chapters 4 and 5, I have reflected on the hybrid roles of participant-as-observer and observer-as-participant, which I adopted in my field. I acknowledged that this role was useful for connecting more directly with persons with dementia and their caregivers since talking with them about their experiences could offer further information about the activities being observed. Taking up this position facilitated casual discussions to serve as important references for extracting additional information about how persons with dementia and their caregivers view the world around them, their place in it, and how and what they do in it.

Throughout my fieldwork and data interpretation, I did not fully engage with my negotiation of boundaries and how this may impinge on my perspective of the events that unfolded. In particular I did not extensively consider my dual practitioner-ethnographer role and how this may have influenced my viewpoint. Consequently, it is possible that some biases exist in this research. As previously noted, critical ethnographers speak on behalf of their participants, with the goal of ensuring that their voices are heard. My method of merging the participants' voices with my observations and voice also suggests that my research findings do not offer an account of older adults with dementia and their care staff's everyday experiences solely from their point of view. My account is also intertwined with theirs. As I have noted in Chapter 4, managing research interactions with persons with dementia and their caretakers proved challenging.

The potentially restricted time I spent sharing a place with participants might have hindered my ability to develop and sustain meaningful relationships with them. Restricted or disrupted social interaction might impact the quality of data and information obtained through fieldwork (Pawluch et al., 2017). When possibilities to develop rapport are reduced, the distance between the researcher and the researched grows (Pawluch et al., 2017). Taking a “collaborative” ethnographic method in this circumstance assisted in overcoming the limited possibilities to create trust and build rapport with the dementia participants and their caregivers in this study.

Lassiter's (2005) definition of cooperation in ethnography is based on participants sharing authorship. Ethnographic partnerships may be explored in a variety of ways by taking into account the viewpoints of both people with dementia and their caregivers. People with dementia are frequently excluded from dementia research, even though the phenomenon of interest is directly tied to decisions that impact upon them (Gibson et al., 2004). People with dementia usually have difficulty retaining material and organising it into a narrative; therefore, research that includes them may limit their capacity to participate by employing retrospective informal conversation to extract their experiences. Dementia residents might also suffer from aphasia, which further inhibits their capacity to express themselves verbally. Compared with other approaches and practises used by health and social researchers, an ethnography that includes people with dementia as participants is already collaborative.

My account of my research findings was also based on thick description, which has been demonstrated to be a rigorous approach (McCabe and Holmes, 2013; Mahon, 2014). On the one hand, the use of thick descriptions during the coding and analysis of data is concomitant with various advantages because it supports the data to be analysed contextually (McCabe and Holmes, 2013). At the same time, this approach is concomitant with some limitations concerning the transferability and generalisability of my research findings. I have, however, countered this limitation in my study by creating an audit trail of my research experience via an intricate account of the process. Although this approach has been criticised for its lack of objectivity, I have attempted to circumvent this limitation by adopting a reflexive approach to address potential researcher biases. Using this reflexive approach, I have considered and thought critically about how my preconceptions and personal views have impinged on the research process, although above, I noted some gaps in my reflexive approach.

This research has been conducted within the context of a single care home in Saudi Arabia; thus, its findings are limited to this context and do not reflect the dynamics in all Saudi Care homes and care homes elsewhere. Further, the everyday experiences of older adults living with dementia and their care staff which have been documented in this study, are also limited to this context. While the findings of this study cannot be generalised, triangulation shows that they have high internal validity and align with similar findings in the literature.

9.3 Chapter Conclusion

In this chapter, I have presented a critical discussion of my findings presented in the previous chapter based on stage five of Carspecken's (1996) framework, which involves using system relations to explain research findings with the assistance of a sociological theory. Following Gidden's (1981) structuration theory of systems, I unpacked relationships between the structures of domination, signification and legitimation that constrain or support the everyday experiences of residents diagnosed with dementia in a care home. I examined the system relationships that influenced the home's routines and schedules of care and the emergent associated concepts, including surveillance, regulations, resistance to care, discipline, conformity and obedience.

I found that institutionalisation provided a blueprint for the organisational culture, placing constraints on the options available to carers and residents alike. Institutionalisation was communicated via cultures of care revolving around the routinisation and depersonalisation of care and the micromanagement of staff. System priorities meant that timetables and routines were prioritised, this encouraged the exertion of control and limited the agency of residents for participating in their own care. A weakness of the organisational culture in the care home that I observed was the complete lack of consideration for the adverse consequences of power differentials between the various groups of staff and what this means for residents. Routines and timetables embody the institutionalisation of care; while they are inherently designed to safeguard the quality of care, there is often very little room for negotiation and individualised care, causing some residents to become resistant. Evidence of excessive control was found, which was linked to assumptions about the capabilities of dementia residents.

In this study, care home staff effectively acted as institutional entrepreneurs who wielded significant authority and resources to exert influence on residents. They maintained and reinforced institutionalisation through the development of routines, this assisted them with navigating the complexity of providing dementia care. Leaders at the top of the hierarchy enforced institutionalised practices through their legitimation as leaders. Since they had both allocative and authoritative resources, they had the capacity to command resources, direct tasks and staff, and exert the authority vested in them via the structure of the organisation. In doing so, they sustained the structure of the care home and reinforced it.

Legitimation structures in the care home were in the form of a formal surveillance culture that governed the social conduct of carers in addition to unstated norms and expectations concerning carers' work. Importantly, these norms were reinforced by formal legitimation structures which were discursive in nature through use of cameras and other monitoring mechanisms. These legitimation structures, which sanctioned modes of conduct, played a powerful role in the system reproduction of institutionalised care. It ensured that carers' behaviour aligned with organisational policies.

In the care home, the most powerful signification structure that shaped the system was a language barrier which worked as a form of differentiation for dementia residents, marginalising their needs. Interpersonal skills are rooted in power relations which ultimately strengthen and weaken the sense of individual and professional power. Power manifests itself in a complex way and permeates all aspects of the organisational culture, which determines the workings of the care home. The systemic nature of these power dynamics ultimately shapes relations at all levels of staff and adversely impacts staff relations. Due to power inequities, care practices are not approached in a collaborative way based on pillars of trust, respect and confidence in each other. On the contrary, power suppresses the role of lower-ranked staff such as care staff which hinders efforts to achieve common goals. The hierarchal nature of work in the care home meant that senior staff adopted a regimented approach to care which undermined opportunities for collaboration with staff and residents. This regimented approach to care was replicated at all levels, including at the level of resident-care staff relations. The failure on the part of care staff to acknowledge residents as competent adults led to poor interpersonal communication. Interpersonal skills also encapsulated issues linked with physical restraint.

As a signification structure that shaped the system, language barriers also worked as a form of differentiation for carers. I found that they resulted in workplace conflicts due to communication lapses and misunderstandings. Aside from the impact of language barriers in terms of undermining care practices, I found that they undermined interpersonal relationships in the workplace, which sometimes resulted in conflicts linked to misunderstandings. Relations between staff were frustrated because of language barriers which culminated in adversarial relationships with other staff in the care home, creating a vicious cycle of work-related stress. Further, there was the issue of language barriers resulting in the formation of cliques among staff, which points to the importance of diversity training for staff. In the next chapter, I present the conclusions of this study, focusing on the research implications and contributions while also pointing to future directions for research. I also present a detailed discussion concerning the limitations of this study and how these can be addressed via future studies or alternative methodologies.

