Exploring how care home staff manage responsive behaviours, associated with dementia, in care homes in Ireland, during the Covid-19 pandemic

By

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

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With a special dedication to Mum, who I walked beside on her journey with dementia.

> "In the midst of winter, I found there was, within me, an invincible summer. And that makes me happy. For it says that no matter how hard the world pushes against me, within me, there's something stronger – something better, pushing right back."
>
> Albert Camus

Thesis abstract

Introduction: Care home residents with dementia often exhibit responsive behaviours including agitation, aggression and wandering. Psychotropic drugs are often prescribed to manage responsive behaviours but contravene guidance as they increase the risk of serious adverse events and death in people with dementia.

Aim: This thesis aims to understand how care home staff manage responsive behaviours to identify the barriers and facilitators to implementing a non-pharmacological approach to behaviour management.

Methods: This thesis was underpinned by the transformative paradigm and critical theory**.** A review of qualitative studies was conducted to synthesise understanding of the facilitators or barriers to implementing non-pharmacological strategies to behaviour management (PROSPERO protocol registration CRD42020165948).

The findings from the review, in addition to a qualitative survey and patient and public Involvement informed the design of the qualitative interview study to understand how responsive behaviours are managed by care home staff in the Republic of Ireland (ROI) prior to, and during the Covid-19 pandemic. In total, 25 interviews were conducted with staff from 21 care homes across Ireland. Reflexive thematic analysis of qualitative data was informed by Braun and Clarke (2019). All participants provided written informed consent. Ethical approval was obtained from Lancaster University.

Findings: The findings from the systematic review and qualitative study found the barriers to taking a non-pharmacological approach to manage responsive behaviours included inadequate staff training and multidisciplinary collaboration. The qualitative study extends current knowledge by showing that a power hierarchy exists between healthcare assistants and nurses that posed a barrier to taking a non-pharmacological approach to behaviour management. Facilitators to taking a non-pharmacological approach included effective leadership and family involvement in resident care.

Conclusion: This thesis extends knowledge by conceptualising how responsive behaviours are managed using both pharmacological and non-pharmacological approaches to identify the facilitators and barriers to implementing non-pharmacological strategies to behaviour management.

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Chapter 1. Introduction

1.1 Chapter overview

The prevalence of dementia is estimated to be approximately 50 million people worldwide (World Health Organisation [WHO], 2021). In Ireland, it is estimated that 55,266 people were living with dementia in 2019 (Pierse et al., 2020) and this figure is expected to increase to 98,946 by 2036 (Pierse et al., 2020). People with dementia often experience changes in behaviour such as aggression and agitation. These behaviours are often referred to as responsive behaviours as they may arise in response to an unmet physical or psychological need (Cohen-Mansfield, 2000). Psychotropic drugs are often prescribed to manage responsive behaviours but are associated with a risk of stroke and death in people with dementia (Yeh et al., 2019). Therefore, guidelines such as the National Institute for Health and Care Excellence (NICE, 2018) guidelines recommend taking a non-pharmacological approach to manage responsive behaviours.

The chapter begins by providing a brief overview of the different types of dementia (Chapter 1.2). In Chapter 1.3 an outline is provided of the structure of long-term residential care for older adults in the context of the Republic of Ireland (ROI). Chapter 1.4 discusses behavioural changes associated with dementia while Chapter 1.5 describes different theoretical models used to conceptualise responsive behaviours. Chapter 1.6 explores the impact of responsive behaviours for other residents and staff. The focus of Chapter 1.7 outlines how care home staff manage responsive behaviours using pharmacological approaches often associated with the use of psychotropic drugs. In addition, a critical discussion is provided of the risks and benefits of psychotropic drug use in people with dementia. Chapter 1.8 addresses the evolving field of dementia policy both from an international and national perspective relating to ROI. In Chapter 1.9 the philosophy of person-centred care is presented while relationship-centred care is the focus of Chapter 1.10. In addition, Chapter 1.11 describes Life-World Led Care theory. In Chapter 1.12, a critical evaluation of the effectiveness of different non-pharmacological interventions for managing responsive behaviours is provided. Issues impacting the care home sector in general are discussed in Chapter

1.13 while in Chapter 1.14 the impact of the Covid-19 pandemic in residential care facilities is described. Moreover, the impact of social isolation, associated with the COVID-19 pandemic is considered in relation to the behaviour of care home residents with dementia. Finally, in Chapter 1.15 a rationale is provided for conducting this PhD research while Chapter 1.16 highlights how, as a researcher, the choice of research question was influenced by my professional background and personal experiences. The chapter concludes by explaining the aim and objectives of the PhD thesis which includes a systematic review of the literature and a qualitative study (Chapter 1.17).

1.2 Dementia

Dementia is an umbrella term that encompasses a range of neurodegenerative conditions including Alzheimer's disease, vascular dementia, Lewy body dementia, frontotemporal dementia and rarer types of dementia including, Huntington's disease and Creutzfeldt-Jacob disease (WHO, 2021). The most common cause of dementia is Alzheimer's disease which accounts for 60% - 70% of cases of dementia (WHO, 2021). Alzheimer's disease is characterised by short-term memory loss, disorientation to place and time and impairment in performing activities of daily living (WHO, 2021).

Vascular dementia is the next most common cause of dementia accounting for 10% - 20% of cases and arises from cerebrovascular disease associated with ischaemia or haemorrhage (Korczyn et al., 2012). General cognitive impairment including memory and language impairment are common in vascular dementia and may be accompanied by impairment in movement. Lewy body dementia accounts for 20% of dementia cases. Lewy body dementia often presents with movement disorders while depression can also be an early symptom. Delusions, hallucinations and sleep disturbance are also symptoms of Lewy body dementia (Perry et al., 1990). Moreover, impairment in movement is also a characteristic feature of Parkinsons' disease dementia (Geldmacher & Whitehouse, 1996).

Frontotemporal dementia accounts for approximately 3% of cases of dementia and is often associated with early onset. It is the most common dementia in adults aged under 55 years and typically has a genetic cause (Ratnavalli et al., 2002). Impairments in executive function such as planning and organisation are frequently observed in people with frontotemporal dementia and may result in changes in behaviour such as disinhibition, hoarding and apathy (Ratnavalli et al., 2002). Frontotemporal dementia is also often associated with aggression and personality changes. This is important because behaviours caused by unmet needs, confusion or distress in other types of dementia can be more responsive to person-centred care and psychosocial interventions (as will be discussed in Chapter 1.5). Individuals with frontotemporal dementia are often seen as more difficult to manage and training may be beneficial to implement different strategies to behaviour management. It is important to note, however, that while different types of dementia typically present with specific impairments, due to the neurodegenerative nature of dementia, eventually all brain functions will be affected irrespective of type of dementia.

1.3 Prevalence of dementia and overview of structure of long-term residential care

The prevalence of dementia is estimated to be approximately 50 million people worldwide. However, this is estimated to treble by 2050 due to growth in the number of people in older age groups (WHO, 2021). This rapid increase in the prevalence of dementia over the next 30 years is anticipated to have huge economic costs, for example, the total global economic costs of dementia care in 2015 alone, was estimated to be $818 billion dollars (WHO, 2020).

In ROI, it is estimated that the number of cases of dementia will increase from 54,877 in 2016 to 98,946 in 2036 and to 157,883 by 2046 (Pierce et al., 2020). Cahill et al. (2014) estimates that of the 30,000 people currently living in long-term residential care in the ROI, the majority have some form of dementia. Indeed, Pierce et al. (2020) estimate that, based on Mini-Mental State Examination (MMSE) scores, 42% of care home residents in ROI have a diagnosis of severe dementia, 27% have a diagnosis of moderate dementia and 20% have a diagnosis of mild dementia. In ROI, most care homes are integrated, this means that people with and without dementia reside in the same long-term care facility although a minority of facilities are dementia specific units solely for residents with dementia.

In terms of ownership, Nursing homes Ireland (NHI, 2021) state that three quarters of care homes in ROI are private or voluntary care homes while the remainder are public care homes. Therefore, according to NHI there are over 460 private and voluntary care homes providing care to over 25,000 people while there are approximately 5,000 people residing in public care homes (Pierce et al., 2020). Private nursing homes are commercial enterprises run on a profit basis. Voluntary nursing homes are run by charities or religious orders on a not-for-profit basis, while public nursing homes are run by the state (NHI, 2021).

The Health Services Executive (HSE) in Ireland provides individuals with financial support (based on a financial assessment) to meet the cost of care associated with being resident long-term in private, voluntary, or public nursing homes in the state. This scheme is referred to as "The Nursing Homes Support Scheme" or more commonly "Fair Deal" (Age Action Ireland, n.d.). Altogether, the costs of dementia care in ROI is estimated at €1.9 billion per year (Connolly et al., 2014).

A range of issues are pertinent to the provision of care to residents of long-term residential care facilities, both in Ireland and internationally. These issues primarily relate to whether the care home operates on a profit-making basis, the availability of financial resources and the staffing levels and skills mix in the care homes (as will be discussed in Chapter 1.13). The Covid-19 pandemic has compounded the challenges encountered by care homes, impacting on the provision of high quality care to residents (as will be discussed in chapter 1.14).

1.4 Behavioural changes associated with dementia

It is estimated that 90% of people with dementia experience changes in behaviour such as agitation, aggression, walking with a purpose and repetitive vocalisations (Cerejeira et al., 2012). These symptoms are commonly described as the 'behavioural and psychological symptoms of dementia (BPSD)', 'neuropsychiatric symptoms of dementia', 'responsive behaviours' or 'behaviour that challenges', as these behaviours may be difficult for carers to manage. Indeed, NICE (2018) guidance uses the term 'behaviour that challenges' to refer to these behaviours. Therefore, the phrase 'behaviour that challenges' was adopted in the systematic review (chapter 2). However, the findings from the review suggested that the term 'behaviour that challenges' is stigmatising because it suggests that the onus of blame is with the person with dementia. Therefore, the term responsive behaviours will be used throughout the rest of the thesis, as it more appropriately reflects that the behaviour arises in response to an unmet physical need, for example, pain or due to an unmet psychological or emotional need, for example loneliness, requiring a person-centred approach to care, (as will be discussed in Chapter 1.5). Several theoretical models have been proposed to conceptualise responsive behaviours. The models present different approaches to understanding responsive behaviours.

1.5 Theoretical models of responsive behaviours

The Need-Driven Dementia-Compromised (NDDC) Behaviour Model proposed by Algase et al. (1996) is a holistic model for understanding responsive behaviours that integrates the influences of proximal factors such as unmet needs and the psychosocial environment with stable background factors such as cognitive or physical heath of the person with dementia. Proximal factors are amenable to change however cognitive and physical health remains more stable over time. The NDDC behaviour model, therefore, provides a comprehensive approach to understanding responsive behaviours (Algase et al., 1996).

The Unmet-Needs Model proposed by Cohen-Mansfield and Werner (1998) is conceptually similar to the NDDC Model, proposing that responsive behaviours may arise in response to residents' unmet needs. For instance, the unmet needs model proposed by Cohen-Mansfield (2000) perceives responsive behaviour as a symptom of an unmet need, that cannot be verbally expressed. Hence, there are a range of explanations for responsive behaviours, such as pain or an infection. Alternatively, the unmet need may be due to an unmet social or emotional need such as a lack of interaction with others (Cohen-Mansfield, 2000). Alternatively, the environment may trigger the responsive behaviour, for example, high noise levels (Cohen-Mansfield & Werner, 1995; Cohen-Mansfield, 2000). These behaviours may be inaccurately interpreted as challenges for carers to manage rather than arising in response to an underlying cause or need that has not yet been addressed (Gallagher-Thompson et al., 1992; Wagner et al., 1995).

The Environmental Vulnerability/Reduced Stress-Threshold model also proposed by Cohen-Mansfield (2000) places even greater emphasis on the importance of environmental factors in triggering responsive behaviours. For instance, The Environmental Vulnerability/Reduced Stress-Threshold model suggests that people with dementia have a lower threshold to environmental stress than people with normal cognition. Therefore, changes in the physical or psychosocial environment may cause distress and result in responsive behaviours in people with dementia at a lower threshold, compared to individuals who do not have dementia (Cohen-Mansfield, 2000).

In contrast, The Learning/Behavioural model proposed by Cohen-Mansfield (2000) is distinctly different from the theories discussed thus far. The Learning/Behavioural model suggests that behaviours arise due to conditioning; this implies that behaviours which are rewarded reinforce the likelihood of the behaviour being repeated. For instance, attention given by carers to supress responsive behaviours may reinforce the occurrence of the responsive behaviour in the future, as attention may be perceived as a reward (Cohen-Mansfield, 2000). This view is dissimilar to the “direct-impact model” also proposed by Cohen-Mansfield (2003) which assumes that responsive behaviours are a consequence of brain dysfunction in people with dementia.

These different theoretical models to explain responsive behaviour are not likely to be separate entities; rather, a certain degree of overlap exists between theories for instance, Kales et al. (2015) developed a conceptual model based on a review of the literature and expert opinion. The model conceptualises that neurodegeneration associated with dementia results in emotional and behavioural dysregulation impairing the person’s ability to interact with others and the environment. Therefore, people with dementia have a lower tolerance to stressful situations and environments, increasing the risk of developing responsive behaviours (Kales et al., 2015).

Hence, it is likely that a comprehensive explanation for responsive behaviour should encompass conceptualisations from all models. The key message is that theoretical models are beneficial in explaining how responsive behaviours arise and therefore enable more tailored approaches to behaviour management. For instance, unmet needs-based models highlight the importance of addressing the unmet need rather than treating the behaviour. This is important as care home staff may choose to suppress responsive behaviours by administering psychotropic drugs rather than addressing the underlying cause, for example, a lack of social interaction. Hence, unmet needs-based model may guide care home staff to adopt personalised approaches to care. It is, therefore, important to understand care home staff views of the causes of responsive behaviours as this is likely to influence the strategies they implement to behaviour management. Hence, care home staff perceptions of responsive behaviours may pose either a barrier or facilitator to taking a non-pharmacological approach to support residents.

These theoretical models are discussed further in the findings chapter (Chapter 6.1.3) and in greater detail in the discussion chapter (Chapter 7.1).

1.6 Impact of responsive behaviours

Responsive behaviours may potentially result in harm to the person with dementia or other residents or staff, for example verbal or physical aggression may cause distress and diminish quality of life. Prolonged exposure to responsive behaviours may result in physical and psychological harm to residents and staff such as high stress levels, “burnout” and decreased job satisfaction which may be associated with high staff turnover and increased expenditure (Holst & Skär, 2017). Therefore, strategies are needed to enable staff to effectively respond to these behaviours (Song et al., 2018). A varied range of pharmacological and non-pharmacological strategies may be used by care home staff to manage responsive behaviours.

1.7 Pharmacological approaches to manage responsive behaviours

Pharmacological approaches are predominantly associated with the use of psychotropic drugs including antipsychotics, anxiolytics, hypnotics and antidepressant medications (Maidment et al., 2016; Gustafsson et al., 2013). Of these, antipsychotic drugs are most frequently used to manage responsive behaviours (Maidment et al., 2016; Gustafsson et al., 2013; Schneider et al., 2005; Gill et al., 2007; Lee et al., 2004). Yet antipsychotic medications have limited benefits in reducing responsive behaviours (Street et al., 2000; Schneider et al., 2005; Banerjee, 2009), for example quetiapine was not found to be more effective than placebo in reducing responsive behaviours and was associated with a decrease in cognition as measured by the Mini-Mental State Examination (MMSE) (Omelan et al., 2006). In contrast, however, a randomised controlled trial (RCT) found that the antipsychotic drug olanzapine improved symptoms of hallucinations and delusions in people with Lewy Body Dementia. Moreover, a review of data from 10 meta-analysis identified modest benefits for the use of atypical antipsychotic drugs to treat severe symptoms of psychosis, aggression and agitation in people with dementia (Tampi et al., 2016). However, data from the 10 meta-analysis also identified a greater risk of adverse effects including strokes and death, associated with the use of antipsychotic drugs in people with dementia (Tampi et al., 2016).

In addition, studies have found that the use of antipsychotic drugs in people with dementia triples the rate of strokes (Kales et al., 2019; Bjerre et al., 2018). These findings are similar to those of an earlier study by Kleijer et al., (2008) that observed a nine-fold increased risk of stroke in the first month after commencing antipsychotics. In other studies, the use of antipsychotic drugs in dementia has also been associated with a significant increase in mortality (Schneider et al., 2005; Schneider et al., 2006; Kales et al., 2007; Kales et al., 2012; Gill et al., 2007; Ballard et al., 2009; Maust et al., 2015; Banerjee, 2009; Bjerre et al., 2018).

Antipsychotic drugs include typical antipsychotics and atypical antipsychotic drugs. Compared to typical antipsychotic medications, atypical antipsychotic drugs significantly reduce extrapyramidal side effects that result in involuntary body movements (Meltzer & Sumiyoshi, 2003). In addition, a retrospective cohort study by Liperoti et al. (2009) found that typical antipsychotic drugs are associated with a higher risk of mortality than atypical agents. However, the use of atypical antipsychotic drugs in dementia is also associated with an increased risk of death compared to placebo. For instance, a meta-analysis of randomised controlled trials evaluating the mortality risk of atypical antipsychotics used for managing responsive behaviours, found evidence that atypical antipsychotics increase the risk of mortality compared to placebo (odds ratio [OR], 1.536; 95% CIs 1.028 – 2.296; P – 0.036) (Yeh et al., 2019).

Moreover, The UK National Dementia Strategy found that in most cases, antipsychotic drugs were inappropriately prescribed to people with dementia and resulted in 1800 deaths and 1620 strokes per year in the UK alone (Banerjee, 2009). More recently Kales et al. (2019) estimated that antipsychotic drug use in dementia doubles the rate of death. In addition, the use of antipsychotic drugs for managing responsive behaviour has been found to increase sedation (Schneider et al., 2006), cognitive decline (Vigen et al., 2011) and the frequency of falls in people with dementia (Rochon et al., 2008) with an overall negative impact on quality of life (Kales et al., 2015; Kirkham et al., 2017).

Regulatory warnings, by the USA Food and Drug Administration (FDA, 2003) (Lenzer, 2005); and European Medicines Agency (EMA, 2004) (Wang et al., 2005) state that antipsychotic drugs should not be prescribed to people with dementia. However, Janus et al. (2016) found that the highest rates of antipsychotic drug prescribing in care homes across Western European countries where in Ireland, Austria, and Belgium. In ROI, 36% of residents with dementia were prescribed antipsychotic drugs despite regulatory warnings not to use antipsychotic drugs in this population (Janus et al., 2016). These observations are similar to those of the Irish National Audit of Dementia Care (INAD, 2014) which found that 46% of care home residents admitted to acute hospital care in the ROI had been prescribed antipsychotic drugs while in the care homes. In comparison only 19% of community dwelling dementia patients admitted to acute hospital care were receiving antipsychotic drugs (O'Shea et al., 2017). The second Irish National Audit of Dementia Care (INAD-2) was conducted in 2019. It was found that 55% of care home residents in ROI admitted to acute hospital care were receiving at least one antipsychotic drug, an increase of 9%, from the previous Irish National Audit of Dementia Care, five years earlier (Bracken-Scally et al., 2020). Indeed, it was observed in INAD-2 (2019) that 31% of patients admitted to acute care from a care home in ROI were receiving two classes of psychotropic drugs (Bracken-Scally et al., 2020).

Although antipsychotic drugs are the most frequently prescribed psychotropic drugs to manage responsive behaviours associated with dementia, other classes of psychotropic drugs are also prescribed to manage these behaviours including, hypnotic drugs, antidepressant drugs and anxiolytic drugs, such as benzodiazepines. Anxiolytic drugs are associated with adverse events such as sedation, impaired cognition, respiratory depression, pneumonia, dizziness, and falls (Rochon et al., 2017). For example, Omelan et al. (2006) associated benzodiazepine use in dementia with an increased rate of falls and a 1.47 increased risk of hip fractures. In addition, The Irish National Audit of Dementia (INAD-2, 2019) observed that 21% of care home residents admitted to acute hospital care in ROI were receiving a benzodiazepine drug compared to 8% admitted from the community. Indeed, 14% of these were receiving more than one type of benzodiazepine drug (Bracken-Scally et al., 2020).

Regarding the use of non-benzodiazepine hypnotics (“Z-drug” hypnotics) used to treat insomnia (Kay & Weinstein, 2012), it was found that 23% of people with dementia admitted to acute hospital care from a care home in ROI were receiving “Z-drug” hypnotics on admission compared to 13% admitted from the community (Bracken-Scally et al., 2020). Similarly, it was observed that 42% of people with dementia admitted to acute care from a care home in ROI were receiving an antidepressant drug on admission. The most common reason cited was to improve low mood and distressed behaviours (Bracken-Scally et al., 2020). In a study that evaluated the efficacy of antidepressant drugs to treat symptoms, associated with dementia, the drug citalopram showed benefits for improving agitation compared to placebo (Sink et al., 2005). However, in other studies, the use of antidepressant drugs has been found to increase the risk of falls in people with dementia (Woolcott et al., 2009) and increase the risks of hyponatremia (low blood sodium levels) that may result in confusion, disorientation and seizures (Coupland et al., 2011).

Furthermore, the adverse effects associated with the use of psychotropic drugs to manage responsive behaviours in dementia are exacerbated by age and co-morbidities, which lead to pharmacodynamic and pharmacokinetic changes in the way the body metabolises drugs. This results in even more frequent occurrences of serious adverse drug effects (Mangoni & Jackson, 2004). Indeed, a hospital study conducted by Klarin et al. (2005), observed that most admissions of people with dementia to acute hospital care were due to adverse drug reactions. Therefore, while psychotropic drugs, for example, antipsychotic drugs have shown modest efficacy for treating severe symptoms including psychosis and aggression in people with dementia who have not responded to non-pharmacological interventions; due to their adverse effects profile in this population, the use of these drugs are inappropriate in the majority of instances. Indeed, Harding and Peel (2013) argue that people with dementia need to be protected from inappropriate prescribing of antipsychotic drugs as these drugs are unlicensed for use in this population due to heightened risks of adverse effects. Hence, reducing inappropriate prescribing of psychotropic medication in dementia should be a high priority for policy development (Walsh et al., 2018).

1.8 The evolving field of dementia policy

In the UK, the NICE (2018) guideline on Dementia [NG97] recommends the use of non-pharmacological strategies to manage responsive behaviours as the first option, while antipsychotic drugs should only be used if the individual is at risk of harming themselves or others or if they are severely distressed. If antipsychotic drugs are prescribed, they should be initiated at the lowest dose for the shortest duration and reviewed every six weeks (NICE, 2018).

In ROI, the Department of Health National Clinical Guideline No. 21 “Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia” (2019) recommends that non-pharmacological interventions should be used initially to treat responsive behaviours. The guideline indicates that people with dementia who exhibit mild to moderate responsive behaviours should not be prescribed antipsychotic medication due to the increased risk of cerebrovascular adverse events and death (Department of Health, 2019).

Similarly, the Irish National Dementia Strategy clinical guidelines (Section 6: “Long-term Care Options”) recommends that antipsychotic drugs should only be used if the person is extremely distressed and/or poses a risk of harm to self or others (Department of Health, 2014). Also, the guidelines recommend that benzodiazepines should not be used to manage responsive behaviours in people with dementia (Department of Health, 2014). Finally, the Health Information and Quality Authority (HIQA) responsible for regulating care homes in the ROI and developing standards for care of older adults in residential care also requires the use of psychotropic drugs to be regularly reviewed and documented in care plans (article 3.4.7). Therefore, the use of psychotropic drugs given on a PRN (when needed) basis are reportable to HIQA in a quarterly return while psychotropic drugs given on a regular basis are not reportable (HIQA, 2016). This will be discussed further in the findings chapter (Chapter 6.1.4) and in greater detail in the discussion chapter (Chapter 7.1).

1.9 Person-centred care approaches to support residents with responsive behaviours

Non-pharmacological approaches to manage responsive behaviours in care homes, for example, reminiscence enable person-centred care. The philosophy of person-centred care envisioned by Kitwood (1997) is underpinned by the concept of "personhood". Personhood is a fundamental characteristic of all human beings regardless of cognitive ability and confers value and dignity to all people including people with dementia. Kitwood defined personhood as a "standing or status that is bestowed upon one human being by others, in the context of relationship and social being" (Kitwood, 1997, pp. 8).

Kitwood developed the "Enrich Model of Dementia" (1997). The model proposes that people with dementia face challenges including neurological impairment, current physical health, personality, personal biography, and the social psychology of the situation. Neurological impairment refers to the decline of cognitive abilities associated with dementia. Current physical health refers to comorbidities such as other health conditions. Personality and personal biography highlights the importance of knowing the person with dementia including their relationships, occupation and interests (Kitwood, 1997). Moreover, the relationship between carer and person with dementia is highly important. Kitwood refers to this as "social psychology" which focuses on creating a positive psychosocial environment to enhance relationships to support personhood. Indeed, Kitwood and Bredin (1992), describe "positive persons work" as the care given to people with dementia that provides love, comfort, secure attachment, a sense of inclusion, usefulness, value, identity and occupation. The model also highlights the importance of collecting information about the life story of the person with dementia to personalise both care and the environment to individual requirements. In contrast, however, Kitwood refers to social malignancy as the behaviours of carers that devalue and de-humanise the person with dementia. Kitwood suggests that social malignancy can spread rapidly in an organisation from one staff member to another. This may not always be intentional but rather result from a lack of knowledge and understanding of dementia and results in poor care practices. Therefore, Kitwood (1997) proposes a person-centred care approach that focuses on communication and building relationships with people with dementia. Kitwood (1997) recommends taking an holistic approach that considers how the personal and social world of the person with dementia influences their behaviour.

Brooker (2003) summarises Kitwood's philosophy of person-centred care into the VIPS framework. VIPS is defined as (V) valuing persons with dementia; taking an (I) individualised approach; understanding the (P) perspective of the person with dementia; and providing (S) supportive social environments to maintain relationships. VIPS supports the unconditional value of all human life and promotes human rights. The framework emphasises the need for an individual approach to care that reflects the uniqueness of each person with dementia and the importance of understanding their perspective. Finally, positive social psychology refers to a social environment that supports the development of relationships by promoting inclusivity (Brooker, 2003). Therefore, the VIPS framework provides guidance on how to implement person centred care into practice, by tailoring care to the individual needs of people with dementia which builds on their capabilities and respects their individual choices and preferences (Brooker, 2003; Brooker, 2012; Kitwood & Bredin, 1992).

The VIPS framework has informed the development of the NICE guideline on Dementia [NG97] (2018) that recommends a person-centred care approach. The VIPS framework has also provided guidance for the Alzheimer's Association Dementia Care Practice Recommendations (2018) and the development of HIQA standards.

1.10 Relationship Centred Care and the Six Senses Framework

Relationship Centred Care and the Six Senses Framework proposed by Nolan et al., (2006) suggests that person-centred care, as envisioned by Kitwood, is inadequately implemented in practice in most care homes. Nolan et al., (2006) argue that person-centred care does not consider the importance of reciprocity in relationships between care home staff, residents and family caregivers. Indeed, research by Ashburner et al., (2004) found that the best care homes had a high degree of interaction and interdependence between caregivers and residents. Therefore, Nolan et al., (1997, 2004 & 2006) proposed the Six Senses Framework. The six senses include, a sense of security, a sense of continuity and consistency and a sense of belonging, relevant to both residents, staff and family caregivers. In addition, the framework focuses on a sense of achievement and a sense of feeling significant and valued, as these are also important features of developing relationships. Nolan et al. (2006) therefore proposed a transition beyond person-centred care to relationship centred care to address the needs of not just residents but also care staff and family caregivers in an interdependent relationship (Nolan et al., 2006). However, evidence is lacking as to the extent that relationship-centred care proposed in the Six Senses framework is implemented in practice.

1.11. Life-World Led Care

Life-World Led Care proposed by Todres and Galvin (2007) conceptualises healthcare underpinned by a humanising philosophical framework that holistically encompasses all aspects of life including subjective experiences and interactions and also interdependent relationships. Therefore, quality of life cannot be quantitatively measured or assessed merely by asking users for their views of a service. In-depth understanding and insight into all aspects of everyday human experience is required which needs to be clearly communicated and reflected upon (Todres and Galvin, 2007). To understand how life-world led care can be operationalised, Boss (1977) describes a case study of how a lifeworld approach was taken to the care of a female patient with a history of gastro-intestinal complaints. Her symptoms could only be explained with reference to all aspects of life including her relationships with others, occupation and activities, concerns and perception of body image. Similarly, to support residents with responsive behaviours, consideration needs to be given to residents' relationship with care staff, family and the wider community and other aspects of life such as the activities they engage in.

Informed by these theoretical frameworks, a wide range of non-pharmacological psychosocial interventions have been developed and implemented in care home settings to reduce responsive behaviours with varying degrees of effectiveness.

1.12 Non-pharmacological interventions to manage responsive behaviours

Strom and Engedal (2020) recommend that psychosocial interventions are implemented in a way that ensures benefit, non-maleficence and justice for people with dementia. Therefore, psychosocial interventions should be tailored to individual needs. This requires knowledge of the person with dementia, their preferences and personal history (Strom & Engedal, 2020). Examples of psychosocial interventions include person-centred behavioural analysis, based on the need-driven dementia-compromised behaviour model (NDDC). Behavioural analysis can help to understand responsive behaviours as unmet needs that cannot be verbally expressed (Tible et al., 2017). Based on this model, Antecedent-Behaviour-Consequence (ABC) approach “ABC” charts are often used in care homes as a behavioural analysis technique to identify and address residents’ needs (James et al., 2020). ABC charts record antecedents (triggers) for behaviours, and consequences for each behaviour (Holle et al., 2017). Other interventions based on the NDDC model include the Serial Trial Intervention, which implements serial assessments to identify the cause of unmet needs and trials different solutions to meet these needs (Tible et al., 2017). The Serial Trial Intervention has been found to reduce responsive behaviours and prescribing of psychotropic drugs (Tible et al., 2017).

Other psychosocial interventions include reminiscence therapy. A recent meta-analysis by Park et al. (2019) found a reduction in responsive behaviours when people with dementia received reminiscence therapy compared to control group. Music therapy has also been found to be effective in managing responsive behaviours; however, the evidence base is weak due to wide variations in study design, implementation of intervention and outcome measures (Abraha et al., 2017; Brasure et al., 2016). A review by Beard (2011) also found that art-based therapy had been effective in managing responsive behaviours. In addition, animal-assisted interventions have also been found to significantly reduce agitation and aggression in nine of fifteen studies (Yakimicki et al., 2018). Indeed, several studies have also found that exercise therapy significantly reduces agitation in people with dementia (Hokkanen et al., 2008; Telenius et al., 2015). A different intervention, bright light therapy is hypothesised to improve changes in diurnal rhythms that may be responsible for “sundown syndrome.” This syndrome refers to disrupted circadian rhythms that occur in two-thirds of people with dementia and may result in responsive behaviours as daylight fades and night-time approaches (Canevelli et al., 2016). However, a review by Wang et al., (2019) found that bright light therapy significantly reduced agitation in some studies but not in others; this may be due to differences in how the intervention is delivered. Cantarella et al., (2018) also found that doll therapy reduced responsive behaviours compared to active control when measured using the Neuropsychiatric Index, in a randomised controlled trial (RCT) employing robust methods. In addition, Remington et al., (2002) and Moyle et al., (2013) found that touch and massage can be beneficial in reducing agitation in people with dementia. Also, aromatherapy has shown effectiveness in reducing responsive behaviours when essential oils are applied at high concentrations but not at low concentrations (Wang et al., 2019). Moreover, cognitive behavioural therapy has demonstrated efficacy in mild and moderate dementia and has been found to be more effective when caregivers are included as receivers of the intervention (Brodaty & Arasaratnam, 2012). Additionally, a study conducted by Aguirre et al., (2013) found that cognitive stimulation therapy improves cognition and quality of life for people with dementia particularly in females and older age groups.

Finally, cognitive rehabilitation aims to maintain independence in people with dementia by enhancing their ability to perform activities of daily life. However, a randomised controlled trial conducted by Brueggen et al. (2017) found that cognitive rehabilitation therapy for people with mild dementia did not have a significant effect on performing activities of daily living compared to cognitive training. The findings may reflect small sample size and further randomised controlled trials are needed to evaluate the effectiveness of cognitive rehabilitation therapy. Despite limited evidence however, the NICE (2018) dementia guideline [NG97] recommends cognitive rehabilitation therapy to support functional ability in people with mild to moderate dementia. NICE guideline [NG97] also recommends therapies including cognitive stimulation therapy and reminiscence therapy for people with mild to moderate dementia.

Overall, non-pharmacological interventions seem to provide safer and effective alternatives for treating agitation in patients with dementia. Indeed, Chenoweth et al. (2018) found that the success of withdrawing pharmacological therapies long term is enhanced by replacing them with non-pharmacological therapies to manage responsive behaviours in people with dementia. For example, in the Halting Antipsychotic use in Long-Term care (HALT) study, approximately three-quarters of care home residents remained free from antipsychotic drug use at 12 months, without demonstrating changes in behaviour, when a person-centred non-pharmacological approach replaced a pharmacological approach to managing behaviours that challenge (Chenoweth et al., 2018).

However, implementing non-pharmacological interventions requires adequate staffing levels and staff with the skills and knowledge to effectively deliver interventions into practice. It also, requires good governance and organisational supports for staff (Owen & Meyer, 2012). Moreover, evidence has shown that the Covid-19 pandemic has compounded the challenges to effectively and sustainably implementing non-pharmacological strategies to support residents (Covid-19 nursing homes expert panel, 2021) (as discussed in Chapter 1.14).

1.13 Issues impacting the care home sector

Numerous issues impact the care home sector both in Ireland and internationally, key areas include care home ownership, for example, profit or non-profit organisations, also, size of the care home, staffing levels, staff skills, funding and regulation. In addition, the use of restraint in care homes, human rights and safeguarding also require important consideration (Brooker and Latham, 2020).

Almost 80% of nursing homes in Ireland are privately owned with considerable variation between homes in the facilities offered. For instance, while newer care homes often provide single occupancy rooms, older care homes often have communal bathrooms and congregated living spaces (Covid-19 nursing homes expert panel, 2021). Congregated living areas have been found to impact on residents behaviour, for instance, increased environmental stimulation may result in increases in responsive behaviours aligned with the Environmental Vulnerability/Reduced Stress-Threshold model (Cohen-Mansfield, 2000) (Chapter 1.5). Indeed, a survey of 199 care home staff in the Netherlands reported that a decrease in environmental stimuli corresponded with a reduction in agitated behaviours in residents with advanced dementia (Knippenberg et al., 2022). In addition, Kleijer et al., (2014) found that large care homes in urban areas often had the highest prevalence of antipsychotic drug use.

Regarding staffing levels in care homes, there are no mandatory minimum staffing requirements in care homes in ROI (Van den Heede et al., 2020). Hence, there is considerable variation in staffing levels across care homes in the ROI. Studies have found that minimum staffing requirements have been beneficial for improving quality of care (Castle, 2011). For instance, in a survey used to collect the views of 177 general practitioners (GPs) in Australia, increasing staffing levels in care homes was considered as the most important factor to reduce the use of psychotropic drugs (Cousins et al., 2017).

There are also variable levels of skills mix in care homes in the ROI (Phelan & McCormack, 2013), for instance, it is estimated that two-thirds of healthcare workers in care homes in ROI are healthcare assistants while one-third are nurses. Moreover, few nurses working in care homes in ROI have qualifications in gerontology, although an educational background in gerontology or dementia is likely to be beneficial as 26% of care home residents are estimated to have maximum needs. It is also predicted that the dependency levels of care home residents will increase in the future and greater level of supports will be required, particularly financial resources (Covid-19 nursing homes expert panel, 2021).

1.14 The impact of the COVID-19 pandemic in care homes

Care homes faced an unprecedented challenge, due to the emergence of the Covid-19 pandemic in the spring of 2020. Inadequate staff levels were a particular challenge during Covid-19 with some care homes experiencing 40-50% absenteeism. This also impacted on governance as many managers were also absent (Covid-19 Nursing Homes Expert Panel, 2021). In many instances the use of agency staff had a detrimental impact on continuity of care. This highlights how residents in care homes are not always cared for by those who are familiar with their needs or preferences during times of crises. This limited residents' rights to choice and autonomy, for instance, residents could not participate in their usual activities. Indeed, during the pandemic, care homes were increasingly seen as medical centres rather than the resident's home, with an enormous impact on residents' quality of life (Covid-19 Nursing Homes Expert Panel, 2021).

During periods of restrictions in care homes studies found that social distancing measures and prohibition of family visits had a significant psychological impact on residents and their well-being due to social isolation (Verbeek et al. 2020). Studies conducted by Santini et al. (2020) and Leigh-Hunt et al. (2017) link social isolation to cognitive decline, depression and disrupted sleep patterns which might increase agitated behaviours in residents with dementia. Furthermore, a survey of 64 care homes across the Netherlands showed that the pandemic and visiting bans resulted in feelings of loneliness, depression and anxiety in residents (Bachhaus et al. 2021). Although these studies do not make a direct link to increases in responsive behaviours, other studies have linked depression and disrupted sleep with responsive behaviours (Rongve et al., 2010). Therefore, Campitelli et al. (2021) suggest that it is possible that care home staff have resorted to using psychotropic drugs, such as antipsychotic medications or anxiolytic medications more often during the Covid-19 pandemic to manage responsive behaviours, potentially because of reduced staff levels or the use of agency staff, who are unfamiliar with the individual needs of residents.

Although Campitelli et al. (2021) acknowledge that uncertainty exists, psychotropic drugs may potentially have been used to manage responsive behaviours because it might not have been possible to implement non-pharmacological approaches such as group activities or family visits as ways to minimise responsive behaviours during the period of Covid-19 restrictions. In addition, residents with more advanced dementia may not have been able to use technologies or have access to Skype, Zoom, or FaceTime to communicate with family members, thereby compounding their sense of isolation (Verbeek et al., 2020). Furthermore, it may be more difficult for staff to engage with residents on a one-to-one basis when gowned in personal protective clothing (PPE) and wearing face masks, especially for residents with sensory impairments, such as hearing loss (Verbeek et al., 2020).

Therefore, it is imperative to understand how social isolation, associated with Covid-19 restrictions, impacts on care home residents with dementia in Ireland, to understand if it increases the occurrence of responsive behaviours and the best way to manage these behaviours without resorting to pharmacological drugs. The research may identify transferable ways by which care home staff may mitigate the effects of social isolation using non-pharmacological approaches.

1.15 The rationale for conducting this research

This research aims to address a gap in knowledge by expanding understanding of how responsive behaviours are managed by care home staff to identify factors that enable non-pharmacological strategies. Therefore, a review of qualitative studies was conducted to synthesise understanding of the facilitators and barriers to implementing a non-pharmacological approach to behaviour management as no other reviews in this specific area have been completed (Chapter 2.2).

The findings from the review were integral to inform the design of the qualitative study (Chapter 4.1 & Chapter 4.6 & Chapter 4.8) to explore how care home staff in the Republic of Ireland (ROI) managed responsive behaviours prior to, and during the Covid-19 pandemic in order to identify the barriers and facilitators to implement sustainable non-pharmacological strategies to support residents. Research on this topic has not been conducted in the ROI. For instance, Foley (2019) examined the experience of dementia in Irish care homes with a view to implementing the Experience Centred Design Intervention. However, this differs from the aim of this thesis which does not involve research in relation to implementing an intervention. Similarly, Jennings (2018) aimed to develop an intervention for general practice to manage responsive behaviours, associated with dementia, which differs from the aim of this thesis to understand care staff experiences of supporting residents with responsive behaviours. In addition, Walsh et al. (2018) aimed to develop and evaluate the feasibility of an intervention to reduce inappropriate prescribing of antipsychotic drugs to care home residents with dementia in Ireland. However, Walsh et al. (2018) did not explore how care home staff in Ireland manage responsive behaviours in people with dementia using both pharmacological and non-pharmacological approaches, which is the focus of this thesis. Moreover, Hennelly (2020) aimed to explore how personhood in dementia is actualised in long-term residential care in Ireland. However, Hennelly did not identify the barriers and facilitators to taking a non-pharmacological approach to behaviour management. Therefore, research to conceptualise the factors that enable or pose a barrier to implementing non-pharmacological strategies is integral to the development of evidence-based dementia care policies, such as Clinical Guideline No. 21 of 'The Irish National Dementia Strategy' (NDO, 2021). Also, the continuing development of HIQA

standards (HIQA, 2016) to facilitate non-pharmacological interventions to support care home residents.
Therefore, this thesis encompasses a systematic review and qualitative study to address a gap in knowledge by expanding understanding of how responsive behaviours are managed by care home staff.

1.16 Personal reflection on the selection of this research topic

It is important to note, that other factors also influenced the selection of research topic. As a researcher it is beneficial to reflect on how my personal experience as a family carer for my mother with dementia and a professional background in pharmaceuticals influenced the selection of this research question. For instance, I was aware that psychotropic drugs are often used to manage responsive behaviours despite being associated with adverse effects in people with dementia. My personal experience of caring for my mother with dementia highlighted how respecting the person with dementia and providing a loving, comforting and supportive home environment was beneficial for preventing the occurrence of responsive behaviours. Also, I perceived that psychotropic drugs are unnecessary for behaviour management in most instances, such as when a person with dementia is supported to maintain their autonomy, interests and connections with family, friends and the community. Therefore, I perceived that this was an area for further exploration to identify the barriers and facilitators to taking a non-pharmacological approach to support people with dementia, particularly in long-term residential care were the prevalence of antipsychotic use is high.

Hence, I maintained a reflexive journal and reflected on how my personal beliefs, experiences and assumptions influenced the research process including the choice of research question, design of the study, data collection, analysis and dissemination (as discussed in Chapter 4). Reflexive boxes are included at relevant points in this thesis that provide brief extracts from my reflexive diary. In Chapter 1.17 an outline is presented of the research question and objectives of the thesis.

1.17 Research question

How are responsive behaviours, associated with dementia, managed by care home staff in pandemic and non-pandemic circumstances?

Objectives

1) To review qualitative studies to synthesise understanding of strategies used by care home staff to manage behaviour that challenges in dementia in order to identify facilitators and barriers to implementing a sustainable non-pharmacological approach.

2) To explore the views and experiences of nurses, care home assistants and care home managers on the use of pharmacological strategies to manage responsive behaviours, associated with dementia, prior to and during the Covid-19 pandemic in care homes in the Republic of Ireland (ROI).

3) To understand how nurses, care home assistants and care home managers implement non-pharmacological strategies to manage responsive behaviours, associated with dementia, prior to and during the Covid-19 pandemic in care homes in the ROI.

4) To explore the views and experiences of nurses, care home assistants and care home managers on how social isolation, associated with the Covid-19 pandemic, impacts on the wellbeing and behaviour of care home residents with dementia in the ROI.

5) To identify barriers and facilitators to implementing non-pharmacological strategies to manage responsive behaviours, associated with dementia, in care homes in the ROI.

Chapter 2. Literature review

Strategies used by care home staff to manage behaviour that challenges in dementia: a systematic review of qualitative studies

Chapter overview

This chapter presents a review of qualitative studies to synthesise understanding of the facilitators or barriers to implementing non-pharmacological approaches to manage behaviour that challenges, associated with dementia. The review protocol is registered at PROSPERO (registration number CRD42020165948). The systematic review presented in this chapter has been submitted to the International Journal of Nursing Studies (IJNS) and has been revised and resubmitted in response to reviewer comments.

2.1. Background

The prevalence of dementia in care homes is estimated to be 73% in the UK (Prince et al., 2014) and 48% in the US (Alzheimer's disease facts and figures, 2021). It is estimated that 90% of people with dementia experience changes in behaviour such as aggression, agitation, wandering and repetitive vocalisations (Steinberg et al. 2008). These behaviours are commonly referred to as behaviour that challenges (Maidment et al., 2016). These behaviours may also be referred to as the behavioural and psychological symptoms of dementia (BPSD), neuropsychiatric symptoms or responsive behaviours as they may arise in response to a specific situation or unmet physical or psychological need that cannot be verbally communicated (Cohen-Mansfield & Werner, 1995; Cohen-Mansfield, 2000; Cohen-Mansfield et al., 2015). However, in this review the term "behaviour that challenges" will be used as these behaviours are often challenging for care home staff to manage.

A varied range of pharmacological and non-pharmacological strategies may be used by care home staff to manage behaviour that challenges. Pharmacological approaches are predominantly associated with psychotropic drugs (Gustafsson et al., 2013) including antipsychotics, anxiolytics, hypnotics and antidepressant medications. (Maidment et al., 2018; Gustafsson et al., 2013) Of these, antipsychotic drugs are most frequently used to manage behaviour that challenges in dementia (Maidment et al., 2018; Gustafsson et al., 2013) despite evidence that antipsychotics increase the occurrence of strokes (Gustafsson et al., 2013; Maidment et al., 2018) and mortality (Maust et al., 2015; Tampi et al., 2016; Ballard et al., 2009; Rochon et al., 2008). A report by Banerjee (2009) found that the use of antipsychotics in dementia resulted in 1,800 deaths per annum in the UK. More recently Ralph and Espinet (2018) found that from a global perspective, little has changed regarding the use of antipsychotics in dementia over the last ten years. It is also suggested that antipsychotics may worsen cognition and quality of life (Maidment et al., 2018; Rochon et al., 2008; Banerjee, 2009; Ballard & Corbett, 2010). Indeed, age and ill-health can lead to pharmacodynamic and pharmacokinetic changes in the way the body metabolises drugs, resulting in more frequent occurrences of serious adverse effects (Mangoni & Jackson, 2004). Thus, regulatory warnings by the European Medicines Agency (EMA, 2004) in Europe and the Food and Drug Administration (FDA, 2005) in the United States advise against prescribing antipsychotic drugs to people with dementia (Banerjee, 2009). However, tighter regulatory control over the use of antipsychotic drugs has caused a shift in decision-making to prescribing anxiolytic drugs, such as benzodiazepines, associated with adverse events such as sedation, impaired cognition, respiratory depression, dizziness and falls (Huybrechts et al., 2011). There has also been a shift to prescribing antidepressant drugs, however, their use in older people has been found to increase the risk of hyponatremia (Coupland et al., 2011). Hence, in the UK the NICE guideline on Dementia [NG97] (2018) recommends non-pharmacological approaches for managing behaviour that challenges in people with dementia. Whilst a wide range of non-pharmacological approaches are available (Livingston et al., 2005; Abraha et al., 2017), it is less certain how effectively non-pharmacological interventions are implemented into usual care practices (Backhouse et al., 2016; Latham, 2018).

Many factors influence the approach taken to behaviour management. Therefore, this review of qualitative studies aims to synthesise understanding of the barriers and facilitators to taking a non-pharmacological approach.

2.2. Rationale for conducting this systematic review

A search of PROSPERO, PubMed, PsycINFO and CINAHL, indicated that no systematic review on this topic was underway. Three previous systematic reviews on related topics were identified: Nybakken et al. (2018) and Holst et al. (2017) both explored the views of care home staff regarding the triggers for residents' aggression but provided few insights into the everyday strategies employed by care home staff to manage aggression or other behaviours associated with dementia, for example, agitation. The systematic review by Walsh et al. (2017) explored factors influencing antipsychotic prescribing to care home residents with dementia but did not aim to understand how care home staff manage behaviour that challenges using a non-pharmacological approach. Therefore, a systematic review synthesising staff experiences of managing behaviour that challenges, that encompasses both non-pharmacological and pharmacological strategies, is warranted, to identify facilitators and barriers to implementing a non-pharmacological approach. This knowledge is integral to develop evidence-based dementia care policies, guidelines and national dementia strategies that enable implementation of sustainable non-pharmacological interventions to manage behaviour that challenges, associated with dementia.

2.3 Aim

To review qualitative studies to synthesise understanding of the factors that facilitate or pose a barrier to implementing a sustainable non-pharmacological approach to manage behaviour that challenges.

2.4 Methods

A thematic synthesis informed by Thomas and Harden (2008) was used to combine findings from studies of care home staff views and experiences of managing behaviour that challenges of residents with dementia, to identify themes conceptualising the facilitators and barriers to taking a non-pharmacological approach to manage these behaviours. The results were reported to conform with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) Statement (Tong et al., 2012) (**Appendix A**). The systematic review protocol was registered at The International Prospective Register of Systematic Reviews (PROSPERO), (registration number CRD42020165948). Available online at, https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=165948t

2.5 Search strategy and eligibility criteria

Three electronic databases, PubMed, PsycINFO and CINAHL were searched from inception until July 2021 to ensure the retrieval of primary qualitative studies that explored how care home staff manage behaviour that challenges in residents with dementia. (The full electronic search strategy used for databases PubMed is available in **Appendix B**). The search strategy was devised with the assistance of a Lancaster University librarian. Concepts emerging from the Sample, Phenomenon of Interest, Design, Evaluation, Research type (SPIDER) framework (Cooke et al., 2012) were used to identify search terms and keywords. Therefore, terms relating to care home staff were combined with terms relating to challenging behaviour and with keywords/terms related to study design. These search terms were then combined with keywords/terms relating to the views and experiences of care home staff and keywords/terms related to qualitative research (**Table 2.1**).

Table 2.1 Terms and keywords based on using the Sample, Phenomenon of Interest, Design, Evaluation, Research type (SPIDER) framework for qualitative research (Cooke et al., 2012).

SPIDER Framework	Search terms/keywords
S - Sample	Nursing home/care home nurses or assistants or aides or managers
PI – Phenomenon of Interest	Challenging behaviours associated with dementia – aggression or agitation or wandering or behavioural and psychological symptoms of dementia (BPSD) or neuropsychiatric symptoms or responsive behaviour
D - Design	Interview or focus group or thematic analysis or narrative or grounded theory or interpretive phenomenological analysis
E - Evaluation	Experience of Health Personnel or view or perception or decision-making of nursing home/care home nurse, assistants, aides, manager
R – Research type	Qualitative research

The comprehensive search was not restricted by date, country of origin or language, to ensure all available studies were retrieved, for example, one paper written in German was retrieved, and the abstract translated to English (chapter 2.9.2). In addition, searches were also conducted of citations and reference lists of studies identified as eligible for inclusion in the review. Moreover, a search of "ProQuest" facilitated retrieval of relevant doctoral theses in the research field. The grey literature also included searches of relevant conference abstracts.

Eligibility

The eligibility criteria for inclusion of papers in the review is specified in **Table 2.2** with a more detailed description provided in **Appendix C** (Inclusion and Exclusion Criteria).

Table 2.2: Table of inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
Peer reviewed published studies or doctoral theses that aim to understand how care home staff manage behaviour that challenges, associated with dementia and factors that influence decision-making.	Purely quantitative studies
Qualitative data collected from interviews and focus groups	Studies evaluating a specific intervention.
Qualitative methods of data analysis.	Studies that focused on other aspects of dementia care, for example, quality of life.
Only the qualitative component of mixed-methods studies was extracted.	Data collected from healthcare professionals other than the care home staff specified.

2.6 Screening and selection of studies

Three reviewers, including the PhD researcher (EOD) and two academic supervisors (CH) and (CS), independently screened 10% of titles and abstracts using a pre-designed form based on the inclusion criteria, aligned with Sundaram et al., (2019). The level of agreement between all three reviewers was high. All three reviewers (EOD) (CH) and (CS) agreed that one reviewer (EOD) should independently screen 90% of titles and abstracts using the same pre-defined form. Studies that did not meet the inclusion criteria, based on reading titles and abstracts were excluded. Remaining papers were read in full by one reviewer (EOD). While two reviewers (CH) and (CS) independently read 10% of full-text papers, randomly selected, corresponding with Ronzi et al. (2018). The level of agreement between all three reviewers was high and consensus achieved through discussion.

2.7 Data extraction and quality appraisal

Data extraction was managed using NVIVO 12 software (QSR International, 2022). One reviewer (EOD) extracted the findings. General data were also extracted from each study including author name, year and country, the aim of the study, setting and participants, also, methods of data collection and analysis.

The next stage involved quality appraisal of each study included in the review using The Critical Appraisal Skills Programme (2017) CASP (Qualitative Research) Checklist (**Appendix D**). 20% of studies (n=7) were randomly selected and quality appraised independently by two reviewers (EOD) and (CS). There was a high degree of agreement between the two reviewers and where discrepancies arose a third reviewer (CH) acted as arbitrator. It was agreed between all three reviewers that one reviewer (EOD) would independently appraise the quality of 80% of studies. It was also decided not to exclude any study based on their quality appraisal, however, the quality of each study underpinning the findings of this review was transparently stated in tabular format **(Appendix E)** and explicitly stated in the results section of this paper **(2.9.3 Results of Quality Appraisal).**

2.8 Data synthesis

A thematic synthesis was conducted aligned with Thomas and Harden (2008). A critical theorist epistemology was used to synthesise the data (Buniss & Kelly, 2010). Critical theory assumes knowledge is co-constructed and constantly revised by individuals and groups and that this process is mediated through social systems and power relations (Buniss & Kelly, 2010). The thematic synthesis involved three stages (Thomas & Harden, 2008). In the first stage data from the findings section of included papers was coded line-by-line in NVIVO 12 software by the reviewer (EOD). The process was inductive and iterative. The next phase involved the reviewer (EOD) developing descriptive themes to describe care home staff experiences in managing behaviour that challenges. (Thomas & Harden, 2008). In the third stage, analytical themes were generated by the reviewer (EOD) that went beyond describing staff experiences of behaviour management, to infer meaning of the barriers or facilitators to implementing non-pharmacological strategies. Interpretations were discussed with reviewers (CH) and (CS). To enhance rigour, the main reviewer (EOD) maintained a reflective diary (Thomas & Harden, 2008) noting how prior experience as a family carer and a critical theory perspective influenced theme construction. An audit trail was maintained documenting changes in theme and sub-theme development as recommended by Thomas and Harden (2008).

2.9 Results

2.9.1 Search results

1151 studies were identified. After reading the titles and abstracts (chapter 2.6), 1014 studies were excluded as they did not meet the inclusion criteria. The remaining 137 papers were read in full according to the protocol for selecting studies (chapter 2.6). 103 papers were then excluded and reasons for exclusion documented. Finally, 34 studies were included in the systematic review. Search strategy results are illustrated as a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow chart (Moher et al., 2010) (**Figure 2.1**).

PRISMA 2009 Flow Diagram (Moher et al., 2009)

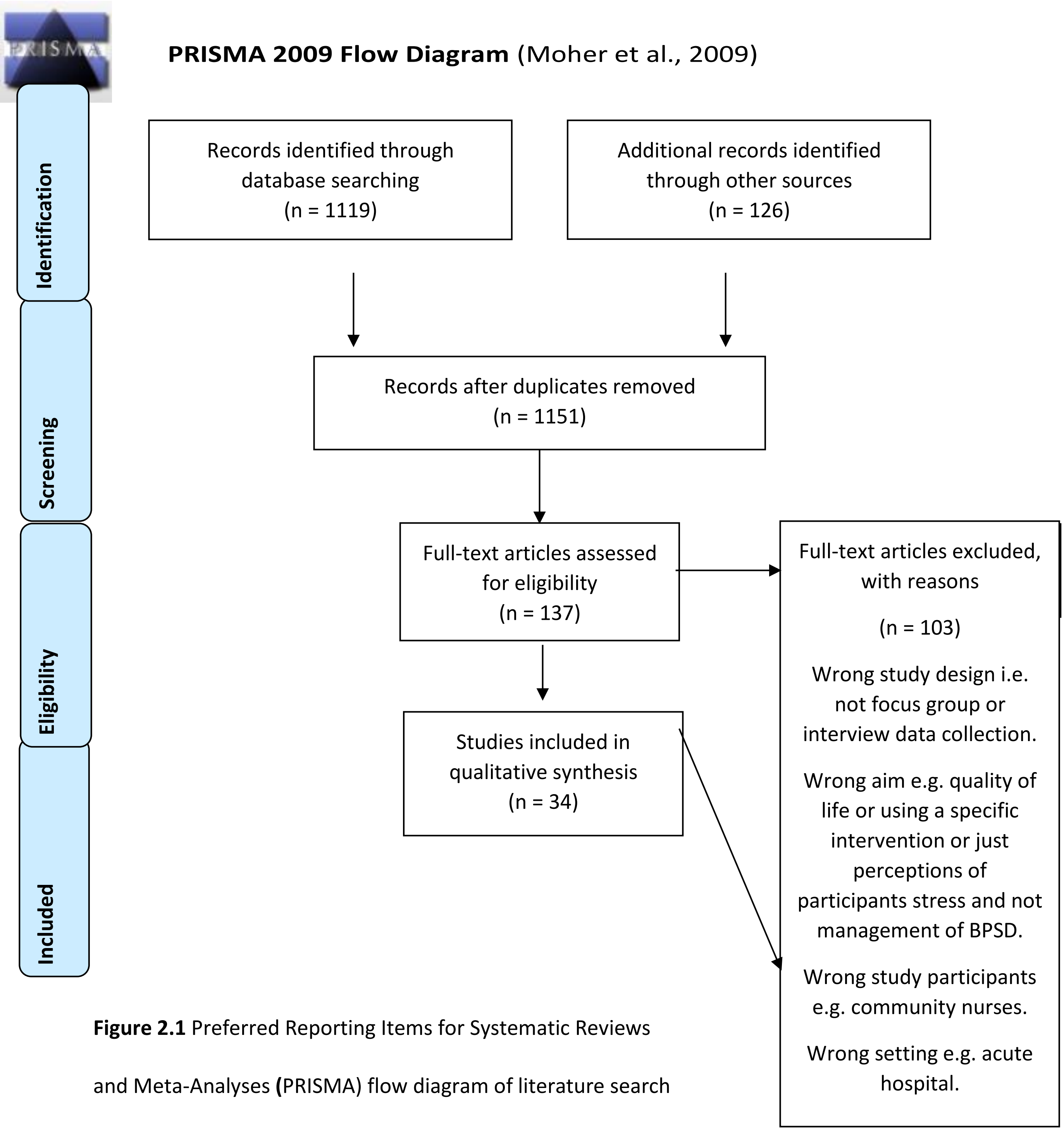


Figure 2.1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses **(**PRISMA) flow diagram of literature search

2.9.2 Characteristics of Included Studies

Thirty-four studies were included with 974 participants across ten countries. Studies were included from the UK (n = 10), the US (n = 8), Canada (n = 3), Australia (n = 3), Sweden (n = 3), Switzerland (n = 2), Netherlands (n=2), Norway (n = 1) Ireland (n = 1) and Japan (n = 1). **(Details are presented in Table 2.3).** One paper written in German was identified. After reading the abstract that had been translated into English, the study was excluded as the aim did not met the inclusion criteria.

Table 2.3: Table of characteristics of the studies included in the review (n = 34)

Author & Year & country	Aim of study	Participants (sample & settings)	Method of data collection	Method of data analysis
Ragnoskog et al. (1997) **Sweden**	Exploring care home staff experiences of agitation in residents with dementia and the pharmacological and non-pharmacological strategies used to manage agitation.	17 experienced formal caregivers, including 8 nurses from 5 nursing homes and 4 collective residential units	Interviews	Qualitative data analysis (not specified).
Hantikainen et al. (2001) **Switzerland**	Exploring how care home staff perceptions of resident's influence decision-making on the use of restraint.	20 trained and untrained nursing staff from two Swiss nursing homes	Unstructured interviews	Colaizzi's phenomenological method

Skovdahl et al. (2003) **Sweden**	Exploring how professional carers in long-term residential facilities deal with the behavioural and psychological symptoms of dementia.	15 caregivers from 3 units.	Interviews	Phenomenological hermeneutic
Foley et al. (2003) **US**	Exploring techniques used by staff to manage disruptive behaviour in nursing homes.	51 nurses, 10 activity staff and 27 secure unit co-ordinators from 36 secure unit nursing homes.	Structured interviews	Content analysis
Robinson et al. (2007) **UK**	Exploring the perspectives of different stakeholders in the management of wandering.	4 health and social care professionals, 6 nursing home staff, 3 family carers and an established group of 6	Focus groups	Thematic framework approach (Ritchie and Spencer 1994), which is both inductive and deductive.

		people with mild dementia		
Kutsumi et al. (2009) **Japan**	Investigating techniques used by care staff to manage the behavioural and psychological symptoms of dementia.	15 care providers in long-term care facilities in Japan	Interviews	Unspecified qualitative analysis
Kolanowski et al. (2010) **US**	Exploring nursing staff perceptions of the barriers to implementing non-pharmacological strategies to manage the behavioural and psychological symptoms of dementia	35 care home staff from 6 nursing homes	Focus groups	Content and thematic analysis
Zeller et al. (2011) **Switzerland**	Exploring the views and strategies used by professional caregivers' to manage aggressive	18 registered nurses, 5 nursing assistants and 7	Focus groups	Qualitative content analysis

	behaviours of care home residents.	nursing students from 4 nursing homes.		
Dupuis et al. (2012) **Canada**	Exploring the views, perceptions and experiences of staff in managing challenging behaviours of care home residents.	48 care home staff from 18 care homes	Interviews	Constant comparative method (Charmaz, 2006)
Isaksson et al. (2013) **Sweden**	Investigating how staff, manage residents' violent/aggressive behaviour in nursing homes.	41 female professional caregivers, including 8 nursing assistants, 23 enrolled nurses and 10 registered nurses from 3 care homes.	Interviews	Qualitative content analysis

Duxbury et al. (2013) **UK**	Exploring effective strategies to manage aggressive behaviour, associated with dementia in residential facilities.	4 dementia care unit managers, 2 registered nurses and 2 care assistants from 4 nursing homes.	Semi-structured interviews	Thematic analysis
Janzen et al. (2013) **Canada**	Exploring the views of care staff regarding the use of non-pharmacological interventions to reduce agitation in residents with dementia.	44 staff members from 5 long-term care units, of which 3 had secure dementia units.	Focus groups	Van Manen’s hermeneutic phenomenology
Yeager (2013) **US PhD thesis** **“The Relationships between Licensed Vocational Nurses' Care, Documentation, and Perceptions of**	Exploring the relationship between nurses' responses to dementia behaviours, documentation, and perceptions of dementia care.	10 nurses from 3 nursing homes participated, 7 worked on secure units and three worked in the general nursing home.	Semi-structured interviews	Unspecified qualitative data analysis

Dementia-Compromised Behaviors in the Nursing Home **University of Texas, 2013.**				
Gyerberg et al. (2013) **Norway**	Exploring strategies or interventions used by care home staff to manage behaviour that challenges, to avoid the use of coercion in care homes.	60 participants including nurses, auxiliary nurses and some members of staff without formal qualifications. Some worked in ordinary units and others in special care units	Interdisciplinary focus group interviews	Bricolage – moved back and forth in the text to create meaning without using a specific technique for analysis.

Smeets et al. (2014) **Netherlands**	Exploring factors and reasons for psychotropic drug prescription for neuropsychiatric symptoms in nursing home residents with dementia.	A total of 29 participants including 14 nurses and 15 physicians from 12 nursing homes.	Semi-structured interviews	Comparative analysis
Snellgrove et al. (2015) **US**	Exploring strategies used by certified nurse assistants to manage resident to resident violence and aggression in nursing homes	11 certified nurse assistants from a single not-for-profit nursing home	Semi-structured interviews	Content analysis and constant comparison.
Ostaszkiewicz et al. (2015) **Australia**	Care home nurse's experiences of responding to behaviour that challenges and strategies implemented to deal with the symptoms.	30 nurses from 3 nursing homes	Focus groups	Thematic analysis

Mallon (2015) **UK** **PhD thesis** **Managing behaviour that challenges within English care homes: an exploration of current practices.** **University of Kent (2015).**	Exploring current practices to manage behaviour that challenges in care homes.	Thirty-eight female participants and three male participants including 11 managers and 30 care home staff from 11 care homes	Interviews	Thematic analysis
Kolanowski et al. (2015) **US**	Exploring how care home staff effectively deliver non-pharmacological therapies and person-centred care to manage the behavioural and psychological symptoms	59 care home staff from 2 care homes	Focus groups	Qualitative content analysis

	of dementia in care homes.			
Shaw et al., (2016) **UK**	To understand how treatment culture in care homes impacts on management of behaviour that challenges.	5 care home managers, 7 nurses, 13 care assistants and 2 GP's.	Interviews	Framework analysis and thematic analysis
Backhouse et al., (2016 & 2018). UK Data derived from a doctoral study; "The management of behavioural and psychological symptoms of dementia in care homes". University of East Anglia (2010 - 2014)	Exploring approaches to manage behaviour that challenges in care homes, including, more questionable practices such as surveillance, forced care and physical restraint strategies. Also, to understand how these strategies impact on the human rights of residents.	40 care home staff from 4 care homes	Interviews	Framework analysis

Sawan et al. (2017) **Australia**	Exploring organisational culture in nursing homes and the subsequent influence on the use of psychotropic medicines.	40 on-site nursing home staff and visiting staff from eight nursing homes	Semi-structured interviews	Thematic analysis
Donyai et al. (2017) **UK**	Exploring the use of false arguments in professionals' decision-making about antipsychotic prescribing to care home residents with dementia.	5 care-home managers (from five different care homes), 5 GPs, 7 community psychiatric nurses, 5 psychiatrists, 2 geriatricians, 2 pharmacists, 1 memory-clinic nurse and 1 social worker	Interviews	Qualitative content analyses
van Wyk et al. (2017) **UK**	To understand how care home staff manage residents with the behavioural and	17 care assistants from 4 care homes	Semi-structured interviews	Thematic and framework analysis

	psychological symptoms of dementia.			
Almutairi et al. (2018) **UK**	To understand the rationale for using antipsychotic drugs in care home residents with dementia.	5 care home managers	Interviews	Constant comparison
Clifford & Doody (2018) **UK**	Exploring nurses' views of managing challenging behaviours in long term residential care.	9 nurses from 1 public and 8 private long-term facilities.	Interviews	Qualitative content analyses
Herron et al. (2018) **Canada**	To understand how carers, understand the actions of people with dementia in relation to their environment.	18 care home staff (17 nurses and 1 nursing aide) from an unspecified number of nursing homes.	Semi-structured interviews	Constant comparison approach (Charmaz, 2014).

		Also, 9 informal carers.		
Kerns et al. (2018) **US**	Factors influencing the adoption of pharmacological approaches to manage the behavioural and psychological symptoms of dementia in care homes and the barriers to taking a non-pharmacological approach.	66 assisted living nurses from 6 nursing homes	Semi-structured interviews	Qualitative data analysis via template, immersion and crystallization, and thematic development.
Rapaport et al. (2018) **UK**	To explore how care home staff understand and manage agitation.	25 care home staff from 6 care homes in S.E. England including both private and charity sector run residential and nursing homes of differing sizes	Interviews	Qualitative thematic analysis

		in urban and rural areas.		
Simmons et al. (2018) **US**	The use of pharmacological strategies to manage the behavioural and psychological symptoms of dementia and the barriers to reduce inappropriate use of antipsychotic medications.	11 licensed nurses, 4 registered nurses, 2 facility administrators, 2 nurse practitioners, 2 directors of nursing, 2 certified nursing assistants, 1 assistant director of nursing, from 3 community nursing homes.	Focus groups	Qualitative data analysis. Coded using a hierarchical coding system. The hierarchical coding system was developed based on the overall purpose of the study and a preliminary review of the transcripts by the moderator.
Walsh et al. (2018) **Ireland**	Exploring the factors that influence antipsychotic prescribing to nursing home residents with dementia.	5 general practitioners, 3 family members, 2 pharmacists,	Semi-structured interviews	Framework Analysis

		2 consultant geriatricians 2 consultant psychiatrists, 8 nurses, 5 healthcare assistants from 4 nursing homes		
van Teunenbroek et al. (2020) **Netherlands**	Exploring the perceived barriers to change regarding management of neuropsychiatric symptoms in nursing homes and to construct a conceptual framework of the relationships between these barriers.	Total of 17 participants including 6 nurses, 1 nursing assistant, 2 unit managers, 2 psychologists and 6 relatives of residents from different dementia units of one nursing home.	Focus groups	Thematic analysis

Rosenthal et al. (2020) **US**	Exploring health professionals’ experiences with decision-making during changes under the National Partnership to improve dementia care in nursing homes.	Total of 40 participants including 30 nursing home staff and 10 prescribing physicians from 14 nursing homes.	Semi-structured interviews	Unspecified qualitative data analysis
Watson & Hatcher, (2021) **Australia**	Exploring staff perceptions of agitation in care home residents and the influence of dementia, when selecting management strategies to reduce agitated behaviour.	Total of 11 participants including 7 nurses and 4 care assistants from two care homes across the same organisation.	Semi-structured interviews	Content analysis

2.9.3 Results of quality appraisal

Quality appraisal using the Critical Appraisal Skills Programme (CASP qualitative research checklist, 2017) identified that almost two-thirds of the primary qualitative studies included in the review were of high quality or moderate to high quality (n=20), while five studies were assessed to be of moderate quality. However, nine studies were assessed to be of low quality or low-to-moderate quality. In 22 studies, a lack of researcher reflexivity limited overall study quality. Also, discussion of ethical issues was judged as being inadequately addressed in 16 studies. Most studies did not provide reasons why potential participants did not take part. In addition, only a few studies reported modifying the interview or focus group schedules during data collection. Also, data saturation was inadequately addressed in most studies, while only one study described patient and public involvement (PPI), although PPI may have been beneficial in ensuring that the aims of the research were relevant. Six studies were assessed to be of low quality due to weaknesses across several Critical Appraisal Skills Programme (CASP) criteria these included Foley et al. (2003); Kutsumi et al. (2009); Kolanowski et al. (2010); Ragneskog et al. (1997); Robinson et al. (2007) and van Wyk et al. (2017) (**Appendix E**).

2.10 Synthesis of findings

The synthesis of findings identified three themes and 10 subthemes **(Table 2.4).**

Table 2.4: Themes and sub-themes

Themes	Sub-themes
"Putting out the fires"	Reactive strategies using a non-pharmacological approach
	Pharmacological interventions
	Physical restraint
Personhood, human rights and respect	Knowing the person not just the disease
	Causes of behaviours, associated with dementia
	Person focused support
Person focused approach – a paradigm shift	Changes in care home culture and staff attitudes

	Collaboration and equitable decision-making
	Training, education, knowledge and experience
	Dementia friendly environment

The theme “Putting out the fires” refers to reactive strategies implemented by care home staff to de-escalate behaviour that challenges using a range of different pharmacological and non-pharmacological strategies.

The theme Personhood, human rights and respect, addresses the concept of personhood in dementia and highlights the importance of the relationship between residents and staff.

The theme Person focused approach – a paradigm shift reflects the changes in care home culture and staff attitudes needed to facilitate implementation of sustainable non-pharmacological approaches to manage behaviour that challenges.

2.11 Theme: “Putting out the fires”

Reactive strategies using a non-pharmacological approach

Care home staff in all studies acknowledged that they reacted to behaviours that challenge using a wide range of non-pharmacological strategies to de-escalate behaviours by “putting out the fires” (Janzen et al., 2013).

> *“At times there’s so little staff and there’s a lot of behaviours all at once, it’s just kind of putting out fires and keep things rolling’’* (nurse) (Janzen et al., 2013).

In several studies, care home staff explained that taking the resident to a quiet room (Janzen et al., 2013; Duxbury et al., 2013) and providing reassurance was beneficial in quelling behaviour that challenges (Snellgrove et al., 2015; Isaksson et al., 2013; Watson & Hatcher, 2021). Using a flexible approach, postponing care tasks, giving residents time and space to calm down or changing carers was also described by staff as effective (Shaw et al., 2016; Gjerberg et al., 2013; Backhouse et al., 2018; Isaksson et al., 2013; Clifford & Doody, 2018; Skovdahl et al., 2003; Kolanowski et al., 2010; Rosenthal et al., 2020; Watson & Hatcher, 2021). In addition, most care home staff describe how they use distraction techniques to de-escalate challenging behaviours by focusing attention elsewhere (Backhouse et al., 2016; Yeager, 2008; Watson & Hatcher, 2021).

> *"Try to distract them from what is actually aggravating them … okay let's go for a walk or let's go in the garden and play football"* (nurse) (Backhouse et al., 2016).

2.11.1 Pharmacological interventions

In many studies, the use of psychotropic drugs was perceived as being beneficial for reducing behaviour that challenges, especially if non-pharmacological strategies had not been sustainably effective or if the resident was reportedly in a very anxious or distressed state to the level it was considered to diminish the resident's quality of life (Janzen et al., 2013; Shaw et al., 2016; Isaksson et al., 2013; Simmons et al., 2018; Donyai et al., 2017; Sawan et al., 2017; Smeets et al., 2014; Tampi et al., 2016).

> *"When it has gone so far as to need a calming tablet, then…I do it for his own good...as a last resort, when there is nothing left to do but to restrain him" (formal carer)* (Isaksson et al., 2013).

In addition, psychotropic drugs were used if care home staff believed that a resident's behaviour posed a serious risk of harm to other residents or carers (Dubuis et al., 2012; Yeager, 2008; Rapaport et al., 2018; Ostaszkiewicz et al., 2015; Watson & Hatcher, 2021; Smeets et al., 2014; Tampi et al., 2016).

> *"I try not to use medication...unless they're about to harm someone else, or their behaviour is really bad" (formal carer)* (Yeager, 2008).

In contrast, care home staff also reflected that psychotropic drugs may be used as a "quick fix" to minimise disruptions and allow carers to complete their duties in a timely manner, particularly in task-based orientated care homes which prioritised completion of work tasks over relationships and social interaction with residents. Task-orientated care therefore, posed a barrier to taking a non-pharmacological approach to behaviour management (Janzen et al., 2013; Shaw et al., 2016; Rapaport et al., 2018; Mallon, 2015; Isaksson et al., 2013; Simmons et al., 2018; Donyai et al., 2017; Sawan et al., 2017).

Antipsychotic medications are a group of psychotropic drugs often used by care home staff to manage behaviour that challenges (Janzen et al., 2013; Isaksson et al., 2013; Simmons et al., 2018; Donyai et al, 2017; Sawan et al., 2017).

> *"When somebody yells at night...and antipsychotics are the only thing that's left,….people can't sleep because one person is yelling…you get a lot of pressure from some facilities [to do something about it]" (formal carer).*(Simmons et al., 2018).

Some care home staff also report using other classes of psychotropic drugs such as hypnotic drugs or anxiolytic drugs including benzodiazepines, to minimise the occurrence of disruptive behaviours (Shaw et al., 2016; Mallon, 2015).

> *"Yes, it would be convenience…they could be given diazepam to keep quiet…because, maybe, I think, that it's not enough time…it's sometimes easier to give a tablet" (nurse)* (Shaw et al., 2016).

These drugs may also be used when a person-centred care approach would be more appropriate.

> *"In place of zopiclone or temazepam, it could be repositioning them overnight, checking incontinence is cared for, that the room is comfortable, things like that" (nurse)* (Shaw et al., 2016).

Indeed, in many studies, staff acknowledged that psychotropic drugs were easier to administer and faster acting than non-pharmacological interventions to de-escalate behaviours that challenge (Janzen et al., 2013; Shaw et al., 2016; Gjerberg et al., 2013; van Wyk et al., 2017; Ostaszkiewicz et al., 2015; Walsh et al., 2018; van Teunenbroek et al., 2020).

> One nurse reflects, *"We [nurses] are very medicine prone, take a pill that makes it [agitation] better*'' (Janzen et al., 2013).

In another study nurses believed that the use of psychotropic drugs was acceptable to manage behaviour that challenges in residents with dementia as they perceived that these behaviours arise due to neurodegeneration (Watson & Hatcher, 2021). This is aligned with the neurobiological model that assumes behaviours that challenge are caused by brain dysfunction in people with dementia (Tascone & Bortino, 2013).

Moreover, a nurse in one study stated that residents were administered psychotropic drugs without their knowledge or consent, raising ethical concerns about human rights (Ostaszkiewicz et al., 2015).

> *"[We] put it [the sedation] in their meals...you know, some people you have to crush it…it's crucial that they get their meds, otherwise the aggression…[their challenging behaviours] just blows up."* (nurse) (Ostaszkiewicz et al., 2015).

Care home staff acknowledge that they are aware of some of the adverse effects associated with the use of psychotropic drugs in dementia such as over-sedation (van Wyk et al., 2017; Kerns et al., 2018; Sawan et al., 2017; Watson & Hatcher, 2021).

"Sometimes they are so overmedicated and are like zombies" (nurse) (van Wyk et al., 2017).

Care home staff also express concerns regarding the increased risk of falls (Kerns et al., 2018) or the adverse effects of polypharmacy (Mallon, 2015). Therefore, staff highlighted the need to monitor the effects of psychotropic drugs when used in people with dementia (van Teunenbroek et al., 2020; Rosenthal et al., 2020). However, care home staff may not be aware of the full spectrum of adverse drug effects since they failed to mention, in any study, the increased risk of stroke and death, associated with psychotropic drug use in dementia.

Furthermore, five studies explored the impact of regulation on prescribing psychotropic drugs to care home residents with dementia (Kolanowski et al., 2010; Walsh et al., 2018; Rosenthal et al., 2020; Smeets et al., 2014; Tampi et al., 2016). In studies conducted in the US (Rosenthal et al., 2020) and the Netherlands (Smeets et al., 2014; Tampi et al., 2016) staff agreed that state regulations were beneficial in reducing rates of antipsychotic prescribing and a catalyst for improvements in the quality of care. However, staff also noted that regulatory requirements focused purely on reducing use of antipsychotic medications fail to consider the complexities of prescribing decisions (Rosenthal et al., 2020).

In addition, care home staff in Ireland were critical that psychotropic drugs prescribed to residents on a Pro re nata (PRN), given when needed basis, are reportable to Health Information and Quality Authority (HIQA) while psychotropic drugs prescribed on a regular basis are not reportable (Walsh et al., 2018). Therefore, this may result in increased prescribing of psychotropic drugs to residents with dementia, as one nurse explains,

> *"What some nursing homes do is, if somebody was on a PRN psychotropic, because the resident might only need it once or twice per month and because it becomes reportable, they get prescribed regularly"* (Walsh et al., 2018).

2.11.2. Physical restraint

Care home staff also report using physical restraint to manage behaviour that challenges (Duxbury et al., 2013; Yeager, 2008; Backhouse et al., 2018; Foley et al., 2003; Hantikainen, 2001; Ragneskog 1997; van Teunenbroek et al., 2020). Physical restraint refers to restricting the movements and behaviours of people with dementia. Methods include locking doors or using belts, restraining chairs and bedrails to restrict movement (Gjerberg et al., 2013; Backhouse et al., 2018; Foley et al., 2003; Ostaszkiewicz et al., 2015; Hantikainen et al., 2001). The use of surveillance technologies to monitor movements, is also described as a physical restraint (Yeager, 2008; Backhouse et al., 2018). Physical restraint is often cited as a last resort for managing behaviour that challenges, only to be used when all other options fail (Duxbury et al., 2013; Gjerberg et al., 2013; Backhouse et al., 2018; Foley et al., 2003; Ostaszkiewicz et al., 2015; Hantikainen et al., 2001).

> *"You have to have tried a PRN [prescribe when needed medication] before you get to [physical] restraint" (nurse)* (Ostaszkiewicz et al., 2015).

Moreover, care home staff may resort to using physical restraint because they could no longer tolerate the behaviour of the resident with dementia (Hantikainen et al, 2001). This highlights issues regarding the attitudes of staff and human right concerns.

> *"After the fifth day I begin to feel that I can no longer put up with this and…I will prefer to tie her down rather than let her walk around and have a go at the others" (formal carer)* (Hantikainen et al., 2001).

Surveillance technologies were often used to monitor residents. These technologies included wander mats and pressure mats that set off an alarm when stood on (Backhouse et al., 2018). Controversially, residents were not always aware that they were being observed (Yeager, 2008; Backhouse et al., 2018). This practice of covert observation violates the human rights of residents in care homes.

2.12 Theme: Personhood, human rights and respect

2.12.1 Knowing the person not just the disease

Many care home staff highlighted the importance of valuing the person with dementia and taking an holistic approach to understanding and knowing the person with dementia (Duxbury et al., 2013; Rapaport et al., 2018).

> *"You have to get to know the patient as an individual, as a person, not as an illness or a risk factor" (manager)* (Duxbury et al., 2013).

Study findings indicate that knowledge of the residents' personal history comes from family and friends (Rapaport et al., 2018; Herron & Wrathall, 2018; Foley et al., 2003; Kolanowski et al., 2010; Smeets et al., 2014; Tampi et al., 2016). This knowledge is essential to build trusting relationships and facilitate social interactions between staff and residents (Duxbury et al., 2013; Rapaport et al., 2018), in addition to understanding the behaviours characteristic of the individual, for example residents may be inherently anxious; this knowledge will alert staff to changes in behaviours that may be uncharacteristic of the resident and may therefore, arise in response to specific situations, the environment or an unmet need (Snellgrove et al., 2015; Yeager, 2008; Rapaport et al., 2018; Herron & Wrathall, 2018, Foley et al., 2003; Kolanowski et al., 2010; Ostaszkiewicz et al., 2015; Kolanowski et al., 2015; Watson & Hatcher, 2021; Smeets et al., 2014; Tampi et al., 2016).

2.12.2 Causes of behaviours, associated with dementia

Knowing behaviours characteristic of the individual is therefore crucial to identify the causes for behaviour that challenges. This facilitates implementation of a sustainable non-pharmacological response to manage behaviour that challenges. Commonly cited causes for aggression and agitation include invasion of privacy during personal care and being given instructions as to when to get up, eat meals and go to bed (Duxbury et al., 2013; Yeager, 2008; Rapaport et al., 2018; Skovdahl et al., 2003; Ragneskog, 1997).

> *"Aggression can be the result of…invading personal space, being told you have to come to the table to eat, we do give quite a lot of orders"* (care assistant) (Duxbury et al., 2013).