Chapter 10. Conclusion

In response to the first research question of this study, “How do residents and staff perceive the 'everyday' aspects of caregiving and care-receiving in a Saudi care home?” This study revealed that for both residents and staff, the everyday aspects of caregiving and care-receiving is highly routinised. The daily experiences of dementia residents in the care home are shaped by timetables and daily routines, which determine care responsibilities. Understanding these timetables and routines and how these are enacted in practice is crucial for understanding the care setting and how the care home delivers care to its residents. The care home management team used the timetable approach to manage care delivery. However, this approach also created the potential for conflict between the reality of the fixed routines inside the care home and how residents require care.

Routines and timetables embody the institutionalisation of care; while they are inherently designed to safeguard the quality of care, there is often very little room for negotiation and individualised care, causing some residents to become resistant. The routinised nature of care in the home was invariably a function of the prevailing power relations whereby power is mainly concentrated in the professional role of the doctor due to her professional knowledge and experience. Many residents in the care home have needs or realities that are not conducive to the organisational structure of care, but this is largely out of their control. Carers are not afforded the resources or power to address these problems which are symptomatic of broader organisational constraints. Despite these organisational challenges and the fact that power moves in one direction only, when it comes to determining the organisational nature of care good communication within care homes can help to mitigate the adverse impact that system priorities have on residents. System priorities mean that timetables and routines are prioritised, which limits residents' agency for participating in their own care.

The routinised and highly structured approach to care in the home created resistance to care and was concomitant with other limitations. For carers, routinisation adversely impacted their autonomy because it went hand in hand with micromanagement. Residents' resistance to care was part of everyday life in the care home. It was defined by staff as any behaviour that staff interpreted as resisting care. During my observational period in the care home this seemed to include any behaviour that prevented or interfered with the care provider performing or assisting with activities of daily living, including bathing, eating, toileting, and dressing. The pattern of resistance throughout the shifts was variable, it could be verbal or physical, and the levels of resistance were highly variable. The regimented timetable means that when residents resist routinised care, it is interpreted by staff erroneously as a feature of the cognitive impairment diagnosis and interpreted as the person lacking capacity, forming behaviours that must be challenged and overcome. In the care home, the staff linked the BPSD with dementia and engaged in diagnostic overshadowing; common features associated with this in this setting are agitation, aggression, paranoid delusions, hallucinations, sleep disorders, including incontinence, and vocalisations or screaming; therefore, they focused on controlling this behaviour rather than focusing on the unmet need that triggered the behaviour.

In the care home in Saudi Arabia, the autonomy of older residents, particularly those with cognitive impairment, becomes challenged because they become increasingly reliant on assistance. Unfortunately, the organisation of the care home on the basis of routines limits older people’s scope for autonomy.

In response to the second research question of this study, "How does the ‘culture’ of a Saudi care home influence the experiences of residents and staff members?” This study revealed that the organisational culture reflected the power relations and hierarchal values in the home, the monitoring and surveillance regimes, as well as practices which resulted in the obstruction of work. It shapes the workflow in the care home, the underlying values about care and the day-to-day behaviours linked with these in practice, as well as the ethos of care built around dementia residents. Given that organisational culture shapes decisions about care, we can assume that it is embedded in managerial practices and work processes which indirectly uphold or undermine the care of residents with dementia. For this reason, understanding the daily routines and rituals of care at the care home requires an appreciation of how the provision of care is shaped by organisational culture.

The observed organisational culture had limited interaction with members of the communal society outside of the care home. In this context, older adults diagnosed with dementia were passive recipients of care, thus it was mainly the healthcare practitioners within the care home who created the culture.

Additionally, the organisational culture in the care home is embedded in the problematic issues that the residents and their care workers are exposed to in their everyday experience; it informs and regulates the everyday activities in the home. Healthcare practices between doctors and nurses are configured based on specific power relations; a hierarchical structure with relationships of order and the power exercised by the doctors who are at the top of the hierarchical structure. This results in tense interpersonal working relationships with nurses, as it is sometimes misappropriated. There is a monitoring and surveillance culture in the care home that is intended to regulate carers’ work. It is designed as a preventive solution aimed at curbing carers from running away and averting the abuse of residents. Further, the surveillance of carers constitutes a form of psychological abuse.

The conditions of work present a risk to carers' physical and mental health, they must work long hours while ensuring resident health and safety. Moreover, punitive measures are in place for carers who cannot keep up with excessive workloads, which they view as inhumane. Strikes, therefore, constituted a response to these conditions, as carers sought to ensure a balance in company policy, their need for safety at work and humane working conditions, and residents' health and safety. The workload on the nurses was dependent on the size of the carer team and the different sites they were required to work. Nurses worked laborious twelve hours shifts, six days a week, which sometimes interfered with their capacity to perform daily tasks and support residents' independence. Moreover, carers work within a micro-managed system which has also been established in other studies. Against this backdrop, work in the care home is occasionally obstructed due to unsatisfactory labour conditions, sometimes resulting in strikes. The organisational culture is unable to attend to the carers’ demands for better conditions and flexibility, and the inability to address these tensions via trade-offs disrupts care practices in the care home.

10.2 Significance of Findings and Contribution to the Literature

Chapter 2 showed that there are gaps in the existing literature with respect to the care experiences of older people living with dementia. Firstly, the majority of studies were conducted in Western countries; thus, there is a literature gap in the context of Saudi Arabia and other middle eastern countries. This meant that prior to this study, the available evidence was not culturally variegated and did not account for the nuances of care home experiences in other cultures. Further, many of the studies reviewed in Chapter 2 are outdated. Against this backdrop, this study has made important contributions to the literature that addresses the above-mentioned gaps. It is the first to qualitatively explore the experience of everyday life for older people living with dementia and their caregivers within a Saudi care home.

In contrast to previous studies, which frame older adults living with dementia as residents with limited agency when compared with their caregivers, this study has offered them a voice and revealed their experiences of 'everyday' in the care home. It describes how the hidden practices in healthcare work, linked to de-personalised care, adversely impacts upon their experiences. The study also revealed that care staff possess limited agency. By describing such de-personalised care practices, this study offers an important starting point for launching the necessary reforms in care homes. Owing to the prevailing biomedical understanding of dementia, older adults diagnosed with the disorder have been viewed through a stigmatised lens that positions them as victims. Such narratives have been concomitant with assumptions about their agency and capabilities. This study, however, offers new interpretations of the everyday by illustrating the aspects of care which are viewed as mundane but that deeply impact the experiences of older adults diagnosed with dementia. Crucially, while the existing literature has increasingly paid attention to the voice of older adults living with mild cognitive dementia or impairment, gaps remain concerning how they perceive everyday life from their insider perspective. Thus, this study, by unpacking the everyday life experiences of older adults diagnosed with dementia and living in a care home setting, offers a novel and rich perspective to the existing literature. This perspective and focus on the mundane is important, especially in the context of older people living with dementia, because everyday life can be concomitant with various complexities and challenges which must be understood.