The unmet needs hypothesis (chapter 1.5) suggests that behaviours that challenge may arise from an unmet need that cannot be verbally expressed (Cohen-Mansfield, 2000). In many studies, staff explain that behaviour that challenges may arise in response to pain, constipation, urinary tract infection (Yeager, 2008; Rapaport et al., 2018; Mallon, 2015; Walsh et al., 2018; Almutairi et al., 2018; Ragneskog, 1997) or hunger or thirst (Rapaport et al., 2018; Zeller et al., 2011; Almutairi et al., 2018; Rapaport et al., 2018; Walsh et al., 2018; Almutairi et al., 2018; Rosenthal et al., 2020; Watson & Hatcher, 2021). Therefore, it is essential that care home staff should aim to understand the causes of residents' behaviours and identify non-verbal cues (Watson & Hatcher, 2021). This will ensure that needs are met to minimise the occurrence of behaviour that challenges; (Smeets et al., 2014; Tampi et al., 2016) however, this does not always happen in practice (Snellgrove et al., 2015).

> *"They [certified nursing assistants] don't seek to understand the behaviour, they just try to address it and that's when you come up on failure because you don't really understand what's causing that behaviour"* (formal carer) (Snellgrove et al., 2015).

2.12.3 Person-focused support

Care home staff in many studies express how people with dementia should be supported to maintain their capabilities and engage in meaningful activities (Snellgrove et al., 2015;

(Yeager, 2008; Rapaport et al., 2018; Mallon, 2015; Clifford & Doody, 2018; Kolanowski et al., 2010; Rosenthal et al., 2020) referred to, in this review, as person-focused support.

A carer describes how she applied her knowledge of the resident to provide person focused support aimed at maintaining the abilities and skills of the person with dementia (Yeager, 2008).

> *"We have other residents who don't talk a whole lot, but you put them in front of the piano, and they can play beautifully; without errors; without looking at anything; just by memory"* (formal carer) (Yeager, 2008).

In addition, person focused support was incorporated into the care plans of residents with dementia to enhance their sense of identity, self-esteem and independence (Backhouse et al., 2016; Snellgrove et al., 2015; Yeager, 2008; Rapaport et al., 2018; Clifford & Doody, 2018; Kolanowski et al., 2010; van Wyk et al., 2017; Rosenthal et al., 2020) to facilitate a non-pharmacological approach to manage behaviours that challenge.

> *"I had a resident who was a farmer and very withdrawn ... not engaged in life, had lost meaning and purpose but by engaging him in therapeutic activities of just gardening…gave him a sense of identity again"* (formal carer) (Kolanowski et al., 2010).

However, it was reported in one study, that residents with behaviour that challenges were excluded from taking part in activities, even though their participation may have been helpful in reducing these behaviours.

> *"[Care staff are] more willing to help people that...have got their full faculties…so I think some dementia people do get mistreated…just like neglected with activities"* (care worker) (Backhouse et al., 2016).

One of the reasons for this may be that residents with dementia require a higher degree of support to safely participate in activities (Backhouse et al., 2016). Providing support requires a high staff to resident ratio impacting on care home finances (Shaw et al., 2016; Rapaport et al., 2018; van Wyk et al., 2017; Simmons et al., 2018; Walsh et al., 2018; Sawan et al., 2017; Rosenthal et al., 2020). Hence, it may not always be feasible to provide one-to-one care without external financial support, posing a barrier to implementing non-pharmacological approaches to support residents (Gjerberg et al., 2013; Rapaport et al., 2018; Sawan et al., 2017; Rosenthal et al., 2020).

2.13: Theme: Person focused approach – a paradigm shift

2.13.1 Changes in care home culture and staff attitudes

Shein (1990) proposed that organisational culture is a pattern of shared basic assumptions developed by a group, including values, norms and attitudes (Schein, 2010). In the context of care home culture, many care home staff assume that psychotropic drugs are necessary, beneficial or convenient for managing behaviour that challenges and this reinforces their use, particularly in homes that prioritise task-orientated care (Snellgrove et al., 2015; Yeager, 2008; Rapaport et al., 2018; Mallon, 2015; Clifford & Doody, 2018; Kolanowski et al., 2010; Walsh et al., 2018). This, therefore, poses a barrier to implementing non-pharmacological strategies to behaviour management. Hence, changes in care home culture are needed to facilitate a non-pharmacological approach.

While care home culture reflects group norms, personal attitudes of staff are individually held beliefs, cognitions and associated emotions (Eagly & Chaiken, 1993) that vary widely between individual staff members (Skovdahl et al., 2003; van Teunenbroek et al., 2020).

> *"One is interested….is there another approach? Someone else might think: Do I care? I work here and that's it…I think there are a lot of differences between colleagues"* (nurse) (van Teunenbroek et al., 2020).

In the context of managing behaviours that challenge, individual staff members evaluate the positive and negative consequences of their actions (Rosenthal et al., 2020; Watson & Hatcher, 2021). Evaluations are influenced by past experiences (Rosenthal et al., 2020; Watson & Hatcher, 2021) and give rise to a pre-disposition to act in a certain way when managing behaviour that challenges (Rosenthal et al., 2020; Watson & Hatcher, 2021), corresponding with the multicomponent approach model (Eagly & Chaiken, 1993). For instance, staff explained how they were fearful of the consequences of harm for colleagues if they did not take a pharmacological approach to manage aggressive behaviour (Rosenthal et al., 2020). While, in a different study, staff believed that non-pharmacological strategies such as distraction techniques, would only have transient effectiveness in managing behaviours that challenge (Watson & Hatcher, 2021).

> *"Distraction cannot continue the whole day [as] the agitation starts after the activity is over"* (nurse) (Watson & Hatcher, 2021).

Therefore, the findings show that staff attitudes may pose a barrier to taking a non-pharmacological approach to manage behaviour that challenges.

2.13.2 Collaboration and equitable decision-making

Studies indicate that nurses are the main decision-makers regarding using a pharmacological approach to manage behaviour that challenges (Shaw et al., 2016; Yeager, 2008; Mallon, 2015; Ostaszkiewicz et al., 2015; Walsh et al., 2018). In several studies, staff suggest that care assistants should be more involved in decisions due to their in-depth knowledge of residents and responsibility for implementing non-pharmacological interventions (Kolanowski et al., 2015; Rosenthal et al., 2020). However, this did not always occur, as a manager explains,

> *"I wonder how much the aides are involved in [decision-making], it tends to be more department head staff…so I think maybe we need to...gather information from the aides because, again, they're the ones dealing with it directly"* (manager) (Kolanowski et al., 2015).

Indeed, many studies, describe how communication and multidisciplinary collaboration between nurses, care assistants, managers and other healthcare professionals is inadequate (Shaw et al., 2016; Rapaport et al., 2018; Mallon, 2015; Foley et al., 2003; Simmons et al., 2018; Sawan et al., 2017; Kolanowski et al., 2015; van Teunenbroek et al., 2020).

> *"We are actually never present at such meetings [multidisciplinary consultation]. It would be relevant if we'd be present there, because we work in the evenings, we work at night, the weekend"* (nurse) (van Teunenbroek et al., 2020).

To improve collaboration, staff indicated that they needed organisational support and effective leadership to promote a team-based approach to implementing non-pharmacological strategies to manage behaviour that challenges (Rapaport et al., 2018; Zeller et al., 2011; Clifford & Doody, 2018). However, several staff members were critical of the support that they have received from managers, stating that they do not feel valued or included as equal team players with senior staff (Rapaport et al., 2018; Sawan et al., 2017). Care staff also expressed how low wages, reduced staffing levels and antisocial working hours, impacted negatively on their motivation to deliver person centred care. This poses a barrier to taking a non-pharmacological approach to manage behaviour that challenges (Rapaport et al., 2018).

In addition, communication between nurses and general practitioners (GPs) was found to be an important influence on decision-making whether to take a pharmacological approach to behaviour management (Shaw et al., 2016; Smeets et al., 2014; Tampi et al., 2016; van Teunenbroek et al., 2020). Nurses described how GPs' used the information that they provided about residents to inform prescribing decisions. (Smeets et al., 2014; Tampi et al., 2016). However, nurses also explained that individual GPs' attitudes to prescribing psychotropic drugs varied widely (van Teunenbroek et al., 2020). Moreover, it was suggested that some GPs lack adequate knowledge in managing behaviour that challenges in dementia, potentially resulting in inappropriate prescribing (Shaw et al., 2016).

> *"There are some GPs who are not well versed with dementia…they prescribe anything and everything under the sun…I'll be saying that I don't think this is right for this person…but who are we to argue with the higher [prescribers]?"* (Manager) (Shaw et al., 2016).

Therefore, GPs' attitudes towards prescribing, their knowledge in managing behaviours that challenge and the degree of shared decision-making, influences whether a pharmacological or non-pharmacological approach is used to support people with dementia.

2.13.3 Training, education, knowledge and experience

In many studies, staff expressed how they used non-pharmacological strategies such as distraction techniques, to de-escalate behaviour that challenges, often with only transient benefits. Care home staff expressed how education in person-centred care and training in managing behaviours that challenge is crucial to facilitate implementation of sustainable non-pharmacological strategies to manage behaviours that challenge (Gjerberg et al., 2013; Rapaport et al., 2018; Clifford & Doody, 2018; Skovdahl et al., 2003; van Wyk et al., 2017; Sawan et al., 2017; Ragneskog & Kihlgen, 1997; Kolanowski et al., 2015; van Teunenbroek et al., 2020; Rosenthal et al., 2020). However, staff training in dementia and behaviour management is often inadequate or absent (Gyerberg et al., 2013).

> *"The unit employs several care assistants, who have no formal training, there really is a difference in awareness of using coercion" (formal carer) (Gjerberg et al., 2013).*

In addition, the findings indicate that care home staff require further education to increase awareness of the full spectrum of adverse drug effects associated with psychotropic drugs use in dementia. This may prove beneficial in changing attitudes about the risk/benefit ratio associated with the use of these drugs and facilitate a non-pharmacological approach (Gjerberg et al., 2013; Rapaport et al., 2018; Clifford & Doody, 2018; Skovdahl et al., 2003; Kolanowski et al., 2010; Sawan et al., 2017; Ragneskog & Kihlgen, 1997; Kolanowski et al., 2015).

> A care assistant succinctly states, *"We are not supposed to know what it (psychotropic medicine) is or what it does, we're just people who give the medication*" (Sawan et al., 2017).

In several studies staff noted that training aimed at improving communication skills with people with dementia proved beneficial in facilitating non-pharmacological strategies to behaviour management (Yeager, 2008; Clifford & Doody, 2018; Kolanowski et al., 2010; van Wyk et al., 2017; Kolanowski et al., 2015).

> *"Before I had the training, I would just pick up and go, but now I know you have to first tell the person what you are going to do, not just go ahead and do it"* (formal carer) (van Wyk et al., 2017).

In addition, care home staff explain that the best training for managing responsive behaviours is "hands on" work experience (Rapaport et al., 2018; Clifford & Doody, 2018; van Wyk et al., 2017).

> *“Being there, dealing with it, doing it, is the best training”* (care assistant) (Rapaport et al., 2018).

2.13.4 Dementia friendly environment

The environmental vulnerability/reduced stress-threshold model assumes that people with dementia have a lower threshold for tolerating stress associated with environmental stimuli, resulting in behaviours that challenge (Cohen-Mansfield, 2010). Indeed, staff acknowledged that environmental factors may trigger behaviour that challenges (Herron & Wrathall, 2018) thereby providing support for the environmental vulnerability/reduced stress-threshold model (Cohen-Mansfield, 2010).

> *“Factors such as noise, movement, congestion, temperature, and lighting were all identified as “triggers”* (formal carer) (Herron & Wrathall, 2018).

In addition, increased movement of staff during shift changes resulted in increased agitation and exit seeking behaviour in residents with dementia (Mallon, 2015). Two studies also highlighted how the design of the lounge area in care homes may trigger behaviour that challenges (Rapaport et al., 2018; Herron & Wrathall, 2018).

> *“There's a lot of people there, the TV's on, there's a lot of stimuli...you get kind of arguments going on”* (nurse) (Herron & Wrathall, 2018).

Changes in the care home environment may be beneficial in facilitating a non-pharmacological approach to reduce behaviour that challenges (Yeager, 2008; Backhouse et al., 2018; Mallon, 2015; Herron & Wrathall, 2018; Simmons et al., 2018; Walsh et al., 2018; Ragneskog, 1997; Rosenthal et al., 2020). For instance, smaller lounges (Rapaport et al., 2018; Herron & Wrathall, 2018) and the use of a circular corridor to support movement of residents (Rapaport et al., 2018; Herron & Wrathall, 2018). In addition, staff highlighted the importance of making the care home as homelike and peaceful as possible to minimise behaviour that challenges (Mallon, 2015; Skovdahl et al., 2003). One way to achieve this was to personalise residents’ bedrooms with furniture, ornaments and photographs from their own home.

> *"Their room should be as near as it was at home…to make them feel secure and comfortable"* (formal carer) (Mallon, 2015).

2.14 Facilitators and barriers to implementing non-pharmacological strategies

Synthesis of the findings from this study highlight an extensive range of factors that may facilitate or pose a barrier to implementing sustainable non-pharmacological strategies to manage behaviour that challenges, associated with dementia. A brief description of these facilitators and barriers is presented in **Table 2.5**

Table 2.5 Barriers and facilitators to implementing a non-pharmacological approach to manage behaviour that challenges.

Approach taken to the delivery of care	**Barrier or Facilitator**
Staff that value and respect people with dementia (Chapter 2.12.1).	Facilitator
Familiar staff that develop trusting relationships with residents, providing social interaction (Chapter 2.12.1).	Facilitator
Knowing the resident well and understanding behaviours characteristic of the resident. This enables identification of behaviours uncharacteristic of the resident that may arise due to an unmet need (Chapter 2.12.1).	Facilitator
Involvement of family in residents care, for example, acquiring information about the residents' personal history to assist the development of trusting relationships between residents and staff (Chapter 2.12.1).	Facilitator
Providing person focused support to promote residents' participation in meaningful activities tailored to their interests. This gives residents a sense of purpose and identity (Chapter 2.12.3).	Facilitator
Residents excluded from participating in meaningful activities (Chapter 2.12.3).	Barrier
Over-reliance on reactive strategies to de-escalate behaviour that challenges, for example non-pharmacological strategies such as distraction techniques that only deliver transient effectiveness (Chapter 2.13.1)	Barrier

Care home staff who use physical restraint or inappropriate levels of surveillance and monitoring to manage behaviour that challenges, thereby diminishing residents' freedom and human rights (Chapter 2.11.2).	Barrier
Organisational factors	
Effective leadership to support staff and enhance teamwork aimed at implementing non-pharmacological approaches to behaviour management (Chapter 2.13.2).	Facilitator
Staff who perceive that they are not supported or valued by managers or senior staff or considered to be equal members of a team (Chapter 2.13.2).	Barrier
Lack of finances to maintain adequate staffing levels to support residents' needs, for example, safe participation in activities (Chapter 2.12.3).	Barrier
Poor work conditions for care staff, for instance, low wages, reduced staffing levels and working antisocial hours, negatively impacting on staff motivation to deliver person-centred care (Chapter 2.13.2).	Barrier
Care home culture	
Staff that adopt group values and norms that assume psychotropic drugs are necessary, beneficial or convenient for managing behaviour that challenges (Chapter 2.13.1).	Barrier
Staff attitudes	
Staff who are fearful of the consequences of not taking a pharmacological approach to manage resident's aggressive behaviour, for example, the potentially risk of harm to colleagues (Chapter 2.13.1).	Barrier
Beliefs that behaviour that challenges in people with dementia are solely caused by brain dysfunction and therefore, require a pharmacological response (Chapter 2.11.1).	Barrier
Perceptions that psychotropic drugs can be used as a "quick fix," for convenience, to facilitate completion of care tasks in a timely manner (Chapter 2.11.1).	Barrier
Collaboration and decision-making	
Inadequate multidisciplinary collaboration and equitable decision-making, for example a hierarchy between care assistants, nurses and GPs. This	Barrier

creates unequal power relationships with a negative impact on communication and teamwork (Chapter 2.13.2).	
Individual general practitioners (GPs') beliefs about psychotropic prescribing influences decision-making (Chapter 2.13.2).	Facilitator or Barrier
GPs lack of knowledge about managing behaviour that challenges or failure to include care staff in shared decision-making (Chapter 2.13.2).	Barrier
Education and training	
Inadequate training of care home staff in managing behaviour that challenges and implementing person-centred care approaches (Chapter 2.13.3).	Barrier
Inadequate education and knowledge of the full spectrum of adverse effects associated with psychotropic drug use in dementia. This results in staff overestimating the benefits of these drugs while lacking awareness of potential risks (Chapter 2.13.3).	Barrier
Regulation	
Overall, regulations have been found to have a positive impact in reducing the use of psychotropic drugs to manage behaviours that challenge (Chapter 2.11.1).	Facilitator
Some care staff suggest that regulations fail to adequately consider the complexities involved in prescribing decisions regarding the use of psychotropic drugs in residents with dementia (Chapter 2.11.1).	Barrier
Exploitation of loopholes in regulations may potentially, increase prescribing of psychotropic drugs to residents (Chapter 2.11.1).	Barrier
Care home environment	
Providing a dementia friendly interior and exterior care home environment (Chapter 2.13.4).	Facilitator
A care home environment personalised to residents' own home environment (Chapter 2.13.4).	Facilitator
Sub-optimal noise, heating and lighting levels in care homes (Chapter 2.13.4).	Barrier

2.15 Discussion

The first theme emerging from the synthesis, “Putting out the fires” demonstrates that care home staff approaches to managing behaviour that challenges are often reactive strategies, adopted to de-escalate potential crisis situations. Reactive strategies, for example, distraction techniques (Backhouse et al., 2016; Zeller et al., 2011) may only have short-term benefits because they do not attempt to understand the causes of behaviour that challenges (Rapaport et al., 2018). This corresponds with the “Need-driven dementia-compromised behaviour model” (Algase et al., 1996) or the “Unmet needs model” (Cohen-mansfield, 2010) (chapter 1.5) which postulate that behaviour that challenges arise in response to an unmet physical, psychological or emotional need that cannot be verbally expressed. Indeed, research by Caspar et al. (2018) found that relationships between staff and residents are integral for understanding the needs of residents with dementia (Casper et al., 2017). The findings of this review also demonstrates the importance of relationships between staff and residents and highlights that, knowing residents well, understanding residents’ personal history (Snellgrove et al., 2015; Yeager, 2008; Rapaport et al., 2018; Herron & Wrathall, 2018; Foley et al., 2003; Kolanowski et al., 2010; Ostaszkiewicz et al., 2015; Kolanowski et al., 2015) and identifying the causes for behaviour that challenges (Duxbury et al., 2013; Yeager, 2008; Rapaport et al., 2018; Skovdahl et al., 2003; Ragneskog & Kihlgen, 1997) are very important facilitators to implementing a non-pharmacological approach to manage behaviour that challenges. These findings are aligned to the philosophy of person-centred care, developed by Kitwood (1997). In the context of person-centred care, social psychology refers to the significance of the relationship between the carer and person with dementia. Kitwood refers to social malignancy as the behaviours of carers that devalue and de-humanise the person with dementia (Kitwood, 1997). The findings of this review indicate that social malignancy is still prevalent as staff describe using psychotropic drugs as a “quick fix” to manage behaviour that challenges for convenience or to complete tasks in a timely manner (Janzen et al., 2013; Shaw et al., 2016; Gjerberg et al., 2013; Rapaport et al., 2018; Mallon, 2015; Kolanowski et al., 2010; Walsh et al., 2018; Kerns et al., 2018). This demonstrates that task-orientated care is a barrier to taking a non-pharmacological approach to managing behaviour that challenges.

Moreover, Walsh et al., (2017) found that care home staff may use psychotropic drugs to manage behaviour that challenges because they are unaware of the serious side effects, associated with the use of these medications in dementia. Indeed, the findings of this review support this, as it has been demonstrated that care home staff vary in their degree of awareness of the adverse side effects of psychotropic drugs. Although some care home staff cited increased risks of sedation and falls associated with psychotropic drugs, (Mallon, 2015; van Wyk et al., 2017; Simmons et al., 2018; Kerns et al., 2018) none of the care staff mentioned increased risks of stroke and death. These findings are comparable to another study which found that care home staff have limited knowledge of the adverse effects of psychotropic drugs in people with dementia (Smeets et al., 2014; Tampi et al., 2016). Therefore, education to raise awareness among staff of the adverse effects associated with psychotropic drugs may facilitate a non-pharmacological approach to behaviour management, hence, further research in this area is required.

A second theme “Personhood, human rights and respect” focuses on the value of people with dementia. Some care home staff are embracing a paradigm shift in attitude that views people with dementia as unique individuals with abilities and skills. The concept of personhood can be traced to Kitwood & Bredin (1992), who refer to “positive persons work” as the care given to people with dementia that provides love, comfort, secure attachment, a sense of inclusion, usefulness, value, identity and occupation. The findings of this review provide evidence that many care home staff provide comfort and reassurance which are shown to reduce behaviour that challenges (Snellgrove et al., 2015; Isaksson et al., 2013). However, our findings demonstrate that people with dementia are sometimes being excluded from participating in meaningful activities, likely to be beneficial in reducing behaviour that challenges (Backhouse et al., 2016). Reasons for this include inadequate staff levels and financial constraints (Shaw et al., 2016; van Wyk et al., 2017; Simmons et al., 2018; Walsh et al., 2018; Sawan et al., 2017).

This review has also found that residents are often coerced to participate in care routines resulting in behaviour that challenges (Duxbury et al., 2013; Yeager, 2008; Rapaport et al., 2018; Skovdahl et al., 2003; Ragneskog & Kihlgen, 1997). These findings are supported by Harmer & Orwell (2008) who found that organisational limitations in care homes result in coercion of residents to participate in activities of little interest, thereby increasing behaviour that challenges. Also, Green & Cooper (2000) noted that care routines often take precedence over relationships with residents. Moreover, in another study it was observed that generic care of residents took precedence over personalised care due to limitations in time and resources (Hennelly & O'Shea, 2021). These findings contrast with the VIPS framework, for implementing person-centred care proposed by Brooker and Latham (2015). VIPS is defined as (V) valuing persons with dementia; taking an (I) individualised approach; understanding the (P) perspective of the person with dementia; providing (S) supportive social environments to maintain relationships (Brooker & Latham, 2015). Therefore, this review has found that lack of choice and autonomy and exclusion of residents with dementia from participating in meaningful activities of interest are barriers to implementing a non-pharmacological approach to behaviour management. This review recommends that guidelines such as the NICE guideline on Dementia [NG97] (NICE, 2018) and the Alzheimer's Association Dementia Care Practice Recommendations (2018) (Fazio & Pace, 2018) in addition to national dementia strategies, incorporate person focused support into person-centred care plans. Person focused support is defined in this review as the support given to a person with dementia to enable them to participate in activities tailored to their individual interests to maintain their self-esteem and identity. This is an important aspect of person-centred care that is poorly implemented in practice as shown in this review, despite being recommended in Kitwood's (1997) vision of person-centred care.

The final theme to emerge from our findings, indicates that changes in care home culture will require moving away from group values and norms that assume that psychotropic drugs are acceptable for behaviour management (Watson & Hatcher, 2021) to adopt group values that promote relationships between staff and residents in a home-like environment (Duxbury et al., 2013; Rapaport et al., 2018; Mallon, 2015; Skovdahl et al., 2003). To achieve culture change and facilitate a non-pharmacological approach, the findings suggest that resources and effective leadership will be required to empower staff by providing training, collaboration and decision-making opportunities (Gjerberg et al., 2013; Rapaport et al., 2018; Zeller et al., 2011; Clifford & Doody, 2018; Sawan et al., 2017; Rosenthal et al., 2020). These findings support a study that identified care home culture as a key determinant in whether a non-pharmacological approach is taken (Roberts et al., 2015).

In addition, the findings indicate that staff attitudes influence decision-making regarding behaviour management (Skovdahl et al., 2003; van Teunenbroek et al., 2020; Watson & Hatcher, 2021). For instance, staff decided to use a pharmacological approach to de-escalate aggressive behaviour because they felt fearful of the potential risk of harm to colleagues (Rosenthal et al., 2020). In a different scenario, staff decided not to opt for a non-pharmacological approach to behaviour management because they believed it would not be effective long term (Watson & Hatcher, 2021). Moreover, some nurses believe that behaviour that challenges arise due to cognitive decline in dementia and requires a pharmacological response (Watson & Hatcher, 2021). This corresponds with neurobiological theories that assume behaviour that challenges, associated with dementia are a consequence of brain dysfunction (Tascone & Bortino, 2013).

Supporting staff in their role is crucial, however, in this review, some staff perceived that they were not supported in their role by senior staff, and this reduced their ability to deliver person-centred care (Rapaport et al., 2018; Sawan et al., 2017). Therefore, attitudes of staff may increase the propensity to use a pharmacological approach to behaviour management. These findings are comparable to the review by Walsh et al., (2017) which found that inadequate training in person-centred care, was a determinant in using antipsychotic drugs to manage behaviour that challenges in care home residents. To facilitate a non-pharmacological approach, staff attitudes need to be addressed. Little research has been conducted in this area although one study exploring nurses' attitudes to dementia in six care homes in India found that nurses lacked specific knowledge in dementia care (Strom et al., 2021). This corresponds with the findings from this review which suggests that training in person-centred care will assist in changing staff attitudes and facilitating non-pharmacological strategies to behaviour management. Indeed, Latham & Brooker (2017) reported on the implementation of the training and support (FITS) into practice programme. This is a training and support intervention for care home staff aimed at minimising inappropriate anti-psychotic use in residents' with dementia by adopting a psychosocial approach. The intervention improved staff attitudes and corresponded with a reduction in antipsychotic use.

In addition, the findings of this review indicate that collaboration, teamwork (Zeller et al., 2011; Clifford & Doody, 2018) and equitable decision-making is often inadequate (Shaw et al., 2016; Mallon, 2015; Foley et al., 2003; Simmons et al., 2018; Sawan et al., 2017; Kolanowski et al., 2015). This lack of collaboration is, therefore, a barrier to non-pharmacological approaches to support people with dementia. This review also highlights that care assistants are not adequately involved in decision-making despite having in-depth knowledge of residents (Dubuis et al., 2012; Sawan et al., 2017; Kolanowski et al., 2015). This corresponds with a recent study that explored how personalised care is implemented in care homes and found that communication between nurses and care assistants is often lacking (Hughes et al., 2019). Therefore, this review recommends that future research should also aim to understand how care assistants may contribute more to collaboration and decision-making, taking into consideration power differentials as this may influence whether a non-pharmacological approach is taken to manage behaviour that challenges.

2.16 Strengths and Limitations of this review

A strength of this review is that it has addressed a gap in knowledge by conceptualising facilitators and barriers to taking a non-pharmacological approach to behaviour management, this knowledge is vital for informing dementia policy. However, a limitation of this review is the risk of bias associated with the main reviewer's (EOD) personal experience as a family carer which may have influenced the interpretation of data. However, the researcher has maintained a reflexivity diary throughout the research process and documented the rationale for decisions taken. Another limitation is that the studies included in the review were conducted in 10 different countries worldwide. Hence, the factors that posed a barrier or facilitator to implementing a non-pharmacological approach to behaviour management in care homes in Japan, for example, may be distinctly different to those factors identified as barriers and facilitators in the context of UK settings, due to cultural and social differences.

2.17 Conclusions

This systematic review contributes to current knowledge by identifying a range of facilitators and barriers to taking a non-pharmacological approach. For instance, the findings of this review indicate that the attitudes of care home staff may pose a barrier to taking a non-pharmacological approach to behaviour management. Therefore, further research is needed to gain in-depth understanding of how the attitudes of care home staff impacts on the approach taken to manage behaviours, associated with dementia and the factors that influence decision-making. In addition, the findings highlighted the importance of developing trusting relationships between residents and staff to facilitate a non-pharmacological approach to support residents. Hence, the findings from the systematic review are used to inform the qualitative study to understand how behaviours, associated with dementia, are managed by care home staff in the Republic of Ireland prior to, and during the Covid-19 pandemic. For instance, the findings from the systematic review informed the design of the online qualitative questionnaire and the development of the interview schedules for care home staff (chapter 4.1 and Chapter 4.6 & Chapter 4.8) to ensure that relevant questions were asked to address the research question. In chapter three the philosophical and theoretical approach underpinning the qualitative study is provided and critically appraised.

Chapter 3: Methodology

3.1 Chapter overview

A research paradigm is a philosophical perspective that reflects the researcher's worldview (Kuhn, 1962 & 1996) and beliefs about the nature of reality referred to as ontology and the researchers view of how knowledge is created, referred to as epistemology (Scotland, 2012). This philosophical perspective underpins all aspects of the research process and determines the research methods that will be used and how data will be analysed to construct meaning (Guba & Lincoln, 1994).

Therefore, in this chapter, my ontological and epistemological perspectives are described and a rationale is provided for the philosophical and theoretical approach taken and the methods used in this research. I will compare these approaches with alternative approaches to justify their use to address the research question.

3.2 Ontology and epistemology

Kuhn (1962 & 1996) described how observations can be interpreted in many ways to create different meanings, influenced by the observer's past experiences, assumptions, beliefs and social and cultural factors. This worldview is underpinned by an ontological perspective that reality is subjectively created, and that knowledge and meaning are created in a research process influenced by both the participant and researcher (MacKenzie & Knipe, 2006). This ontological perspective is aligned with epistemologies such as constructivism which assumes that knowledge is continuously constructed and reconstructed by observers (Bryman, 2016); and interpretivism which claims that observations are interpreted to create knowledge (Ormston et al., 2003).

The worldview that reality is subjective contrasts sharply with an alternative worldview that reality is objectively created and that observations are identical for all observers irrespective of age, gender, ethnicity, culture, education or social status (Goldenberg, 2006). The view that reality is objective underpins the positivist epistemology. Hence, for positivist researchers, the acquisition of knowledge occurs independently of the influence of the observer (Crossan, 2003) and is unbiased, value-free, measurable and reproducible (Mays & Pope, 1995). Positivism is the dominant philosophical approach underpinning the scientific method which uses mainly quantitative methods such as statistical analysis to test hypotheses and establish causality that are generalisable to specific populations (Crossan, 2003).

However, the fallacy of a universal truth becomes more apparent when examining the inherent uncertainty of scientific knowledge. A study by Ian et al., (2019) provides an example of how physicians' knowledge of best prescribing practice was influenced by pharmaceutical corporations. Data were collected from 177 physicians in Romania, the findings indicated that physicians who perceived the pharmaceutical corporation to be reputable were more likely to prescribe their drugs (Ian et al., 2019). Therefore, this suggests that evidence-based medicine is influenced by social and economic interest.

In contrast, the transformative paradigm recognises that reality and knowledge creation is influenced by social, economic, political and cultural factors whereby certain groups of individuals occupy positions of authority and power while other groups are excluded from decision-making (Mertens, 1999). Therefore, the transformative paradigm recommends that research should aim to identify issues of social inequality and ensure that research outcomes are action orientated to achieve social justice (Mertens, 1999). For instance, in care homes, research outcomes may aim to minimise inappropriate prescribing of psychotropic drugs to residents with dementia. For this reason, the experiences of marginalised individuals or groups in society, for example, care home residents are of particular focus to proponents of the transformative paradigm (Mertens, 2007).

As a former family carer for a person with dementia, my own philosophical perspective aligns with the transformative paradigm that perceives that people with dementia are a marginalised group in society with limited freedom or autonomy to make decisions. Therefore, research should aim to understand inequalities in dementia care and take action to address these inequalities. Inequalities in dementia care have been identified in many studies, for example, people with dementia from rural regions or from ethnic minority groups are less likely to have access to dementia care services (Giebel, 2020). In another study by Backhouse et al., (2016), care home residents with dementia were more likely to be excluded from activities than residents without dementia, even though these activities may have been beneficial in reducing responsive behaviours. Indeed, inequalities were apparent not only at the level of residents but also for staff. For example, the systematic review by O'Donnell et al. (submitted) (Chapter 2) found that care assistants did not participate in collaboration or equitable decision-making with other health care professionals, demonstrating disparities in power relations.

3.3 Theoretical Perspective

Critical theory is commensurate with the transformative paradigm (Kincheloe & McLaren, 2011). Critical theory was developed at the University of Frankfurt in the 1920's and has also been influenced by scholars including Lukács, Gramsci and Habermas (Mosqueda-Diaz, 2014). Critical theorists assume that social, cultural, economic and political factors influence social phenomena and the experiences of individuals and groups (Kincheloe & McLaren, 2011).

Mosqueda-Diaz (2014) suggests that care home research underpinned by critical theory should identify instances of inequality and power differentials within organisational structure. Action plans and strategies to address inequalities and protect human rights involves the contribution of key stakeholders (Mosqueda-Diaz, 2014). For example, research based on critical theory can be used to identify barriers that prevent family members of care home residents with dementia from contributing to decision making about how to manage responsive behaviours. This is because evidence has shown that family members of residents are not always listened to and their concerns not followed up (Baumbusch & Phinney, 2014; Holmgren et al., 2014). For instance, the family's knowledge of the resident is not always valued by care home staff (Bern-Klug & Forbes-Thompson, 2008; Davies & Nolan, 2008) although the systematic review (chapter 2) showed that this knowledge is vital for providing a non-pharmacological, person-centred approach to care. In addition, care staff may not consider family members to be members of the care team and their involvement is often limited to discussing the resident's care in the context of formal meetings (Bauer et al., 2014). This devaluing of family involvement in managing responsive behaviours is a key example of unequal power relations, and is of particular interest to a critical theorist (Holmgren et al., 2014).

Therefore, critical theory congruent with the transformative paradigm is the theoretical lens through which this thesis was conceived from the choice of topic, development of the research question, study design, methods, interpretation of data, and dissemination. This research is based on the premise that the use of psychotropic drugs to manage responsive behaviours, is inappropriate in the majority of cases and may result in significant harm to care home residents with dementia (see chapter 1.7). Aligned with critical theory, this research aims to understand this phenomenon, to identify the barriers and facilitators to taking a non-pharmacological approach to manage responsive behaviours of care home residents with dementia. Recommendations to address these barriers will assist in the development of dementia care guidelines to implement sustainable non-pharmacological approaches to manage responsive behaviours. A diagrammatic representation of the philosophical and theoretical frameworks informing the PhD research, is illustrated in **Figure 3.1**

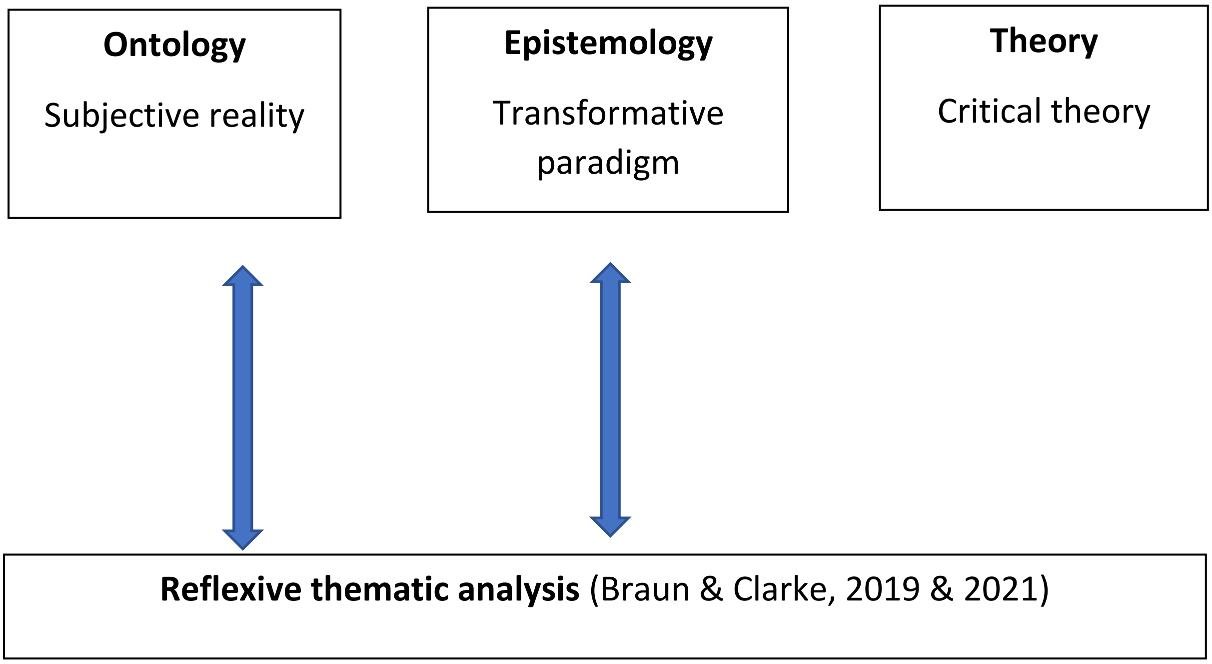


Figure 3.1: Philosophical and theoretical framework informing the research.

In line with critical theory, it is highly important for researchers to consult with individuals and groups most likely to be affected by the research when making decisions about research design and methods to ensure that the research is relevant and useful (Mertens, 2007). For this reason, patient and public involvement (PPI) was established with the Irish Dementia Working Group while designing the research study. PPI contributors provided advice on this research. For example, the development of the interview schedules by adding questions related to the involvement of family members in decision-making and the impact of care home board of management decisions on dementia care for residents (Chapter 4.8). PPI collaborators also reviewed the study recommendations and provided feedback to ensure recommendations would be impactful in improving care for people with dementia (Chapter 7.2). PPI collaborators will also contribute to disseminating the research findings.

This research may have been underpinned by a different methodological approach, for example, grounded theory. Grounded theory aims to understand social relationships and phenomena where little prior research has been conducted, in order to generate new theory based on the data (Bryant and Charmaz, 2007). However, grounded theory fails to recognise the role of the researcher in constructing meaning from the data (Bryant and Charmaz, 2007). Therefore, grounded theory is incongruent with my own epistemological perspective that meaning is created by the participant and researcher. For example, participants' responses to interview questions may vary depending on the prompts used to delve deeper into individual experiences.

Another methodological approach that may have been taken to inform the research process is interpretive phenomenological analysis (IPA) which explores lived experiences of individuals to understand the meanings people assign to their experiences (Smith & Osborn, 2007). However phenomenological approaches do not seek to explain how or why these experiences occur (Tuffour, 2017). The research aims to explore how care home staff manage responsive behaviours in relation to how these responsive behaviours occur in the context of specific care home cultures. Hence, the transformative paradigm and critical theory is a more appropriate philosophical and theoretical approach since it considers the influence of social, cultural, economic and political factors on social phenomena and the experiences of individuals and groups (Kincheloe & McLaren, 2011).

Critical theory is aligned with qualitative and quantitative research methods. Therefore, a mixed methods study design could have been used. The underlying assumption of mixed methods research is that it can address the research question more comprehensively than by using either qualitative or quantitative methods alone (Tariq & Woodman, 2013). For example, quantitative data could have been collected from a survey to identify the prevalence of antipsychotic prescribing in care homes, prior to collecting qualitative data from care home staff. However, this is unnecessary as the second Irish National Audit of Dementia Care (INAD-2) conducted in Ireland in 2019 assessed the prevalence of psychotropic use in care home residents admitted to acute care (Bracken-Scally et al., 2020) (Chapter 1.7). Therefore, a qualitative study design was more appropriate than a mixed-methods design, in order to understand the experiences of managers, nurses and healthcare assistants from different care home organisations regarding how they manage responsive behaviours in residents with dementia. For instance, how organisational structure impacts on the use of psychotropic drugs to manage responsive behaviours. The findings from the qualitative study may be used to develop recommendations and guidelines for policy and practice.

3.4 Reflexive thematic analysis (Braun & Clarke, 2019 & 2021).

The transformative paradigm and critical theory highlight the importance of the participant and researcher in constructing meaning from the data, therefore, reflexive thematic analysis is an appropriate method for data analysis (Braun & Clarke, 2019 & 2021). Reflexive thematic analysis aims to interpret data to understand specific phenomena or the experiences of individuals and groups in particular contexts or settings (Braun & Clarke, 2019).

This is particularly relevant to address the aim of this research to explore the experiences of care home staff in managing responsive behaviours of residents with dementia and the barriers and facilitators to taking a non-pharmacological approach.

Rather than attempting to discover knowledge hidden in the data, the reflexive thematic analyst immerses themselves in the data to create meaning and knowledge in a thoughtful and reflective way that recognises the subjective influence of the researcher in meaning-making (Braun & Clarke, 2021). Researcher subjectivity is considered to be a positive attribute, when reflected upon and explicitly stated (Gough & Madill, 2012) rather than being considered a threat to knowledge creation as proposed by Boyatzis (1998).

Therefore, reflexive thematic analysis is fully aligned with conceptualisations of qualitative research methods including researcher subjectivity, in-depth reflection and immersion in the data (Braun & Clarke, 2021). In this thesis the coding process reflects on the influence of personal beliefs and values on knowledge production. Therefore, the process of constructing themes was influenced by my personal beliefs, assumptions and philosophical worldview as a critical theorist (Braun & Clarke, 2021).

Reflexive thematic analysis, congruent to critical theory (Braun & Clarke, 2013) is therefore, an appropriate choice of data analysis for this research whereas other types of thematic analysis would not be appropriate. For instance, coding reliability thematic analysis uses a codebook to ensure consistent and unbiased coding across several analysts to ensure objectivity (Braun and Clarke, 2020). In contrast, reflexive thematic analysis assumes that subjectivity is an intrinsic element of the research process. Hence, the importance of reflecting on personal beliefs in constructing knowledge (as discussed in Chapter 3.5).

In framework analysis the researcher decides on areas of interest before they start the analysis, often based on hypotheses testing (Gale et al., 2013). Therefore, it is an incongruent approach and is not suited to analysing a wide range of heterogeneous data (Gale et al., 2013). This research generates a high degree of heterogeneous data. This is because data are collected from different professional groups of care home staff with different perspectives and experiences.

3.5 Reflexivity

From a critical and transformative perspective, it is assumed that knowledge creation is far from being unbiased. Therefore, as a researcher I continually needed to interrogate my personal beliefs and values in relation to conducting the research and analysing the data (Fine et al., 2003; Lather, 2004). On reflection, I was aware of several preconceptions and assumptions that influenced how I interpreted meaning from the data. Being female and a former carer for my mother with dementia, I perceive that individuals' with dementia are often excluded from the wider community and carers are not valued with little opportunity to contribute to decision-making. Most family carers are female, typically working long hours with low income and status in the community. In addition, access to dementia care services and respite is inequitable and varies in relation to geographical location. In addition

to my former experiences as a family carer, I also volunteer in Alzheimer's cafes and, prior to the emergence of the COVID-19 pandemic, I often had contact with care home residents and staff which may have influenced my preconceptions of how care home staff manage responsive behaviours.
Therefore, because of these experiences and worldview as a critical theorist, I am aware that I may potentially derive conclusions that are not accurately supported by the data. To prevent this occurrence, I maintained a reflexivity journal and made notes on any issues that arose (Finlay & Gough, 2003), extracts from my reflexivity diary are included in reflexive boxes at relevant points in this thesis. I was also aware that during interviews the way that I interacted with participants may influence their response, for example, if care staff perceived that I used a negative tone when asking questions regarding the use of psychotropic drugs in dementia, they may not have disclosed using these drugs to manage responsive behaviours. Therefore, after every interview I made notes in the journal on how I may have subconsciously led the participant to give a particular answer. I also made notes on how the participants' personality, emotions or tone during the interview may have influenced how I interpreted the data. I referred to the journal notes during the process of data analysis in order to check how my assumptions, beliefs and emotions influenced the construction of themes (chapter 4.13).

In chapter 4, the methods used in this PhD research, underpinned by critical theory and the transformative paradigm, will be presented and a rationale given for the choices made. In addition, justification will be provided for the selection of specific methods in preference to alternative methods that could have been used. Consideration will also be given to the influence of the Covid-19 pandemic on study design, data collection and analysis.

Chapter 4. Methods

4.1 Overview

The rationale for conducting this study was described in Chapter 1.15, to address a gap in knowledge of how responsive behaviours are managed by care home staff to identify facilitators and barriers to implementing non-pharmacological strategies. However, it is important to note that the selection of this specific research question was also influenced by personal experiences as a family carer and professional background in pharmaceuticals (Chapter 1.16).

Since the aim of the research was to gain in-depth understanding of the experiences of staff in long-term residential care, a qualitative study design was an appropriate approach to take. This qualitative study referred to in this thesis as 'the present study' involved collecting data from care home managers, nurses and healthcare assistants from private and voluntary care homes across the Republic of Ireland (ROI).

The emergence of the Covid-19 pandemic in 2020, influenced the design of the study and the methods for data collection and analysis (Chapter 4.5). A systematic review of the literature (Chapter 2) and a qualitative survey informed the study design, for example, development of interview schedules (Chapter 4.8). The qualitative survey was also beneficial for facilitating recruitment (Chapter 4.9). Patient and public involvement (PPI) with members of the Irish Dementia Working Group also informed the design of this study (Chapter 4.2). Ethical approval was obtained from Lancaster University Research Ethics Committee (FHMREC20099).

4.2 Patient and Public Involvement (PPI)

In 2019, contact was made with the Dementia Research Advisory Team in the Republic of Ireland. They facilitated the process of recruiting individuals from the Irish Dementia Working Group to participate as collaborators in the research process. Two members of the Irish Dementia Working Group agreed to provide patient and public involvement (PPI). Due to the Covid-19 pandemic, contact with PPI collaborators was maintained by telephone, email and zoom meetings. PPI collaborators were sent regular reports on research progress and they have contributed to the development of the interview schedules (see chapter 4.9). PPI collaborators agreed to promote the research through their networks and contacts to enhance recruitment (Chapter 4.9). PPI collaborators also reviewed recommendations aimed at addressing the barriers and facilitators to taking a non-pharmacological approach to behaviour management (Chapter 7.2). Moreover, PPI collaborators have also agreed to assist in disseminating research findings.

4.3 Study setting and sampling

Participants were purposively sampled to ensure maximum variation according to nursing home type (voluntary and private sector) and location, urban and rural from a dispersed spread across the Republic of Ireland. This adds rigour to the research process as it supports the transferability of the findings to other care homes settings (Lincoln & Guba, 1985). This is also aligned with Cohen et al. (2001) recommendations that conducting qualitative research from a diverse sample is useful when little is known about a phenomenon, for instance, how staff manage responsive behaviours of residents in care homes across Ireland. All participating nursing homes had a proportion of residents with dementia, most homes had a high proportion of residents with dementia although several homes had a low proportion of residents with dementia. Snowball sampling was also used whereby participants informed colleagues about the study resulting in the recruitment of further care home staff. However, data saturation was not a criterion for determining when data collection should cease as it is a concept that is not congruent with the principles of reflexive thematic analysis. For instance, it is not a case of how much data is “out there” waiting to be discovered but rather how the researcher interprets data to construct meaning and understanding relevant to addressing the research question (Braun & Clarke, 2019).

4.4 Sample

The inclusion and exclusion criteria for participating in the study is presented in **Table 4.1.** Staff must have worked in a care home for a minimum of three months to ensure they have encountered instances of responsive behaviours. (The characteristics of the sample who participated in the qualitative interview study are discussed in Chapter 4.15).

Table 4.1: Participant inclusion/exclusion criteria:

Participant inclusion Criteria
Manager/person in charge: >18 years old and have worked in a care home for a minimum of three months.
Care home nurses: >18 years old and have worked at a care home for a minimum of three months.
Healthcare assistants: >18 years old and have worked at a care home for a minimum of three months.
Participant exclusion criteria
Other healthcare professionals including general practitioners, consultants, speech therapists, occupational therapists, physiotherapists and pharmacists were excluded from participating as the views and experiences of these groups of healthcare professionals do not have long term day-to-day interactions with the residents.

4.5 The influence of the pandemic on study design

Prior to the pandemic, a variety of methods of data collection were considered for this qualitative study. For instance, conducting interviews or focus groups with care home staff were potential options for collecting data. The rationale for collecting data from interviews rather than focus groups is due to the sensitive nature of the research area and the need to ensure confidentiality (Bryman, 2012), for instance the use of psychotropic drugs in dementia may contravene guidelines. In relation to the format of interviews, a semi-structured design was preferred as it provided more flexibility than structured interviews (Silverman, 2014). For instance, the researcher could ask follow-up questions in response to replies from the participant (Braun & Clarke, 2013) to construct meaning of how care home staff manage responsive behaviours. Moreover, semi-structured interviews were preferred to unstructured interviews as they provide a framework to ensure that relevant questions were asked (King, 2010). Therefore, Ethical approval from Lancaster University's Faculty of Health and Medicine Research Ethics Committee (FHMREC) was obtained in January 2020 (prior to Covid-19 restrictions) to conduct interviews in person with 12 - 20 care home staff including managers, nurses and healthcare assistants at four or five care homes in the North-West of Ireland (FHMREC19026).

Reflexive Box 1. Extract from my reflexive diary

It is important to reflect that care homes in the North-West of Ireland were all located within an accessible 100 miles distance from where I reside and this influenced the choice of geographical location to conduct the research.

The emergence of the Covid-19 pandemic in March 2020, resulted in the instigation of restrictions prohibiting access to care homes in the Republic of Ireland. Since, it was no longer possible to visit care homes to recruit potential participants or interview staff in person, as originally intended, the methods of data collection needed to change. Several options for remote collection of data were considered. These included, collecting data from postal, online or telephone-based questionnaires /surveys or collecting data from telephone or Microsoft Teams interviews or using a combination of these methods to collect data.

There were several challenges in selecting appropriate methods of remote data collection. Firstly, previous studies or guidelines had not been published of how sensitive data can be effectively collected from hard-to-reach groups such as care home staff in the context of a global pandemic. However, a study conducted by Johnston et al. (2020) aimed at avoiding burn out of care home workers, involved care home staff completing a qualitative survey followed by qualitative telephone interviews to develop more in-depth understanding to address the research question. This also seemed to be a promising method to collect data in the present study. Pragmatically, care home staff could complete an online qualitative survey, in their own time, by saving responses and completing the questionnaire at a convenient time. This was important due to the time pressures encountered by staff in care homes during the pandemic. To gain more in-depth understanding of survey responses, it was decided that a sub-set of survey respondents would take part in a telephone or Microsoft Teams interview, if they provided informed consent. This would enable conceptualisation of the barriers and facilitators to taking a non-pharmacological approach to manage responsive behaviours. In addition, because the situation during the Covid-19 pandemic was so novel, it seemed appropriate to collect data using more than one method as it was uncertain which methods would prove to be the most effective.

Therefore, in May 2020, ethical approval was granted for an amendment to change the design of the study so that data could be collected from care home staff using an online qualitative survey developed in Qualtrics, followed by qualitative telephone or online interviews using Microsoft Teams with 12 – 20 survey respondents to explore their answers in greater depth (FHMREC19080).

4.6 Development of the online questionnaire

In the present study an online qualitative survey **(Appendix F)** was developed in Qualtrics survey platform, based on the findings of the systematic review (Chapter2). Apart from demographic questions, most questions were open-ended questions requiring a text response. For example, part two of the survey focused on the participants experiences of supporting residents during the Covid-19 Pandemic. Part three of the survey, incorporated a vignette. The vignette was a hypothetical story about a resident exhibiting responsive behaviours in a care home. Respondents had to explain how they would support the resident and the approach they would take to behaviour management. Vignettes are beneficial as they are a less threatening way of asking sensitive questions (Barter & Renold, 1999). The development of the vignette, as well as other survey questions, were informed by the qualitative synthesis completed as part of the thesis (chapter 2). For instance, the review found that care home staff often resorted to pharmacological approaches for convenience, as a “quick fix” to suppress responsive behaviours. Therefore, survey questions aimed to understand why care home staff may select a pharmacological approach rather than a non-pharmacological approach to behaviour management, particularly in the context of the Covid-19 pandemic.

The online survey was reviewed by two senior academics at the Centre for Ageing Research, Lancaster University and modified in response to their comments. The questionnaire was also sent for review to PPI collaborators, however, no further revisions were required.

4.7 Collection and analysis of data using the online survey

The online survey was sent by Qualtrics software to 443 private and voluntary care homes across Ireland. The contact details for these care homes were identified from the Health Information and Quality Assurance (HIQA) website which monitors the quality and safety of care homes in the Republic of Ireland. A participant information sheet was attached to the online survey and respondents were informed on the cover page of the online survey that by completing and submitting the survey it was assumed that they consented to their data being anonymised and used for the purposes of this research study (**Appendix F**).

In total only 23 fully completed questionnaires (approximately 5%) were submitted by 18 care home managers, two nurses and three healthcare assistants from 21 private care homes across the Republic of Ireland presumably due to time constraints and reduced staff levels during the periods of lockdown, associated with the Covid-19 pandemic. 56 incomplete responses were also made. However, data obtained was too limited to answer the research question. For instance, Braun and Clarke’s (2019) approach to reflexive thematic analysis recommends that sufficient data needs to be collected to answer the research question. However, this did not occur although strategies had been implemented for example, an email campaign and social media posts to recruit participants to complete the questionnaire. Indeed, Burmeister and Aitken, (2012) suggest that poor response rates are a potential source of bias since the results could be misleading and only representative of a few individuals who participated (Burmeister and Aitken, 2012). Therefore, due to the low response rate to the survey it was decided not to include this data in the overall study findings due to the risk of bias, for instance, interpretations may be inaccurate since insufficient data was collected to address the research question.

However, it was decided to use the survey findings to contribute to the development of the interview schedules for care home staff. Therefore, reflexive thematic analysis was applied to the survey data, informed by (Braun & Clarke, 2019 & 2021). Initially, the data collected in the online qualitative survey was anonymised and extracted to NVIVO-12. After reading anonymised surveys several times, the data was coded using an inductive approach. Themes and sub-themes were constructed from the data, conceptualising how care home staff managed responsive behaviours and the influence of the pandemic on the strategies used to support residents. Themes were refined and named. The three themes constructed from the survey data included 'Covid-19: A catalyst for innovative strategies to manage responsive behaviours'; 'Importance of families as caregivers in long-term residential care'; also, 'Familiar staff trained in dementia are key to implementing person-centred care'.

The theme 'Covid-19: A catalyst for innovative strategies to manage responsive behaviours'; highlighted how care home staff attempted to mitigate the impact of social distancing and absence of family visits by conducting activities in much smaller groups than usual. Care home staff also facilitated the use of virtual technologies such as Zoom and Skype, to maintain contact between residents and family and friends.

Despite using these technologies, the absence of in-person family visits was distressing for residents with dementia, in particular. Therefore, the theme 'Importance of families as caregivers in long-term residential care', highlights the important role of family members as caregivers; and the influence that their presence has on alleviating resident's distress and agitation and other responsive behaviours.

Themes highlighted how social isolation had increased anxiety and low mood in many residents due to the absence of family visits and isolating in rooms for longer periods of time. Many care staff reported using psychotropic drugs more often to manage responsive behaviours.

The theme 'Familiar staff trained in dementia are key to implementing person-centred care' reflects upon the importance of consistent, familiar and skilled staff to ensure continuity of person-centred care. This was particularly relevant in the context of the Covid-19 pandemic, as staff absences and the use of agency staff was found to have a detrimental impact on the delivery of person-centred care.

Throughout the process, I reflected on how my own assumptions and pre-conceptions impacted on interpretations, aligned with Braun and Clarke (2019).

Reflexive box 2 – Extract from reflexive diary

Construction of the theme 'Importance of families as caregivers in long-term residential care', aligns with my own experiences as a family carer. For instance, during respite care my mother, who was diagnosed with dementia, occasionally exhibited distressed or agitated behaviours when separated from family members. To ensure that I had constructed the theme based on survey responses rather than my own personal experiences, I carefully read the survey responses three times and highlighted key words and phrases. For example, I made notes and compared patterns across survey responses to ensure interpretations were based on the data.

4.8 Development of the interview schedules

One interview schedule was developed for care home managers and nurses (**Appendix G**) and a different interview schedule was developed for healthcare assistants (**Appendix H**). As stated previously, the findings from the survey contributed to the design of interview schedules for care home managers and staff (Chapter 4.7) in addition to findings from the systematic review (Chapter 2). For instance, findings from the survey highlighted the importance of residents' families as caregivers in long-term residential care; therefore an interview question aimed at managers and nurses, probed the degree of involvement of family members in making decisions about the resident's care (**Appendix G**). In addition, a question targeted at healthcare assistants probed to understand the strategies implemented by staff to manage responsive behaviours during the pandemic compared to strategies used prior to the pandemic (**Appendix H**).

Reflexive box 3 – Extract from my reflexive diary

During my time as a family carer, I perceived that family members of people with dementia are not always included in decision-making. Therefore, I had to consider whether the development of the interview question, probing the involvement families in decision-making in the care home, was based on my own experience or the findings of the survey. Therefore, I checked survey responses again to ensure that the data supported the interpretations derived.

Findings from the systematic review also contributed to the development of the interview schedules. For instance, the systematic review highlighted how training of care staff in dementia is often inadequate. Therefore, interview questions probed whether care staff required further training in managing responsive behaviours. The review also indicated that multidisciplinary collaboration is often suboptimal, therefore, interview questions aimed to understand the reasons why care staff did not participate in collaboration.

The interview schedules were reviewed by PPI collaborators, as recommended by Flick (2008). PPI collaborators provided advice and contributed additional questions to the interview schedule for managers and nurses **(Appendix G).** These questions related to the involvement of family members of residents in decision-making in the running of the care home; as well as the impact of providers (board of management) decisions on the care of residents with dementia**.**

The key differences between the interview schedule designed for managers and nurses (**Appendix G**) and the interview schedule for healthcare assistants (**Appendix H**) was that in the latter case, healthcare assistants were not asked questions relating to how HIQA regulations impacted on the approach taken to manage responsive behaviours. The reason is that healthcare assistants are not likely to be aware of HIQA regulations. In addition, the interview schedule for healthcare assistants did not include questions that asked if care homes were well supported by government departments and the board of management during the Covid-19 pandemic as these questions were targeted at managers and senior staff. The same interview schedule was used for managers and nurses since managers in the study were also qualified nurses. Moreover, care home nurses were likely to be aware of HIQA regulations and standards.

The interview schedule was interactively modified after interviews to ensure that relevant questions were asked to address the aim of the research. All changes to the schedule were documented, for example, the interview schedule was changed to ask care staff if they thought GPs required further training in dementia after one participant suggested that GPs do not consider psychosocial causes for responsive behaviours.

4.9 Recruitment of care home staff to participate in an interview

Due to challenges and uncertainties around recruiting care home managers, nurses and healthcare assistants to participate in a telephone or Microsoft Teams interview, during the Covid-19 pandemic, multiple strategies were used to facilitate recruitment to this study. A key tool for recruitment was the use of the online qualitative survey, as discussed below.

The online qualitative survey facilitated recruitment of care home staff to participate in an interview.

The survey facilitated recruitment of care home staff to participate in an interview as respondents were asked to indicate at the end of the survey if they were interested in taking part in a telephone or Microsoft Teams video call meeting with the researcher (**Appendix F**). This was particularly beneficial as one healthcare assistant and six managers who completed the survey also participated in an interview and one of these managers informed their staff about the research resulting in the recruitment of a further two nurses and one healthcare assistant. Therefore, the survey facilitated recruitment of 40% of care staff who took part in the interview study (n=10). This was particularly important due to challenges and uncertainties in recruiting care home staff in the context of the Covid-19 pandemic.

Additional recruitment strategies

Additional strategies were also employed to enhance recruitment. For instance, a poster/flyer was designed (**Appendix I**) and sent to 125 care homes identified on the HIQA website as providing care for residents with dementia. A few days after posting flyers a telephone call was made to the manager of each of these homes to inform them about the research and to answer their queries. Managers were asked to display the posters/flyers in the care home so that their staff could take part in the study, if interested. The posters/flyers displayed the researcher's contact details so that staff could make contact the researcher. Approximately 90% of care home managers contacted, declined to take part in the research, saying that they were too busy working in the care home during the Covid-19 pandemic. However, 10% of managers contacted expressed an interest in participating, therefore, a participant information sheet (**Appendix J**) and consent form (**Appendix K**) was emailed to them. Managers who provided written informed consent were invited to attend for interview. At the end of the interview, care home managers were reminded to ask their staff if they wanted to participate in the research. This snowball sampling technique proved effective as in two care homes, the manager and three staff members were interviewed while in a further two care homes, the manager and one other staff member took part in interviews. The managers assured me that they had not selected or coerced any staff members to take part in the study. This minimises selection bias and enhances the rigour of the research process (Lincoln & Guba, 1985).

Another recruitment strategy involved promoting the research using social media platforms such as twitter whereby care home staff could make contact by following links from media posts. To assist recruitment, letters were sent to the Alzheimer's Association Ireland, Nursing Homes Ireland, the Dementia Research Network Ireland (DRNI), the, All Ireland Gerontological Nurses Association (AIGNA), the Irish Association of Healthcare Assistants (IAHA) and the Alliance of Health Care Assistants in Ireland (AHCAI. Ireland) **(Appendix L).** Of these, only two organisations responded, the DRNI and AHCAI Ireland promoted the study on their websites, social media posts and newsletters. These strategies had limited effectiveness however, one manager was recruited to participate in the study following links from DRNI twitter posts. Finally, PPI contributors at the Irish Dementia Working Group were asked to promote the research through their network. Since recruiting care home nurses and healthcare assistants was challenging, it was decided to offer a 20-euro shopping voucher to nurses and healthcare assistants as an incentive to participate in the study (Chapter 4.12).

4.10 Obtaining informed consent to participate in an interview

Care home managers, nurses and healthcare assistants who expressed an interest in taking part in an interview were contacted by the researcher. They may have expressed an interest by ticking a box on the questionnaire indicating that they were interested in participating in a telephone or Microsoft Teams interview. Other care home staff that had not completed a questionnaire also contacted the researcher expressing an interest in taking part in a telephone or Microsoft Teams interview. They may have been informed about the study by their care home manager or colleagues or by posters and information leaflets posted to the care home, or from social media posts which included the contact details of the researcher.

Once contacted, the researcher provided potential participants with information about the study and addressed any questions that they had. The researcher also sent them a participant information sheet by email so that they could read through the information before making a decision (**Appendix J**). The participant information sheets specified the estimated duration of telephone or Microsoft Teams interviews also, audio (or visual recording) of the interview, data usage, and storage, data confidentiality, potential benefits and risks of participating, the voluntary nature of participating and the right to withdraw from the study (Glesne, 2016). For instance, participants were informed that it was only possible to withdraw interview data, up to two weeks following data collection as once the data has been anonymised and pooled with other participants and analysed, it was no longer feasible to remove individual responses (Glesne, 2016).

The researcher also informed potential participants about the limitations to confidentiality, for instance, the researcher had a duty of care and should it be disclosed during the interview that residents or carers were at serious risk of harm, then in these circumstances, the researcher would share this information with their research supervisors. Participants were also made aware of this reporting procedure when signing the consent form. Potential participants were also informed that access to their anonymised interview data would be restricted in accordance with ethical approval.

The researcher then waited 48 hours after sending the participant information sheet before emailing a written informed consent form for potential participants to read and sign **(Appendix K).** Potential participants were asked to confirm that they have read the participant information sheet and that they had been given the opportunity to have their questions addressed. Prior to providing written informed consent, potential participants had to confirm that they had given permission for Lancaster University to archive typed up versions of their interviews (transcriptions) after they have been fully anonymised and identifiable characteristics removed. Potential participants then had to sign and date the consent form to confirm that they wanted to participate in an interview and email the consent form back to the researcher. The characteristics of the care home staff who provided written informed consent to participate in this study are presented in Chapter 4.15

4.11 Collection of interview data.

A single telephone or online semi-structured interview was conducted with each individual participant. Telephone interviews were audio recorded (with consent) with a password protected encrypted digital voice recorder. Interviews ended by collecting demographic details from staff. Immediately after each interview, audio data was transferred to Lancaster University subscription to OneDrive. Notes were recorded in the reflexivity journal, including how the participant engaged in answering specific questions, for example, whether they made emotional responses. This was particularly relevant in care homes where residents had contracted or died from Covid-19 (see reflexive box 4). Notes were also made on how my own preconceptions of managing responsive behaviours, based on being a former carer for my mother with dementia, related to accounts given by care home staff; for example similarities or differences in strategies used to support a person with responsive behaviours.

NVIVO 12 automated transcription was used to automatically transcribe and fully anonymise audio data. Audio data was then deleted from audio recorders and One Dive while anonymised interview transcripts were stored in Lancaster University's subscription to One Drive until the researcher submitted their thesis, after this anonymised transcript were transferred to Lancaster University repository, PURE, according to the protocol approved by FHMREC.

Data collection continued until sufficient data had been collected to develop in-depth understanding of how care home staff manage responsive behaviours, thereby addressing the aim of the research as recommend by Braun and Clarke (2019).

Reflexive box 4 - Extract from reflexive diary

During the interviews, several staff members who worked in care homes were residents had died from Covid-19 made emotional responses and explained how they had felt traumatised by these events. They found the interview a therapeutic experience because they could talk to someone about their experiences. Hearing these accounts also triggered personal memories of when my mother experienced seizures. I felt empathy for care home staff as I understood the stress associated with being responsible for the wellbeing of a person with dementia.

4.12 Research ethics

As stated in Chapter 4.5, the original research ethical approval (FHMREC19080) was amended to facilitate changes in data collection as face-to-face interviews in care homes was no longer possible due to the emergence of the Covid-19 pandemic. However, recruitment of staff was very challenging, therefore, a further ethics amendment was approved in June 2020 (FHMREC19120) which allowed care home managers to be contacted by telephone, to ensure they received and accurately interpreted information about the study. This strategy proved effective in recruiting participants to a study which investigated outbreaks of Covid-19 in care homes in Ireland (Kennelly et al., 2020). This strategy subsequently proved effective in recruiting participants to the present study.

In November 2020, an ethics amendment was granted to offer nurses and healthcare assistants a 20-euro shopping voucher for participating in the research (FHMREC20048). The rationale for giving an incentive is to ensure the participation of a diverse range of care home staff. Therefore, financial incentives may help to avoid the bias that may occur if the views and perspectives of specific groups of stakeholders are omitted, corresponding with Thompson (1996). This recruitment strategy proved effective in the Enabling Research in Care Homes (ENRICH) study by giving shopping vouchers to care home staff participating in telephone interviews (Giebel, 2020).

In February 2021, there was a rapid increase in the number of care home nurses and healthcare assistants expressing an interest in contributing to the study. Therefore, a fifth and final ethics amendment was requested to increase the number of participants that could be interviewed from 20 participants to a maximum of 35 participants (FHMREC20099)**.**

4.12.1 *Risk of harm*

A protocol had also been put in place **(Appendix N)** whereby, if any participant became distressed during the interview, the interview would be paused or terminated, if deemed appropriate and the contact details of mental health support would be provided. However, no participant became distressed during the interview, for instance, in a care home where ten residents had died of Covid-19, a manager, a nurse and two healthcare assistants were interviewed. Although they related being emotionally and psychological impacted by these events, none became distressed during the interview. After the interview, an email was sent to participants, but none reported feeling upset, rather, they seem to have benefitted by sharing their experiences and contributing to research.

4.12.2 *Data Access and storage*

Access to the interview data transcripts are restricted to protect the anonymity of participants. This is because interview data has been collected from a limited sample of participants, and, although the interview transcripts are anonymised, it is possible that, given the limited number of participants in the interview study, there is a potential risk that the participants may not be fully unidentifiable. After 10 years, the interview transcripts will be deleted from PURE by Lancaster University data manager.

4.13 Data analysis

Reflexive thematic analysis (Braun & Clarke, 2019) was applied to data collected from interviews with care home staff. Reflexive thematic analysis was selected as it recognises the subjective influence of the researcher in meaning-making (Chapter 3.4). For example, how previous experiences influences data interpretation and the construction of themes (Chapter 3.5 and Chapter 7.4). An inductive and latent approach was taken to interpret barriers and facilitators to taking a non-pharmacological approach. Since the research was underpinned by critical theory and the transformative paradigm, inequalities at the organisational level and power differentials between different groups of staff were an important focus in constructing themes.

A six-phase approach to reflexive thematic analysis was taken, informed by Braun & Clarke (2006 & 2019 & 2021). These phases included familiarisation; coding; generating initial themes; reviewing and developing themes; refining, defining and naming themes; and writing up, as outlined in **Table 4.2.** The phases were iterative rather than linear, facilitated by NVIVO-12 data management software (QSR International, 2022).

Table 4.2: Data analysis informed by Braun & Clarke (2006 & 2019 & 2021) six-phase approach to reflexive thematic analysis.

Familiarisation	• Familiarisation - transcribing and reading transcripts several times (chapter 3.4) • Making notes of ideas to interpret meaning • Returning to the data to gain new insights (Gough and Lyons, 2016).
Coding	• Initial codes were generated using an inductive and reflexive process (Chapter 3.5).
Initial themes	• Generating initial themes related in content around a central idea.

Review themes	- Themes were reviewed by examining their consistency with the data.
Refined and name themes	- Themes were refined and named in a reflective process to create a compelling story.
Writing up	- The final report discussed findings, themes and sub-themes. - Relevant quotations were included to support themes. - Discussion on how themes addressed research objectives and related to the wider literature.

Therefore, theme development came later in the process after immersion in the data for several months, in a process that involved reading interview transcripts several times and coding the entire data set of 25 interviews from care home staff. Hence, time to reflect resulted in the generation of themes based on my own subjective interpretation (Chapter 3.5). For example, analysis identified that care of residents must also include care of staff, and factors including relationships, capabilities, training, support, valuing, respect, communication, collaboration and equitable decision-making, are just as important for staff as they are for residents. Therefore, themes and sub-themes were constructed after deep immersion in the data as well as maintaining continuous reflexive accounts in a reflexive diary. Extracts from the diary are included in this thesis.

Also, an audit trail was maintained to document the construction and refinement of themes. This enhanced the dependability of the findings (Lincoln & Guba, 1985). The themes and sub-themes constructed in the analysis are discussed in chapter 5 and 6 and supported with relevant quotations. (An example of the codes generated are available in **Appendix O**). The quality of the reflexive thematic analysis was evaluated using Braun and Clarke (2020) 'Twenty questions to evaluate the quality of thematic analysis' **(Appendix P).** A brief description of this quality appraisal is presented in Chapter 4.14. By using various strategies to ensure rigour, the trustworthiness of the reflexive thematic analysis has been enhanced.

Reflexive box 5 - Extract from my reflexive diary.

My experience as a carer made me realise that people with dementia are intrinsically valuable and should be treated with respect and their human rights ensured. These perceptions, corresponded with findings from the interview study. However, analyses of the interview data highlighted the importance of the bi-directional relationship between care home staff and residents and that care for residents must also include the care of staff. This was a concept that I had not previously considered.

4.14 Quality of reflexive thematic analysis

The quality of the reflexive thematic analysis was evaluated using Braun and Clarke (2020) ‘Twenty questions to evaluate the quality of thematic analysis’ (**Appendix P**). For example, one of the questions asks if “the authors clearly specify and justify which type of thematic analysis they are using?” In this thesis, the justification for using reflexive thematic analysis is stated in Chapter 3.4.

A different question asks if “the theoretical underpinnings of the use of thematic analysis are clearly specified.” In this thesis, it is clearly stated that the transformative paradigm and critical theory underpin this research, congruent with reflexive thematic analysis (Chapter 3.4).

In addition, a different question asks if researchers discuss their personal and social standpoint and positioning.” In this thesis, my personal and social standpoint are explicitly stated in the reflexivity statement (Chapter 3.5).

Chapter 4.15 presents the characteristics of the managers, nurses and healthcare assistants who participated in the interview study. Demographic information about the care homes are also provided.

4.15 Participant characteristics

Twenty-five interviews were conducted with 16 care home managers, four nurses and five healthcare assistants from 21 care homes across Ireland providing care for 1,349 residents. Twenty-four interviews were conducted by telephone and one interview with a manager was conducted via Microsoft Teams. Interviews ranged in duration from 25 minutes to 81 minutes, with an average duration of 46 minutes. All participants consented to being audio recorded, no participant declined to answer a question or terminated the interview.
Four managers identified themselves as providers, one of whom had responsibility for two private care homes. Eleven managers identified themselves as people in charge (PIC) or Directors of Nursing (DON) who were employed by the provider. One manager identified themselves as a clinical services manager with responsibility for four private care homes. In total, seventeen care homes were in the private care home sector while four care homes had charitable status and were run on a not-for-profit basis (voluntary sector). Twelve care homes were located in urban areas while nine care homes were located in rural regions. In care home K, a manager, two nurses and a health care assistant were interviewed. At care home T, a manager, a nurse and two healthcare assistants were interviewed. In care home S, a manager and a nurse were interviewed, while at care home O, a manager and a healthcare assistant were interviewed and at care home U, one healthcare assistant was interviewed. At all other care homes, only the manager was interviewed. Care home staff had an average of 19 years of experience. Participant characteristics are shown in **Table 4.3**

Table 4.3 Participant and care homes characteristics

Participant ID	**Job title:** M = Care home manager N = Nurse HCA = healthcare assistant	**Gender** F = female M = male	**Years of experience**	**Ethnicity**	**Care home ID**	**Care home Location Urban/rural**	**Care home Sector**	**No. of residents**
1	M	F	29	White/Irish	A	Rural	Charity	9
2	M-Clinical services manager	F	17	White/Irish	B,C, D, E	Urban	Private	571 (B n=163; C n=139; D n=141; E n=128)
3	M-Provider	F	35	White/Irish	F&G	Urban	Private	77 (F n=29; G n=48)
4	M	F	18	White/Irish	H	Rural	Private	58
5	M	F	9	Indian	I	Rural	Private	18
6	M	F	22	White/Irish	G	Rural	Private	64
7 18 19 23	M N N HCA	F F F F	36 10 11 15	White/Irish Indian Hispanic White/Irish	K	Urban	Private	56
8	M	F	21	White/Irish	L	Rural	Private	42
9	M	F	22	White/Irish	M	Rural	Private	47

10	M	F	29	White/Irish	N	Urban	Charity	60
11 22	M-provider HCA	F M	34 3	White/Irish White/Irish	O	Urban	Charity	33
12	M	F	27	White/Irish	P	Urban	Private	42
13	M	F	25	White/Irish	Q	Rural	Charity	48
14	M	F	28	White/Irish	R	Urban	Private	71
15 17	M-provider N	F	36 13	White/Irish White/Irish	S	Rural	Private	30
16 20 24 25	M-provider N HCA HCA	F F F M	35 12 2 2	White/Irish Indian White/Irish White/Irish	T	Rural	Private	60
21	HCA	M	6	White/Irish	U	Urban	Private	63

4.16 Conclusion

This chapter has described the methods used in this qualitative study and highlighted the uncertainties pertaining to recruitment and data collection during a pandemic. Difficulties involved accessing and informing care home nurses and healthcare assistants about the study during periods of restrictions. Identifying appropriate methods of remote data collection during the Covid-19 crises was particularly challenging as previous research or guidelines had not been published. The approach taken in the present study involved using more than one strategy to collect data to mitigate these uncertainties.

Although, it was deemed that insufficient data was collected from the online qualitative survey to address the research question, findings were used to inform the development of the interview schedules for care home staff and also resulted in recruitment of 40% of the participants who took part in an interview. Additional recruitment strategies were also implemented to ensure a diverse data set was collected. Moreover, reflexive thematic analysis was considered an appropriate approach as it takes into account the influence of the researcher when constructing themes.

In Chapter 5, an overview of the findings of this study are presented including an illustration of the themes and sub-themes (figure 5.1). Since the theme ‘Managing responsive behaviours during the Covid-19 pandemic’ is quite distinct from the other themes it will be presented in Chapter 5, while the remaining themes will be discussed in Chapter 6.

Chapter 5: Findings

In this chapter, the findings of the qualitative study are explored. The qualitative study involved collecting data from telephone or Microsoft Teams interviews with care home staff across the Republic of Ireland, during the Covid-19 pandemic. Reflexive thematic analysis was applied to data to conceptualise understanding of the facilitators and barriers to implementing non-pharmacological strategies to manage responsive behaviours.

5.1 Overview of findings

Informed by Braun and Clarke, (2019), reflexive thematic analysis was applied to the data. Initial codes were generated using inductive and reflexive coding. From these codes, three initial themes were constructed. One theme related to pharmacological and non-pharmacological approaches to manage responsive behaviours. However, after reviewing themes, this theme was separated into two distinct themes:

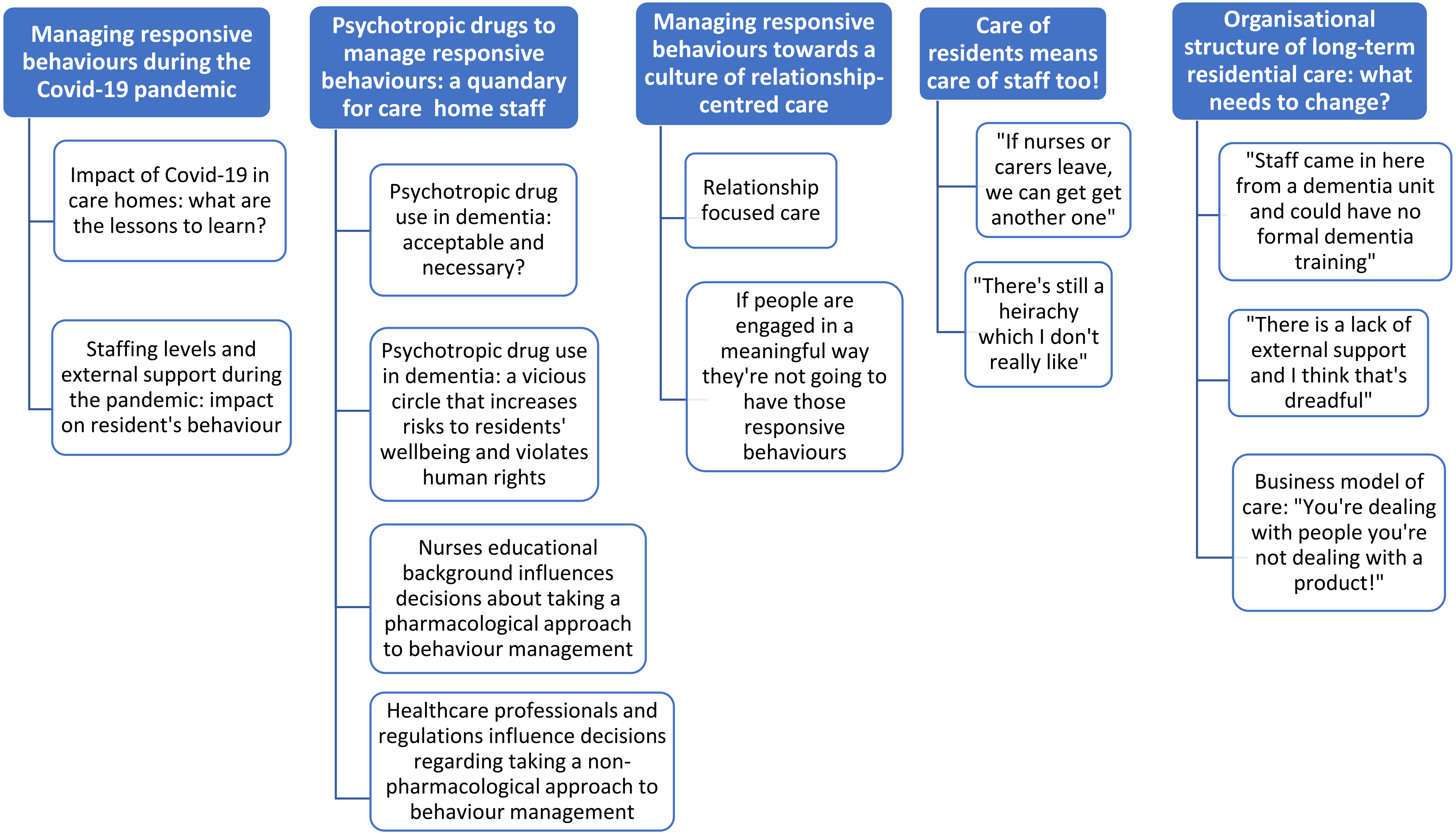
1) Psychotropic drugs to manage responsive behaviours: a quandary for care home staff.

2) Managing responsive behaviours: towards a culture of relationship-centred care.

The reason for this was because the codes relating to psychotropic drug use were distinctly different from codes relating to relationship-centred care.

It was also decided to add an additional theme relating to the management of responsive behaviours during the Covid-19 pandemic. Hence, in total five themes and 13 sub-themes were constructed in the reflexive thematic analysis, as illustrated in **Figure 5.1.**

The theme 'Managing responsive behaviours during the Covid-19 pandemic' is quite distinct from the remaining four themes as the global pandemic was an unprecedented time in care homes and the experiences of staff at this time varied significantly from experiences prior to the pandemic. Therefore, this theme will be discussed in this chapter while the other four themes are analysed in Chapter 6.



- **Managing responsive behaviours during the Covid-19 pandemic**
  - Impact of Covid-19 in care homes: what are the lessons to learn?
  - Staffing levels and external support during the pandemic: impact on resident's behaviour
- **Psychotropic drugs to manage responsive behaviours: a quandary for care home staff**
  - Psychotropic drug use in dementia: acceptable and necessary?
  - Psychotropic drug use in dementia: a vicious circle that increases risks to residents' wellbeing and violates human rights
  - Nurses educational background influences decisions about taking a pharmacological approach to behaviour management
  - Healthcare professionals and regulations influence decisions regarding taking a non-pharmacological approach to behaviour management
- **Managing responsive behaviours towards a culture of relationship-centred care**
  - Relationship focused care
  - If people are engaged in a meaningful way they're not going to have those responsive behaviours
- **Care of residents means care of staff too!**
  - "If nurses or carers leave, we can get get another one"
  - "There's still a heirachy which I don't really like"
- **Organisational structure of long-term residential care: what needs to change?**
  - "Staff came in here from a dementia unit and could have no formal dementia training"
  - "There is a lack of external support and I think that's dreadful"
  - Business model of care: "You're dealing with people you're not dealing with a product!"

Figure 5.1. Illustration of themes and sub-themes constructed from interview data with care home staff.

5.2 Theme: Managing responsive behaviours during the Covid-19 pandemic

This theme analyses how challenges impacting the care home sector intensified during the Covid-19 pandemic. For instance, the impact of reduced staffing levels on continuity of care. The Covid-19 pandemic also highlighted the importance of family support and how the absence of family visits and social distancing measures, associated with restrictions, affected the behaviour of care home residents with dementia. The theme also highlights approaches used to manage responsive behaviours during the pandemic.