Finally, the present study extends previous research by providing a contextual account of the everyday experience of dementia and showing how the quality of life and care is highly subjective and relative to residents' sense of autonomy and self. This is an important perspective that will develop the current understanding of life for people with dementia, especially since this study attends to the subjective experiences of residents' realities.

10.3 Implications of the Research Findings for Healthcare

The research findings of this study have important implications for healthcare practices in the context of dementia care. Existing studies suggest that care home routines such as mealtimes should constitute important social events for residents that provide a sense of normalcy while concurrently reinforcing their identities and agency (Maluf et al., 2020; Watkins et al., 2017; Philpin et al., 2011; Gibbs-Ward and Keller, 2005). However, the present study shows how routines can be an institutionalising experience, which can lead to residents’ loss of control. It thus evokes important questions about how to provide care that is responsive to the individual preferences and needs of residents while, at the same time, reflecting the realities of institutionalised care. It is a reality that routines are a fundamental part of the care provided by care homes, and moreover, they embody the structured aspects of living in an institution. A balance must, however, be achieved via healthcare practices in negotiating the boundaries that govern institutionalisation and residents' freedom. However, this study has shown how routinisation in care homes can create an environment that is antithetical to this goal, thus fostering an alienating experience for residents.

The findings of this study concerning the impact of the use of physical restraint on older adults living with dementia. In the Saudi context, as elsewhere, resident safety is one of the key reasons cited for the use of restraint, but this study shows that the use of restraint does not necessarily protect residents. On the contrary, the vulnerability of residents to psychological harm is heightened, as are infringements to their rights. In the care home that was observed for this study, a lack of guidelines concerning the use of physical restraints led to instances of abuse, as reported by the supervisors themselves. The implication here is that carers are insufficiently aware of the contexts where the use of restraint is permissible and do not have a nuanced understanding of the negative impact on residents. Care homes must therefore devise appropriate interventions to support the proper management of restraint in their care homes.

Although older adults with dementia may have reduced decision-making capacity due to cognitive impairment, this study shows that healthcare providers must consider how they can balance the resident-provider relationship to achieve shared decision-making, so that treatment decisions can balance both health expertise as well as resident values and preferences. This study shows that care homes that do not work to create a better power balance are at risk of undermining shared decision-making. Older adults diagnosed with dementia who are not invited to partake in the decision-making process despite their impairment feel marginalised and unwelcome in the planning of their care. The findings of this study also show that the issue of power hierarchies does not only apply to resident-provider relationships. Power imbalances also affect the organisational culture to the detriment of resident safety initiatives, for example, when carers go on strike and interrupt resident care.

The micromanagement of carers is also another area within which power imbalances are manifested. This study revealed that the micromanagement of carers was fostered by a monitoring and surveillance culture that regulated their work and violated their privacy and dignity, which influenced their approach to care. There is a suggestion that healthcare providers must consider approaches for recognising which levels of supervision are appropriate based on the needs of nurses and nurses' subjective interpretation of their training requirements. The findings of this study show that micromanaging carers' behaviour, attitudes, and work contradicts the goal of many healthcare providers to promote their progressive autonomy. Further, there is a suggestion from this study that micromanagement can have an adverse impact on organisational culture because it stifles members of the healthcare team, causing them to have low morale which can impact on resident care. Further, the findings of this study imply that healthcare providers must better consider how whole-system approaches are crucial for tackling important aspects of dementia residents' experiences because they are ultimately affected by wider organisational systems and the power dynamics within them. Organisational contexts linked to power hierarchies affect the implementation of resident care, yet within the care home issues concerning power are not sufficiently considered as part of the model for resident experience.

10.4 Recommendations

Based on the research findings of the present study, the following practical recommendations are suggested for the care home and similar care homes encountering the issues that were observed:

- To prevent care home routines from becoming an institutionalising experience, strategies such as ‘appropriation' during routines such as mealtime should be adopted. Appropriation entails residents' habits of having the routine use of the same space, for example, in the dining or socialisation room or having the same companions during tasks so that they can maintain their place within a particular social group (Maluf et al., 2020). This approach has supported residents to achieve a sense of security and mitigate their anxieties during routines (Maluf et al., 2020). Further, when residents are granted the opportunity to 'appropriate' their seats or roles within the care home, there is the indication that they have an active choice in their life and care and that they are exercising their agency. Thus, the taking up of appropriation in care homes may support residents to lead more self-fulfilling and autonomous lives, thus mitigating their feelings of marginalisation. The practice of appropriation in care homes can assist residents in developing an attachment to spaces within the home, which is essential for improving their daily experiences and creating a sense of home, albeit in the context of a care home.

- Ongoing training and support for carers to become better at recognising and responding to the unique needs of each person with dementia this will foster a more compassionate effectual care environment. This will benefit not only the PLWD but also the well-being of caregivers through reduced stress and an overall improvement in the caregiving experience. Principles integrated into measures from person-centred care and RCC empower carers to have a stronger, more empathetic relationship with PLWD, which will also ensure better outcomes for them.

- To promote person-centredness, it is important that residents play a more active role in the care planning process and that carers engage in self-reflection as part of training programmes within the care home. Carers should be encouraged to think reflectively and critically about their residents' well-being and what de-personalised care means for this. From the viewpoint of self-reflection, they must also think about how they can encourage the well-being of residents via personalised care. This process of self- reflection must also grapple with a paradigmatic shift in how personalised care is understood. Carers should be encouraged to think about care as a form of partnership, within which they have been ascribed a role to safeguard the resident's well-being above all else.

- It is important that guidelines are developed to manage the use of restraint. The care home featured in this study lacked guidelines about the use of physical restraint, this introduced loopholes regarding how it was applied by nurses and care staff. Based on the reality that restraint use in the care home is informed by various complexities, guidelines must be developed by a multidisciplinary group that focuses on 1) supporting carers to reduce the use of physical restraints and thus improving the quality of care that older adults diagnosed with dementia receive, 2) devising a careful and deliberate approach to placing limits on the use of restraint in the care home and 3) boosting awareness about the hazards of restraint use via knowledge boosting initiatives. These guidelines should emphasise that restraints must be used only as a last-measure and temporary resort.

Evidence from Scheepmans et al. (2020) indicates that the development of guidelines alone is not sufficient for reducing the use of restraints in care homes. Thus, the success of reducing restraint use from a long-term perspective will require a multi-component strategy with the end goal of achieving policy change and improving education and training in this area (Scheepmans et al., 2020). This multi-component strategy must include a sensitisation element that aims to improve carers' awareness of the consequences and of the impact that the use of a restraint has on residents. Care homes will need to invest in some key areas to promote the implementation of the guidelines and its associated multicomponent strategy. For example, investment must be made in educating healthcare providers with specific attention given to carers since they manage residents' care on a daily basis.

- It is important that person-centred care is adopted to uphold residents' dignity, regimented routines linked with institutionalisation can have an adverse impact on residents' sense of control. The competence and attitudes of carers can positively contribute to the experiences of residents in a care home. When carers know their residents, are cognisant of their needs and have an understanding of their life story, this helps residents to be perceived as who they are and who they once were. Not only does this help to deliver person-centred care, but it also fosters residents' self-worth and feelings of attachment. Additionally, the perspectives that older people have concerning autonomous decisions can offer valuable insight into best practices for providing care in relation to their autonomy. Care homes, despite dependency, require that carers attend to residents' desires; thus, a framework for ethical discussions about care is important for enhancing awareness of the practices that support or undermine personalised care. The organisation of care should be shaped according to best practices for older people.

- To improve the resident experience, changes beyond the micro and meso level are required, and these changes must be based on a critical understanding of the broader healthcare system within the home and how power operates within various hierarchies to either support or constrain action. Specifically, a framework for person-centred care in Saudi care homes must adopt a meaningful understanding of these issues whilst also addressing the factors that assist or undermine resident experiences by focusing on the operation of power inequities and adopting empowering approaches. These empowering approaches should prioritise participatory co-production from not only residents but carers and families to deliver person-centred care.

- To address power hierarchies within the organisational culture and how this undermines working relationships within the care home, care homes must actively promote a culture of communication to enhance collaboration and promote psychological safety within the workplace. Ensuring that the organisational culture is built around the provision of psychological safety will allow subordinates to comfortably discuss issues that are of importance to them and that interfere with their work. As Kramer and Cook (2004) have noted, psychological safety pertains to individuals' willingness to express themselves on the basis of how they think others will respond. A working environment that promotes psychological safety mitigates the incidence of anxiety for carers and will promote positive interpersonal behaviour such as requesting feedback, seeking help, and speaking up about dissatisfaction. This not only promotes a learning environment but supports healthy interpersonal relationships between superiors and subordinates. Ultimately, care homes should strive to create an environment within which there is a culture of respect for all workers despite their position in the hierarchy so that they feel valued and worthy.

10.5 Recommendations for Future Studies

- While this study has addressed an important gap in the literature, there are additional areas that future studies can focus on to further enrich the literature. For example, there is a need for future qualitative studies that explore the everyday experiences of carers more extensively in the context of Saudi Arabia. While this study partly focused on carers' experiences, there is still a need for further research. This study has offered a starting point and illustrated how complex their work can be.

- This study relied on informal conversations and observations as its primary data source; however, semi-structured informal conversation can elicit more nuanced and comprehensive data about their experiences. Alternatively, longitudinal studies based on observation can track the nature of their work over a period of time in order to document their unique experiences. Longitudinal studies can also employ observations to unpack the everyday experiences of older adults living in care homes more extensively.

- This study focused primarily on the experiences of older Saudi women diagnosed with dementia living in a care home; therefore, there is still a significant gap concerning the experiences of men. Due to the varying cultural experiences of men and women in Saudi Arabia, it is likely that studies oriented towards the experiences of men can elicit novel data. Mixed-methods studies can also be employed to address some of the limitations associated with qualitative research by drawing upon the strengths of quantitative approaches.

10.6 Self-reflection on the research process

This section aims to reflect on the research process, pulling together various threads and drawing out additional dimensions of my experience. Conducting research in a care home for older adults living with dementia presented unique challenges and learning opportunities, both professionally and personally. The emotional labour involved in this research was significant. Observing and engaging with individuals living with dementia, along with their caregivers, often invoked strong emotions. Witnessing the daily struggles and moments of joy highlighted the vulnerability and resilience of both residents and staff. To manage these emotions, I implemented regular debriefing sessions with my supervisory team and peers. These sessions provided a space to discuss my feelings and receive support; this helped me process my experiences and maintain emotional well-being.

Entering the care home as an observer presented initial difficulties. Establishing trust with residents and staff required time and patience. Initially, I faced scepticism and curiosity about my presence and intentions. To overcome this, I spent considerable time in the care home, participating in daily activities and engaging in casual conversations. Over time, these interactions helped build rapport and facilitated more in-depth and authentic exchanges. My persistence and genuine interest in understanding their experiences gradually led to acceptance and cooperation from both residents and staff.

My background as a nurse educator with cultural insider knowledge of Saudi Arabia played a dual role in the research process. On one hand, it provided me with a deep understanding of the cultural context and healthcare practices, enabling me to navigate the setting effectively. This insider perspective allowed me to gain insights into the cultural nuances that shaped the experiences of residents and caregivers. On the other hand, my professional identity occasionally created distance, as some participants perceived me as a figure of authority. I addressed this by emphasising my role as a researcher and by ensuring participants felt comfortable sharing their perspectives without fear of judgment.

As I reflect on my journey, I recognise the profound impact this research has had on my professional development. The experience has deepened my understanding of dementia care and the complexities involved in providing compassionate and culturally sensitive care. Moving forward, I aim to integrate these findings into my teaching, advocating for improved training and support for caregivers. Additionally, I plan to continue researching dementia care, focusing on developing interventions that enhance the quality of life for residents and support for caregivers in similar settings. This journey has not only contributed to my growth as a researcher but also reaffirmed my commitment to advancing dementia care through education and continued research

10.7 Chapter Conclusion

This chapter has provided a context for the thesis findings summary. It also documents the significance of findings that contribute to the literature context within which the provision of care is located. This ultimately impinges on the work of care staff and the everyday experiences of care for older adults diagnosed with dementia. This chapter also considers the implications of the research findings for healthcare, providing additional clarity on the recommendations for future studies needed that may shape the individual daily experiences of care home residents who are diagnosed with dementia in Saudi Arabia.

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Appendices

Appendix-I: Literature review search strategy

Databases: PsycINFO, PubMed, CINAHL Plus, ScienceDirect, and Google Scholar including the updated search in 2023

Search in November	***Updated search in 2023***
Cognitive Impairment (6500)	7896
Dementia/Dementia.tw. (34873)	3678
Cognitive adj2 impair).ti,ab. (33440)	35765
Cognitive adj2 capacity).ti,ab. (34500)	38612
(Cognitive adj2 status).ti,ab. (56780)	62899
(Memory adj2 impaired).tw. (89)	124
Alzheimer disease/(89056)	91034
(Alzheimer$ adj2 disease).tw.“dementia” OR “Alzheimer’s” OR “Alzheimer’s disease (328986)	334997

“Elderly” OR "Older People" OR "Patient" OR "Resident" OR "Senior Resident" OR "People" OR" Service user" (224678)	256897
“caregiver” OR “care givers” “care provider” OR "Carer adj2 carers" OR	163214
"Staff" OR "Nurse" OR "Caring" “health professional” OR “healthcare provider” OR “primary care provider” (159465)	
Within a care home setting “residential facilities” OR “residential” OR “care institutions” OR “long-term care” OR “nursing homes” OR “care homes” OR “residential care homes” OR “residential aged care”.(3256)	3467
"Experiance*" OR "Main experiance" OR " life experiance" OR "Dailylife*""Everyday" OR"Living" "Perspective""perception" "attitude (114)	225

Appendix-II: Characteristics of the included Studies used in the literature review