5.2.1 Impact of Covid-19 in care homes: what are the lessons to learn?

Several care homes participating in this study reported outbreaks of Covid-19 among residents and staff in the period March 2020 to February 2021. In one care home, all residents and staff tested positive for Covid-19 and sadly many deaths occurred, which was traumatic for residents, staff, families and the wider community.

> *"Covid-19, within a week, I think, all of us had it, between residents and staff about fifty of us had it…none of them [residents]…that were sick…got sent into hospital…they wouldn't be candidates for ventilation" (Manager, 16).*

In a different care home, twelve residents and staff tested positive with Covid-19. Outbreaks of Covid-19 were also reported in a chain of four care homes participating in the research. Care home staff reported that the Covid-19 pandemic had a profound impact on residents. For instance, in homes were residents and staff had outbreaks of Covid-19, staff noted that residents were very depressed, anxious and distressed.

> *"There was a huge impact, they started wandering around, they were tearful at times" (Nurse, 20).*

Seeing staff wearing personal protective equipment (PPE) also heightened residents' anxiety levels. This resulted in residents being unable to sleep and led to increased instances of “wandering” and other responsive behaviours. For example, it was not possible to enforce residents with dementia to remain in their bedroom and “wandering” may have potentially contributed to the spread of Covid-19. Also, staff reported using psychotropic medications to manage responsive behaviours or to alleviate extreme anxiety, including panic attacks, associated with Covid-19 trauma.

> *“We had lots of issues with challenging behaviour and residents had sleepless nights and [were] wandering around all night looking for the families. Some of them were started on the medication just to settle their mood and behaviour*” (Nurse, 20).

Even in care homes that remained free of Covid-19, residents were also affected by the pandemic, for instance daily routines changed, social distancing was introduced, the regular large group activities stopped and family visits were prohibited. Yet, the impact on individual residents spread across a continuum and whilst many residents experienced negative consequences from the pandemic some residents experienced positive benefits from a quieter environment and fewer visitors.

For residents who were negatively impacted, staff expressed how social isolation associated with separation from family members and friends resulted in increases in responsive behaviours including aggression and agitation. Care home staff explained how they tried to mitigate the impact of social isolation by using virtual technologies including Zoom, WhatsApp, Skype and also the telephone to maintain contact between residents and family. Although these technologies worked well for residents without impairments in cognition, residents with dementia found these technologies difficult to comprehend, limiting their effectiveness. Similarly, residents with dementia could not understand why relatives remained outside during window visits, resulting in distress and an increase in responsive behaviours. Care home staff also reported how the absence of face-to-face family visits increased resident’s movement through the home as they looked for family members.

> *“They have become more aggressive, they have got very confused, they just don't really understand why they are not allowed to talk to the family” (Nurse, 19).*

Even though family visits were generally prohibited, several managers acknowledged that if residents became very distressed and exhibited responsive behaviours, a short family visit would be permitted to calm the resident down and reduce responsive behaviours.

In contrast to these findings, several care home managers explained how the absence of visitors to the care home had a beneficial impact for the wellbeing and behaviour of some residents. For instance, the environment was quieter with less movement and activity which corresponded to a decrease in responsive behaviours in some residents who may have had a lower threshold for tolerating noise and environmental stimulation, aligned with the Environmental Vulnerability/Reduced Stress-Threshold model (Cohen-Mansfield, 2000). This model assumes that responsive behaviours arise when people with dementia are less tolerant and have reduced coping strategies to respond to external stimuli.

> *"Challenging behaviour…in some of our dementia residents actually started declining because there wasn't the constant hustle and bustle and there wasn't the noise levels of visitors coming in" (Manager, 8).*

A manager of a big care home in an urban setting also suggested that responsive behaviours declined during the pandemic due to less resident-to-resident aggression as a result of social distancing measures and isolating in rooms. In addition, care home staff observed a decrease in responsive behaviours associated with illness, discomfort and pain, as residents did not contract infections, such as the flu or the vomiting bug during the period of Covid-19 restrictions, presumably due to stringent hygiene protocols and the absence of visitors. In these instances, care home staff reported that they did not use medications more often to manage responsive behaviours.

Furthermore, care home staff described how they implemented strategies to mitigate the impact of social isolation by organising activities with participants in small pods of four of five residents, in line with social distancing measures. Staff perceived that conducting activities in smaller groups than usual enhanced residents' feelings of social and psychological wellbeing, compared to conducting activities in larger groups. Hence, in future waves of the pandemic or in a post-Covid era, encouraging residents to engage in activities in small groups is likely to be beneficial for facilitating a non-pharmacological approach to manage responsive behaviours.

5.2.2. Staffing levels and external support during the pandemic: impact for residents' behaviour

Several care home staff described how external support from government departments was not in place at the beginning of the Covid-19 pandemic in March and April 2020. This was a critical time for care homes and information about infection control and managing responsive behaviours during the pandemic was not available for most care home staff until the summer of 2020, as a manager explains,

> *"[We felt] sort of alone in terms of support from the HSE, in terms of support from Nursing Homes Ireland" (Manager,13).*

Some staff perceived that care homes in rural areas in the West of Ireland received less support from government departments during the Covid-19 pandemic than care homes located in urban city areas. Indeed, the lack of external support from government departments at the start of the pandemic created feelings of fear and panic for staff and residents. In these instances, panic among residents, associated with the Covid-19 pandemic, was treated with psychotropic medications.

Care home managers and nurses also reported that access to healthcare professionals was limited due to restrictions on visiting care homes in person. However, care home staff reported that the use of virtual technologies, including audio visual meetings with healthcare professionals, were beneficial during periods of restrictions; particularly to consult with psychiatry and mental health services to support residents who were anxious or depressed or experiencing responsive behaviours. Therefore, the use of remote conferencing with psychiatry professionals is likely to facilitate a non-pharmacological approach to support residents with responsive behaviours in future waves of the pandemic or to complement in-person visits in a post-Covid era.

Regarding staffing levels, many care home staff, particularly managers, expressed how staff absenteeism was a serious challenge during the Covid-19 pandemic. Many staff were absent during the Covid-19 pandemic due to contracting Covid-19 or self-isolating due to being a close contact of a person with Covid-19. Other nurses and healthcare assistants in private and voluntary nursing homes were recruited by the Health Services Executive (HSE) during the pandemic to work in acute hospitals. A manager explains,

> *"We had big rows with the HSE about this…I'm losing a nurse in two weeks' time and I am losing three care staff to the HSE, after them promising not to touch the nursing home staff" (Manager, 9).*

Therefore, the remaining staff were asked to work extra shifts and not to take holiday leave. Staff described feeling distressed and exhausted. This had a very detrimental impact on continuity of care for residents as some care homes had to recruit agency staff during the crises. Some managers found that recruiting agency staff during the pandemic was extremely difficult and therefore recruited any staff available even though they lacked specific training in dementia care and were unfamiliar with residents and their individual needs.

> *"We also required agency in a number of our homes to supplement the staffing at a very critical time…completely impacting on the continuity of care on the familiarity side of things…I think probably responsive behaviours did happen" (Manager, 2).*

Therefore, the findings suggest that the Covid-19 pandemic had a detrimental impact on care for many residents with dementia. This was due to low staffing levels, unfamiliar staff, the absence of family visits, disruption of routine, restricted movements and activities and social isolation. This created fear, anxiety, low mood and sleeping difficulties for many residents and increases in responsive behaviours in many care homes, particularly homes with Covid-19 outbreaks. Some homes reported using psychotropic drugs more often to manage responsive behaviours.

Therefore, the findings indicate that taking a non-pharmacological approach to manage responsive behaviours was particularly difficult and highlighted areas for improvement in future waves of Covid-19 or other pandemics. Importantly, residents should not be prohibited from seeing their family members as this has a detrimental impact on psychological and emotional wellbeing. Careful planning is also required to ensure adequate staffing levels are maintained at times when staff are likely to be absent due to outbreaks of Covid-19, to ensure continuity of care. It is also essential that care homes are supported by government departments to facilitate a non-pharmacological approach to managing responsive behaviours.

Importantly, however, the findings also highlighted the benefits of providing activities in small groups presumable due to a high staff to resident ratio and a quieter environment with less opportunities for aggressive resident-to-resident interactions. The findings also demonstrate the benefits of ensuring stringent infection protection and control in care homes to prevent illness, since pain and illness are triggers for responsive behaviours, this is also likely to facilitate a non-pharmacological approach to supporting residents.

The next chapter, explores how factors other than the Covid-19 pandemic influence the approach taken by care home staff to manage responsive behaviours and the barriers and facilitators to implementing a non-pharmacological approach to support residents.

Chapter 6. Findings

This chapter discusses the four remaining themes including, ‘Psychotropic drugs to manage responsive behaviours: a quandary for care home staff’; ‘Managing responsive behaviours towards a culture of relationship-centred care’; ‘Care of residents means care of staff too!’ and ‘Organisational structure of long-term residential care: what needs to change?’ As illustrated in figure 5.1 (Chapter 5.1).

Themes explore how factors, other than the Covid-19 pandemic, influence the approach taken by care home staff to support residents experiencing responsive behaviours, for instance, the educational background of nurses and healthcare assistants, support from healthcare professionals, regulation, financial resources, staffing levels, staff skills and knowledge, organisational factors, collaboration and the model of care provision. These factors may facilitate or pose a barrier to implementing non-pharmacological strategies to behaviour management.

6.1 Theme: Psychotropic drugs to manage responsive behaviours: a quandary for care home staff

This theme outlines the pharmacological approaches taken by care home staff to manage responsive behaviours. This involved exploring factors that influence decision-making about using psychotropic drugs for behaviour management, resulting in the identification of barriers and facilitators to taking a non-pharmacological approach to support residents with responsive behaviours.

6.1.1 Psychotropic drug use in dementia: acceptable and necessary?

The use of psychotropic drugs was seen as acceptable by most care home staff, as a routine part of dementia care. Several managers and nurses reported that a lot of residents were prescribed psychotropic drugs on a regular basis. In this quotation from a nurse, she acknowledged that almost a third of residents in her care home were being given one or more psychotropic drugs.

> "*Fourteen residents out of forty-six residents are on psychotropic drugs*" (Nurse, 18).

Regular use of psychotropic drugs was perceived to be more acceptable than psychotropic drugs administered on a pro-rat nata (PRN), given when needed basis. This appears to be because psychotropic drugs given on a regular basis have been prescribed in consultation with general practitioners (GPs) and psychiatrists while care home nurses decide when to administer psychotropic drugs to residents on a PRN basis. Therefore, PRN medications were perceived by some care home staff to be a potential mechanism of chemical restraint.

Most care home staff justified taking a pharmacological approach to reduce the risk of harm. For instance, psychotropic drugs were given to calm residents down when behaving aggressively in order to reduce the risk of harm to self or others.

> "*When they become aggressive and they're a risk to themselves or other residents or other family or staff we would look at medication then for some of those behaviours*" (Manager, 8).

Therefore, psychotropic drugs were seen as necessary in certain cases to de-escalate behaviours prior to attempting a non-pharmacological approach although this contravenes guidelines that recommend a non-pharmacological approach as the first option for behaviour management. A care home manager explains,

> "*Aggression is so severe that you can't ask them to sit down and carry out some flower arranging to calm them down, because that would just be ridiculous (laughs). It wouldn't work until their behaviour modified itself after medication"* (Manager, 7).

In addition, most participants described how they gave psychotropic drugs to residents to alleviate distress or anxiety and sometimes low mood. However, the optimum therapeutic dose varied between residents. Indeed, all care home staff agreed that psychotropic drugs had a different effect on each individual resident, as illustrated in this quotation from a care home manager,

> "*Two milligrams of diazepam to one person may be like drinking water, this lady it knocked her for six, completely lethargic for about three days.*" (Manager, 9)

Psychotropic drugs were perceived as effective if they reduced responsive behaviours and improved mood without sedating the residents. Indeed, several nurses reported that they used charts to monitor the impact of psychotropic medications on residents on a monthly basis.

> *"Helpful [if] she is not sleeping with that tablet, we don't want them to sleep, we want their behaviour to be…in control but to stay awake."* (Nurse, 20).

When psychotropic drugs were deemed to be effective to manage a resident's responsive behaviour, this reinforced their acceptability and continued use without further monitoring of adverse drug effects. Most care home staff agreed that the antipsychotic drugs, seroquel and risperidone are most often used to manage responsive behaviour. In addition, benzodiazepines, particularly lorazepam are frequently given to manage aggressive or agitated behaviours or anxiety while antidepressants drugs may also be used to improve low mood for example, withdrawal, self-harm or crying. One healthcare assistant suggested that hypnotic drugs are less effective for managing responsive behaviours. Most staff refuted that psychotropic drug were given to manage behaviour for the convenience of staff or as a form of restraint, using psychotropic medications in this way was seen as unacceptable.

> *"There are times that medication has been given just to calm them down a bit because of their distress levels, but it's not used in a restraining way."* (Healthcare assistant, 21).

The findings from this sub-theme highlight that the main rationale for using psychotropic drugs in residents with dementia is to minimise the risk of harm associated with aggressive behaviour or to alleviate distress or low mood. Understanding the factors that influence taking a pharmacological approach, is beneficial to facilitate non-pharmacological strategies. For instance, to pre-empt and address the triggers for aggressive behaviours before they escalate. Therefore, strategies may be developed that specifically target individual needs to facilitate a non-pharmacological approach to support residents experiencing low mood and anxiety without needing to resort to psychotropic drugs.

In addition, the findings highlighted that regular use of psychotropic drugs are perceived to be more acceptable than drugs prescribed on a PRN basis; and this may, potentially result in increased use of these drugs in people with dementia, posing a barrier to taking a non-pharmacological approach. Also, the findings indicate that while residents are monitored initially for adverse drug reactions, monitoring over longer durations is required to identify if psychotropic drugs result in harm and this may be incorporated in the residents care plan.

6.1.2. Psychotropic drug use in dementia: a vicious circle that increases risks to residents' wellbeing and violates human rights.

Several care home managers expressed that the use of psychotropic drugs in dementia was a fine balance between maintaining residents' human rights and minimising risks, such as the risk of harm associated with aggressive behaviour. One care home manager succinctly stated how the use of psychotropic drugs violates residents' human rights by limiting residents' freedom.

> *"There has to be a balance of risk, they need their freedom…When you introduce medication, they just fall and that's not [the] right answer. Just because somebody's got dementia it doesn't mean…they shouldn't be allowed freedom to move around."* (Manager, 3).

Several care home staff explained how the use of psychotropic drugs in residents with dementia was a vicious circle. Psychotropic drugs often cause residents to feel lethargic; when this occurs, residents with dementia are less likely to drink fluids and become dehydrated. This then results in confusion, disorientation, increasing the likelihood that residents will fall. For instance, healthcare assistants reported that the use of psychotropic drugs, such as risperidone increased the frequency of falls experienced by residents. In addition, dehydration resulted in constipation and agitation and other responsive behaviours requiring further medication. Therefore, care home staff suggested that the use of psychotropic drugs may worsen symptoms and responsive behaviours by masking the underlying problem rather than solving it. A healthcare assistant explained,

> *"I do believe that psychotropic drugs…mask the problem…you stop the behaviours but haven't cured the problem."* (Healthcare assistant, 22).

Therefore, many care home managers and staff adopt a false rationale by arguing that psychotropic drug use in people with dementia is necessary and therefore, acceptability.

This is despite awareness that psychotropic drugs do not address the causes of responsive behaviours but instead increase the risk of sedation and falls in residents. Hence, this violates residents' human rights to freedom and autonomy and poses a barrier to implementing non-pharmacological strategies to support residents.

6.1.3 Nurses' educational background influences decisions about taking a pharmacological approach to behaviour management

Care home managers noted that the approach taken to manage responsive behaviours depended primarily on individual nurses and highlighted how some nurses only attempt a pharmacological approach. Managers suggest that nurses with an educational background in general nursing are more likely to assume that behaviours, associated with dementia, arise due to a progressive neurodegenerative condition that requires pharmacological treatment. This corresponds with neurobiological theories for responsive behaviours (Shinosaki et al., 2000).

> *"Responsive behaviours can be extremely difficult and very disruptive…to the other residents and then obviously to the staff…I've seen people wander for night after night and are completely exhausted, well, they may have psychotic symptoms….the content of their speech is quite confused…what I see is a psychotic presentation…but then with medication those symptoms can become less."* (Manager, 7).

In contrast, care home managers perceived that nurses trained in mental health, gerontology, dementia or intellectual disabilities, are more likely to assume that responsive behaviours are a form of communication that may arise due to a physical or psychological cause, for example, pain, illness or lack of social interaction. This corresponds with theoretical frameworks such as the need-driven dementia-compromised behaviour model (Algase et al., 1996) or the unmet needs model (Cohen-Mansfield, 2000) which assume that responsive behaviours arise in response to an unmet physical, psychological or emotional need that cannot be verbally expressed.

In addition, a mental health nurse suggests that responsive behaviours may arise due to environmental factors, such as increased noise levels that people with dementia find particularly stressful. This is aligned with the environmental vulnerability/reduced stress-threshold model (Cohen-Mansfield, 2000) that predicts that people with dementia have a lower threshold for tolerating stress associated with environmental stimuli, resulting in responsive behaviours Therefore, managers highlight the importance of identifying the causes of responsive behaviours.

> *"If you have people with dementia they don't need to be treated differently, if you just understand what the reasons are for responsive behaviours. I believe that responsive behaviours are a form of communication, that they are looking for something, if you just understand it, before it escalates."* (Manager, 5).

Therefore, the findings show that the nurses' educational background influences their assumptions about the aetiology of responsive behaviours and this, in turn, impacts on decision-making whether to use psychotropic drugs to manage responsive behaviours. This suggests that educational programmes to enhance nurses' knowledge of dementia and the biological, psychological, environmental and social causes for responsive behaviours are likely to facilitate a non-pharmacological approach to support residents exhibiting responsive behaviours.

6.1.4 Healthcare professionals and regulations influence decisions regarding taking a non-pharmacological approach to behaviour management

Most care home managers perceive that general practitioners (GPs) have inadequate knowledge of how to manage responsive behaviours and suggest that they need further training in dementia care, particularly if they work in care home settings. Therefore, enhancing GPs understanding of responsive behaviours, that encompasses social, environmental and psychological factors, rather than solely biological causes for these behaviours, is likely to facilitate a non-pharmacological approach to support residents.

Several care home managers also noted that the GP's personality and attitudes impacted on their willingness to communicate with nurses and the quality of care provided to residents with dementia.

> “*Some GPs are quite distant...some are not willing to engage with the nurses*” (Manager, 7).

In addition, several managers’ report that GPs are often too busy to be involved in case conferences, collaboration or shared decision-making although this is likely to be beneficial for developing person-centred care plans and taking a non-pharmacological approach to managing responsive behaviours.

> *“GPs they’re in the door and then they’re gone in half an hour, they’re not staying for any case conference.”* (Manager, 16).

A few care home managers noted that GPs primarily take a pharmacological approach to managing responsive behaviours; and that some nurses may lack the confidence to question the GP’s judgements even if they believe prescribing to be inappropriate. This extends to nurses who have trained overseas, where there may be cultural differences in practice. This, therefore, suggests that strategies to enhance collaboration between nurses and GPs and empower nurses to have greater involvement in prescribing decisions, may facilitate a non-pharmacological approach to support residents with responsive behaviours.

Psychiatrists were also found to influence the approach taken to support residents with responsive behaviours. For instance, care home managers highlighted how psychiatrists were eager not to take a pharmacological approach to manage responsive behaviours. They also described how psychiatrists were involved in case conferences and contributed to the development of person-centred care plans for residents, facilitating a non-pharmacological approach to support residents.

Pharmacists were also found to influence the approach taken to behaviour management, for example, most care home staff explained that pharmacists reviewed medications and instigated recommendations to stop psychotropic medications whenever appropriate. This may have occurred when residents made the transition into long term residential care from their own home, or if they were prescribed more than one psychotropic drugs. Therefore, pharmacist reviews were beneficial in identifying instances of polypharmacy or inappropriate prescribing that may otherwise have gone unchecked. Hence, the involvement of pharmacists in prescribing decisions and medication review is likely to facilitate non-pharmacological approaches to support residents with responsive behaviours and care home staff should collaborate extensively with pharmacists when formulating prescribing decisions.

Finally, the Health information and Quality Authority (HIQA) regulations and standards for older persons care in residential settings in Ireland were found to impact on decisions about taking a non-pharmacological approach to support residents exhibiting responsive behaviours. Most care home staff expressed how HIQA regulations and standards, have been beneficial for improving care for residents with dementia. The HIQA standards require care homes to return quarterly reports in which they disclose the use of psychotropic medications prescribed on a ‘PRN’ (given when needed) basis. HIQA has the power to enforce care homes to minimise ‘PRN’ psychotropic drug use. A manager highlights the positive impact of HIQA standards to regulate care homes,

> *“[HIQA standards have] got rid of the bad ones [care homes] and they've brought them [care homes] up to a good standard, they really are needed.”* (Manager 15).

Overall, care home staff agreed that HIQA standards facilitate a non-pharmacological approach to managing responsive behaviours by ensuring that each resident has an assessment of the benefits and risks associated with managing responsive behaviours, that promotes a person-centred approach to care, as this quotation from a manager illustrates,

> *“[HIQA standards] you think outside the box, you do your risk assessments…I think it's been fantastic for care of the older person”* (Manager, 6).

However, several managers suggested that HIQA standards are too overprotective diminishing residents’ individual freedom. This conversely, posed a barrier to implementing person-centred care. Managers also suggest that fulfilling regulatory requirements was time consuming and burdensome for staff and that this time could have been better spent engaging with residents. Therefore, the findings suggest that refinement of HIQA standards may be required in the future, to minimise regulatory burden and facilitate non-pharmacological approaches to support residents.

Therefore, this theme has shown that decision-making is a quandary for most care home staff. The findings highlight that care home staff use false arguments to justify the use of psychotropic drugs in people with dementia. This proves to be a vicious circle that increases the occurrence of responsive behaviours resulting in further use of these drugs for behaviour management. Education programmes in dementia for nurses and GPs will be beneficial in facilitating a non-pharmacological approach to support residents. In addition, the increased participation of GPs in case conferences is also likely to facilitate a person-centred care approach. Medication review by pharmacists and oversight by psychiatrists was also found to facilitate a non-pharmacological approach to supporting residents. Finally, the findings indicate that ensuring compliance with HIQA regulations on the use of psychotropic drugs enhances delivery of person-centred care and a non-pharmacological approach to support residents' needs.

6.2. Theme: Managing responsive behaviours: towards a culture of relationship-centred care.

This theme reflects on the importance of the relationship between care staff and residents to deliver person-centred care. Family involvement in residents' care and in their participation in meaningful activities is highly beneficial in implementing a non-pharmacological approach to manage responsive behaviours.

6.2.1 Relationship focused care

Care staff explained how their relationship with residents was crucial for implementing a non-pharmacological approach to care. The relationship needed to transcend that of merely giving and receiving care, to provide a secure attachment, friendship and trust. This corresponds with Kontos' phenomenological model that postulates that people with dementia retain a sense of self and can form trusting relationships (Kontos, 2004). A healthcare assistant explains,

> *"He [resident] was there it was his first day, he needed to find the friend…who will speak up for them….to find trust and someone that they can talk to"* (Healthcare assistant 22).

Several participants expressed how they needed to be "family" to residents with dementia and treat them with love and respect. This is aligned with Kitwood & Bredin's (1992) concept of “positive persons work,” defined as the care given to a person with dementia that provides love, comfort and secure attachment. A nurse explains,

> *“They will really know the love…the most important thing with dealing with dementia is love…you have to respect and love them”* (Nurse 19).

Relationship focused care requires that care staff know residents extremely well with insight into their personal history, preferences and interests. Yet, it is important to note that the relationship is multidirectional with benefits for staff and family members. For instance, staff expressed how their sense of satisfaction and achievement was heightened when they had good relationships with residents. Several nurses explained that residents also cared for them and they felt a sense of attachment to the resident.

All staff agreed that families and friends of residents with dementia provide biographical information that is documented and shared with other care home staff. This allows staff to reminisce with residents about their youth. Reminiscence was identified as an effective technique in reducing responsive behaviours. One care home manager explained how family members created a photo book of the resident detailing life events. Acquiring knowledge of the resident’s youth is important as people with dementia have poor short-term memory while long-term memory remains largely intact. Hence, the perception of reality is often different for people with dementia, and they may become focused on their early years, as this quotation from a manager illustrates.

> *“We spend a lot of time at the beginning trying to gather all the information about them and not so much [about] them as parents, but what they were like when they were children”* (Manager 9).

Therefore, understanding the residents’ personal history and reminiscing about their early life, facilitated a non-pharmacological approach to support residents.

Care home managers also explained how they would contact family members if a resident became very distressed and exhibited responsive behaviours. It was observed that visits were beneficial in calming the resident and reducing responsive behaviours. However, not every resident with dementia had family members who were supportive or wanted to be involved in the resident’s care. This, lack of support meant that some residents did not receive any visitors and relied totally on their relationship with staff members to provide comfort, reassurance and support.

Therefore, a lack of family involvement in residents' care meant that staff could not acquire information about the resident's past, posing a barrier to implementing non-pharmacological strategies. For instance, a manager explains how knowledge of the residents' personal history is essential for building trusting relationships and engaging with residents in a meaningful way.

> *"One gentleman…was a sheep farmer. He could be very aggressive…he would have been pulling furniture he would have been nearly pulling doors of the hinges…but if you got him settled to be able to sit and talk about farming and sheep, that's all it took, then he forgets the agitation. It's very important to know the person, know what they were like in the past"* (Manager, 9).

These findings highlight how knowing the resident very well is extremely important for identifying the triggers for responsive behaviours to prevent escalation of responsive behaviours to the point where staff may consider it necessary to use psychotropic drugs for behaviour management. For instance, understanding residents' personal history enables staff to deliver person-centred care specific to each individual's needs and preferences. This, ensures that relationships between staff and residents are meaningful, facilitating a non-pharmacological approach to care.

6.2.2. "If people are engaged in a meaningful way, they're not going to have those responsive behaviours"

All care home staff agreed that residents with dementia need to be occupied in meaningful activities of individual interest as documented in the person-centred care plan. This is in line with principles of person-centred care developed by Kitwood (1997). Person-centred care focuses on personhood in dementia. It is an holistic approach that respects and values people with dementia as unique individuals, promoting autonomy and independence. However, providing activities tailored to individual needs, is difficult to achieve in the context of a busy care home environment. Certainly, a wide range of activities are offered to residents with dementia, however, most appear to be targeted generically at residents rather than specifically at individual interests. For instance, activities on offer ranged from bingo, jigsaw puzzles, sunset TV, hairdresser, walking, playing cards, arts and crafts, music, dancing, aromatherapy, massage, rummaging box, pet-assisted therapy, doll therapy, storytelling, and day trips.

However, few staff mentioned residents being engaged in jobs around the care home where they may feel useful and needed, including making the beds, helping in the laundry or the garden, for example growing fruit or vegetables in green houses, or assisting in the kitchen, as one manager succinctly states,

> *“They don't want you to hand them a cup of tea they will throw it back at you, they want to do it themselves”* (Manager, 3).

However, residents were often not allowed to make tea or engage in activities that would make them feel useful due to the risk of harm. For instance, some managers expressed how they were fearful of regulatory action by HIQA if residents had an accident while engaged in jobs around the care home. Conversely, HIQA standards promote positive risk taking to empower residents to exercise their right of choice to engage in activities of their own preference even if participation in these activities poses a degree of risk, while also encouraging staff to mitigate potential risks as much as possible.

A healthcare assistant described the benefits to residents when a positive approach is taken to risk taking, by empowering residents to engage in meaningful activities of interest.

> *“Yes, doing jobs, you see it, they're much calmer, they're not acting out as much, they're not becoming violent, they're more content in themselves”* (Healthcare assistant, 24).

Therefore, this suggests that care home managers and staff are not fully aware of HIQA guidance’s posing a barrier to taking a non-pharmacological approach to support residents with responsive behaviours.

A human rights-based approach to care also ensures that residents have the right to practice religious or spiritual beliefs. For instance, most care home staff discussed the importance of religious practices and personal faith to enhance the psychological and emotional wellbeing of residents with dementia. Staff described how religious practices were a central part of the Irish culture particularly in relation to older adults and that even at advanced stages of dementia, residents remained aware of their faith.

> *"If there's an advanced dementia or not, because of their age and their heritage and their background, their religion is very important to them all through their life and so that doesn't change with dementia"* (Manager, 15).

Religious practices and personal faith were found to be beneficial for managing residents' stress, agitation and responsive behaviours. Spiritual counselling from a priest gave hope to people with dementia that a higher spiritual power may intervene to improve their situation and alleviate their distress; this provided residents with comfort and a sense of calm by alleviating distress, anxiety and agitation. In addition, care home staff suggested that religious activities provided a sense of inclusion in a caring community that was meaningful and supportive and enhanced residents' feelings of self-worth, as illustrated in this quotation from a nurse,

> *"She loves to go to church…so every time she gets agitated, I will sing hymns…and then she will calm down, we tried quetiapine but it was not working for her… I tell my other colleagues, if she is agitated, [say to her] Father wants you to be the lead singer in the choir and she will calm down with that"* (Nurse, 18).

Therefore, the findings indicate that care home staff should identify religious or spiritual needs and incorporate them into personal care plans. Maintaining religious practices appears to assist residents in coping with stress with a positive impact on minimising responsive behaviours, thereby facilitating a non-pharmacological approach. These are novel findings that extend understanding of the beneficial effects of participation in meaningful activities and practices in supporting residents with responsive behaviours.

6.3. Theme: Care of residents means care of staff too!

Care home staff are central to the implementation of non-pharmacological approaches to care. Therefore, it is essential that staff are capable and motivated to deliver person-centred care. Attitudes of staff towards residents with dementia influence how responsive behaviours are managed. Staff need to feel valued and secure in their role to be effective team players and provide support to residents with dementia. Therefore, this theme addresses how the wellbeing of residents must also holistically encompass the wellbeing of staff.

6.3.1 'If nurses or carers leave, we can get another one'

Several care home staff expressed how the wellbeing of staff is not considered as important as the wellbeing of residents and perceived that they were not valued in their role by management, this led to a sense of disempowerment and in many instances, was combined with a perception of job security whereby care staff felt that they could easily be replaced.

> *"When you look at the residents, you're looking at the psychological well-being and also the emotional,…the same model isn't applied to staff. The staff have those very same needs, and they need to feel, I am valued here rather than I'm usually replaced here." (Healthcare assistant, 21).*

Healthcare assistants, in particular, felt that they were not supported by senior staff members and that their achievements were not acknowledged. This sense of not being valued had a negative impact on healthcare assistants' motivation to form relationships with residents and deliver person-centred care, posing a barrier to implementing non-pharmacological strategies to behaviour management. For example, several healthcare assistants described working conditions in private nursing homes, as being poor. A healthcare assistant acknowledged that pay had not increased in line with other healthcare workers,

> *"I didn't get a raise for 10 years. I mean, when we're talking about money, you're talking about ten-euro plus an hour and for ten years didn't get a rise"* (Healthcare assistant, 21).

In addition to pay conditions, care home staff perceived that they were not provided with opportunities for career progress in the private sector. This was found to be detrimental for staff morale and reduced the motivation of carers to develop relationships with residents.

> *"There's no job progression,….I was talking to the nurse the other night and she was saying what's to stop the carer being trained in how to take blood pressure and oxygen levels…not enough attention is paid to retention of staff and better career progression of staff,…we can get other staff, so what?"* (Healthcare assistant, 21).

Several care home staff noted that recruiting the right staff posed challenges and that if an experienced staff member leaves it can take six months to train a new staff member to the same level. Indeed, once new staff gain experience, they may be enticed to leave the private care home sector to work in the public sector in the hope of better conditions and prospects. The loss of familiar staff impaired continuity of care for residents and it could take a long time for new staff to know residents to the extent that they could identify the triggers for residents' behaviour essential for delivering a non-pharmacological approach to care, as illustrated in this quotation from a healthcare assistant,

> "*[Familiar staff] they have more trust in you, rather than seeing different faces, residents used to say, God another new face*" (Healthcare assistant, 23).

In contrast, in care homes with a low staff turnover, familiar staff knew residents extremely well and developed trusting relationships with residents essential for understanding residents' behaviour. Therefore, ensuring that staff feel valued and retaining staff long-term are important facilitators to maintaining continuity of care. To effectively implement non-pharmacological approaches to behaviour management, strategies will need to consider ways to retain staff long-term, for instance by empowering healthcare assistants, enhancing job security and providing career progression opportunities.

6.3.2 "There's still a hierarchy which I don't really like"

Nurses assumed responsibility for decisions regarding resident's care, as they considered their skills and competency levels to be higher than those of healthcare assistants, this created a hierarchy between nurses and healthcare assistants, whereby healthcare assistants were not perceived to be equal team players. Moreover, healthcare assistants considered communication with nurses to be inadequate, contributing to an unequal power relationship. The hierarchy between healthcare assistants and nurses also excluded their participation in multidisciplinary collaboration and decision-making, for example, case conferences with family members and healthcare professionals as a manger explains,

> *"You need to have a team that are working as equals and that everybody is seen as an equal within that team…so, the health care worker can sit at that table, discussing this resident feeling exactly the same as the consultant…and that doesn't happen…there's still a hierarchy which I don't really like."* (Manager, 1).

In addition, many managers agreed that healthcare assistants know residents better than anyone else and that their in-depth knowledge of residents is essential for identifying the causes of responsive behaviours and implementing solutions. However, despite their knowledge of residents, managers acknowledged that healthcare assistants were often not included in decision-making regarding how to manage responsive behaviours.

> *"They are the ones that know the person inside out and they are the ones that developed the close relationships with the residents more so than the nurses… nobody pays any attention to things that they have to say, and their knowledge could be far better utilised."* (Manager, 3).

Healthcare assistants also noted that their opinion was sometimes discarded by senior staff and management. Therefore, healthcare assistants suggest that their sense of feeling valued would improve if they were provided with opportunities for collaboration and shared decision-making, as this quotation from a healthcare assistant illustrates,

> *"Having an input, given your thoughts and your ideas...we don't want to be just talking to a brick wall…People work better if they have more input…more decision making"* (Healthcare assistant, 23).

When asked why healthcare assistants do not participate more in multidisciplinary collaboration such as case conferences, managers offered several explanations, for example they suggested that due to low staffing levels, healthcare assistants do not have time to withdraw from essential care duties to take part in case conferences. Other explanations suggest that healthcare assistants lack confidence and do not wish to take part in collaboration. It was also suggested that the presence of too many people at case conferences may overwhelm family members, particularly as family involvement is crucial for formulating decisions and person-centred care plans. Indeed, the involvement of healthcare assistants in case conferences was deemed to be irrelevant, as one manager explains,

> *“You have to be careful that you don't allow a meeting to be the world and his wife, you know, it has to be the relevant people” (Manager, 12).*

Therefore, healthcare assistants’ sense of having lower status than nurses, an unequal power relationship and inadequate communication with nurses in addition to the absence of equitable decision-making, impacted negatively on healthcare assistants’ motivation to develop relationships with residents. This posed a barrier to implementing non-pharmacological strategies to behaviour management. Strategies should focus on dismantling the hierarchical structure between nurses and healthcare assistants by improving communication and equitable decision-making. This may require that healthcare assistants receive further training in dementia care to reduce disparities in relation to education, knowledge and skills, to facilitate non-pharmacological approaches to support residents.

6.4 Theme: Organisational structure of long-term residential care: what needs to change?

This theme focuses on the organisational changes required to facilitate implementation of non-pharmacological strategies to manage responsive behaviours, for instance, the findings indicate that nurses and healthcare assistants need specific training in dementia care. Improvements are also required in accessing other healthcare professionals including the mental health team, physiotherapists and occupational therapists to facilitate a non-pharmacological approach to behaviour management. Finally, changes are needed in the model of care provided from the typically large care homes run on a profit-making basis to smaller homes integrated into dementia friendly communities.

6.4.1. “Staff come in here from a dementia unit and could have had no formal dementia training”

The findings indicate that training for care home staff is inadequate both in terms of the formal education programme and additional training after qualification, for instance, it was reported that staff who had previously worked in a dementia unit had no formal dementia training. The findings also highlighted how staff inexperience and a lack of confidence in managing residents’ behaviour resulted in an escalation of responsive behaviours, such as verbal or physical aggression.

A lack of training in dementia care also influenced the ‘mindset’ of some nurses and healthcare assistants. ‘Mindset’ refers to the beliefs, emotions, and assumptions, of nurses and healthcare assistants that impairs their relationship with residents with dementia, for instance, they may have poor communication skills and dictate to residents what is to be done rather than explaining, being flexible and giving choices. Indeed, residents who were non-compliant with instructions may be perceived as being challenging, one manager referred to this as an institutional attitude. Managers also explained how some staff members made inappropriate comments to residents. This highlights the mindset and attitudes that some care staff have towards residents with dementia.

> *“The times that I hear things being said [by staff]…that make me cringe…and I think…just stop, this is not the way to go… I don't think you dictate [to residents] what's going to be done, these are older people that we have no right to dictate too”* (Manager, 1).

Therefore, the mindset of staff may pose a barrier to delivering a non-pharmacological approach to managing responsive behaviours. Hence, education in dementia care is likely to influence the ‘mindset’ of staff towards people with dementia and enhance delivery of a person-centred care approach.

Care home managers explained how healthcare assistants need more training to improve communication skills with people with dementia since communication is vital to develop relationships and meaningful connections. Communication skills would also give healthcare assistants more confidence in voicing their opinion on how to address instances of responsive behaviours and improve collaboration with nurses and senior staff to facilitate implementation of a non-pharmacological approach to manage responsive behaviours.

> *“[HCA's] would be a bit reluctant to come and say, oh, I think the person is getting agitated we try X, Y and Z and that they're not working?”* (Manager, 8).

Moreover, care home staff highlighted the importance of having a qualification in caring for the person with dementia, prior to commencing employment in a care home environment. Quality and Qualifications Ireland (QQI) level 5 in healthcare is the mandatory qualification for working as a healthcare assistant in the Republic of Ireland, however, care home staff explain that there is no specific training in dementia care as part of the QQI level 5 qualification and that work experience placements undertaken as part of the qualification are not beneficial in acquiring relevant skills.

> *“If you are coming into dementia care then….having that that module about dementia awareness and looking at the pharmaceutical side of it and looking at responsive behaviour, I think that would be a massive help”* (Manager, 14).

Several different education providers deliver the QQI level 5 educational programme for healthcare assistants, however, the structure and content, delivery and duration of the programme varies widely between providers. A manager suggests that the duration of training required to qualify as a healthcare assistant should be extended to two years to ensure that students have time to gain the knowledge, skills and practical work experience to effectively implement person-centred care and facilitate a non-pharmacological approach to managing responsive behaviours. Care home managers discussed a range of different techniques for training staff in dementia care and managing responsive behaviours. Indeed, managers agreed that educational programmes for healthcare assistants should incorporate practical work experience focused on delivering person-centred dementia care.

> *“I think they [healthcare assistants] need more practical hands-on work experience. The training isn't up to scratch, but I don't know, maybe it depends which schools have been to and how they’ve done the [QQI] level 5, sometimes, you know, I wonder about that training”* (Manager, 10).

Therefore, managers recognise that work experience placements should be relevant and meaningful to ensure that students spend time with people with dementia and learn how to implement person-centred care rather than just being given menial jobs of cleaning and making beds.

In addition, healthcare assistants acknowledged that they were not provided with any information about the adverse effects of psychotropic drugs as part of their education program. However, they indicated that training in this area would be beneficial to identify instances of adverse drug reactions in residents taking psychotropic medication. This is crucial as healthcare assistants spend longer periods of time with residents than do nurses. Hence, awareness of the presenting symptoms of adverse drug reactions is likely to result in timely action to terminate administration of the drug to prevent further harm.

> *“We [would] know what to look out for, if they're having side effects or not”* (Healthcare assistant, 24).

The findings indicated that a regulatory governing body for healthcare assistants working in care homes may be beneficial to ensure they have opportunities for continuing professional development to enhance their skills in delivering person-centred care. This is likely to facilitate a non-pharmacological approach to care. However, healthcare assistants confirmed that in ROI only nurses have a regulatory body. This is an area for further research in the future.

Regarding newly qualified nurses, managers also noted that they lack experience in implementing person-centred care relevant to a care home environment. This indicates that newly qualified nurses would also benefit from further education in supporting care home residents exhibiting responsive behaviours, in order to facilitate a non-pharmacological approach to behaviour management. Care home managers also noted that nurses should have a greater understanding of the adverse drug effects of psychotropic medications. This is because formal education programs for general nurses currently lack in-depth coverage of medications management.

> *“Knowledge of adverse drug effects is brushed over in formalised training and education and sometimes unfortunately, it's seen as the easy and quick answer, but there is no quick answer”* (Manager, 3).

Therefore, expanding nurses' knowledge of the adverse drug effects of psychotropic drugs in dementia is likely to be beneficial in facilitating implementation of non-pharmacological approaches to manage responsive behaviours. Hence, nurses should also receive further training in this area. Moreover, care home managers suggest that student nurses should be given a work placement in a care home to gain practical experience in implementing person-centred dementia care in a long-term residential setting, as part of their formal education program.