Author (s)	Country of Publication	Title	Year	Methodology
Achterberg, P., Pieper, M. J., Van Dalen-Kok, A. H., Wm De Waal, M., Husebo, B. S., Lautenbacher, S., Kunz, M., Scherder, J. and Corbett, A.	The Netherlands	Pain management in patients with dementia	2013	Review
Alatram, H., Alkhaldi, A., Fadhel, A., Almalki, K., Aldhamen, K., Alghamdi, R., Al Zhrani, S., Alenizi, A., Altamimi, A., Baawad, F. and Afif, W.B.	Saudi Arabia	Measuring the needs of dementia patients' caregivers: An assessment study from King Abdul-Aziz Medical City, Jeddah, Saudi Arabia	2023	Cross-sectional design
Black, B. S., Finucane, T., Baker, A., Loreck, D., Blass, D., Fogarty, L. and Rabins, P. V.	USA	Health problems and correlates of pain in nursing home residents with advanced dementia.	2006	Quantitative study
Chang, F., Patel, T. and Schulz, M. E.	Canada	The "Rising Tide" of dementia in Canada: What does it mean for pharmacists and the people they care for?	2015	Review
Corbett, A., Nunez, K. M., Smeaton, E., Testad, I., Thomas, A. J., Closs, S. J., Briggs, M., Clifton, L., Gjestsen, M. T.and Lawrence, V.	UK	The landscape of pain management in people with dementia living in care homes: a mixed methods study	2016	Mixed methods study

Ellis-Smith, C., Higginson, I. J., Daveson, B. A., Henson, L. A. and Evans, C. J.	UK	How can a measure improve assessment and management of symptoms and concerns for people with dementia in care homes? A mixed-methods feasibility and process evaluation of IPOS-Dem.	2018	Mixed methods study
Faraday, J., Abley, C., Beyer, F., Exley, C., Moynihan, P. and Patterson, J. M.	UK	How do we provide good mealtime care for people with dementia living in care homes?	2021	Systematic review
Felton, N., Lewis, J. S., Cockburn, S. J., Hodgson, M. and Dawson, S.	Switzerland	Pain assessment for individuals with advanced dementia in care homes: A systematic review.	2021	Systematic Review
Fisher, L. H., Edwards, D. J., Pärn, E. A. and Aigbavboa, C. O.	UK	Building design for people with dementia: a case study of a UK care home.	2018	Qualitative case study
Gaugler, J.E., Edwards, A.B., Femia, E.E., Zarit, S.H., Stephens, M.A.P., Townsend, A. and Greene, R.	USA	Predictors of institutionalization of cognitively impaired elders: family help and the timing of placement	2000	Quantitative study
Gehrman, P.R, Martin, J.L. and Shochat, T.	USA	Sleep disordered breathing and agitation in institutionalized adults with Alzheimer's disease	2003	Quantitative Study
Groenvynck, L., Khemai, C., de Boer, B., Beaulen, A., Hamers, J.P., van Achterberg, T., van Rossum, E., Meijers, J.M and Verbeek, H.	The Netherlands	The perspectives of older people living with dementia regarding a possible move to a nursing home	2023	Qualitative Phenomenological Study
Griffiths, Alys W., Smith, S. J., Martin, A., Meads, D., Kelley, R. and Surr, C. A.	UK	Exploring self-report and proxy-report quality-of-life measures for people living with dementia in care homes.	2020	large cluster randomised controlled trial
Griffiths, Alys Wyn, Robinson, O. C., Shoesmith, E., Kelley, R. and Surr, C. A.	UK	Staff experiences of implementing Dementia Care Mapping to improve the quality of dementia care in care homes: a qualitative process evaluation.	2021	Qualitative process evaluation
Gruber-Baldini, A.L., Boustani, M., Sloane, P.D. and Zimmerman, S.	USA	Behavioral symptoms in residential care/assisted living facilities: prevalence, risk factors, and medication management.	2004	Quantitative cross sectional study
Guu, T.W., Aarsland, D. and Ffytche, D.	Taiwan	Light, sleep-wake rhythm, and behavioural and psychological symptoms of dementia in care home patients: Revisiting the sundowning syndrome	2022	Systematic Review

Hadjri, K., Rooney, C. and Faith, V.	UK	Housing choices and care home design for people with dementia.	2015	Review
Hayward, J. K., Gould, C., Palluotto, E., Kitson, E. C. and Spector, A.	UK	Family involvement with care homes following placement of a relative living with dementia: A review.	2021	Review
Hilmer, S. N. and Gnjidic, D.	Australia	The effects of polypharmacy in older adults.	2009	Review
Jordan, S., Logan, P., Panes, G., Vaismoradi, M. and Hughes, D.	UK	Adverse Drug Reactions, Power, Harm Reduction, Regulation and the ADRe Profiles.	2018	Qualitative study
Khachiyants, N., Trinkle, D., Son, S.J. and Kim, K.Y	USA	Sundown syndrome in persons with dementia: An update	2011	Review
Kupeli, N., Leavey, G., Harrington, J., Lord, K., King, M., Nazareth, I., Moore, K., Sampson, E. L. and Jones, L.	UK	What are the barriers to care integration for those at the advanced stages of dementia living in care homes in the UK? Health care professional perspective.	2018	A realist approach and indepth interactive interviews
La Frenais, F., Vickerstaff, V., Cooper, C., Livingston, G., Stone, P. and Sampson, E. L.	UK	Factors influencing prescription and administration of analgesic medication: A longitudinal study of people with dementia living in care homes.	2021	Longitudinal study
Lee, K. and Bartlett, R.	UK	Material Citizenship: An ethnographic study exploring object–person relations in the context of people with dementia in care homes.	2021	Ethnographic study
Leroi, I., Chauhan, N., Hann, M., Jones, L., Prew, S., Russell, G., Sturrock, R. A., Taylor, J., Worthington, M. and Dawes, P.	UK	Sensory Health for Residents with Dementia in Care Homes in England: A Knowledge, Attitudes, and Practice Survey.	2021	Practice survey
Martin, J., Marler, M., Shochat, T. and Ancoli-Israel, S.	USA	Circadian rhythms of agitation in institutionalized patients with Alzheimer's Disease	2000	Quantitative study
McCleary, L., Thompson, G. N., Venturato, L., Wickson-Griffiths, A., Hunter, P., Sussman, T. and Kaasalainen, S.	Canada	Meaningful connections in dementia end of life care in long term care homes.	2018	Descriptive qualitative study
McPherson, S., Hiskey, S. and Alderson, Z.	UK	Distress in working on dementia wards–a threat to compassionate care: A grounded theory study	2016	Qualitative study

Morandi, A., Lucchi, E., Turco, R., Morghen, S., Guerini, F., Santi, R., Gentile, S., Meagher, D., Voyer, P., Fick, D.M. and Schmitt, E.M.,	Italy	Delirium superimposed on dementia: a quantitative and qualitative evaluation of informal caregivers and health care staff experience.	2015	Mixed methods
Mulders, A.J., Smalbrugge, M., Zwijsen, S.A., Appelhof, B., Zuidema, S.U., de Vugt, M.E., Verhey, F.R., Bakker, C. and Koopmans, R.T.	The Netherlands	Nursing staff distress associated with neuropsychiatric symptoms in young-onset dementia and late-onset dementia.	2018	Quantitative retrospective study
Murphy, J. and Aryal, N.	UK	Improving the provision of nutritional care for people living with dementia in care homes.	2020	Online survey questionnaire
Navti, B. and Apampa, B.	UK	Pharmaceutical care services to people living with dementia in care homes: A qualitative study of community pharmacists' perceptions.	2017	Qualitative study
Neikrug, A.B. and Ancoli-Israel, S.	USA	Sleep disturbances in nursing homes	2010	Review
Newman, A., Goulding, A., Davenport, B. and Windle, G.	UK	The role of the visual arts in the resilience of people living with dementia in care homes.	2019	Qualitative study
Paulson, C. M., Monroe, T. and Mion, L. C.	USA	Pain Assessment in Hospitalized Older Adults With Dementia and Delirium.	2014	Qualitative study
Petyaeva, A., Kajander, M., Lawrence, V., Clifton, L., Thomas, A. J., Ballard, C., Leroi, I., Briggs, M., Closs, J., Dening, T., Nunez, K. M., Testad, I., Romeo, R., Johar, I. and Corbett, A.	UK	Feasibility of a staff training and support programme to improve pain assessment and management in people with dementia living in care homes.	2017	Mixed methods
Pitfield, C., Shahriyarmolki, K. and Livingston, G.	UK	A systematic review of stress in staff caring for people with dementia living in 24-hour care settings	2011	Systematic Review
Qato, D. M., Alexander, G. C., Conti, R. M., Johnson, M., Schumm, P. and Lindau, S. T.	USA	Use of prescription and over-the-counter medications and dietary supplements among older adults in the United States.	2008	Quantitative study
Quinci, M. A. and Astell, A. J.	Canada	Assessing the feasibility of heart rate variability as an objective indicator of anxiety in older adults with dementia living in care homes.	2021	Quantitative study

Scerri, A. and Scerri, C.	Malta	Outcomes in knowledge, attitudes and confidence of nursing staff working in nursing and residential care homes following a dementia training programme.	2019	Quantitative pre-post test
Shiells, K., Pivodic, L., Holmerová, I. and Van den Block, L.	Czech Republic	Self-reported needs and experiences of people with dementia living in nursing homes: A scoping review.	2020	Scoping Review
Snowden, M., Sato, K. and RoyByrne, P.	USA	Assessment and treatment of nursing home residents with depression or behavioral symptoms associated with dementia: A review of the literature.	2003	Review
Steele, L., Carr, R., Swaffer, K., Phillipson, L. and Fleming, R.	Australia	Human Rights and the Confinement of People Living with Dementia in Care Homes.	2020	Qualitative study
Steele, L., Swaffer, K., Phillipson, L. and Fleming, R.	Australia	Questioning Segregation of People Living with Dementia in Australia: An International Human Rights Approach to Care Homes.	2019	Qualitative study
Watson, J.	UK	Developing the Senses Framework to support relationshipcentred care for people with advanced dementia until the end of life in care homes.	2019	Qualitative study
Zwijsen, S.A., Kabboord, A., Eefsting, J.A., Hertogh, C.M.P.M., Pot, A.M., Gerritsen, D.L. and Smalbrugge, M.	The Netherlands	Nurses in distress? An explorative study into the relation between distress and individual neuropsychiatric symptoms of people with dementia in nursing homes.	2014	Quantitative crosssectional study

Appendix-III: List of excluded studies from the literature review

Study (Author, year, title)	Reason for exclusion

1. Afram, B., Verbeek, H., Bleijlevens, M. H. C. and Hamers, J. P. H. (2015). Needs of informal caregivers during transition from home towards institutional care in dementia: A systematic review of qualitative studies. *International Psychogeriatrics*, *27*(6), pp.891–902.	Revised search terms
2. Burke, R. L. and Veliz-Reyes, A. (2021). Socio-spatial relationships in design of residential care homes for people living with dementia diagnoses: a grounded theory approach. *Architectural Science Review*, pp.1–15.	Revised search terms
3. Caspi, E. (2018). The circumstances surrounding the death of 105 elders as a result of resident-to-resident incidents in dementia in long-term care homes. *Journal of Elder Abuse and Neglect*, *30*(4), pp.284–308.	Revised search terms
4. Cottrell, L., Duggleby, W., Ploeg, J., McAiney, C., Peacock, S., Ghosh, S., Holroyd-Leduc, J. M., Nekolaichuk, C., Forbes, D., Paragg, J. and Swindle, J. (2018). Using focus groups to explore	Revised search terms

caregiver transitions and needs after placement of family members living with dementia in 24-hour care homes. *Aging and Mental Health*, *24*(2), pp.227–232.	
5. Crosbie, B., Ferguson, M., Wong, G., Walker, D. M., Vanhegan, S. and Dening, T. (2019). Giving permission to care for people with dementia in residential homes: Learning from a realist synthesis of hearing-related communication. *BMC Medicine*, *17*(1), pp.1–16.	Revised search terms
6. Gillam, J., Davies, N., Aworinde, J., Yorganci, E., Anderson, J. E. and Evans, C. (2022). Implementation of eHealth to Support Assessment and Decision-making for Residents With Dementia in Long-term Care: Systematic Review. *Journal of Medical Internet Research*, *24*(2), p. e29837.	Revised search terms

7. Grigorovich, A., Kulandaivelu, Y., Newman, K., Bianchi, A., Khan, S. S., Iaboni, A. and McMurray, J. (2021). Factors affecting the implementation, use, and adoption of real-time location system technology for persons living with cognitive disabilities in long-term care homes: Systematic review. *Journal of Medical Internet Research*, *23*(1). https://doi.org/10.2196/22831	Revised search terms
8. Hamiduzzaman, M., Kuot, A., Greenhill, J., Strivens, E. and Isaac, V. (2020). Towards personalized care: Factors associated with the quality of life of residents with dementia in Australian rural aged care homes. *PLoS ONE*, *15*(5), pp. 1–24.	Revised search terms

9. Hayward, J. K., Gould, C., Palluotto, E., Kitson, E. C. and Spector, A. (2021). Family involvement with care homes following placement of a relative living with dementia: a review. *Ageing and Society*, pp. 1–46.	Revised search terms
10. Höbler, F., McGilton, K. S., Wittich, W., Dupuis, K., Reed, M., Dumassais, S., Mick, P. and Pichora-Fuller, M. K. (2021). Hearing Screening for Residents in Long-Term Care Homes Who Live with Dementia: A Scoping Review. *Journal of Alzheimer's Disease*, *84*(3), pp. 1115–1138.	Revised search terms
11. Nunez, K. M., Khan, Z., Testad, I., Lawrence, V., Creese, B. and Corbett, A. (2017). Current practice and challenges in night-time care for people with dementia living in care homes: a qualitative study. *International Journal of Geriatric Psychiatry*, *33*(1), pp.e140–e149.	Revised search terms