Managers stated that training and workshops should be interactive and delivered in small groups to stimulate discussion among staff. In addition, it was suggested that inexperienced staff members could "shadow" experienced staff members to observe how they approach and manage instances of responsive behaviours. Therefore, mentoring programs whereby senior staff members mentor new staff by reviewing instances of responsive behaviour and reflecting on techniques to improve behaviour management may be beneficial in facilitating a non-pharmacological approach.

One manager also described the importance of effective leadership in stimulating learning. To achieve this, two nurses from the care home completed 'train the trainer' courses so that they could provide internal training to other staff members to facilitate implementation of person-centred, non-pharmacological strategies to manage responsive behaviours.

> *"All the staff know that our ethos here, is that, it is not the first thing [to] jump in and get some tablets…we look at it is a very person-centred and holistic approach….Two of our nurses were sent on…train the trainer course…so that they could do more in-house training…specific to the nursing home needs" (Manager, 13).*

However, while managers agreed that continuing professional development was important, time and the availability of funding limited the provision of training, and this posed a barrier to adopting non-pharmacological strategies to behaviour management. Future research should consider how policies supporting long-term residential care promotes staff training initiatives and facilitates non-pharmacological approaches to support residents with responsive behaviours.

6.4.2. “There is a lack of external support and I think that's dreadful”

Responsive behaviours may often arise due to an unmet physical, psychological or emotional need that has not been met, corresponding with the unmet needs model (Cohen-Mansfield, 2000). For instance, pain, poor mobility, difficulties hearing or communicating, eating, or a lack of social interaction may all increase responsive behaviours in residents with dementia. Therefore, it is important that allied healthcare professionals including physiotherapists, occupational therapists, speech and language therapists, dieticians and mental health support are accessible to support residents by assessing their needs and tailoring therapies to individual requirements. However, accessing healthcare professionals often poses challenges, particularly for care homes located in rural regions of Ireland, for instance a manager reported that residents paid fifty euro per hour to visit a private physiotherapist. In addition, there were difficulties accessing dieticians and occupational therapists although one manager described how monthly visits from an occupational therapist would be very beneficial for resident’s wellbeing. Regarding speech and language therapy, a manager from a private care home acknowledged that the HSE would not provide them with a speech and language therapy service. Similarly, managers in rural areas of Ireland also faced challenges accessing mental health nurses although managers of care homes in urban areas found that they were well supported by psychiatry services. A care home manager in a rural location explains,

> “*Mental health nurses are impossible to access here…The mental health services in this area of rural Ireland are very limited. The psychiatric services want to discharge people who were on their books….Psychiatric services are just so stressed and so much of a Cinderella service*” (Manager, 4).

Therefore, inequitable access to support from healthcare professionals, particularly psychiatry services in rural regions of Ireland, poses a barrier to implementing non-pharmacological approaches to behaviour management. Hence, it may be beneficial to develop policy and practice to improve equitable access, for example, incentives for psychiatrists to locate in rural areas. Moreover, care home managers noted that the use of telepsychiatry services, such as audio visual conferencing with psychiatrists, were beneficial during the Covid-19 pandemic. Further research should aim to evaluate the acceptability, effectiveness and cost effectiveness of providing telepsychiatry services in care homes to identify if these services facilitate a non-pharmacological approach to behaviour management.

6.4.3. Business model of care: “You're dealing with people you’re not dealing with a product!”

Care home staff explained that under the ‘Fair deal initiative’ the Health Service Executive (HSE) allocates 60% more funding to individuals taking up residency in public HSE run care homes than they do to individuals taking up residency in a private care home. Staff noted that this makes it more difficult for the private sector to offer the same pay and conditions as the public sector.

> *“The HSE, they're not paying them [private nursing homes] what they would pay their own nursing homes to take the same people…The HSE model [is where] a lot of the problems arise”* (Healthcare assistant, 21).

One manager from a private care home described how “Fair deal” funding provided by the HSE is insufficient to meet resident’s needs. Therefore, a different manager suggested that more funding should be allocated by the Department of Health to private care homes. However, some care home staff suggested that the main reason why working conditions are not as good in the private sector is because the aim of private care homes is to make a profit. A healthcare assistant explains,

> *“There are things that have not been given the priority they deserve, …private nursing homes trying to resource on a shoestring”* (Healthcare assistant, 21).

Minimising investment on resources impacted on staffing levels in care homes. For instance, some managers explained that whilst a high staff to resident ratio is beneficial for supporting residents with responsive behaviours, in reality this was not possible without significant financial resources. Hence, several managers acknowledged that, due to limitations in finances, staffing levels were not adequate to provide high quality person-centred care, as illustrated in this quotation,

> *“You just don't have the money,….here you don't have one to one, you have one carer to five residents and….supervising the carers you would have four nurses”* (Manager, 16).

The findings showed that private care homes minimise expenditure, including employee wages, to ensure a financial return on their investment. However, there are ethical implications associated with the business model of care provision for people with dementia. For instance, care home managers explained that people with dementia often have significant care needs and may have limited decision-making capacity. Therefore, it is questionable whether it is ethical to make a profit from the provision of care to vulnerable groups of people in society, particularly as these residents may not have the capacity to defend their right to access the individualised care they need.

> “*In the profit-making nursing homes…they are using every facility they can and there primary goal is to make money…and you really have to ask yourself, is it really morally right for people to be making money out of vulnerable people”* (Manager, 1).

Alternative models of care include the voluntary care homes which are run on a not-for-profit basis and may have charitable status. One manager from a small voluntary care home in a rural location explained how small homes run on a not-for-profit basis facilitated person-centred care and a non-pharmacological approach to the management of responsive behaviours.

> *“It's a non-profit making nursing home, we really are a charity and are person-centred, we really do get to know residents”* (Manager, 1).

Therefore, because voluntary care homes are usually smaller, staff can form stronger relationships with their residents and develop better understanding of individual preferences and triggers for responsive behaviours enhancing continuity of care. This is likely to facilitate a non-pharmacological approach to supporting residents’ with responsive behaviours.

Moreover, a care home manager described an alternative and innovative model of long-term residential care specifically designed for people with dementia, called the household model of care. In the household model six residents with dementia live in each house with a live-in nurse. They continue to engage in the usual activities of daily living assisted by the nurse. Large outdoor spaces allow residents to grow vegetables. Shops and cafes are also onsite, and members of the local community integrate with residents on a daily basis in a dementia inclusive community. The manager explains how the household model of care facilitates a non-pharmacological approach and has effectively eradicated the use of PRN psychotropic drugs to manage responsive behaviours.

> *"It's a house with six people living together [and] a staff member…They [residents] are included in cooking [and] cleaning, they are involved in everything. We don't have any PRN psychotropics….Early stages of dementia have one house [while another house] is focused on people that have [more advanced dementia] but they would not need PRN's either."* (Manager, 5).

These findings correspond with continuity theory and postulates that people in the early stages of dementia want to continue living their life as they had done prior to being diagnosed with dementia (Menne et al., 2002). Engagement in activities that promote independence and autonomy and social interactions with the local community minimised the occurrence of responsive behaviours. Therefore, the benefits of the household model of care in facilitating non-pharmacological approaches to support residents with responsive behaviours needs to be explored further, in different contexts and settings. Future research should evaluate the feasibility and cost-effectiveness of the household model of care in different geographical locations.

Overall, the findings suggest that the profit-making nature of private care homes impacts on working conditions for care home staff. This perpetuates a hierarchical structure in care home organisations, whereby healthcare assistants do not feel valued as equal team players with nurses and do not contribute to shared decision-making. This, therefore, impairs relationships with residents and the delivery of person-centred care posing a barrier to adopting non-pharmacological approaches to behaviour management. Hence, future research should explore alternative models of long-term residential care that facilitate implementation of effective and sustainable non-pharmacological strategies to support care home residents with responsive behaviours.

In the next chapter, the findings of this study will be discussed in relation to the findings of the systematic review and the wider literature. The strengths and limitations of this research will also be considered. Finally, recommendations will be presented to address the barriers and facilitators to taking a non-pharmacological approach to behaviour management, identified in this thesis.

Chapter 7: Discussion

7.1 Discussion

This thesis addresses the research question, “How are responsive behaviours, associated with dementia, managed by care home staff in normal and Covid-19 pandemic circumstances?” A systematic review was conducted that aimed to review qualitative studies to synthesise understanding of the facilitators and barriers to implementing a sustainable non-pharmacological approach to behaviour management (Chapter 2). A wide range of facilitators and barriers to taking a non-pharmacological approach were identified (Chapter 2.14). These findings, in addition to findings from a qualitative survey, informed the design of the qualitative study that involved conducting interviews with 25 care home staff. In this thesis, the qualitative study is referred to as “the present study”. The aim of the present study was to gain in-depth understanding of how care home staff manage responsive behaviours and the factors that facilitated or posed barriers to taking a non-pharmacological approach to support residents with responsive behaviours, in Irish care homes prior to; and during the Covid-19 pandemic.

The present study used inductive and iterative approaches to reflexive thematic analysis underpinned by critical theory and the transformative paradigm that proposes that reality and knowledge is both socially constructed and influenced by power relations (Kincheloe & McLaren, 2011) (chapter 3.3). This is relevant to a care home environment were power relations influence how care staff interact with each other and form relationships with residents. In the present study, five themes were constructed from the data. ‘Managing responsive behaviours during the Covid-19 pandemic’ (Chapter 5.2); ‘Psychotropic drugs to manage responsive behaviours: a quandary for care home staff’ (Chapter 6.1); ‘Managing responsive behaviours: towards a culture of relationship-centred care’ (Chapter 6.2); ‘Care of residents means care of staff too!’ (Chapter 6.3); and ‘Organisational structure of long-term residential care: what needs to change?’ (Chapter 6.4).

The theme, “Psychotropic drugs to manage responsive behaviours: a quandary for care home staff” explores the factors that influence decision-making whether to take a pharmacological approach. Care home staff explained that the reasons they use psychotropic drugs to manage aggressive behaviours is because of the potential risk of harm to self or others or to manage residents' distress or agitation. This corresponds with findings from the systematic review (chapter 2) that care staff are fearful of the risks of harm if they do not take a pharmacological approach to manage responsive behaviours. For instance, in a study conducted in Ireland, Walsh et al. (2018) explored the factors that influence antipsychotic prescribing to nursing home residents with dementia. They found that care home staff perceived psychotropic medications to be necessary to manage resident's aggressive behaviour. Similarly, Donyai et al. (2017) found that false arguments and rationale validated the prescribing of antipsychotic drugs to people with dementia, for example, concerns regarding what may happen if a pharmacological approach is not taken to manage aggressive behaviour. Therefore, beliefs, cognitions, assumptions and emotions of care staff may pose a barrier to implementing non-pharmacological strategies to behaviour management, particularly if staff assume that non-pharmacological interventions will be ineffective in reducing responsive behaviours or only have transient benefits.

In addition, care staff in the present study deemed psychotropic drugs to be effective if they reduced responsive behaviours without sedating the resident. This positively reinforced the use of psychotropic drugs in these residents without further monitoring of adverse effects. This corresponds with findings by Almutairi et al. (2018) that the perceived benefits of psychotropic drugs are more perceptible to care staff than the adverse effects associated with their use in people with dementia. However, psychotropic drugs, such as antipsychotic drugs may also increase the increase the risk of strokes in people with dementia (Kales et al., 2019; Bjerre et al., 2018). In addition, benzodiazepines are associated with respiratory depression (Rochon et al., 2017). Despite this, nurses in the present study appeared unaware of the need to monitor for these potentially adverse drug effects, for example, some nurses prefer to give antidepressant drugs believing them to be effective in improving resident's low mood. However, a Cochrane review by Dudas et al. (2018) found high quality evidence of little difference in symptoms of depression between people with dementia treated with antidepressants and those treated with placebo for three months. Moreover, side effects were more frequently observed in the group receiving antidepressant treatment (Dudas et al., 2018), for example the risk of having a seizure is significantly increased in people taking antidepressant drugs. This risk is extenuated in people with dementia since they are more likely to have seizures than the general population (Hommet et al., 2008). However, nurses in the present study failed to mention heightened risks of seizures associated with antidepressant drugs in residents with dementia.

This corresponds with the findings from the systematic review (chapter 2.11.1) that care staff have inadequate knowledge of the full spectrum of adverse effects associated with the use of psychotropic medications in dementia suggesting that further education in adverse drug effects is required to facilitate a non-pharmacological approach to managing responsive behaviours.

Moreover, findings from the present study suggest that care home staff perceive the use of psychotropic drugs given on a regular basis as more acceptable than the use of psychotropic drugs given on a pro-rat nata (PRN), given when needed basis, which was conceived to be a potential mechanism of chemical restraint. For example, several managers and nurses acknowledged that a third of residents took one or more psychotropic drugs on a regular basis. This is similar to a study by Guftafsson et al. (2013) which found that care home residents with dementia were prescribed antipsychotic drugs regularly for periods of six months or longer. However, this contravenes dementia care guidelines, such as NICE guidelines that recommend that treatment should be over the shortest duration possible. Hence, it is concerning that care staff perceive that regular use of psychotropic drugs is more acceptable than psychotropic drugs given on a PRN basis. Furthermore, there is no mandatory requirement for care homes to report the use of psychotropic medications given on a regular basis to HIQA, responsible for regulating care homes in the ROI whereas the use of psychotropic drugs given on a PRN basis are reportable to HIQA. The findings from the systematic review (chapter 2.11.1) suggest that this may have resulted in psychotropic drugs being prescribed on a regular basis, rather than on a PRN basis to evade the reporting system, thereby increasing the propensity to use psychotropic drugs. Hence, a review of HIQA standards may be required.

In contrast to the findings from the systematic review (chapter 2.11.1) care staff in the present study noted that, in their experience, PRN medications, were not given to residents as a “quick fix” to manage responsive behaviours for the convenience of staff, however, they believed that psychotropic medications could still be used as a mechanism of restraint. This is because decision-making about giving residents a PRN medication depends on the subjective clinical judgements of individual nurses, for instance, in the present study nurses with an educational and clinical background in general nursing were found to be more likely to adopt a pharmacological approach to manage responsive behaviours than nurses with specialised training in gerontology, dementia or mental health. This is because nurses trained generally to work in the acute hospital setting are more likely to align to the medical model of dementia that assumes that responsive behaviours emerge due to neurodegeneration requiring pharmacological treatment. This corresponds with neurobiological theories of dementia which predict that responsive behaviours are a consequence of brain dysfunction (Tascone & Bottino, 2013). These findings are similar to a study by Stubbing et al. (2019) that found that judgements of when PRN psychotropic medications “were needed” may be inconsistently applied by individual nurses. This may result in PRN medications being administered to residents with dementia who are already taking one or more psychotropic drugs on a regular basis (Thapa et al., 2003). Therefore, residents may, potentially, receive high doses of psychotropic drugs, increasing the risk of adverse effects (Kreyenbuhl et al., 2007). Hence, specialist training for nurses in dementia and the adverse effects of psychotropic drugs are important facilitators to taking a non-pharmacological approach to support residents with responsive behaviours.

The findings of the present study highlight how general practitioners (GPs) influence decision-making in relation to taking a pharmacological approach to behaviour management. For instance, care staff suggest that GPs lack of training in dementia poses a barrier to taking a non-pharmacological approach to support residents with dementia. Similarly, a study by Cahill et al. (2008) showed that two-thirds of GPs lack confidence in supporting people with dementia. Also, that GPs beliefs and emotions towards people with dementia influences how they manage responsive behaviours. Indeed, the findings of the present study extends this view by showing that GPs’ attitudes to care home staff also impacts on whether a non-pharmacological approach is adopted. For instance, care home managers noted that while some GPs are supportive, other GPs are not willing to communicate with nurses and are too busy to take part in multidisciplinary collaboration. Therefore, while education in dementia care may be beneficial, GPs’ training should also aim to change attitudes and beliefs to people with dementia and care home staff to facilitate implementation of non-pharmacological approaches to manage responsive behaviours.

The focus of the theme, “Managing responsive behaviours: towards a culture of relationship-centred care,” reflects on the importance of developing a trusting relationship between care staff, residents and family members. The findings of the present study show that reciprocal caring relationships enable a non-pharmacological approach to support residents with responsive behaviours. For instance, care home staff explain how they are family to residents, giving and receiving love with a beneficial impact in reducing residents’ agitation and aggression. This is aligned with Kontos’ phenomenological model that postulates that people with dementia retain a sense of self, and relationships with others should be encouraged, for instance people with dementia are still part of a community and participate in a continuing narrative shared with family members, other residents and staff (Kontos, 2004).

Nolan et al. (2004) use the term “relationship-centred care” to highlight the importance of the bi-directional relationship between staff and residents and their families that they argue is often overlooked in person-centred care. Therefore, Nolan (1997) proposed the Senses Framework, encompassing six senses important to residents, staff and family members. These include a sense of security that residents, staff and families feel safe and secure. The Senses Framework also highlights the importance of applying knowledge of the resident’s life story to plan for future events to provide a sense of continuity. This is important in a care home community were residents and staff engage in relationships that enhance their sense of belonging. In addition, participating in meaningful activities provides a sense of purpose. Hence, when significant goals are accomplished, residents and staff feel a sense of achievement. Finally, the Senses Framework highlights how residents and staff feel a sense of significance when they perceive they are valued and respected (Nolan, 1997).

Regarding a sense of continuity, findings from the systematic review (Chapter 2) highlight how knowledge of the residents’ personal history is essential to build trusting relationships between staff and residents and that this information comes from family and friends. This corresponds with findings from the present study that biographical information provided by family members enable staff to reminisce with residents. Similarly, reminiscence was identified as an effective technique in reducing responsive behaviours, in line with a study by Moon and Park (2020) that showed that reminiscence therapy can help to improve mood by alleviating depression in people with dementia. However, further research in this area is required to identify how best to deliver reminiscence therapy, what works best and for whom, in the context of busy care home environments, to facilitate non-pharmacological approaches to support residents.

Other studies reported in the literature also show that families share their knowledge about relatives' life story with care home staff (Bern-Klug & Forbes-Thompson, 2008; Brown Wilson et al., 2009; Nolan et al. 2006) and highlighted the importance of families being involved in decisions about their relative's care (Nolan et al. 2006; Reid & Chappell, 2017). However, the findings of the present study show that not all family members are supportive or want to be involved in resident's care. Similarly, a study conducted by Helgesen et al., (2015) found that the degree to which families are actually involved in decisions regarding resident's care varies widely. Therefore, a lack of family involvement in residents' care poses a barrier to taking a non-pharmacological approach to manage residents' responsive behaviours; for example, inadequate knowledge about the resident's history or preferences makes it challenging to identify triggers or underlying causes for responsive behaviours. This corresponds with the need-driven dementia compromised behaviour model (Algase et al., 1996) and the unmet needs model (Cohen-Mansfield, 2000) that assume that responsive behaviours arise due to an unmet physical, psychological or emotional need that cannot be verbally expressed.

The findings of the present study and the systematic review (chapter 2) demonstrate that engagement in meaningful activities improves residents' sense of self-esteem, thereby reducing responsive behaviours. These findings also correspond with values central to the philosophy of person-centred care proposed by Kitwood & Bredin (1992) who referred to "Positive persons work" as the care given to people with dementia that provides love, secure attachment, a sense of inclusion, usefulness, value, identity and occupation. Indeed, the VIPS framework, defined as, (V) valuing persons with dementia; taking an (I) individualised approach; understanding the (P) perspective of the person with dementia; and providing (S) supportive social environments to maintain relationships, provides guidance on how to implement person centred care into practice, by tailoring activities to residents' individual preferences (Brooker, 2004; Brooker, 2006; Brooker, 2012; Kitwood & Bredin, 1992).

The findings from the systematic review (chapter 2) show that people with dementia are sometimes being excluded from participating in meaningful activities, likely to be beneficial in reducing responsive behaviours. In addition, the findings from the present study show that residents often participate in generic activities but do not often engage in activities and occupation of individual interest as specified in the person-centred care plan. Reasons for this include constraints in care home resources such as finances and staffing levels. However, the findings from the present study extends current understanding by showing that risks associated with residents' engagement in activities of daily living poses a barrier to participation. For instance, a fine line was found to exist between balancing rights and risks of harm. On one hand, residents wanted to undertake activities of daily living as they had done at home, such as making a cup of tea. Conversely, staff perceived that HIQA standards were sometimes overprotective and restricted residents from participating in activities, associated with a risk of harm. Therefore, although HIQA standards were perceived to be very beneficial for improving standards of person-centred care and facilitating a non-pharmacological approach to managing responsive behaviours, refinement of standards may be required to ensure that residents have individual freedom to engage in activities of daily living and only receive assistance when needed.

Moreover, the present study recognises the importance of religious practices, such as attending church services or visits from priests, as enhancing the psychological and emotional wellbeing of residents with dementia. In the present study this was found to be beneficial for managing residents' stress, agitation and reducing responsive behaviours. This extends current understanding as findings from the systematic review failed to identify religious practices as a facilitator to implementing a non-pharmacological approach to support residents with responsive behaviours. However, previous studies indicated that for people with Alzheimer's disease, belief in God provides a sense of hope that a higher power will intervene to improve their current situation (Lombrozo et al., 2007). In addition, Beuscher and Grando (2009) found that personal faith, prayer and participation in church services helped to maintain a positive outlook in people with dementia. Agli et al. (2015) identified engagement in religious practices as a coping mechanism for people with

Alzheimer's disease that corresponded with improvements in quality of life. In addition, Coin et al. (2010) observed a reduction in cognitive decline in people with Alzheimer's disease who actively engage in religious practices. Indeed, Richards (1990) suggests that one reason for this may be that faith practices and rituals spark long-term memories.

Therefore, the findings from our study and the wider literature indicate that identifying residents' religious and spiritual needs and incorporating them in the person-centred care plan is likely to be beneficial in improving the wellbeing of residents and facilitate a non-pharmacological approach to reduce responsive behaviours. In the future, research is required to elucidate how and to what extent, religious and spiritual practices support residents with responsive behaviours as religious practices were identified as particularly helpful to alleviate distress during the Covid-19 pandemic (Giannouli & Giannoulis, 2020).

Indeed, one theme explores how responsive behaviours are managed during the period of Covid-19 lockdown in the Republic of Ireland and provides novel insight into the challenges faced by care home staff, residents and their families during the period of Covid-19 restrictions and the impact of these challenges on managing responsive behaviours. In care homes were residents and staff had outbreaks of Covid-19, staff noted that the absence of family visits and social isolation, associated with separation from other residents resulted in distress, depression and anxiety with increases in responsive behaviours. Care staff describe using psychotropic drugs to alleviate responsive behaviours and panic attacks, associated with Covid-19 trauma. These findings are similar to those of studies conducted in care homes in the UK and Canada that explored the prevalence of psychotropic drug use in care home residents during the Covid-19 pandemic. For instance, a cross-sectional study in Canada calculated the changes in proportion of residents receiving psychotropic drugs during the first seven months of the pandemic (Stall et al., 2021). They found increased prescribing of psychotropic drugs, including antipsychotic drugs, antidepressant drugs, and anxiolytic drugs from the onset of the Covid-19 pandemic that persisted through September 2020 (Stall et al., 2021).

In addition, a study in the UK, also reported increased prescribing of antipsychotic medications among people with dementia during the pandemic (Howard et al., 2020). Therefore, it is likely that increases in psychotropic prescribing are associated with social isolation during Covid-19 restrictions and challenges in implementing non-pharmacological strategies due to reduced staffing levels.

These findings may also be applied more widely in a post-Covid era, for instance, the present study shows that periods of prolonged social isolation and the absence of family visits result in low mood and responsive behaviours in many residents. This, therefore, highlights the importance of human interaction and relationships for residents at all stages of dementia, aligned with theories of relationship-centred care (Nolan et al., 1997). Hence, care home managers should ensure that family members are encouraged to engage in resident's care and decision-making at every opportunity.

In contrast to these findings however, a study in care homes in the Netherlands exploring the impact of Covid-19 restrictions on the wellbeing and behaviours of care home residents noted both increases and decreases in responsive behaviours during the period of restrictions (Gerritsen & Oude Voshaar, 2020). For instance, the ban of family visits resulted in increases in depressive symptoms, anxiety, agitation and other responsive behaviours in some residents while for other residents a reduction in responsive behaviours was observed (Gerritsen & Oude Voshaar, 2020). Indeed, in the present study, although many residents experienced increases in responsive behaviours, particularly in care homes with Covid-19 outbreaks, some residents especially in Covid-free homes benefitted from a quieter environment associated with the absence of visitors. Indeed, in larger homes, less resident-to-resident aggression was observed due to engagement in activities in smaller groups resulting in reductions in responsive behaviours. This, therefore, highlights that care staff should minimise excess movement within homes particularly at busy times and conduct activities in smaller cohorts of three to five residents to facilitate a non-pharmacological approach to managing responsive behaviours.

However, conducting activities in small groups may be challenging in some care homes due to low staffing levels. This was particularly relevant during the Covid-19 pandemic as the findings from the present study highlighted that staff from private care homes in the Republic of Ireland were recruited by the Health Services Executive (HSE) to work in the acute hospital setting during the crises with a very negative impact on continuity of care for residents and increased work burden and “burnout” for the remaining staff. This corresponds with statements by the Chief Executive of Nursing Homes Ireland that the detrimental impact of HSE enticing staff away from the private care home sector to work in the acute public sector, was likely to endanger the lives of residents (Daly, 2020). Indeed, the Covid Expert Panel Report recommends that government departments such as the HSE should prioritise the essential role fulfilled by staff in private care homes. Therefore, government supports for care homes should ensure that the HSE do not actively recruit private care home staff to public healthcare settings if future crises situations arise.

The importance of retaining and valuing staff is the focus of the theme “Care of residents means care of staff too;” that considers how the mindset of care home staff and their sense of being valued in their role influences the delivery of non-pharmacological approaches to support resident’s responsive behaviours. The mindset of staff is a term operationalised by Smeets et al. (2014) in their study to explore reasons for using psychotropic drugs to manage behaviours associated with dementia, in twelve care homes in the Netherlands. They defined mindset as the feelings and attitudes that were considered to reflect the personality and beliefs of care home staff towards residents and how this impacted on effective communication with people with dementia.

Moreover, Kitwood (1997) proposed that person-centred care approaches should focus on communication. However, the findings from the present study highlight that some staff members dictate to residents what is to be done rather than explaining, being flexible and giving choices. In the wider literature, studies report that care home staff attitudes, such as a lack of respect for people with dementia, results in poor communication (Eggers et al., 2005). This may potentially increase responsive behaviours, as a study by Judd (2017) found that it is necessary to communicate clearly to residents what is to be done, to prevent outbursts of aggressive behaviour. However, in one study, nurses caring for people with dementia, perceive communication to be the most challenging aspect of their work. Blackhall et al., (2011) and Smythe et al., (2017) suggest that training in communication skills is not incorporated into formal education programmes. Indeed, there appears to be a lack of theory on how to communicate effectively with people with dementia (Fleischer et al., 2009). Therefore, future research should aim to develop theories aimed at improving communication skills between residents with dementia and care staff and incorporate them into training programmes for care staff (Graneheim et al., 2001). Training may also need to include a behavioural change component aimed at changing the “mindset” of staff towards people with dementia, to facilitate a non-pharmacological approach to support residents.

Moreover, the findings from the systematic review (chapter 2) highlight that some care staff, have a perception of not being valued in their position. Indeed, the findings of the present study highlights the existence of a hierarchy between healthcare assistants and nurses that impairs effective communication and teamwork. This extends current theory such as the Senses Framework (Nolan, 2004) by showing that power differentials between nurses and healthcare assistants impairs communication, teamwork and equitable decision-making with a detrimental impact for supporting residents with responsive behaviours. This is because nurses do not receive adequate information from healthcare assistants as to the triggers of responsive behaviours and this, impairs their ability to effectively manage responsive behaviours.

Similarly, Dahlke and Baumbusch (2015) found that communication between healthcare assistants and nurses was challenging. In another study, Drennan (2018) found that carers were excluded from participating in “handovers”. Handovers are opportunities to update staff, starting a new shift, about resident’s care. Therefore, care staff starting a new shift received inadequate information to meet residents care needs. Drennan (2018) concluded that carers rarely contribute their opinion or input to resident’s care. In addition, Vail et al., (2011) explain that healthcare assistants perceive their role as being a helper to nurses and having low status. These findings are in-line with the findings of the present study that healthcare assistants’ sense of not being valued, being subservient to nurses and not being recognised for their vital contribution to the care of residents poses a barrier to implementing non-pharmacological strategies to manage responsive behaviours.

In addition, findings from the present study suggest that feelings of job insecurity impacts negatively on the motivation of care staff to engage in relationships with residents although Life-World Led Care theory (Todres & Galvin, 2007) highlights that healthcare should holistically encompass all aspects of life including, subjective experiences and interdependent relationships; indeed this will be crucial for implementing a non-pharmacological approach to support residents with responsive behaviours.

Moreover, healthcare assistants, in the present study, perceived that they could be easily replaced at any time. Similarly, a study by Mauno et al. (2007) collected survey data from 736 health care workers in one Finnish health care district found that employees with high levels of job insecurity had negative attitudes to their work (Mauno et al., 2007). In addition, a study of 39,893 nurses from care homes and hospitals, found that the effects of job insecurity can be reduced if nurses perceive they are valued and their opinion considered. (Laine et al., 2009). Indeed, viewing the findings of the present study through the lens of critical theory, the existence of power differentials demonstrates that healthcare assistants are not equal team members, posing a barrier to implementing non-pharmacological approaches to manage responsive behaviours. Hence, education and training opportunities, continuous professional development, opportunities for career progression and a regulatory body for healthcare assistants will be beneficial in reducing the power disparities between nurses and healthcare assistants.

The theme, “Organisational structure of long-term residential care: what needs to change?” focuses on the organisational changes required to facilitate implementation of non-pharmacological strategies to behaviour management. The sub-theme, “Staff come in here from a dementia unit and could have no formal dementia training,” highlights that training for care home staff in dementia is sub-optimal. For instance, healthcare assistants were found to lack confidence and did not have the appropriate skills and competencies to implement non-pharmacological strategies to support residents. Therefore, it is vital that care staff have a qualification in caring for the person with dementia, prior to commencing employment in a care home environment. Currently healthcare assistants in the Republic of Ireland are expected to have a Quality and Qualifications Ireland (QQI) level 5 in healthcare before commencing work, however, training in dementia care is not part of the QQI level 5 qualification. These findings are consistent with research by Drennan (2018) that perceived the level 5 qualification to become a healthcare assistant in the Republic of Ireland to be inappropriate to develop skills essential for the role of healthcare assistant.

In addition, the findings of the present study show that the work experience placements undertaken as part of the QQI level 5 qualification are not beneficial in learning relevant skills in dementia care, indeed in the present study some care staff perceived that they were “used” during work placements to complete mundane tasks such as making beds. Indeed, in a report by Glackin (2016), it was reported that healthcare assistants in the Republic of Ireland can acquire their qualification without adequate clinical practice to align with the theoretical component of the course. Therefore, there has been little improvement in the content and delivery of the practical component of the level 5 qualification since the Glackin report in 2016 and further policy changes are required to ensure the quality of training meets high standards.

Similarly, care home managers in the present study explain how the structure, content, delivery and duration of the QQI Level 5 education programme to become a healthcare assistant in the Republic of Ireland is inconsistently delivered by different providers. Therefore, due to the variability in training, managers were uncertain of the competencies of healthcare assistants. These findings compare to a study by Afzal et al. (2018) that recommends greater standardisation of education programmes for healthcare assistants.

Moreover, managers in the present study describe how newly qualified nurses lack confidence and experience in implementing non-pharmacological approaches to support residents. Therefore, student nurses are also likely to benefit from work placements in care home settings to gain practical experience in dementia care and communication skills. The findings from the present study also suggest that further education in the adverse drug effects of psychotropic drugs, will also be beneficial in facilitating a non-pharmacological approach to manage responsive behaviours.

These findings are consistent with those of the systematic review (chapter 2.13.3) which indicate that training in dementia care is likely to change nurses' beliefs regarding the necessity of giving psychotropic drugs to manage responsive behaviours, such as aggression. These findings are also in line with a review by Walsh et al. (2017) that found that training in person-centred care influences the approach taken to manage responsive behaviours. Care home staff in the present study suggest that mentoring programs may be beneficial for training inexperienced nurses and healthcare assistants (chapter 6.4.1). Similarly, Janzen et al. (2013) found that communicating in the team and sharing successful strategies facilitated implementation of a non-pharmacological approach to dementia care.

Altogether, the findings of this thesis highlights the importance of multidisciplinary collaboration with allied healthcare professionals, as accessing healthcare professionals often poses challenges, particularly for care homes located in rural regions of Ireland. This has a detrimental impact on residents' welfare. In particular, the difficulties accessing psychiatry services in rural regions compared to urban areas, poses a barrier to taking a non-pharmacological approach to managing responsive behaviours. The reason for this is uncertain since there is a paucity of research in this area however, it may be due in part to difficulties recruiting psychiatrists to work in rural locations. In the present study, care home staff noted that during Covid-19 restrictions, telepsychiatry, which provides psychiatric evaluations and therapy via videoconferencing (Sharma & Devan, 2021), proved to be a very effective and useful resource to manage residents with responsive behaviours especially since face-to-face visits were not possible. In these circumstances, psychiatrists used virtual technologies to maintain contact with care home residents and staff.

Research by Hubley et al. (2016) indicated that telepsychiatry is comparable to face-to-face services in terms of reliability of clinical assessments and treatment outcome. Hence, in a post-Covid era, telepsychiatry may be beneficial in providing mental health services to care home residents in rural regions of Ireland. In addition, it may be necessary for the Department of Health to provide incentives to psychiatrists to relocate to rural areas. Further research is urgently needed to understand how to improve equitable access to healthcare professionals in rural geographical locations and to evaluate the effectiveness of remote healthcare services, such as telepsychiatry to facilitate a non-pharmacological approach to manage residents' responsive behaviours.

The final sub-theme "Business model of care: You're dealing with people you're not dealing with a product!" explores how residential care, run on a profit-making basis, impacts on implementation of a non-pharmacological approach to support residents. In the present study, care staff explained how the government scheme "Fair Deal" makes it challenging for care homes in the private sector to compete with care homes in the public sector in relation to workers' pay and conditions. Similarly, Cahill (2021) explains that there is a wide disparity between what the HSE pays public and private nursing homes per patient per week, under the "Fair Deal" scheme set by the National Treatment Purchase Fund (NTPF). Indeed, a government-commissioned report stated that the pricing model was unfair and inconsistent by making lower payments to private and voluntary care home providers compared to public run homes. Hence, more equitable pricing models should be allocated to private, voluntary and public care homes to ensure retention of care staff in the private sector. This will be essential for maintaining staffing levels and continuity of care to facilitate a non-pharmacological approach to support residents' responsive behaviours (Cahill, 2021).

In the present study, care staff also note that the disparity in working conditions between the private and public sector arises due to the profit-making nature of private care homes aimed at maximising financial returns. This corresponds with a research study exploring the relationship between financial performance, care staff wellbeing, and resident wellbeing as they relate to care home ownership in the United States (Bos et al., 2017). Care homes run on a profit-making basis were found to have better financial performance but poorer outcomes in terms of staff wellbeing and resident wellbeing, compared to not-for-profit care homes.

The findings from the present study highlight how alternative models of residential care may prove to be more effective in delivering a person-centred approach to care. For instance, managers from care homes in the voluntary sector, run on a charitable, not-for-profit basis were found to be more effective at facilitating a non-pharmacological approach to behaviour management. In addition, an innovative model of residential care, referred to as the household model of care, effectively eradicated the use of PRN psychotropic drugs to manage responsive behaviours. This is likely due to enhanced interactions that residents, staff and families have with the wider community. Therefore, further research is required to explore alternative models of long-term residential care to facilitate implementation of a non-pharmacological approach to care. This is in-line with priority areas highlighted in the Irish National Dementia Strategy that recommends the HSE considers alternative options for housing people with dementia when making plans for long-term residential care.

It is apparent that greater policy and organisational support is required to improve care for residents and staff in long term residential facilities to facilitate a non-pharmacological approach to manage responsive behaviours. The findings of this thesis are anticipated to have a significant impact on policy and practice both at the national and international level.

S).

7.2 Impact of findings for policy and practice

Recommendations have been developed for policy and practice to overcome barriers to taking a non-pharmacological approach to manage responsive behaviours. For instance, recommendations have been proposed to assist in the development of the Irish National Dementia Strategy (INDS) - Clinical Guideline No. 21, due for review in 2022.

INDS Clinical Guideline No. 21, addresses “Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia.”

Recommendations

- Based on the findings of this thesis, it is recommended that care home nurses and healthcare assistants should receive education and training on the full spectrum of adverse effects associated with the use of psychotropic drugs.
- In addition, ‘Priority area 11’ of the INDS refers to the provision of dementia-specific training by the HSE to relevant professional groups such as GPs, and care home staff. The findings of this thesis indicate that priority area 11, has not been fulfilled and is an area requiring substantial improvement.

Therefore, recommendations will be sent to the HSE National Dementia Office (NDO) in the ROI responsible for the Irish National Dementia Strategy. (Full recommendations to be sent to NDO are available in **Appendix Q**).

Recommendations for HIQA standards for older person’s care.

- Refinement of standards to ensure that they do not restrict resident’s freedom unnecessarily.
- Regular use of psychotropic drugs in care homes should be reported in quarterly returns to HIQA.

(Full recommendations to be sent to HIQA are available in **Appendix R**).

Summary of recommendations for the HSE. (Full recommendations available in **Appendix S).**

- Improve equitable access to healthcare professionals providing essential services, for example, psychiatric services in rural regions of Ireland.
- Dementia specific training for care home staff and GPs.

Summary of recommendations for care home sector/management. (Full recommendations available in **Appendix T**).

- Engage residents in meaningful occupation of personal interest as defined in their person centred care plan.
- Involve the family members of residents in their care and in decision-making.
- Effective leadership that prioritises retaining staff long-term by improving working conditions and providing training opportunities, enhancing collaboration and equitable decision-making.
- A regulatory body for healthcare assistants that ensures continuous professional development and career progression opportunities.

Recommendations for training care home nurses and healthcare assistants are available in **Appendix U**

The recommendations of this thesis have been reviewed by PPI collaborators who have provided additional recommendations. Areas where PPI recommendations correspond with; or add to the findings of this thesis are outlined in **Table 7.1.**

Table 7.1: PPI recommendations that correspond with, or add to the findings of this thesis.

PPI recommendations	**PPI recommendations that add to the findings of this thesis**
Decision-making should always include the person with dementia even at advanced stages of dementia.	The recommendation by PPI collaborators that decision-making should include the person with

	dementia, adds to the findings of this thesis.
The human rights of people with dementia should be ensured by enabling them to engage in everyday activities of daily life.	Corresponds with the findings of this thesis.
Training of care home staff to ensure they have the competency to take a non-pharmacological approach to support people with dementia.	Corresponds with the findings of this thesis.
Staff training should be standardised across the care home sector and not the responsibility of care home managers.	Corresponds with the findings of this thesis.
Care staff in long-term residential care need to be valued in their role.	Corresponds with the findings of this thesis.
Healthcare assistants know the residents well; and should be provided with opportunities to participate in collaboration and decision-making.	Corresponds with the findings of this thesis.
Improve working conditions for care staff, for example, the rate of pay to ensure staff retention.	Corresponds with the findings of this thesis.
Currently, specific training in dementia care is not mandatory for GP's; and there is little incentive for them to train in this area. Mandatory training for GPs in dementia care should be considered.	The recommendation for mandatory training for GPs in dementia, adds to the findings of this thesis.
Equitable access to allied healthcare professionals providing essential services. Charges for these services should not be applied as additional fees for residents.	The recommendation that additional charges should not apply to access services of allied healthcare professionals, adds to the findings of this thesis.

A summary of the findings and recommendations of this thesis will be sent to all participants.

7.3 Reflexivity statement

The themes were constructed from the data based on my subjective interpretation of meaning, viewed through the lens of critical theory and influenced by personal experiences (Chapter 3.5). Therefore, I maintained a reflexivity diary throughout the research process and documented the rationale for decisions taken. Aligned with the principles of reflexive thematic analysis (Braun & Clarke, 2019 & 2021), reflexive boxes are included at relevant points in this thesis that provide brief extracts from my reflexive diary. This will enable the reader to understand how my views of reality and personal experiences influence the findings of this thesis. For instance, the theme, "Care of residents means care of staff too" reflects on the need to value care home staff, to retain staff and ensure continuation of care. As a critical theorist, I perceived that a lack of communication and shared decision-making arose due to power differentials between nurses and healthcare assistants, whereby nurses were deemed to have a higher social status and value than healthcare assistants. However, a different researcher may have assumed that due to the separation in caring duties, nurses and healthcare assistants had less opportunities to interact. Hence, a different theme may, potentially, have been constructed from the data. Therefore, it is highly important as a researcher to reflect on my ontological and epistemological perspective as a critical theorist underpinned by the transformative paradigm.

In addition, my previous experience as a female family carer influences how I interpret data. For instance, the theme, "Managing responsive behaviours: towards a culture of relationship-focused care," emphasises the importance of developing a trusting relationship with a person with dementia, that provides love, comfort and reassurance. Indeed, from my own experience of caring for my mother, providing love and support had a very beneficial impact on her wellbeing and reduced agitated behaviours. This ensured that psychotropic drugs were never required to manage her behaviour. Therefore, when constructing this theme, I may have interpreted data differently to a researcher who did not have these experiences. An extract from my reflexive diary is presented in reflexive box 6.

Reflexive box 6. Extract from my reflexive diary

During an interview, a nurse described how she perceived that responsive behaviours arise due psychotic symptoms, associated with dementia, and that psychotropic drugs are required to manage aggressive behaviour. This contrasted with my own experiences of caring for a family member with dementia. I perceived that responsive behaviours arise in response to specific situations or due to pain or discomfort and that providing reassurance, love and support is very beneficial for reducing responsive behaviours. Therefore, I needed to ensure that I was constructing meaning from participants' data rather than from my own assumptions.

Moreover, on reflection, I perceive that I have acquired a wide range of skills and experience in study design, research ethics, research methodology and qualitative data collection, analysis and dissemination skills. This has enhanced my sense of autonomy as a researcher, essential for pursuing post-doctoral research. This thesis reflects, personal, professional and intellectual growth. For instance, I have acquired a high degree of confidence in my ability to interact with research participants, PPI collaborators, supervisors and the wider research community to complete this project on time. In terms of intellectual growth, I have expanded current understanding of the barriers and facilitators to taking a non-pharmacological approach to managing responsive behaviours and developed recommendations to assist in the development of dementia guidelines to improve care for residents with dementia (Chapter 7.2). I have also acquired excellent communication skills by presenting the research findings at oral and poster presentations at numerous conferences.

7.4 Strengths and limitations of this study

Strengths of the study is that PPI collaborators were involved throughout the research process, for example, PPI collaborators from the Irish Dementia Working Group contributed questions to be asked in interviews with care home staff (Chapter 4.8). They also reviewed recommendations to address the barriers to taking a non-pharmacological approach to manage responsive behaviours (chapter 7.2). PPI collaborators have also agreed to participate in dissemination of findings.

Another strength of the study was the participation of staff from 21 care homes across Ireland providing care for 1,349 residents. Care homes from both the private and voluntary sector participated in the research. The care homes were of various sizes throughout Ireland, including rural and urban regions. This supports the transferability of the findings to other care homes settings. Qualitative research from a diverse sample is useful when little is known about a phenomenon (Cohen et al. 2001), for instance, how care home staff manage responsive behaviours of residents in care homes across Ireland. Moreover, the 16 care home managers who participated in an interview were highly experienced with an average of 27 years' of work experience, ensuring they had extensive experience of implementing strategies to manage responsive behaviours of residents' with dementia. This enhanced the trustworthiness of the findings. Although data saturation is not a desirable concept in reflexive thematic analysis (Braun & Clarke, 2019), the data obtained from managers addressed the research question extremely well. It is also important to note that although managers informed their staff about the research, they acknowledged that they had not selected participants. Indeed, participants stated that they were willing to participate in this study and did not perceive that they were coerced by managers.

Other strengths of this research are that well established methods of data collection and analysis were used and clearly reported; for instance, reflexive thematic analysis (Braun & Clarke, 2019) was applied to data. Moreover, a reflexive journal was maintained to ensure confirmability, that the findings were derived the data (Lincoln & Guba, 1985). Also, an audit trail documented the construction and refinement of themes. This enhanced the dependability of the findings (Lincoln & Guba, 1985). The quality of the reflexive thematic analysis was evaluated using Braun and Clarke (2020) 'Twenty questions to evaluate the quality of thematic analysis' (Appendix P). Therefore, a rigorous and trustworthy reflexive thematic analysis was conducted.

The research had several limitations; 90% of care home managers approached declined to participate citing they were too busy during the Covid-19 pandemic to take part. Recruitment was largely dependent on the manager informing staff about the study, given the small number of responses received from nurses and healthcare assistants, it could reasonable be assumed that the sharing of information by managers was limited combined with the circumstances at the time. For instance only four nurses and five healthcare assistants participated in an interview, this is a limitation given that the findings indicated that healthcare assistants perceive that they are not valued and that a hierarchy exists between healthcare assistants and nurses that prevents effective teamwork and equitable decision-making. In addition, it is possible that only healthcare assistants with these particular views were interested in taking part in the research, while other healthcare assistants declined to participate, hence, the potential for selection bias is possible. However, many of the managers acknowledged that the views of healthcare assistants in relation to residents' care were seldom considered despite their extensive knowledge of residents. This corresponds with responses provided by healthcare assistants and enhances the trustworthiness of the findings. It may be beneficial to conduct focus groups with healthcare assistants and nurses in future research, to explore their views further to understand how the hierarchical structure in care home organisations can be dismantled to improve team work.

Another limitation is that only care home staff from private and voluntary care homes in the Republic of Ireland participated in the study, therefore, the views and experiences of care staff from public long-term residential care facilities, have not been obtained. Also, due to the sensitive nature of the data collected, for instance the premise that the use of psychotropic drugs may cause harm to residents, participants may not have disclosed their full range of views and experiences, for instance, using psychotropic drugs as a means of constraint or for the convenience of staff to complete tasks in a timely manner.

In the next chapter the conclusions of the thesis will be presented.

Chapter 8. Conclusion

8.1 Conclusion

This thesis, underpinned by the transformative paradigm and critical theory, encompasses a systematic review and a qualitative study that addresses the research question; How are responsive behaviours, associated with dementia, managed by care home staff in pandemic and non-pandemic circumstances? (Chapter 1.17).

The findings from the qualitative study and the systematic review indicate that barriers to taking a non-pharmacological approach to manage responsive behaviours include inadequate staff training and multidisciplinary collaboration. The qualitative study extends current knowledge by showing that a power hierarchy exists between healthcare assistants and nurses posing a barrier to taking a non-pharmacological approach. Facilitators to taking a non-pharmacological approach include effective leadership and family involvement in resident care. The findings of this thesis extends current knowledge in the research field and will have an impact on the development of dementia guidelines and policy both at a national and international level.

8.2 Contributions to knowledge and practice

To date, research on managing responsive behaviours, associated with dementia has been limited to studies exploring a narrow aspect of the topic such as the factors influencing psychotropic prescribing in dementia. For instance, studies by Smeets et al. (2014), Donyai et al. (2017), Almutairi et al. (2018), Kerns et al. (2018), Simmons et al. (2018), Sawan et al. (2017) and Walsh et al. (2018) explore reasons for taking a pharmacological approach to manage responsive behaviours and the factors influencing decision-making. While studies by Kolanowski et al. (2010 & 2015), Janzen et al. (2013) and Mallon (2015) explore non-pharmacological strategies implemented by staff to support residents with responsive behaviours. However, this thesis extends current understanding by holistically exploring how responsive behaviours are managed using both pharmacological and non-pharmacological approaches and the facilitators and barriers to taking a non-pharmacological approach to behaviour management.

This thesis extends theory, for example, The Senses Framework (Nolan et al., 1997) by showing that a hierarchy exists between nurses and healthcare assistants whereby, nurses hold a higher position of power. This hierarchical structure in care home organisations prevents healthcare assistants from participating in equitable decision-making with a detrimental impact in supporting residents with responsive behaviours and implementing a non-pharmacological approach.

Moreover, this thesis extends current knowledge by highlighting the influence of healthcare professionals, for example, General Practitioners (GPs) in relation to prescribing of psychotropic drugs. Also, this research examines how regulation by HIQA in ROI, impacts on resident's care, as there is a paucity of research in this area. This research considers how the model of care provision, for instance, homes run on a profit or non-profit basis impacts on the approach taken to manage responsive behaviours as this is a research area that has not previously been explored. For instance, poor working conditions for care staff had a detrimental impact on the provision of person-centred care. Furthermore, this is the only study to explore how care home staff managed responsive behaviours during the Covid-19 pandemic in ROI. This thesis has identified barriers and facilitators to taking a non-pharmacological approach to behaviour management. Recommendations to address these barriers will inform dementia policy nationally and internationally.

8.3 Future research directions

- Future research should aim to expand understanding of the hierarchy between healthcare assistants and nurses. This may involve conducting focus groups with healthcare assistants and nurses to explore their views and experiences in greater depth; to identify ways to improve team work and dismantle the hierarchical structures in care homes.
- To develop and evaluate education programmes for care home staff in dementia care.
- To explore how to improve equitable access to allied healthcare professionals including mental health services in rural areas of Ireland.

- To evaluate the effectiveness of telepsychiatry services in quantitative and qualitative research.
- To develop and evaluate education programmes for GPs in dementia.
- To explore how religious practices may assist in supporting residents with responsive behaviours.
- To explore how to communicate effectively with people with dementia.
- To explore the effectiveness and cost effectiveness of alternative models of long-term residential care.

8.4 The final word

The use of psychotropic drugs to manage responsive behaviours is still prevalent in care homes. This thesis has found that risks associated with residents' aggressive behaviour and residents' distress are the primary reasons why care home staff adopt a pharmacological approach to behaviour management. The relationship between carers and residents was found to be crucial for taking a non-pharmacological approach to manage responsive behaviours. This relationship needed to be based on familiarity, trust and love. However, the motivation of care home staff to develop relationships with residents and implement a non-pharmacological approach is influenced by their sense of feeling valued. Healthcare assistants especially perceived that they were not valued in their role and a hierarchy was evident between nurses and healthcare assistants that impaired collaboration and equitable decision-making. Future research should aim to understand how to bridge this disconnect and dismantle the hierarchical structure associated with the medical model of care prevalent in residential facilities, for instance, healthcare assistants should be provided with opportunities for career progression. Training will be beneficial in empowering healthcare assistants to communicate with colleagues and residents effectively. Training in dementia and medicine management will be a crucial aspect of ensuring care home staff possess the competencies for taking a non-pharmacological approach to support residents. These recommendations will assist in the development of dementia guidelines, such as the Irish National Dementia Strategy, particularly Clinical Guideline No.21 due for review in 2022. The recommendations are also anticipated to have an impact internationally, to assist in the development of NICE guidelines and the National Dementia Strategies of other countries.

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Appendices

Appendix A: ENTREQ Statement (Tong et al., 2012).

Enhancing transparency in reporting the synthesis of qualitative research: the ENTREQ statement

Item	Guide and Description
1.Aim	To review qualitative studies to synthesise understanding of strategies used by care home staff to manage behaviour that challenges in dementia to identify facilitators and barriers to implementing a sustainable non-pharmacological approach (**see page 34).**
2. Synthesis methodology	A thematic synthesis informed by Thomas & Harden (2008) (**see page 38).**
3. Approach to searching	Pre-planned systematic and comprehensive search to identify all relevant studies **(see page 35).**
4. Inclusion criteria	Phenomenon of interest: Everyday strategies used by care home managers, nurses and care assistants to manage behaviours that challenge in residents with dementia and factors that influence decision-making. Population: Care home managers, care home nurses and care home assistants. Language: No restrictions on language Year Limits: None Types of studies: Primary studies using qualitative research methods for data collection and data analysis Articles published in full in a peer-reviewed journal or doctoral thesis, **(see page 36 and Appendix C: Table of Inclusion and Exclusion Criteria).**
5. Data sources	Electronic databases searched: PubMed, PsycINFO, CINAHL. A search of ProQuest facilitated retrieval of doctoral theses in the research field. The grey literature also included searches of relevant conference abstracts. In addition, reference and citation searches of key papers were conducted. Search was conducted in July 2021 **(see page 34).**
6. Electronic search strategy	Literature search terms and keywords based on the Sample, Phenomenon of Interest, Design, Evaluation, Research type (SPIDER) framework are described in **Table 1: Terms and keywords based on using the SPIDER framework for qualitative research** (**see page 36).** For further detail see Appendix B**: Full search strategy for electronic databases PubMed.**
7. Study screening methods	1151 studies were identified. Three reviewers (EOD) (CH) and (CS) independently screened 10% of titles and abstracts using the pre-designed form based on the inclusion criteria, aligned with Sundaram et al., (2019). The level of agreement between all three reviewers was high.

	All three reviewers (EOD) (CH) and (CS) agreed that one reviewer (EOD) should independently screen 90% of titles and abstracts using the same pre-defined form. One reviewer (EOD) read the remaining full text papers for eligibility with 10% of full-text papers independently screened by two reviewers (CH) and (CS), aligned with Ronzi et al., (2018). The level of agreement between all three reviewers was high and consensus achieved through discussion, with reasons for exclusion documented (**see page 37).**
8. Study characteristics	Details of the study characteristics are provided in **Table of characteristics of the studies included in the review (see page 42).**
9. Study selection results	The study selection results are illustrated in **Figure 1**: **PRISMA flow diagram** (**see page 40).**
10. Rational for appraisal	The rational for quality appraisal was to assess the quality of each study underpinning the findings of this systematic review **(see page 38).**
11. Appraisal items	The Critical Appraisal Skills Programme (2017) CASP (Qualitative Research) Checklist, was used as an assessment tool to appraise the quality of each study included in the review. Available in Appendix D
12. Appraisal process	20% of studies (n=7) were randomly selected and quality appraised independently by two reviewers (EOD) and (CS) there was a high degree of agreement between the two reviewers and where discrepancies arose a third reviewer (CH) acted as arbitrator. It was agreed between all three reviewers that one reviewer (EOD) would independently appraise the quality of 80% of studies. **(see page 38**).
13. Appraisal results	Study quality assessments are available in Appendix E Studies were not excluded based on quality assessment as studies of low quality were found to have weaknesses across just a few CASP domains, as explicitly stated in the main Results section of the review.
14. Data Extraction	One reviewer (EOD) extracted the findings from each included study, where data had been collected at interviews or focus groups with care home assistants, nurses and managers **(see page 38).** General data extracted from each study includes, authors name, year of publication, country of conduct, study aim, participants (sample & settings) and methods of data collection and data analysis.
15. Software	NVivo 12 **(see page 38).**
16. Number of reviewers	Three reviewers in total. See screening and selection of studies **(page 37)** and quality appraisal **(page 35).**
17. Coding	Comprehensive, line-by-line coding of text to capture context, meaning and ideas **(see page 38).**

18. Study Comparison	Concepts that represented the entire dataset were formulated after reading all the included papers several times **(see page 35).**
19. Derivation of themes	The approach taken to developing the themes and sub-themes was inductive and iterative **(see page 38).**
20. Quotations	Quotations extracted from the primary studies are presented in italics with quotation marks in the main body of the results to support the findings (**Synthesis of findings, page 58).**
21. Synthesis output	A line of argument was derived which represents how care home staff manage behaviours that challenge using both non-pharmacological and pharmacological approaches. The synthesis contributes to existing knowledge by identifying facilitators and barriers to taking a non-pharmacological approach. Recommendations have been made to overcome these barriers. This knowledge is integral for the development of dementia guidelines to enable implementation of sustainable non-pharmacological strategies to manage behaviours that challenge in care home residents with dementia (**see Chapters 2.10 – 2.14**).

Appendix B: PUBMED electronic database search strategy (July 2021 = 680 results)

Search	Actions	Details	Query	Results	Time
#50			Search: **((((((("Dementia"[Mesh]) OR (Dementia[Title/Abstract])) OR ("Alzheimer Disease"[Mesh])) OR (Alzheimer's disease[Title/Abstract])) AND (((((("Nursing Homes"[Mesh]) OR "Residential Facilities"[Mesh]) OR "Homes for the Aged"[Mesh]) OR (care home[Title/Abstract])) OR (care facilities[Title/Abstract])) OR (nursing home[Title/Abstract]))) AND (((((((((((((((("Wandering Behavior"[Mesh]) OR "Behavior and Behavior Mechanisms"[Mesh]) OR "Behavior Therapy"[Mesh]) OR "Psychomotor Agitation"[Mesh]) OR "Aggression"[Mesh]) OR "Behavior Control"[Mesh]) OR "Behavior"[Mesh]) OR (neuropsychiatric symptoms[Title/Abstract])) OR (BPSD[Title/Abstract])) OR (challenging behavior[Title/Abstract])) OR (behavio*[Title/Abstract])) OR (agitation[Title/Abstract])) OR (wandering[Title/Abstract])) OR (aggressive behavio*[Title/Abstract])) OR (behavio* control[Title/Abstract])) OR (behavio* management[Title/Abstract]))) AND (((((((((((((("Attitude of Health Personnel"[Mesh]) OR "Health Personnel"[Mesh]) OR (care home managers[Title/Abstract])) OR (care home assistants[Title/Abstract])) OR (care home aides[Title/Abstract])) OR (care home nurses[Title/Abstract])) OR (nursing home managers[Title/Abstract])) OR (nursing home assistants[Title/Abstract])) OR (nursing home aides[Title/Abstract])) OR (view[Title/Abstract])) OR (perception[Title/Abstract])) OR (experience[Title/Abstract])) OR (attitude[Title/Abstract])) OR (decision-making[Title/Abstract]))) AND (((((((((("Qualitative Research"[Mesh]) OR ("Focus Groups"[Mesh])) OR (Interview*[Title/Abstract])) OR (Focus group*[Title/Abstract])) OR (thematic[Title/Abstract])) OR (narrative[Title/Abstract])) OR (grounded[Title/Abstract])) OR (IPA[Title/Abstract])) OR (phenomenolog*[Title/Abstract])) OR (qualitative[Title/Abstract]))**	680	08:17:59
#49			Search: **((((((((("Qualitative Research"[Mesh]) OR ("Focus Groups"[Mesh])) OR (Interview*[Title/Abstract])) OR (Focus group*[Title/Abstract])) OR (thematic[Title/Abstract])) OR (narrative[Title/Abstract])) OR (grounded[Title/Abstract]))**	660,268	08:16:34

Search	Actions	Details	Query	Results	Time
			OR (IPA[Title/Abstract])) OR (phenomenolog*[Title/Abstract])) OR (qualitative[Title/Abstract])		
#48			Search: **qualitative[Title/Abstract]**	261,774	08:12:44
#47			Search: **phenomenolog*[Title/Abstract]**	29,071	08:12:17
#46			Search: **IPA[Title/Abstract]**	6,100	08:11:39
#45			Search: **grounded[Title/Abstract]**	23,508	08:11:24
#44			Search: **narrative[Title/Abstract]**	42,324	08:11:10
#43			Search: **thematic[Title/Abstract]**	40,909	08:10:54
#42			Search: **Focus group*[Title/Abstract]**	52,479	08:10:08
#41			Search: **Interview*[Title/Abstract]**	389,287	08:09:34
#40			Search: **"Focus Groups"[Mesh]** Sort by: **Most Recent**	32,494	08:08:31
#39			Search: **"Qualitative Research"[Mesh]** Sort by: **Most Recent**	65,509	08:07:59
#38			Search: **((((("Dementia"[Mesh]) OR (Dementia[Title/Abstract])) OR ("Alzheimer Disease"[Mesh])) OR (Alzheimer's disease[Title/Abstract])) AND (((((("Nursing Homes"[Mesh]) OR "Residential Facilities"[Mesh]) OR "Homes for the Aged"[Mesh]) OR (care home[Title/Abstract])) OR (care facilities[Title/Abstract])) OR (nursing home[Title/Abstract]))) AND (((((((((((((("Wandering Behavior"[Mesh]) OR "Behavior**	1,849	08:04:32

Search	Actions	Details	Query	Results	Time
			and Behavior Mechanisms"[Mesh]) OR "Behavior Therapy"[Mesh]) OR "Psychomotor Agitation"[Mesh]) OR "Aggression"[Mesh]) OR "Behavior Control"[Mesh]) OR "Behavior"[Mesh]) OR (neuropsychiatric symptoms[Title/Abstract])) OR (BPSD[Title/Abstract])) OR (challenging behavior[Title/Abstract])) OR (behavio*[Title/Abstract])) OR (agitation[Title/Abstract])) OR (wandering[Title/Abstract])) OR (aggressive behavio*[Title/Abstract])) OR (behavio* control[Title/Abstract])) OR (behavio* management[Title/Abstract]))) AND (((((((((((((("Attitude of Health Personnel"[Mesh]) OR "Health Personnel"[Mesh]) OR (care home managers[Title/Abstract])) OR (care home assistants[Title/Abstract])) OR (care home aides[Title/Abstract])) OR (care home nurses[Title/Abstract])) OR (nursing home managers[Title/Abstract])) OR (nursing home assistants[Title/Abstract])) OR (nursing home aides[Title/Abstract])) OR (view[Title/Abstract])) OR (perception[Title/Abstract])) OR (experience[Title/Abstract])) OR (attitude[Title/Abstract])) OR (decision-making[Title/Abstract]))		
#37			Search: **((((((((((((("Attitude of Health Personnel"[Mesh]) OR "Health Personnel"[Mesh]) OR (care home managers[Title/Abstract])) OR (care home assistants[Title/Abstract])) OR (care home aides[Title/Abstract])) OR (care home nurses[Title/Abstract])) OR (nursing home managers[Title/Abstract])) OR (nursing home assistants[Title/Abstract])) OR (nursing home aides[Title/Abstract])) OR (view[Title/Abstract])) OR (perception[Title/Abstract])) OR (experience[Title/Abstract])) OR (attitude[Title/Abstract])) OR (decision-making[Title/Abstract])**	1,911,702	08:02:38
#36			Search: **decision-making[Title/Abstract]**	157,034	07:59:23
#35			Search: **attitude[Title/Abstract]**	58,982	07:58:58
#34			Search: **experience[Title/Abstract]**	715,977	07:58:39

Search	Actions	Details	Query	Results	Time
#33			Search: **perception[Title/Abstract]**	189,394	07:58:17
#32			Search: **view[Title/Abstract]**	309,495	07:57:40
#31			Search: **nursing home aides[Title/Abstract]**	19	07:57:05
#30			Search: **nursing home assistants[Title/Abstract]**	18	07:56:46
#29			Search: **nursing home managers[Title/Abstract]**	44	07:56:14
#28			Search: **care home nurses[Title/Abstract]**	31	07:55:43
#27			Search: **care home aides[Title/Abstract]**	14	07:55:18
#26			Search: **care home assistants[Title/Abstract]**	8	07:54:52
#25			Search: **care home managers[Title/Abstract]**	55	07:54:26
#24			Search: **("Attitude of Health Personnel"[Mesh]) OR "Health Personnel"[Mesh]** Sort by: **Most Recent**	640,061	07:53:47
#23			Search: **((((("Dementia"[Mesh]) OR (Dementia[Title/Abstract])) OR ("Alzheimer Disease"[Mesh])) OR (Alzheimer's disease[Title/Abstract])) AND (((((("Nursing Homes"[Mesh]) OR "Residential Facilities"[Mesh]) OR "Homes for the Aged"[Mesh]) OR (care home[Title/Abstract])) OR (care facilities[Title/Abstract])) OR (nursing home[Title/Abstract]))) AND ((((((((((((((("Wandering Behavior"[Mesh]) OR "Behavior and Behavior Mechanisms"[Mesh]) OR "Behavior Therapy"[Mesh]) OR "Psychomotor Agitation"[Mesh]) OR "Aggression"[Mesh]) OR "Behavior Control"[Mesh]) OR**	5,026	07:49:03

Search	Actions	Details	Query	Results	Time
			"Behavior"[Mesh]) OR (neuropsychiatric symptoms[Title/Abstract])) OR (BPSD[Title/Abstract])) OR (challenging behavior[Title/Abstract])) OR (behavio*[Title/Abstract])) OR (agitation[Title/Abstract])) OR (wandering[Title/Abstract])) OR (aggressive behavio*[Title/Abstract])) OR (behavio* control[Title/Abstract])) OR (behavio* management[Title/Abstract]))		
#22			Search: **((((((((((((((("Wandering Behavior"[Mesh]) OR "Behavior and Behavior Mechanisms"[Mesh]) OR "Behavior Therapy"[Mesh]) OR "Psychomotor Agitation"[Mesh]) OR "Aggression"[Mesh]) OR "Behavior Control"[Mesh]) OR "Behavior"[Mesh]) OR (neuropsychiatric symptoms[Title/Abstract])) OR (BPSD[Title/Abstract])) OR (challenging behavior[Title/Abstract])) OR (behavio*[Title/Abstract])) OR (agitation[Title/Abstract])) OR (wandering[Title/Abstract])) OR (aggressive behavio*[Title/Abstract])) OR (behavio* control[Title/Abstract])) OR (behavio* management[Title/Abstract])**	3,946,312	07:47:08
#21			Search: **behavio* management[Title/Abstract]**	87,977	07:44:31
#20			Search: **behavio* control[Title/Abstract]**	260,637	07:43:35
#19			Search: **aggressive behavio*[Title/Abstract]**	16,573	07:42:21
#18			Search: **wandering[Title/Abstract]**	4,090	07:40:47
#17			Search: **agitation[Title/Abstract]**	17,477	07:38:19
#16			Search: **behavio*[Title/Abstract]**	1,370,237	07:37:44
#15			Search: **challenging behavior[Title/Abstract]**	438	07:37:05

Search	Actions	Details	Query	Results	Time
#14			Search: **BPSD[Title/Abstract]**	1,186	07:36:28
#13			Search: **neuropsychiatric symptoms[Title/Abstract]**	4,765	07:36:08
#12			Search: **((((("Wandering Behavior"[Mesh]) OR "Behavior and Behavior Mechanisms"[Mesh]) OR "Behavior Therapy"[Mesh]) OR "Psychomotor Agitation"[Mesh]) OR "Aggression"[Mesh]) OR "Behavior Control"[Mesh]) OR "Behavior"[Mesh]** Sort by: **Most Recent**	3,103,379	07:34:52
#11			Search: **(((("Dementia"[Mesh]) OR (Dementia[Title/Abstract])) OR ("Alzheimer Disease"[Mesh])) OR (Alzheimer's disease[Title/Abstract])) AND (((((("Nursing Homes"[Mesh]) OR "Residential Facilities"[Mesh]) OR "Homes for the Aged"[Mesh]) OR (care home[Title/Abstract])) OR (care facilities[Title/Abstract])) OR (nursing home[Title/Abstract]))**	9,093	07:17:38
#10			Search: **((((("Nursing Homes"[Mesh]) OR "Residential Facilities"[Mesh]) OR "Homes for the Aged"[Mesh]) OR (care home[Title/Abstract])) OR (care facilities[Title/Abstract])) OR (nursing home[Title/Abstract])**	77,090	07:16:01
#9			Search: **nursing home[Title/Abstract]**	23,508	07:15:02
#8			Search: **care facilities[Title/Abstract]**	17,333	07:14:44
#7			Search: **care home[Title/Abstract]**	2,599	07:14:13
#6			Search: **(("Nursing Homes"[Mesh]) OR "Residential Facilities"[Mesh]) OR "Homes for the Aged"[Mesh]** Sort by: **Most Recent**	54,847	07:12:51

Search	Actions	Details	Query	Results	Time
#5			Search: **((("Dementia"[Mesh]) OR (Dementia[Title/Abstract])) OR ("Alzheimer Disease"[Mesh])) OR (Alzheimer's disease[Title/Abstract])**	266,572	07:08:08
#4			Search: **Alzheimer's disease[Title/Abstract]**	130,914	07:05:51
#3			Search: **"Alzheimer Disease"[Mesh]** Sort by: **Most Recent**	101,151	07:05:24
#2			Search: **Dementia[Title/Abstract]**	120,421	07:04:36
#1			Search: **"Dementia"[Mesh]** Sort by: **Most Recent**	177,769	07:03:30

Showing 1 to 50 of 50 entries

The search conducted in the electronic database PubMed, was based on the Sample, Phenomenon of Interest, Design, Evaluation, Research type (SPIDER) framework for qualitative research[34] (**Table 1, page 8**).

Search #5 relating to dementia, was combined with search #10, relating to the care home setting, this created search #11.
Search #11 “**AND”** search #22, relating to the topic of behaviour, were then combined. This created search #23, which represents the phenomenon of interest, specifically, challenging behaviours of care home residents with dementia.
Search #23 was combined with search #37, related to the views and experiences of study participants, this created search #38.
Search #38 was combined with search #49, relating to study design, to create search #50.
Therefore, search #50 identifies qualitative research that describes the views and experiences of care home staff in managing behaviours associated with dementia. The search of PubMed was conducted in July 2021 and generated 680 results.

Appendix C: Table of Inclusion and Exclusion Criteria (Systematic Review)

	Inclusion criteria	Reason – (if required)
Sample	Studies selected if they include the views or perspectives or experiences or decision-making processes of care home nurses or assistants or managers regarding pharmacological and/or non-pharmacological strategies to manage behaviour that challenges, associated with dementia in care homes.	This review aims to understand strategies used by care home staff to manage challenging behaviours, associated with dementia. Therefore, the sample selected includes care home staff, but not other health care professionals, for example, physicians.
PI – Phenomenon of interest	Challenging behaviours associated with dementia – aggression or agitation or wandering or disruptive behaviours, frequently referred to as behaviour that challenges or the behavioural and psychological symptoms of dementia (BPSD) or neuropsychiatric symptoms of dementia or responsive behaviours.	Studies will be included if they explore general approaches taken by care home staff to manage challenging behaviours and factors that influence decision-making, rather than specific interventions (e.g. aromatherapy). Studies will be included even if they primarily focus more on pharmacological strategies than non-pharmacological strategies to manage challenging behaviours or vice versa. The justification is that some care homes may focus more on person-centred care while others may take a more pharmacological approach.
D - design	Only data collected via interview or focus group and analysed using qualitative methods including (but not limited to) thematic analysis, narrative analysis, grounded theory, framework analysis, interpretive phenomenological analysis or discourse analysis will be included. Studies taking a mixed-methods approach to data collection will only be included if some data has been collected via interviews or focus groups, in these instances only	Only qualitative data from interview and focus group studies will be extracted, to gain in-depth understanding and insight into the strategies used by care home staff to manage challenging behaviours associated with dementia and factors that influence decision-making. While quantitative findings may be useful, they will not provide the detailed information required to

	data collected by interview and focus groups will be extracted.	achieve the objectives of this systematic review.
E - Evaluation	Attitudes, views, perceptions or experiences or decision-making processes of care home nurses, care assistants or managers regarding strategies to manage behaviour that challenges.	Justification as above
R – Research type	Qualitative research utilising qualitative methods of data collection and analysis.	Justification as above

	Exclusion criteria	**Reason – (if required)**
Sample	Studies will be excluded if they do not include the views or perspectives or experiences or decision-making processes of care home nurses or care assistants or managers regarding pharmacological and/or non-pharmacological strategies to manage behaviour that challenges, associated with dementia in care homes. For instance, if studies include the views/experiences of physicians or occupational therapists or speech therapists or physiotherapists or community nurses or activity therapists or volunteers or family members, this data will not be included in the review. In addition, the views of nurses or formal carers in acute hospital settings or short stay respite care facilities are excluded from this review.	The justification is that the views and experiences of other health care personnel (or health professionals in other health care settings) are beyond the scope of this review, which specifically explores how care home staff manage behaviour that challenges. In addition, the perspectives of other health professionals may have already been synthesised in other systematic reviews e.g. Jennings et al., (2018) exploration of physician's management of behaviour that challenges.
PI – Phenomenon of interest	Challenging behaviours not associated with dementia – but due to other mental health conditions such as schizophrenia or bipolar disorder or antipsychotic use in	The justification is that inclusion of other mental health conditions is not congruent with the aims of this review

	people with learning difficulties, will be excluded.	
D - design	Studies that have not collected any data via interview or focus group will be excluded. Data collected form cross-sectional studies including surveys and questionnaires are excluded. Even if open questions on questionnaires are analysed qualitatively, this data is also excluded. Data from observational studies is also excluded. Data from intervention before and after studies is also excluded. For example, data collected from participants via interview or focus group following implementation of a specific intervention (e.g. aromatherapy) is excluded from this review.	Justification is that studies with a quantitative data collection and analysis design will not provide the in-depth knowledge to develop a model of the everyday strategies used by care home staff to manage behaviour that challenges or conceptualise the facilitators and barriers to taking a non-pharmacological approach. Also, specific intervention studies, for example, the efficacy of aromatherapy to manage behaviour that challenges, are beyond the scope of this review
E - Evaluation	Studies will be excluded if they do not collect data relating to the attitudes, views, perceptions or experiences or decision-making processes of care home nurses, care assistants or managers regarding strategies to manage challenging behaviours. For example, if the views of care home staff relate to their own perceptions of stress in coping with behaviour that challenges, this data will be excluded.	The justification is that the aim of this review is to understand how behaviour that challenges is managed in care homes not how stressful it may be carers to deal with these behaviours.
R – Research type	Quantitative studies are excluded. Mixed methods studies are excluded if none of the data is collected from participants via interviews or focus groups.	Justification as above

Appendix D: Critical Appraisal Skills Programme (CASP) checklist for Qualitative Research.

Please follow link https://casp-uk.b-cdn.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-2018_fillable_form.pdf

Appendix E: Results of quality appraisal. Quality appraisal of individual studies included in the review using the Critical Appraisal Skills Programme (CASP qualitative research checklist).

Author & Year	**Clear aims**	**Qualitative methods appropriate**	**Research design**	**Recruitment**	**Data collection**	**Reflexivity**	**Ethics**	**Data analysis**	**Discussion of findings**	**Value**	**Overall quality**
Almutairi, 2018[55]	Yes	Yes	No	No	Yes	No	Yes	No	Yes	Yes	Low to moderate
Backhouse, 2016[38] & 2018[45]	Yes	Yes	Yes	Yes	Cannot tell	No	Yes	Cannot tell	Yes	Yes	Moderate to high
Clifford & Doddy 2018[51]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High
Donyai, 2017[59]	Yes	Yes	Cannot tell	No	Yes	Yes	No	Yes	Yes	Yes	Moderate
Dupuis, 2012[39]	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	High
Duxbury, 2013[40]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	High
Foley, 2003[52]	Yes	Yes	No	No	Cannot tell	No	No	Yes	Yes	Yes	Low
Gyerberg, 2013[44]	Yes	Yes	Cannot tell	No	Cannot tell	No	Yes	Yes	Yes	Yes	Low to moderate
Hantikainen, 2001[63]	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High
Herron, 2018[50]	Cannot tell	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	High
Isaksson, 2013[49]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	High
Janzen, 2013[37]	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	High
Kerns, 2018[60]	Yes	Yes	No	Yes	Cannot tell	No	No	Yes	Yes	Yes	Moderate
Kutsumi, 2009[66]	Yes	Yes	Cannot tell	Cannot tell	Cannot tell	No	No	No	Yes	Yes	Low
Kolanowski, 2010[54]	Yes	Yes	Yes	Yes	Cannot tell	No	No	No	Cannot tell	Cannot tell	Low

Smeets, 2014[71]	Yes	Yes	Yes	No	Cannot tell	No	Yes	Yes	Yes	Yes	Moderate
Kolanowski, 2015[65]	Cannot tell	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Moderate to high
Mallon, 2015[47]	Yes	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	High
Ostaszkiewicz, 2015[57]	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	Yes	High
Ragneskog, 1997[64]	Yes	Yes	Cannot tell	No	Cannot tell	No	No	Yes	Yes	Yes	Low
Rapaport, 2018[46]	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Moderate - high
Robinson, 2007[67]	Yes	Yes	Yes	Cannot tell	Yes	No	No	Yes	Yes	Yes	Low
Sawan, 2017[62]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High
Shaw, 2016[42]	Yes	Yes	Yes	Cannot tell	Yes	Yes	No	Yes	Yes	Yes	Moderate
Simmons, 2018[57]	Yes	Yes	Cannot tell	Yes	Cannot tell	No	No	Cannot tell	Yes	Yes	Low to moderate
Skovdahl, 2003[53]	Yes	Yes	Cannot tell	Cannot tell	Yes	Yes	No	Yes	Yes	Yes	Moderate - high
Snellgrove, 2015[41]	Yes	Yes	Yes	Cannot tell	Yes	Yes	No	Yes	Yes	Yes	High
van Wyk, 2017[55]	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	Low
Walsh, 2018[58]	Yes	Yes	Yes	No	Yes	No	No	Yes	Yes	Yes	Moderate - high
Yeager, 2013[43]	Yes	Yes	Yes	Cannot tell	Yes	Yes	No	Yes	Yes	Yes	High
Zeller, 2011[48]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High
van Teunenbroek, 2020[72]	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes	Moderate
Rosenthal, 2020[73]	Yes	Yes	Yes	Yes	Cannot tell	No	Yes	Yes	Yes	Yes	High
Watson & Hatcher, 2021[74]	Yes	Yes	Yes	Cannot tell	Cannot tell	Yes	Yes	Yes	Yes	Yes	High

Quality appraisal using the Critical Appraisal Skills Programme (CASP qualitative research checklist)[38] identified that almost two-thirds of the primary qualitative studies included in the review were of high quality or moderate to high quality (n=20), while five studies were assessed to be of moderate quality. However, nine studies were assessed to be of low quality or low-to-moderate quality. In 22 studies, a lack of researcher reflexivity limited overall study quality. Also, discussion of ethical issues was inadequately addressed in 16 studies. Most studies did not provide reasons why potential participants did not take part. In addition, only a few studies reported modifying the interview or focus group schedules during data collection. Also, data saturation was inadequately addressed in most studies, while only one study described public and patient involvement (PPI), although PPI may have been beneficial in ensuring that the aims of the research were relevant. Six studies were assessed to be of low quality due to weaknesses across several Critical Appraisal Skills Programme (CASP) criteria these included, Foley et al. (2003); Kutsumi et al. (2009); Kolanowski et al. (2010); Ragneskog et al. (1997); Robinson et al. (2007) and van Wyk et al. (2017).

Appendix F: Online qualitative survey

Online questionnaire cover page

You are being invited to participate in a research study titled: “Exploring how care home staff manage responsive behaviours, associated with dementia, in care homes in Ireland, during the Covid-19 pandemic. This study is being done by Elizabeth O’Donnell a researcher based in Co. Donegal, who is completing a doctorate in mental health at the Division of Health Research at Lancaster University. This research aims to understand how responsive behaviours, associated with dementia, are managed in care homes in Ireland, during the Covid-19 pandemic. Also, how social isolation impacts on responsive behaviours and the resources nursing home staff need to care for people with dementia during and after this pandemic.

You are invited to complete this online questionnaire, your participation is greatly appreciated by the research team and the findings will be used to inform policy and practice to improve the care of residents with dementia, in Ireland.

Further details, including information about data protection are available in the participant information sheet that you can download here.

If you are interested in taking part, please read the participant information sheet. If you have any questions, please email or telephone the PhD researcher Elizabeth O’Donnell. Email. e.odonnell@lancaster.ac.uk or Tel. 00353 (0)861214618

By completing and submitting this questionnaire you are consenting to participating in this research and agree that your data can be used as described in the participant information sheet.

Your participation is entirely voluntary, and you can withdraw at any time. You are free to omit any question.

[Start button]

NATIONWIDE ONLINE QUESTIONNAIRE FOR CARE HOME STAFF

(Care home manager/person in charge, nurses and healthcare assistants)

> You can take a break from the questionnaire and return to saved answers any time before submission of the questionnaire. However, it is not possible to edit or remove responses to questions after submission of the questionnaire.

Part one: Introductory questions

We have asked for you to provide your name and email address, this is because if you make a disclosure of risk of harm to carers or residents, we may be able to contact you again. If no such disclosure is made, the researcher will remove (delete) your name and email address after submission of the questionnaire and your data will be will fully anonymised. We have also asked for some general information about your job role, responsibilities and duration of work experience to ensure your data is eligible for inclusion in the study.

Q1. Name……

Q2. Email address………..

Q3. Are you over 18 years old? Yes/no

Q4. What is your Job title/position at the care home where you now work?

………

Q5. What are your main responsibilities at the care home where you now work?

………

………

………

Q6. How long have you worked in this position at **<u>ANY</u>** care home?

Years………………..months…………………….

Q7 (a) Have you worked in a different position at **<u>ANY</u>** care home? Please specify previous job

title……….

(b) How long did you work in this position? Years…………….months…………………..

Part two: Your experiences of the Covid-19 Pandemic

Q8. Has the Covid-19 pandemic resulted in an increase in responsive behaviours, in residents with dementia (for example, agitation, aggression, wandering)?

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Q9. During the Covid-19 pandemic how has social isolation affected residents with dementia?

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Q10. What are your main concerns in caring for residents with dementia during the Covid-19 pandemic?

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Q11. What has been the most effective way of managing responsive/challenging behaviours in residents with dementia, during the covid-19 pandemic?

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……...

Q12. What would help you to care for people with dementia during the covid-19 pandemic, for example, what resources would be useful? Please specify
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……

Part 3: Please read the story below and answer the following questions.

John is a 73-year-old man with Alzheimer's disease who recently moved into Meadowpark Nursing Home. Since the start of the Covid-19 pandemic, John spends more time on his own, in his bedroom, he has not seen his family for quite some time and has little contact with other residents. John is frequently agitated, yesterday evening he managed to get out of his room and wandered down the corridor. When the carer tried to bring John back to his room, John became aggressive, shouting and cursing and pushing the carer away. The nurse came and gave John the antipsychotic drug risperidone (risperdal) prescribed on a PRN (to be given when needed basis), shortly after taking the drug, John was quieter and calmer.