12. Obayashi, K., Kodate, N. and Masuyama, S. (2020). Measuring the impact of age, gender and dementia on communication-robot interventions in residential care homes. *Geriatrics and Gerontology International*, *20*(4), pp. 373–378.	Revised search terms
13. Ravn, M. B., Klingberg, T. and Petersen, K. S. (2018). The Adult Sensory Profile™ in Care Homes Targeting People Diagnosed with Dementia: A Qualitative Study from the Care Provider Perspective. *Rehabilitation Research and Practice*, *2018*, pp.1–7.	Revised search terms
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15. Robertson, Sarah, Cooper, C., Hoe, J., Lord, K., Rapaport, P.and Livingston, G. (2019). Why do staff and family think differently	Revised search terms

about quality of life in dementia? A qualitative study exploring perspectives in care homes. *International Journal of Geriatric Psychiatry*, *34*(12), pp. 1784–1791.	
16. Samsi, K., Cole, L., Orellana, K. and Manthorpe, J. (2022). Is it worth it? Carers' views and expectations of residential respite for people living with dementia during and beyond the COVID-19 pandemic. *International Journal of Geriatric Psychiatry*, *37*(2). https://doi.org/10.1002/gps.5680	Revised search terms
17. Webster, L., Gonzalez, S. C., Stringer, A., Lineham, A., Budgett, J., Kyle, S., Barber, J. and Livingston, G. (2020). Measuring the prevalence of sleep disturbances in people with dementia living in care homes: A systematic review and metaanalysis. *Sleep*, *43*(4), pp.1–14.	Revised search terms
18. Westera, A., Fildes, D., Grootemaat, P. and Gordon, R. (2020). Rapid response teams to support dementia care in Australian aged care homes: Review of the evidence.	Revised search terms

Australasian Journal on Ageing, *39*(3), pp.178–192.	
19. Whittemore, R. and Knafl, K. (2005). The integrative review: updated methodology. *Journal of advanced nursing*, *52*(5), pp.546-553.	Revised search terms

Appendix-IV: Quality appraisal tool (GASP) used in the literature review

Table 2. Appraisal of Review Studies Using CASP

Y- indicate YES / N-indicate NO / N/A-indicate Not Applicable

	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?
Cottrell et al. (2018)	Y	Y	Y	Y	Y	N	N	Y	Y
Crosbie et al. (2019)	Y	Y	Y	Y	Y	N	N	Y	Y
Fisher et al. (2018)	Y	Y	Y	Y	Y	N	N	Y	Y
Griffiths et al. (2021)	Y	Y	Y	Y	Y	N	N	Y	Y
Jordan et al. (2018)	Y	Y	Y	Y	Y	N	N	Y	Y

La Frenais et al. (2021)	N	N	N	N	Y	N	N	Y	Y
Lee and Bartlett (2021)	N	N	N	N	Y	Y	N	Y	Y
McCleary et al. (2018)	Y	Y	Y	Y	Y	N	N	Y	Y
Navti and Apampa (2017)	Y	Y	Y	Y	Y	N	N	Y	Y
Newman et al. (2019)	Y	Y	Y	Y	Y	N	N	Y	Y
Paulson et al. (2014)	Y	Y	Y	Y	Y	N	N	Y	Y
Steele et al. (2020)	Y	Y	Y	Y	Y	N	N	Y	Y
Steele et al. (2019)	Y	Y	Y	Y	Y	N	N	Y	Y
Watson (2019)	Y	Y	Y	Y	Y	N	N	Y	Y
Groenvynck et al. (2023)	Y	Y	Y	Y	Y	N	N	Y	Y
McPherson et al. (2016)	Y	Y	Y	Y	Y	N	N	Y	Y

Table 2. Appraisal of Review Studies Using CASP

Y- indicate YES / N-indicate NO / N/A-indicate Not Applicable

	1.Did the review address a clearly focused question?	2. Did the authors look for the right type of papers?	3.Do you think all the important, relevant studies were included?	4. Did the review's authors do enough to assess quality of the included studies?	5. Can the results be applied to the local population?	6. Were all important outcomes considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?
Achterberg et al. (2013)	Y	Y	N	Y	N	N	N/A	Y	Y
Afram et al.(2015)	Y	Y	N	Y	Y	Y	N/A	Y	Y
Chang et al. (2015)	N	Y	N	Y	N	N	N/A	Y	Y

Faraday et al. (2021)	Y	Y	N	Y	N	Y	N/A	Y	Y
Felton et al.(2021)	N	Y	N	Y	N	N	N/A	Y	Y
	N	Y	N	Y	N	N	N/A	Y	Y
Hayward et al. (2021)									
Hilmer and Gnjidic (2009)	Y	Y	N	Y	N	Y	N/A	Y	Y
Westera et al. (2020)	Y	Y	N	Y	N	Y	N/A	Y	Y
Guu et al. (2022)	Y	Y	N	Y	N	Y	N/A	Y	Y
Hadjri et al.(2015)	Y	Y	N	Y	N	Y	N/A	Y	Y
Khachiyants et al. (2011)	Y	Y	N	Y	N	N	N/A	Y	Y
Neikrug et al. (2010)	Y	Y	N	Y	N	Y	N/A	Y	Y
Pitfield et al. (2011)	Y	Y	N	Y	N	Y	N/A	Y	Y
Shiells et al. (2020)	Y	Y	N	Y	N	Y	N/A	Y	Y
Snowden et al. (2003)	Y	Y	N	Y	N	Y	N/A	Y	Y

Table 3. Appraisal of Quantitative Studies Using CASP

Y- indicate YES / N-indicate NO / N/A-indicate Not Applicable

	1. Did the study address a clearly focused issue?)	2. Did the authors use an appropriate method to answer their question?	3. Were the cases recruited in an acceptable way?	4. Were the controls selected in an acceptable way?	5. Was the exposure accurately measured to minimise bias?	6. (a) Aside from the experimental intervention, were the groups treated equally?	7. (b) Have the authors taken account of the potential confounding factors in the design and/or in their analysis?	8. Can the results be applied to the local population?	9. Do the results of this study fit with other available evidence?

Black et al. (2006)	Y	Y	Y	Y	Y	Y	N	N	Y
Corbett et al. (2016)	Y	Y	Y	Y	Y	Y	N	N	Y
Ellis-Smith et al.	Y	Y	Y	Y	Y	Y	N	N	Y

Griffiths et al. (2020)	N	Y	Y	Y	Y	Y	N	N	Y
Leroi et al. (2021)	Y	Y	Y	Y	Y	Y	N	N	Y
Gehrman et al. (2003)	Y	Y	Y	Y	Y	Y	N	N	Y
GruberBaldini (2004)	Y	Y	Y	Y	Y	Y	N	N	Y

Murphy and Aryal (2020)	Y	Y	Y	Y	Y	Y	N	N	Y
Petyaeva et al. (2017)	Y	Y	Y	Y	Y	Y	N	N	Y
Qato et al. (2008)	Y	Y	Y	Y	Y	Y	N	N	Y
Quinci and Astell (2021)	Y	Y	Y	Y	Y	Y	N	N	Y
Scerri and Scerri (2019)	Y	Y	Y	Y	Y	Y	N	N	Y
Morandi et al. (2015)	Y	Y	Y	Y	Y	Y	N	N	Y
Mulders et al. (2018)	Y	Y	Y	Y	Y	Y	N	N	Y
Zwijsen et al. (2014)	Y	Y	Y	Y	Y	Y	N	N	Y
Martin et al. (2000)	Y	Y	Y	Y	Y	Y	N	N	Y

Appendix-V: Participant Information Sheet

Participant Information Sheet

Study Title

An ethnographic study of the experience of everyday life of older people who are living with dementia, and their caregivers, within a Saudi care home

Study information:

This information sheet will explain the purpose of this study and what is required if you choose to take a part. If any of the information remains unclear please contact the student researcher Manal Hamithi , it is important you understand why the research is being done and what it will involve. It is important to also note that taking part is entirely voluntary. Thank you for reading this.