Q13. Did care home staff manage John's responsive behaviour well, or do you think they could have managed it
differently?……
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…………………

Q14 (a)How has Covid-19 pandemic changed the way you have managed responsive
behaviour?……
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(b) What do you think are the reasons for these changes, in the way responsive behaviours are managed during the Covid-19 pandemic?

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……………………………………

Q15. Please can you rate your level of agreement, in normal or Covid-19 circumstances, with each of the below statements:

i. Drugs may be required to manage WANDERING.

Strongly agree/agree/neutral/disagree/strongly disagree

ii. Drugs may be required to manage AGITATION.

Strongly agree/agree/neutral/disagree/strongly disagree

iii. Drugs may be required to manage instances of WORRY including sundowning.

Strongly agree/agree/neutral/disagree/strongly disagree

iv. Drugs may be required to manage VERBAL AGGRESSION including cursing, shouting, yelling, disruption, annoying other people.

Strongly agree/agree/neutral/disagree/strongly disagree

v. Drugs may be required to manage PHYSICAL AGGRESSION including hitting out, kicking, pushing, pinching or self-harm.

Strongly agree/agree/neutral/disagree/strongly disagree

vi. Drugs may be required to manage NON-COMPLIANCE.

Strongly agree/agree/neutral/disagree/strongly disagree

vii. Drugs may be required to manage INAPPROPRIATE SEXUAL BEHAVIOUR or taking clothes off

Strongly agree/agree/neutral/disagree/strongly disagree

viii. Are there any other behaviours that may be managed with drugs (please specify)

……

Q16. How often should drugs be given to manage challenging/responsive behaviours, associated with dementia?

All the time/frequently/occasionally/only as a last resort after trying non-drug approaches/never.

Q17 (a) Are drugs used more frequently, during the Covid-19 pandemic, to manage responsive behaviours in residents with dementia, than they were before the Covid-19 pandemic? Yes/No

(b) If yes, what are the reasons for this?...

Q18. What drugs (if any) do you think are the most appropriate to manage responsive/challenging behaviour in residents with dementia?

Please score the drugs below from 1 to 4. With 1, the least appropriate, to manage responsive behaviour, to 4, the most appropriate to manage responsive behaviour in people with dementia. If you think no drugs are appropriate, put 5 in row E.

A) Antipsychotic drugs (example, Risperdal) ……..

B) Benzodiazepines (e.g. Valium or Xanax) ……..

C) Antidepressants (e.g. Prozac) ………

D) Z-drugs (e.g. Zopiclone for insomnia) …………

E) No drugs should be used to manage responsive/challenging behaviour ……….

Other drugs that may be appropriate to manage responsive/challenging behaviours (please specify)

…….

Part 4

Q19. Please can you rate your level of agreement with each of the below statements:

i. DISTRACTION is an approach that may be useful to manage responsive/challenging behaviours in people with dementia (e.g. making them a cup of tea, strolling around the garden).

Strongly agree/agree/neutral/disagree/strongly disagree.

ii. KNOWING THE PERSON WITH DEMENTIA, is an approach that may be useful to manage responsive behaviours in people with dementia (e.g. talking to them, understanding the cause of their behaviour).

Strongly agree/agree/neutral/disagree/strongly disagree.

iii. FAMILY MEMBER INVOLVEMENT in care and decision-making, may be useful to manage responsive behaviours in people with dementia.

Strongly agree/agree/neutral/disagree/strongly disagree.

iv. COLLABORATION between healthcare professionals to develop a person-centred individual care plan may be useful to manage responsive behaviours in people with dementia.

Strongly agree/agree/neutral/disagree/strongly disagree.

v. CARE HOME ENVIRONMENT may be useful to manage responsive behaviours in people with dementia.

Strongly agree/agree/neutral/disagree/strongly disagree.

vi. BEFRIENDING VOLUNTEER SERVICES may be useful to manage responsive behaviours in people with dementia.

Strongly agree/agree/neutral/disagree/strongly disagree.

vii. REMINISCENCE THERAPY may be useful to manage responsive behaviours in people with dementia.

Strongly agree/agree/neutral/disagree/strongly disagree.

viii. MUSIC THERAPY may be useful to manage responsive behaviours in people with dementia.

Strongly agree/agree/neutral/disagree/strongly disagree.

ix. PET THERAPY may be useful to manage responsive behaviours in people with dementia.

Strongly agree/agree/neutral/disagree/strongly disagree.

x. ART THERAPY may be useful to manage responsive behaviours in people with dementia.

Strongly agree/agree/neutral/disagree/strongly disagree.

xii. SENSORY ROOM may be useful to manage responsive behaviours in people with dementia.

Strongly agree/agree/neutral/disagree/strongly disagree.

xiii. AROMATHERAPY may be useful to manage responsive behaviours in people with dementia.

Strongly agree/agree/neutral/disagree/strongly disagree.

xiv. SOCIAL ACTIVITIES (e.g. Alzheimer café or dancing) may be useful to manage responsive behaviours in people with dementia.

Strongly agree/agree/neutral/disagree/strongly disagree.

xv. SPIRITUAL GUIDANCE (e.g. prayer groups, mass) may be useful to manage responsive behaviours in people with dementia.

Strongly agree/agree/neutral/disagree/strongly disagree.

Q20. What do you think are the best approaches to manage responsive behaviours, that do not use drugs?

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Q21. Are these non-drug approaches to manage responsive behaviours still achievable, during the Covid-19 pandemic?……
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Q22. What would help to implement non-drug approaches to manage responsive behaviours, (for example, training) Please specify
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Q23. What prevents implementation of non-drug approaches to manage challenging/responsive

behaviours (example: Rapid turnover of staff, with inadequate personal knowledge of residents).

Please specify
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Q24. Is there anything else they would like to say that has not been covered?
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[QUESTIONNAIRE END]

Online questionnaire submission page

Online questionnaire final submission page

Please indicate if you would be interested in participating in a follow up telephone or Microsoft teams visual call interview with the researcher, to discuss your responses in greater detail.

If interested, please indicate your preference by placing a tick in the appropriate box. It will only be possible to conduct interviews with a sample of interested participants.

Telephone interview	
Microsoft teams visual call interview	

By clicking the 'Submit' button below, you are consenting to participate in this study, as it is described in the participant information sheet. It is not possible to edit, change or remove responses to questions after submission of the questionnaire.

[Submit button]

Thank you!

Appendix G: PPI collaborators review of the interview schedule for managers and nurses

(Questions added by PPI collaborators are highlighted in yellow).

Interview schedule for care home managers and nurses (reviewed by PPI collaborators).

Introductory general information: - Job position, duration working in care home, previous experience in care homes.

The researcher will explain to the participant the meaning of the phrase “responsive behaviours”, as behaviours such as aggression, agitation, wandering and shouting. Responsive behaviours are also sometimes referred to “behaviour that challenges” or “behavioural and psychological symptoms of dementia (BPSD)”.

Q1. During the COVID-19 pandemic do you feel that you have received adequate support from government departments, including the HSE and HIQA. Also, have you had enough support from GP’s, the mental health team, and other healthcare professionals? Have you received support from your board of management? /

Q2. During the Covid-19 pandemic, do residents feel isolated due to restrictions on visiting and social distancing policies? How has this impacted on residents, has it changed their behaviour? (Prompt: Has it resulted in changes in responsive behaviours? What types of behaviour?)

Q3. How have you managed responsive behaviours during the COVID-19 pandemic, it this the same way as before COVID-19?

Q4. What resources would help you to manage responsive behaviours and improve care for residents with dementia during COVID-19 circumstances and in a post-COVID era?

Q5. Are there certain behaviours that you think may need a drug approach? If so, what are the reasons for using drugs to manage responsive behaviours?

Q6. What type of drugs would be used to manage responsive behaviours?

Q6. Are care home staff aware of all the adverse drug effects associated with antipsychotic medications, anti-anxiety drugs such as benzodiazepines, antidepressants and sleeping tablets when used in people with dementia?

Q7. How has guidelines and regulations, particularly HIQA regulations, impacted on use of drugs to manage responsive behaviours?

Q8. What non-pharmacological strategies are used to manage responsive behaviours? (Prompt: How often are they used, rarely or often?)

Q9. How effective are these non-pharmacological approaches to manage responsive behaviours, are they as effective during the Covid-19 pandemic, as before?

Q10. Have care home staff got the capabilities and skills required to manage responsive behaviours without resorting to drugs?

Q11. What resources would facilitate taking a non-drug approach to manage responsive behaviours? (Prompts: Resources in terms of staff, training, knowledge and finance?)

Q12. What sort of training would be useful to learn how to manage responsive behaviours without using drugs?

Q13. Do all healthcare assistants, residents and family members participate in collaboration and equitable decision-making? (Prompt: For example, contribute to case conferences?) If not, what prevents them from collaborating in case conferences?

Are family members concerns taken into account? Have been told of several families being asked to take their loved one from a home because they or the loved are too difficult to deal with!!!!!

Q14. What are the barriers to taking non-drug approaches to manage responsive behaviours and what would need to change?

Just wondering if you could ask about the restrictions regarding family visits and how this has impacted on residents? Do they think its necessary? Can they see benefit of even one family member being given access…

Appendix H: Interview schedule for healthcare assistants
(Reviewed by PPI collaborators – no changes).

Introductory general information: - Job position, duration working in care home, previous experience in care homes.

The researcher will explain to the participant the meaning of the phrase "responsive behaviours", as behaviours such as aggression, agitation, wandering and shouting. Responsive behaviours are also sometimes referred to "behaviour that challenges" or "behavioural and psychological symptoms of dementia (BPSD)".

1. How has the Covid-19 pandemic, impacted residents? Any changes in behaviour? (Prompt: Did residents have to spend longer periods of time alone in their rooms or had to self-isolate? How has this made them feel?)
2. Do care assistants manage challenging/responsive behaviours the same way as before COVID-19? (Prompt, non-drug approaches or drug approaches taken to manage responsive behaviours?)
3. Are there certain behaviours that you think need a drug approach and why? (Prompt: What are the reasons for taking a drug-approach to manage challenging/responsive behaviours?)
4. Are drug approaches to manage behaviours, associated with dementia, effective? If so, how are they effective, how do they change behaviour?
5. Are there any harmful side effects from taking a drug approach to manage challenging/responsive behaviours?
6. Are all care home staff aware of the types of adverse side effects associated with drug approaches to manage responsive behaviours? (Prompt: side effects of giving antipsychotic medications or anti-anxiety drugs or anti-depressants or sleeping tablets to people with dementia?)
7. What non-drug approaches are used to manage challenging/responsive behaviours or agitation. (Prompt: person-centred care approaches? any particular activities?)
8. Are non-drug approaches effective at reducing challenging or disruptive behaviours?
9. Do care home staff have adequate skills to manage challenging or disruptive behaviours?

10. Would further training in managing challenging/responsive behaviours be beneficial or do you think care home staff have sufficient training to support people with dementia? (Prompt: Is the training to become healthcare assistant sufficient or would additional training be beneficial?)
11. What sort of training would be useful for healthcare assistants to learn how to manage challenging or disruptive behaviour or agitation, aggression or wandering? (Prompt: for example, face-to-face workshops, role playing, videos, online training?).
12. Do you feel supported by management and nurses in terms of training and support, for example, do you feel you can approach senior staff to talk about any difficulties you may encounter, are they supportive?
13. Do you have a say in making decisions concerning residents? Also, do you have input into decisions about the general running of the care home?
14. Do healthcare assistants, and family members discuss residents at, case conferences with managers and GPs. If not, what prevents them from collaborating in case conferences?
15. Do healthcare assistants and nurses work well together as a team? Do they have good communication and feel nurses listen to your opinion?
16. Is there anything that would need to change to support HCA in carrying out their work (resources, for example, training, pay, support from management, regulatory body?).

Appendix I: Promotional poster/flyer

Care home nurses and healthcare assistants in Ireland, take part in a telephone or Microsoft Teams interview with the PhD researcher and receive a 20-euro shopping voucher. Have your ***voice*** heard. How do you manage responsive behaviours during the COVID-19 pandemic? What resources would help? Contact, Elizabeth for further information at e.odonnell@lancaster.ac.uk

Health & Medicine | Lancaster University

CENTRE FOR AGEING RESEARCH
LANCASTER UNIVERSITY

Care home staff in Ireland
What resources do you
need during Covid-19?

Take part in our
Interview Study

(Telephone or Microsoft teams)

Contact Elizabeth
e.odonnell@lancaster.ac.uk
086 1214618

Appendix J: Participant information sheet for taking part in an interview

Participant Information Sheet for Care Home Staff

Study title: Exploring how care home staff manage responsive behaviours, associated with dementia, in care homes in Ireland during the Covid-19 pandemic

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

What is the study about? The purpose of this study is to gain in-depth understanding of how responsive behaviour, associated with dementia, is managed in different care homes in the Republic of Ireland, in normal and Covid-19 circumstances. Therefore, telephone or Microsoft Teams interviews will be conducted with care home managers, nurses and care home assistants to explore in how they manage responsive behaviours. Findings from this study will be presented to the HSE and HIQA, to inform policy and practice to improve the care of residents with dementia, and support residents with responsive behaviour.

Why have I been approached? You have been approached because you are a manager, nurse or healthcare assistant in a care home in the Republic of Ireland.

Do I have to take part? No. It’s completely up to you to decide whether or not you take part.

What will I be asked to do if I wish to take part? If you decide you would like to take part, you will be invited, to participate in a telephone or Microsoft teams interview with our PhD researcher, (estimated duration of interview 30 – 60 minutes). With your consent the audio from the telephone (or Microsoft teams) interview will be recorded, typed up after the interview and anonymised to remove any identifiable information, thereby protecting your anonymity. During the telephone interview you will be asked questions, relating to the responses you gave in the questionnaire.

You have the right to withdraw from the study up to and during the telephone (or Microsoft teams) interview and request the withdrawal of your data up to two weeks after the interview. If you agree to participate in an interview, you will be asked to sign a written informed consent form.

Will my data be identifiable?

The information you provide is confidential. The information you provide for this study will be stored securely and fully anonymised so that no-one will be able to identify you from the responses you give.

o After the telephone (or Microsoft teams) interview, audio recordings will be transferred to secure storage at Lancaster University (no-one other than the researcher will be able to access the audio recordings).

o Once a typed version of your interview is made fully anonymous by removing any identifying information, then the audio file of your interview will be destroyed. Anonymised direct quotations from your interview may be used in the reports or publications from the study, but your name or other identifiable information will not be attached to them.

o Once the PhD researcher submits their thesis, fully anonymised typed versions of your interview will be transferred to Lancaster University's PURE secure data storage for 10 years, and access to your interview data will be restricted (no-one will be able to identify you from your data because identifiable information has been removed).

o All your data will be deleted after 10 years by Lancaster University data manager.

o Your written consent forms will be kept total separate from your interview responses, in a locked box in a locked room on Lancaster University campus.

There are some limits to confidentiality, the researcher has a duty of care and should there be disclosure of serious risk of harm to carers or residents then in these circumstances, the researcher will share this information with their research supervisors.

Sensitive questions will be asked hypothetically and not directly about daily practice and you are not obliged to answer questions.

What will happen to the results?

A summary of the findings will be sent to care homes in Ireland and disseminated to the health services executive (HSE) and Health Information and Quality Authority (HIQA). The results will also be summarised and reported in a doctoral thesis and may be submitted for publication in an academic or professional journal and disseminated at conferences. However, the data will be anonymised and pooled with data from other participants so that no-one will know who made the comments.

Are there any risks?

Since participation in this study involves taking part in a single telephone (or Microsoft teams) interview risks of physical harm are not expected but there is a risk of emotional harm and distress.

o Risk of distress: There is a risk that participants may feel distressed talking about the care of people with dementia, during the Covid-19 pandemic. Should this be the case the telephone (or Microsoft teams) interview will be stopped temporarily with the opportunity to end the interview should this be deemed appropriate by either the participant or the researcher. The researcher will also provide contact details of relevant counselling and information services including, Mental Health Ireland, Grow and the Irish Advocacy Network (Peer advocacy in mental health), if required.

o **Risks to anonymity:** Since only a limited number of participants will be taking part in interviews, individual responses given by participants at interview will be fully anonymised and pooled with interview data from care home staff from different care homes, thereby protecting participants anonymity.

Are there any benefits to taking part? Although direct benefits are not anticipated, indirect benefits are likely to be altruistic, such as improving the care of residents with dementia. It may also be empowering and therapeutic to share experiences, especially during the Covid-19 pandemic and feel valued for your contribution to research. No financial incentives will be offered for participating.

Who has reviewed the project? This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee (FHMREC) at Lancaster University.

Where can I obtain further information about the study if I need it? If you have any questions about the study, please contact the main researcher:

Name: Elizabeth O'Donnell. Email: e.odonnell@lancaster.ac.uk Tel: 00353 (0) 861214618

Or other members of the research team:

Name. Dr Caroline Swarbrick. Email: c.swarbrick2@lancaster.ac.uk Tel: 00441524594278

Name. Professor Carol Holland Email: c.a.holland@lancaster.ac.uk Tel: 00441524510436

Complaints: If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Fiona Lobban Tel: +44 (0)1524 593752 or email: f.lobban@lancaster.ac.uk at the Division of Health Research, Faculty of Health and Medicine, Lancaster University, Lancaster LA1 4YX, UK.

If you wish to speak to someone outside of the Mental Health Doctorate Programme, you may also contact: Dr Laura Machin Tel: +44 (0)1524 594973. Chair of FHM REC.
Email: l.machin@lancaster.ac.uk
Faculty of Health and Medicine (Lancaster Medical School) Lancaster University, Lancaster
LA1 4YG, UK.

Resources in the event of distress: Should you feel distressed either as a result of taking part in this project, or in the future, the following resources may be of assistance: - Your local GP Support from Mental Health Ireland. Email: info@mentalhealthireland.ie Tel: (01) 284 1166 Grow. Email: info@grow.ie Tel: 1890 474 474 Irish Advocacy Network (Peer advocacy in mental health). Tel: (01) 872 8684

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

Appendix K: Consent form (for care home managers, nurses and healthcare assistants participating in an interview).

Consent Form

Study title: Exploring how care home staff manage responsive behaviours, associated with dementia, in care homes in Ireland, during the Covid-19 pandemic

We are asking if you would like to take part in research to understand how responsive behaviours, associated with dementia, are managed in care homes in Ireland, in normal and Covid-19 circumstances. The findings will be used to improve the care of residents with dementia. Before you consent to participate in this study, we ask that you read the participant information sheet and this form, if you agree with each statement below, please initial each box and sign and date this consent form. If you have any questions before signing, please speak to the principal investigator, Elizabeth O'Donnell.

Please initial each statement

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study ☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that my telephone interview (or Microsoft teams interview, if preferred) will be audio recorded and then made into an anonymised typed version (written transcript). ☐
4. I understand that the audio recordings will be deleted as soon as a typed version of the telephone (or Microsoft teams) interview (transcript) has been anonymised. ☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, before and during the telephone (or Microsoft teams) interview and that I can withdraw my data for up to two weeks after the interview. ☐
6. I understand that I do not need to answer any questions that I do not want to and that I can terminate the telephone (or Microsoft teams) interview at any time. ☐
7. I consent to fully anonymised information and quotations from my interview being used in reports, conferences and training events. ☐

8. I understand that the information from the interview will be pooled with other participants responses, anonymised and submitted as a doctoral thesis, and may be published. All reasonable steps will be taken to protect the anonymity of the participants involved in this project. ☐

9. I understand that any information I give will remain strictly confidential and anonymous, however, should there be disclosure of serious risk of harm to carers or residents then in these circumstances, the researcher will share this information with their research supervisors. ☐

10. I consent to Lancaster University securely storing anonymised written interview transcripts for 10 years in Lancaster University PURE data repository and I understand that access to these transcripts will be restricted. ☐

11. I consent to take part in the above study. ☐

Name of Participant __________________ **Signature** ____________________
Date ___________

Name of Researcher __________________ **Signature** ____________________
Date ___________

Appendix L: Email/letter to relevant associations (Dementia Research Network Ireland or Nursing Homes Ireland or The Alzheimer Society of Ireland or relevant associations).

Study title: Exploring how care home staff manage responsive behaviours, associated with dementia, in care homes in Ireland, during the Covid-19 pandemic

Dear [Nursing Homes Ireland or The Alzheimer Society of Ireland or other associations]

I am Elizabeth O'Donnell, a doctoral researcher based in Ireland. I am conducting a research study with Dr. Caroline Swarbrick and Professor Carol Holland at the Division of Health Research, Lancaster University. The research aims to understand how care home staff in Ireland manage responsive behaviour, associated with dementia, before and during the Covid-19 pandemic. The findings will be presented to the HSE and HIQA to inform policy and practice.

The study involves an online survey and telephone or Microsoft Teams interviews with care home managers, care home nurses and care home assistants in the Republic of Ireland, who are over 18 years old and have worked in a care home for a minimum of 3 months.

Participation is voluntary and data will be fully anonymised, as described in the participant information sheet, in accordance with General Data Protection Regulation (GDPR). This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee (FHMREC) at Lancaster University.

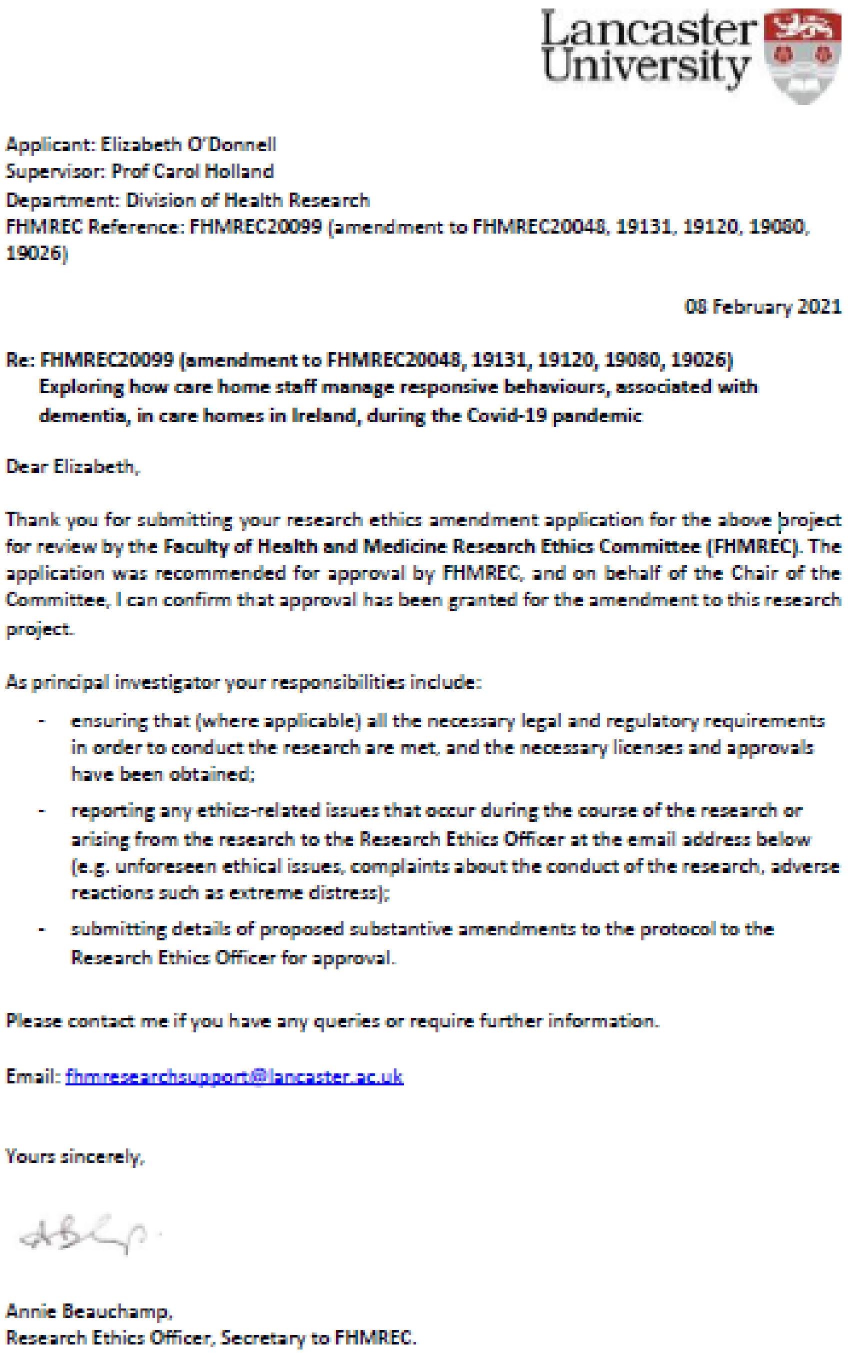
Your support in promoting this research will be highly valued and appreciated by the research team. I would be very grateful if you could circulate the poster and participant information sheet attached.

If you have any questions regarding this research, please contact the researcher Elizabeth O'Donnell, the Division of Health Research. Email: e.odonnell@lancaster.ac.uk or telephone 00353 (0)861214618.

Yours Sincerely,

Elizabeth O'Donnell

Appendix M: Letter of ethics approval



Lancaster
University

Applicant: Elizabeth O'Donnell
Supervisor: Prof Carol Holland
Department: Division of Health Research
FHMREC Reference: FHMREC20099 (amendment to FHMREC20048, 19131, 19120, 19080, 19026)

08 February 2021

Re: FHMREC20099 (amendment to FHMREC20048, 19131, 19120, 19080, 19026)
Exploring how care home staff manage responsive behaviours, associated with dementia, in care homes in Ireland, during the Covid-19 pandemic

Dear Elizabeth,

Thank you for submitting your research ethics amendment application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Email: fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Annie Beauchamp,
Research Ethics Officer, Secretary to FHMREC.

Appendix N: Distress protocol.

Due to the sensitive nature of the subject area, supportive information will be given to any participants feeling distressed. It will be stated on the participant information sheet attached to questionnaires that care home staff can exit the questionnaire at any time, if they feel distressed or no longer want to continue. The participant information sheet attached to the online questionnaire also includes the contact details of relevant counselling and information services including, Mental Health Ireland, Grow and the Irish Advocacy Network (Peer advocacy in mental health).

Similarly, for care home staff taking part in telephone or Microsoft Teams interviews, the researcher will provide the contact details of the (above mentioned) counselling and information services to participants. If, during the interview, the participant feels distressed, the telephone or Microsoft Teams interview will be stopped temporarily with the opportunity to end the interview should this be deemed appropriate by either the participant or the researcher. Similarly, the researcher will also follow up the participant after the interview, with a courtesy call (with their consent), as recommended by Draucker and colleagues (2009).

Appendix O: Codes developed in NVIVO-12

Codes
Areas for future research
Delicate balance
Dementia care means care of the staff too!
Collaboration
Healthcare assistants’ collaboration
Barrier to healthcare assistants participating case conferences
Mentorship for Healthcare assistants (HCAs)
Collaboration with family members and person with dementia
Collaboration with pharmacist
Hierarchy between care staff and other healthcare professionals
Equitable decision making
Finances
Personal relationship & attachment between staff & resident
Resources needed
safeguarding
Staffing levels
Support
Manager Support of Staff
Support from registered providers
Teamwork, support and peer support
The care home
Board of management - the providers

Codes
Business model of private nursing homes
Culture change
Future changes in care homes
Size of care home impacts on person-centred care
Care home environment likely to change in the future?
Importance of retaining staff
Models of care
Residents with dementia integrated with residents without dementia
The staff
Attitudes of Care Home Staff
Competence and capabilities of staff
Experience in managing responsive behaviours
Familiar long term stable staff
Getting staff with right attributes & characteristics
Governing body for nurses
Lack of career progression in private care homes
Poor pay conditions for HCA in private nursing homes
Regulatory body for HCA and CPD
International staff - cultural differences in dementia care
Valuing & empowering staff
Training
Do nurses and HCA have enough training
Insufficient training for HCA's
Inconsistency in Level 5 training for HCA

Codes
New Healthcare Assistants lack confidence
Nurse training
Training less effective during COVID-19 pandemic
Delivery of training for care home staff
Online vs classroom
Who needs training?
Is work experience beneficial or are students being ‘used?’
Education in adverse drug effects in dementia
Demographic information of participants
Experience
Number of residents with dementia
Non-profit making nursing home.
Profit making nature of private care homes
Environment/size of care home
Documentation
Managing responsive behaviours
Impact of COVID-19 in care homes
Care homes that remained Covid negative
Covid positive care homes
Deaths from Covid -19 in care home
External support e.g. government departments
Impact of Covid on residents with dementia
Anticipatory prescribing
Strategies to manage responsive behaviours during Covid-19 pandemic

Codes
Impact of Covid on staff wellbeing
Impact of not receiving family visits
Allowing family visits during lockdown
Compassionate grounds for visiting during Covid level 5 restrictions
Impact of wearing masks and PPE on residents
Responsive behaviours during COVID
Staffing levels in Covid
Poaching of staff by HSE
Technology to assist family visits
Families
Family support
support needed for family
Families need to be educated in side effects of drugs too!
GPs
GP’s support for care homes
GP's knowledge
HIQA regulations
Mental health team support & other HCP
Disparity in different areas
Access to allied HCP’s in rural Ireland compared to urban areas
Non-pharmacological interventions (NPI’s) to manage responsive behaviours
Barriers to NPI’s
Behaviour management strategies
Surveillance

Codes
Symptoms of responsive behaviours
Validation
compassionate communication
Different perception of reality
Distraction and diversion techniques
Facilitators to NPI’s
Giving residents time & coming back
Knowing your residents
Case study - knowing the farmer
Case study of knowing resident life story to manage responsive behaviours
If you know residents well, they to trust you
Life story
Life story - case story
Life story example – ‘cloud system’
Person-Centred Care
Activities and NPI's
‘All you need is love’
Change of carer
People with dementia have a different concept of time
Empathetic approach
End of life wishes
Labels & stigma
Having meaning and a purpose in life
Case study – meaningful occupation for residents with dementia

Codes
New residents need a friend
No one size fits all for residents
One-to-one care
Personhood in dementia
‘They are not just the person in the bed’
Reassurance
Residents who do not get visitors
Why people come into care homes
Underlying causes of responsive behaviours
Resident-to-resident aggression
Pharmacological management of behaviours
Balancing rights and risks of drug use
Case study example of when to initiate antipsychotics for verbal aggression
Evaluating efficacy & safety of psychotropic drugs for residents
Medication review
Pharmacological approaches
Religious and spiritual practices - part of Irish culture
Very important quotes
Flower arranging don’t work for aggression, medications needed first!
Medications usually at the top of the list
Psychotropic medications are a vicious circle
Psychotropic drugs just mask the underlying problem

Appendix P: Results of Braun & Clarke (2021) “20 questions to evaluate the quality of thematic analysis”.

20 questions to evaluate the quality of thematic analysis (Braun & Clarke, 2021)	**Evaluation of quality**
Do the authors explain why they are using TA, even if only briefly?	Yes
Do the authors clearly specify and justify which type of TA they are using?	Yes
Is the use and justification of the specific type of TA consistent with the research questions or aims?	Yes, the use and justification of using reflexive thematic analysis is consistent with addressing the research question and aims.
Is there a good ‘fit’ between the theoretical and conceptual underpinnings of the research and the specific type of TA (i.e. is there conceptual coherence)?	Yes
Is there a good ‘fit’ between the methods of data collection and the specific type of TA?	Yes, reflexive thematic analysis is congruent with collecting data at interviews with care home staff.
Is the specified type of TA consistently enacted throughout the paper?	Yes, reflexive thematic analysis is consistently implemented.
Is there evidence of problematic assumptions about, and practices around, TA? These commonly include: Treating TA as one, homogenous, entity, with one set of – widely agreed on – procedures. ● Combining philosophically and procedurally incompatible approaches to TA without any acknowledgement or explanation. Philosophical and procedurally compatible approaches to thematic analysis have been implemented. ● Confusing summaries of data topics with thematic patterns of shared meaning, underpinned by a core concept.	No, the researcher explains how they have applied reflexive thematic analysis to the data and reflected on how their own assumptions and preconceptions have influenced the construction of themes. No.
Assuming grounded theory concepts and procedures (e.g. saturation, constant comparative analysis, line-by-line coding) apply to TA without any explanation or justification. ● Assuming TA is essentialist or realist, or atheoretical. ● Assuming TA is only a data reduction or descriptive approach and therefore must be supplemented with other methods and procedures to achieve other ends.	No, these concepts have not been used. No, it has not been assumed that thematic analysis is essentialist or realist, or atheoretical. No, these assumptions have not been made.
. Are the theoretical underpinnings of the use of TA clearly specified (e.g. ontological, epistemological assumptions,	Yes

guiding theoretical framework(s)), even when using TA inductively (inductive TA does not equate to analysis in a theoretical vacuum)?	
Do the researchers strive to 'own their perspectives' (even if only very briefly), their personal and social standpoint and positioning? (This is especially important when the researchers are engaged in social justice-oriented research and when representing the 'voices' of marginal and vulnerable groups, and groups to which the researcher does not belong.)	Yes
Do the researchers strive to 'own their perspectives' (even if only very briefly), their personal and social standpoint and positioning? (This is especially important when the researchers are engaged in social justice-oriented research and when representing the 'voices' of marginal and vulnerable groups, and groups to which the researcher does not belong.)	Yes
. Are the analytic procedures used clearly outlined, and described in terms of what the authors actually did, rather than generic procedures?	Yes
Is there evidence of conceptual and procedural confusion? For example, reflexive TA (e.g. Braun and Clarke 2006) is the claimed approach but different procedures are outlined such as the use of a coding frame, multiple independent coders and consensus coding, inter-rater reliability measures, and/or themes are conceptualised as analytic inputs rather than outputs and therefore the analysis progresses from theme identification to coding (rather than coding to theme development).	No evidence of any of these.
. Do the authors demonstrate full and coherent understanding of their claimed approach to TA? A well-developed and justified analysis.	Yes
Is it clear what and where the themes are in the report? Would the manuscript benefit from some kind of overview of the analysis: listing of themes, narrative overview, table of themes, thematic map?	Yes, a table of themes is available.
Are the reported themes topic summaries, rather than 'fully realised themes' – patterns of shared meaning underpinned by a central organising concept? -- ● If so, are topic summaries appropriate to the purpose of the research? ○ If the authors are using reflexive TA, is this modification in the conceptualisation of themes explained and justified? --- ● Have the data collection questions been used as themes? --	No, the themes are not topic summaries. --- Not applicable. Not applicable. -- No. --

● Would the manuscript benefit from further analysis being undertaken, with the reporting of fully realised themes?	Fully realised themes are reported.
● Or, if the authors are claiming to use reflexive TA, would the manuscript benefit from claiming to use a different type of TA?	No, a different type of thematic analysis would not be appropriate.
Is non-thematic contextualising information presented as a theme? (e.g. the first 'theme' is a topic summary providing contextualising information, but the rest of the themes reported are fully realised themes).	No.
In applied research, do the reported themes have the potential to give rise to actionable outcomes?	Yes.
Are there conceptual clashes and confusion in the paper? (e.g. claiming a social constructionist approach while also expressing concern for positivist notions of coding reliability, or claiming a constructionist approach while treating participants' language as a transparent reflection of their experiences and behaviours?	No.
Is there evidence of weak or unconvincing analysis, such as:	
● Too many or two few themes?	No.
Too many theme levels?	No.
Confusion between codes and themes?	No.
Mismatch between data extracts and analytic claims?	No.
Too few or too many data extracts?	No.
Overlap between themes?	No.
Do authors make problematic statements about the lack of generalisability of their results, and or implicitly conceptualise generalisability as statistical probabilistic generalisability (see Smith 2017)? No.	No.

Appendix Q: Recommendations for the Irish National Dementia Strategy

Clinical Guideline No.21. (National Dementia Office).

Recommendation 1 **“Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia.”**	Care home nurses and healthcare assistants should receive education and training on the full spectrum of adverse effects associated with the use of psychotropic drugs to manage behaviours, associated with dementia. This is because the findings from this thesis indicate that care home staff, including nurses and healthcare assistants, although aware of some adverse effects associated with the use of psychotropic drugs in people with dementia, are unaware of the full spectrum of adverse effects. These include: the risk of strokes associated with the use of antipsychotic drugs in dementia; the increased risk of respiratory depression associated with the use of psychotropic drugs for example benzodiazepines; the increased risk of hyponatraemia and seizures in people with dementia treated with antidepressants. Moreover, these adverse effects are likely to be compounded by pharmacokinetic changes in the way older people metabolise drugs and risks associated with polypharmacy.
Recommendation 2 **Priority area 11 of the Irish National Dementia Strategy Training and Education states that “The Health Service Executive**	The findings of this thesis indicate that priority area 11: Training and Education to provide dementia specific training, including peer-led support and education

will engage with relevant professional and academic organisations to encourage and facilitate the provision of dementia-specific training, including continuous professional development, to relevant occupational and professional groups, including peer-led support and education for GPs, and to staff of nursing homes."	for staff of nursing homes, has not been fulfilled as care home managers and staff indicate that more training in the areas of dementia care and communication skills is required to facilitate a non-pharmacological response to managing responsive behaviours.

Appendix R: Full recommendations for HIQA

Recommendation 1	HIQA standards and inspections facilitate a non-pharmacological approach; however, refinement of standards may be needed to ensure that standards do not restrict individual freedom unnecessarily.
Recommendation 2	Regular use of psychotropic drugs should be reported quarterly by care homes in addition, to reporting "PRN" use of psychotropic drugs.

Appendix S: Full recommendations for Health Services Executive (HSE)

	Recommendations for HSE: Care home residents should have equitable access to the services of allied healthcare professionals
1	Improved equitable access to healthcare professionals in rural regions of the Republic of Ireland, especially psychiatry services and mental health team support.
2	Research into the effectiveness of telepsychiatry services to care homes in rural areas of Republic of Ireland.
3	Research into the feasibility of developing incentive schemes to encourage psychiatrists to locate to rural regions.

4	Improving equitable access to other healthcare professionals including physiotherapists, occupational therapists, speech therapists and dieticians in rural regions of Republic of Ireland.

Recommendations for the HSE to support care home residents during the COVID-19 pandemic

	Recommendations for the HSE to support care home residents during the COVID-19 pandemic
1	Government supports for care homes should ensure that the Health Services Executive (HSE) do not actively recruit private care home staff to public healthcare settings if future crises situations arise.
2	Facilitation of safe family visits should be ensured if visiting restrictions are re-imposed due to the COVID-19 pandemic.

Appendix T: Recommendations for Care Home Sector/Management

	Recommendations for Care Home Sector/Management
1	Engaging residents in meaningful and purposeful occupation and activities of daily living to give them a sense of self-worth and value, for example making the beds and helping in the laundry.
2	Involvement of family and friends, including family visits, participation of family members in residents’ activities. In addition, families should always be involved in decision-making about residents’ care.
3	Conducting activities in small groups of four or five residents.
4	Minimise excess movement and noise at busy times in the care home, for example, visiting times or shift changes.
5	Identifying any spiritual and religious needs and incorporating them into a personal care plan, as continuation of religious practices appears to assist residents in coping with stress and minimising responsive behaviours.

6	Low staff turnover, with a focus on retaining care home staff long term to ensure they are familiar with resident's needs and develop trusting relationships with residents and their families.
7	Improving working conditions, including pay, holiday, sickness and maternity leave, particularly in the private care home sector to enhance retention of care staff. Therefore, government schemes such as "Fair Deal" (chapter 5.7.3) should ensure that equitable financial support is allocated to individuals' resident in private, voluntary and public care homes in the Republic of Ireland.
8	Opportunities for healthcare assistants to be included in collaboration with other healthcare professionals, families and participation in case conferences.
9	Establishment of peer networks between nurses and healthcare assistants to bridge the disconnect and improve communication and teamwork.
10	Equitable decision-making for healthcare assistants in resident's care and the running of the care home.
11	A regulatory body, continuous professional development and career progression opportunities for healthcare assistants.

Appendix U: Recommendations for training (care home healthcare assistants, nurses and GPs).

	Recommendations for training healthcare assistants
1	Training in dementia for healthcare assistants as part of the mandatory QQI level five qualification in healthcare to become a healthcare assistant in Ireland.
2	Training in communicating with people with dementia and managing responsive behaviours.
	Training in adverse drug effects associated with the use of psychotropic drugs in dementia.
3	A substantial component of the level five QQI qualification should include a practical work placement in a care home setting.
4	Consistency in structure, content, delivery and duration of programme to become a healthcare assistant, in the ROI.

	Recommendations for training nurses
1	Nurses should receive training in dementia as part of their formal education program.
2	Training in communicating with people with dementia and managing responsive behaviours.
3	Training in full spectrum of adverse effects associated with the use of psychotropic drugs in dementia
4	Student nurses should undertake a clinical work placement in a care home.

	Recommendations for training General Practitioners
1	GPs should receive training in dementia, communicating with people with dementia and managing responsive behaviours.
2	The “mindset” of GPs to people with dementia and care home staff also influences behaviour management and should be a focus of education programmes in dementia care.

Appendix V: Recommendations to explore alternative models of long-term residential care

	Recommendations to explore alternative models of long-term residential care
1	Research and pilot studies exploring the impact on residents’ care and cost effectiveness of alternative models of long-term residential care, such as dementia villages aligned with the Netherlands Model (Haeusermann, 2017).
2	Smaller not-for-profit care homes, or individual houses accommodating several residents with dementia integrated into dementia friendly communities.