What is the project’s purpose?

I aimed to provide further clarity about the possibilities, needs and environmental factors that shape the individual daily experiences of care home residents who are diagnosed with dementia, since there is a notable academic gap in the context of Saudi Arabia. Thus, I specifically sought to investigate the following research questions from a cultural perspective:

a) How do residents and staff perceive the 'everyday' aspects of caregiving and care-receiving in a Saudi care home?
b) How does the ‘culture’ of a Saudi care home influence the experiences of residents and staff members?

My explicit focus was on the impact of everyday life on individuals with cognitive impairments specifically, dementia, as well as their professional care staff.

Do you have to take a part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be able to keep a copy of this information sheet and you should sign a consent form. You can still withdraw at any time. You do not have to give a reason.

What will taking part involve?

The participants will be observed for study purpose and involved in private social conversation with the researcher. There are no other commitments or lifestyle restrictions associated with participating.

Will the participants contact in the future?

The participants will not be contacted in the future.

Are there any disadvantages or risks involved in taking part?

Participating in the research is not anticipated to cause you any disadvantages or discomfort. The level of risk involved if you do choose to join this study is very minimal and will not include anything physical or mentally challenging**.**

What are the possible benefits of taking part?

Whilst there are no immediate benefits for those people participating in the project, it is hoped that Joining this research will have a beneficial impact on understanding the everyday life of individuals with cognitive impairments specifically, dementia, as well as their professional care staff.

Will my taking part in this project be kept confidential?

All the information that the researcher collect about the participants during this study will be kept strictly confidential. participants will not be able to be identified or identifiable in any reports or publications. If you choose to take part, your information will remain anonymous and provided with pseudonyms so you are not personally identifiable, with answers only being available to the student researcher and academic supervisor. If, at any point, you decide you no longer want to take part in this study, you can ask to be removed at any point before the data is published.

What information will be recorded and how will this be kept?

The participants will not be recorded in any way.

Who is organising this research?

This study is being conducted by University in the UK with the help of Elderly Care Home (ALDAR) in city in Saudi Arabia.

What if something goes wrong?

This research involves having informal conversations and we think any risks of taking part are very low . If you do have any concerns during the study, please do speak to the student researcher who will assist you and answer any questions you might have. If you are still unhappy and would like to put in a formal complaint, you can do so by contacting:

School of Healthcare Sciences:

In the highly unlikely event that something does go wrong and you are harmed during this study, you will have the grounds to take legal action.

What happens now?

If you have any further questions about joining the study, the student researcher's contact details are provided below for you to reach out to and get involved:

Researcher Name;

Thank you for taking the time to read this Information Sheet.

Appendix-VI: RESEARCH PARTICIPANT CONSENT FORM

RESEARCH PARTICIPANT CONSENT FORM

Name of Researcher(s)
Manal Ali Hamithi
Title of study
An ethnographic study of the experience of everyday life of older people who are living with dementia, and their caregivers, within a Saudi care home

Please read and complete this form carefully. If you are willing to participate in this study, If you do not understand anything and would like more information, please do not hesitate to ask.

• I have had the research satisfactorily explained to me in verbal and / or written form by the researcher.	**YES / NO**
• I understand that I may withdraw from this study at any time without having to give an explanation. <u>This will not affect my future care or treatment.</u>	**YES / NO**
• I understand that all information about me will be treated in strict confidence and that I will not be named in any written work arising from this study.	**YES / NO**
• <u>I understand that any material of me will be used solely for research purposes and will be destroyed on completion of your research.</u>	**YES / NO**
• I understand that the researcher will be discussing the progress of this research with others …………………………………………. at Cardiff University	**YES / NO**

I

freely give my consent to participate in this research study and have been given a copy of this form for my own information.

Participant Name: ………………………………………………………………

Signature: ……………………………………………………………………… Date:

………………………………………………………………………………

Appendix-VII: RESEARCH CONSENT OF PROXY

RESEARCH CONSENT OF PROXY

Name of Researcher(s)
Manal Ali Hamithi
Title of study
An ethnographic study of the experience of everyday life of older people who are living with dementia, and their caregivers, within a Saudi care home

I, ____________________________, hereby agree to serve as the proxy (representative) for ___________________________ ("the participant"), with the power to make research participation decisions for the subject if she/he is unable to do so her/himself in the study that conducted by Manal Hamithi, which aim to

An ethnographic study of the experience of everyday life of older people who are living with dementia, and their caregivers, within a Saudi care home.

I agree on behalf of the participant's proxy that:

• I have had the research satisfactorily explained to me in verbal and / or written form by the researcher.	**YES / NO**
• I understand that I can withdraw ("participant's"), from this study at any time without having to give an explanation. This will not affect my future care or treatment.	**YES / NO**
• I understand that all information about ("participant's"), will be treated in strict confidence and that ("the subject"), will not be named in any written work arising from this study.	**YES / NO**
• I understand that any material of ("participant's"), will be used solely for research purposes and will be destroyed on completion of your research.	**YES / NO**
• I understand that the researcher will be discussing the progress of this research with others …………………………………………… at Cardiff University	**YES / NO**

I have read the information in this consent form. I have had the chance to ask any questions I have about this study and they have been answered for me. I freely give my consent to be a participant in this study.

_____
Printed Name of Participant

_____
Printed Name of Proxy

_____
Signature of Proxy Date

_____

Appendix-VIII: Written Pledge Form

Written Pledge

Name of Researcher(s)
Manal Ali Hamithi
Title of study
An ethnographic study of the experience of everyday life of older people who are living with dementia, and their caregivers, within a Saudi care home

By Signing this consent you are responsible to follow the instruction below:

1- **The researcher is allowed to observe and communicate with the residents and staff only.**

2- **The researcher is not allowed to record the participants under any circumstances that includes; pictures, video record, audio record.**

3- **The researcher is not allowed to take a pictures of the building and it is facilities**

4- **The researcher is not allowed to participate in the direct residents care under any circumstances**

5- **Any concern should be reported directly to the home manager with no further action**

6- **Any practical concern should be reported directly to the nurses and supervisors in charge with no further action**

7- **The researcher should not obstacle the duty of the care home staff under any circumstances.**

Any violation to the above will cause you a legal consequences.

Signature: ………………………………………………………………………………. Date:
……………………………………………………………………………………